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## The Lived Experience of Parents with Newborns in the Neonatal Intensive Care Unit (NICU): A Heuristic Inquiry

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# Walden University

College of Allied Health

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Abigail Bilyk

has been found to be complete and satisfactory in all respects,  
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the review committee have been made.

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Walden University  
2024

Abstract

The Lived Experience of Parents with Newborns in the Neonatal Intensive Care Unit

(NICU): A Heuristic Inquiry

by

Abigail Bilyk

MS, Florida State University, 2012

BGS, University of Kansas, 2010

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

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August 2024

## Abstract

Parents with newborns who require medical care in the Neonatal Intensive Care Unit (NICU) immediately following birth are at an increased risk of experiencing psychological distress. While quantitative research studies have determined that a NICU admission can have detrimental effects on parents, a better understanding of the lived experience for both mothers and fathers is necessary to ensure adequacy in the standard of care given to parents while their newborn is admitted to the NICU. The phenomenon has not previously been explored using the phenomenological approach of heuristic inquiry. Constructivism, social constructivism, and the transactional model of stress and coping were used as theoretical frameworks to inform the development of this heuristic inquiry, to include the semi structured interview and data analysis. Eight parents with newborns previously admitted to the NICU were included as co-researchers of the study. The seven processes central to heuristic inquiry were used to facilitate exploration, self-reflection, and meaning making. Data were analyzed using embodied relational transcription. Key findings of the study included participant perceptions of NICU staff, the importance of spousal and familial support, the experience of stress, trauma, depression, PTSD, and postpartum anxiety, posttraumatic growth, and an absence of mental health checkups or follow-ups for parents. The study will contribute to positive social change by allowing parents to lend voice to their experience, inform parents of coping strategies to help them manage stressors associated with the NICU, and inform mental health professionals of resources best suited for parents with newborns in the NICU.

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## Dedication

With a grateful heart, I dedicate this work to my family. They were the inspiration behind this passion project-turned-dissertation. Their grace, patience, and encouragement have fueled me to pursue and complete this academic journey.

## Acknowledgments

Words cannot express my gratitude to my professor and chair of my committee, Dr. Alethea Baker, for her expertise, feedback, encouragement, and care. Dr. Baker inspired me to remain connected to my passion and reminded me of the importance of this work. I could not have completed this journey without my second committee member, Dr. Karine Clay, who has provided valuable insight and feedback throughout the process. I owe immense gratitude to my mentor, Dr. Hoffman, who pushed me to work hard and meet what often felt like unrealistic deadlines.

This endeavor would not have been possible without the loving support of my family, especially my husband, parents, and children. The pursuit of a doctorate degree takes a village, and I could not have asked for more support, empathy, and grace. They believed in me when I doubted myself, they kept my spirits lifted when I wanted to give up, and they supported me when the nights were late, and the mornings were early, and when their mom was always busy working on school. Thank you all for holding this family together and helping me show our boys that it is never too late to chase your dreams.

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## Chapter 1: Introduction to the Study

### **Introduction**

Parents who give birth prematurely or who have newborns that require medical intervention in the neonatal intensive care unit (NICU) are at an increased risk of experiencing psychological distress (Aftyka et al., 2020; Loewenstein, 2018). Research findings have indicated that mothers often experience immense sadness, guilt, depression, stress, and trauma as a result their newborn requiring a NICU admission (Brelsford & Doheny, 2022; Dickinson et al., 2020). When compared to mothers whose newborns do not require medical intervention in the NICU following childbirth, mothers with newborns in the NICU are at a greater risk of developing postpartum depression (PPD) (Galea et al., 2022). The experience of psychological distress is not limited to mothers. Researchers have also found that fathers experience adverse psychological symptoms as well, to include trauma, anxiety, and posttraumatic stress (Dickinson et al., 2020; Gundogdu et al., 2022). A NICU admission can permeate to other areas of parents' lives. Family dynamics, the transition to parenthood, and social relationships have also been found to become disrupted due to a NICU admission (Loewenstein, 2018; Thomson et al., 2023). Research also indicates that parental distress can impact attachments between parents and their infant and can lead to unresponsive parenting and withdrawn behavior (Eshraghi et al., 2022).

Many researchers have examined the impact of the NICU on mothers; however, fewer studies have been conducted to explore the NICU experience for both parents (Gundogdu et al., 2022; Thomson et al., 2023). After conducting an exhaustive review of

the literature and the research that has been conducted to examine the mental health and psychosocial wellbeing of parents whose newborns have been admitted to the NICU, Lowenstein (2018) identified the need for qualitative research to provide more detailed and descriptive accounts of the lived experience of parents. Heuristic inquiry, a phenomenological approach to qualitative research, allows for the discovery of a phenomenon through self-reflection and exploration (Djuraskovic & Arthur, 2010). After conducting an extensive review of the literature, I concluded that researchers have not explored the phenomenon through heuristic methodology.

In this study, I integrated my own experience as a mother of two children born prematurely, each requiring medical intervention in the NICU, with the experiences of other NICU parents. Profound and life-altering experiences, such as an admission to the NICU, can facilitate or even necessitate the in-depth process of self-reflection and self-inquiry. This type of intentional self-reflection allows an individual to develop a greater sense of awareness, inspiration, and meaning (Moustakas, 1990). Heuristic inquiries allow the researcher to study a phenomenon intimately, through the process of immersion. The process of heuristic inquiry requires the researcher to become part of the experience, to identify themes, patterns, and nuances of a phenomenon that cannot be holistically described through quantitative or traditional qualitative designs.

There are a series of conditions that lend themselves to a heuristic inquiry study: a crisis, a search for self, an expansion of awareness, immersion into the phenomenon, a sense of awareness and an integrated vision, refinement, and a conduit to express themes and values to overcome a crisis or adversity (Moustakas, 1990). Through the heuristic

process of searching and studying with openness, genuineness, authenticity, self-inquiry, and a dialogue with others who have experienced the same phenomenon, the phenomenon can be explained in greater detail and with purpose and meaning (Moustakas, 1990). Heuristic inquiry also accounts for the uniqueness that each co-researcher brings to the experience (e.g., values, beliefs, and culture) to discover the meaning of an experience (Sultan, 2019). The inclusion of co-researchers in the study has provided a rich, in-depth account of a phenomenon that often leads to psychological distress and posttraumatic growth.

One of the goals of the study was to contribute to social change at various echelons. This study has contributed to positive social change by allowing mothers and fathers with newborns in the NICU to give voice to their experience and provide rich, detailed insight into how the stressors of the NICU have manifested in their lives. Without nuanced understanding of the lived experience, mental health professionals cannot adequately provide the care necessary for families of newborns fighting for their lives. While newborns receive life-saving medical care while admitted to the NICU, they are not the only individuals who experience trauma. This study has not only facilitated positive social change for parents and healthcare professionals, but it will facilitate social change for the community. Results of this study will be used to inform parents of coping strategies that will help them manage stressors associated with the NICU more effectively and, ideally, experience posttraumatic growth rather than symptoms associated with anxiety, depression, and posttraumatic stress. Additionally, this study will facilitate social change by informing mental health professionals of resources best suited for parents with

newborns in the NICU, so they are better equipped to be stewards of exceptional care. Lastly, this study will facilitate social change at the community level by increasing the standard of care given to parents who have newborns in the NICU.

The major sections of this chapter include background literature related to parents' NICU experience, the problem statement, purpose of the study, research question(s), the theoretical and conceptual framework underpinning the study, the nature of the study, definitions of key concepts and constructs, assumptions, the scope and delimitations of the study, limitations related to design and potential biases, the significance and potential contributions of the study that will advance knowledge in the field of psychology, implications for positive social change, and a summary.

### **Background**

A newborn's admission to the NICU can impact the health and wellbeing of parents and caregivers both instantaneously and long-term. Anxiety, depression, guilt, sadness, trauma, posttraumatic stress, and postpartum depression are only a few of the adverse psychological symptoms experienced by both mothers and fathers (Barton et al., 2021; Dickinson et al., 2020). In addition to the experience of adverse psychological symptoms, many parents with newborns in the NICU resort to unhealthy coping strategies to manage the stressors associated with the NICU environment and the overall experience of caring for an infant who is medically fragile. In addition to clinically significant symptoms of depression and anxiety, Dickinson et al. (2020) found that between 4% and 26% of parents reported alcohol use within the first two weeks of NICU admission. While a NICU admission can adversely impact the psychological wellbeing of



mothers and fathers in the short-term, effects of the NICU have been found to linger, and is associated with parents experiencing long-term symptoms such as postpartum depression and posttraumatic stress.

After conducting an extensive literature review, it became evident that there are gaps in the literature that justify further exploration. After searching multiple databases, I concluded that most of the research conducted thus far has focused on the mental health and wellbeing of mothers who have given birth prematurely or who have newborns requiring medical intervention in the NICU (Barton et al., 2021). While this is an important population to study, it is also necessary to understand the impact a NICU admission can have on fathers as well. The experience of fathers with newborns in the NICU is complex, as they are charged with juggling many responsibilities such as work, supporting their partner, and upholding the household (Barton et al., 2021).

To accurately understand the experience of the NICU and the intricate and nuanced ways the experience manifests in the lives of parents, more qualitative studies are required. While the phenomenon has been studied qualitatively, there have been no heuristic inquiry studies conducted to explore the experience in greater depth. While heuristic inquiry studies are a lesser-known qualitative research method, they are important in understanding the integration of the lived experience of the researchers and the co-researchers. Heuristic inquiry allows the researcher to pursue the essence of a phenomenon, which cannot be identified or explored in as much detail utilizing other quantitative or qualitative methodologies (Brisola & Cury, 2016). The study was needed to make meaning of a profoundly impactful experience and provide parents with coping

strategies that will allow them to overcome the stressors and demands of a NICU admission and experience posttraumatic growth rather than symptoms associated with depression, anxiety, and posttraumatic stress. The study was also necessary to better inform healthcare providers and mental health professionals about the standard of care required facilitate effective coping strategies that will enhance the mental health and wellbeing of parents with newborns in the NICU.

### **Problem Statement**

Parents who give birth prematurely or who have newborns that require medical intervention in the neonatal intensive care unit (NICU) are at an increased risk of experiencing psychological distress (Loewenstein, 2018). The experience of a NICU admission can impact the health and wellbeing of parents and caregivers both instantaneously and long-term. The results of an extensive review of the literature revealed that researchers have primarily focused on the experience of mothers with newborns in the NICU (Barton et al., 2022; Nelson et al., 2022). Few qualitative studies have been conducted to explore and understand the lived experience of fathers with newborns in the NICU (Barton et al., 2022). While an admission to the NICU is correlated with adverse mental health outcomes for fathers, researchers have found that mental health symptoms exhibited by fathers manifest differently than mental health symptoms exhibited by mothers (Ocampo et al., 2021). To fully understand the profound and potentially lasting impact a NICU admission can have on a family, it is critical to understand what the experience was like for both mothers and fathers (Thomson et al., 2023).

Lowenstein (2018) recommended that researchers focus their efforts on understanding the experience of a NICU admission by conducting qualitative research that provides a robust, rich narrative. Heuristic inquiry, a qualitative approach to research, allows for the in-depth exploration of a meaningful phenomenon (Moustakas, 1990). To date, there have been no qualitative heuristic inquiry studies conducted to explore and understand the lived experience of parents with newborns requiring medical care in the NICU.

### **Purpose of the Study**

Parents who give birth prematurely or who have newborns that require a medical intervention in the NICU are at an increased risk of experiencing psychological distress (Lowenstein, 2018; Dickinson et al., 2020). Newborns admitted to the NICU receive specialized care for various medical conditions. While some newborns are discharged after a short duration of time, other newborns require care in the NICU for weeks and even months. Parents often report feeling unprepared for a NICU admission, which can lead to psychological distress, anxiety, depression, and posttraumatic stress (Thomson et al., 2023). There are many factors that can impact the distress experienced by parents (e.g., the duration an admission, the severity of a newborn's medical condition, the NICU environment, and the resources available to help parents cope with the additional stress). As such, an admission to the NICU is experienced differently by every parent.

While there have been qualitative studies exploring the lived experience of parents with newborns in the NICU, there has not been a heuristic investigation aimed at exploring and understanding the lived experience through reflective learning and creative

connection between researchers and a profoundly impactful phenomenon. The intent of the study was to explore, discover, and understand the underlying nature and meaning of the NICU experience for parents.

Results of the study have provided many practical implications to inform parents of adaptive coping strategies, enlighten medical professionals about the specific and unique needs of parents with newborns in the NICU, and improve the overall standard of care given to families who are supporting their newborn in a critically important time of their life. Specific intervention strategies and psychosocial support opportunities designed to address the unique needs of mothers and fathers can not only help mitigate symptoms of psychological distress, but they can help parents support one another, their child, and express their needs, responsibilities, and emotions more effectively (Ocampo et al., 2021).

### **Research Question**

What is the lived experience of mothers and fathers with newborns in the neonatal intensive care unit (NICU)?

### **Theoretical Framework**

The theoretical frameworks that grounded this study were constructivism (also referred to as cognitive constructivism), social constructivism, and the transactional model of stress and coping. The constructivism theory posits that individuals create an understanding of the world through the reflection of personal experiences (Akpan et al., 2020; Creswell, 2009). Every parent of an infant admitted to the NICU experiences the

phenomenon differently. Through intentional, in-depth reflection, parents make meaning of the experience.

The social constructivism theory postulates that an individual's reality is constructed based on the subjective meaning-making of personal experience (Ponterotto, 2005). Furthermore, the central component of social constructivism is that knowledge and experiences are interconnected and socially constructed through the multiple realities of subjective experience (Creswell, 2009; Sultan, 2019). Subjective experiences are valuable for many reasons. They help the researcher(s) identify and make sense of attitudes, beliefs, and values, and explore topics or phenomenon that are inaccessible to many (Sultan, 2019). Heuristic inquiry requires the researcher to connect with the co-researchers to discover the nature and meaning of an experience (Moustakas, 1990). Together, the researcher and the co-researchers will integrate and make meaning of the shared experience of their newborn's admission to the NICU. Constructivism and social constructivism, then, provide the framework for understanding the essential nature of a human experience. Furthermore, analyzing the data through the lens of constructivism and social constructivism allow for the construction of a subjective reality and integrate individual experiences into a universal experience that will allow for a greater understanding of a meaningful and complex phenomenon (Sultan, 2019).

In addition to constructivism and social constructivism, the transactional model of stress and coping was also used as a theoretical framework to better understand how a parent's perception of the stressor influences their coping strategies. The transactional model of stress and coping, developed by Lazarus and Folkman in 1984, is based upon

the idea that a stress response is influenced by the appraisal process of the stressor (Lazarus & Folkman, 1984). When an individual is faced with a stressor, they undergo a primary appraisal. The primary appraisal is the evaluation of the relevance of a stressor (Lazarus & Folkman, 1984). Following the primary appraisal is a secondary appraisal. The secondary appraisal occurs when an individual evaluates the resources they perceive they possess to overcome the stressor (Lazarus & Folkman, 1984). Both appraisals influence the coping strategies used to overcome the stressor (Obbarius et al., 2021). The coping strategies implemented directly impact the stress response, health, social functioning, and wellbeing of the individual (Lazarus & Folkman, 1984). An admission to the NICU can serve as a significant stressor in the lives of parents. The perceived threat and available resources can play a substantial role as parents make meaning of the experience.

The transactional model of stress and coping as a theoretical framework was used to inform the construction of semi-structured interview questions and facilitate the identification of themes during data analysis. The co-researchers were all parents of newborns who have required an admission to the NICU. They have all experienced a wide variety of stressors that have most likely lead to some form of psychological distress. Furthermore, it is likely that each co-researcher has adopted adaptive, maladaptive, or a combination of adaptive and maladaptive coping strategies to manage distress. Coping strategies have been defined as efforts (both cognitive and behavioral) to manage the demands appraised by an individual experiencing a stressor (Lazarus, 1984).

The stressors and coping strategies are integral components to the subjective experience of each co-researcher participating in the study.

### **Conceptual Framework**

The conceptual framework that underpinned the study included the seven processes and six phases of heuristic inquiry. Moustakas (1990) outlined seven processes that guide the journey of the researcher in the quest for meaning making and understanding. The seven processes are: identifying with the focus of inquiry, self-dialogue, tacit knowing, intuition, indwelling, focusing, and internal frame of reference. The seven processes allow the researcher to immerse and engage with the experience more fully. The seven processes allow the researcher to take a creative approach to research and inquiry, as the heuristic inquiry process is genuine, fluid, and flexible (Sultan, 2019).

In addition to the seven processes of heuristic inquiry, there are six phases. The six phases include: initial engagement, immersion, incubation, illumination, explication, and creative synthesis (Sultan, 2019). The initial engagement serves as the catalyst for the study, as it is the first encounter with a deeply meaningful experience, or the phenomenon being explored. Both of my children were admitted to the NICU following childbirth. My oldest son was born at 33 weeks' gestation and spent forty-two days in the NICU. My second-born son was born at 36 weeks' gestation and spent seven days in the NICU. While the NICU admissions different in duration, both profoundly shaped my life. Following the initial engagement is the immersion phase of heuristic inquiry. Immersion

involves fully connecting with the phenomenon through curiosity and reflection (Moustakas, 1990; Sultan, 2019).

Immersing completely into an experience that inevitably caused previous traumatic memories to resurface necessitated the third phase of heuristic inquiry; incubation. Incubation is a temporary pause from the weightiness of the study (Mihalache, 2019). The fourth phase of heuristic inquiry is illumination, which is defined as an awareness of understanding (Douglass & Moustakas, 1995). Illumination is intimately connection with the fifth stage of heuristic inquiry; explication. Explication occurs when the researcher examines themes that arose as a result if immersion, incubation, and illumination. The sixth and final phase of heuristic inquiry is creative synthesis. Creative synthesis involves the integration of data obtained through interviews with the co-researchers. In tandem, the seven processes of heuristic inquiry and the six phases of heuristic inquiry will be used to guide the study and the researcher in the quest for developing meaning and understanding about the lived experience of parents with newborns in the NICU.

### **Nature of the Study**

To address the research question in this heuristic inquiry, the specific research design included individual interview transcripts with parents whose newborns have required medical care in a NICU environment. There are multiple hospitals in the region and across the United States that provide different levels of care for newborns requiring medical intervention. I conducted interviews with parents from multiple hospitals in multiple states within the United States to gain a more comprehensive understanding of



the NICU experience. I interviewed mothers and fathers separately to ensure their answers were authentic and not influenced by external sources. Following individual interviews, I conducted one interview with parents together, to better understand how the NICU admission may have altered their relationship. Unique to heuristic inquiry, the parents interviewed served as co-researchers. The data from the interview transcripts was integrated with my own experience to gain an in-depth understanding of the phenomenon being studied.

I conducted informal conversational interviews with parents who have recently had a newborn that required medical intervention in the NICU by using the online platform Microsoft Teams. I analyzed data from the perspectives of mothers, fathers, and parents as a couple, to identify themes and meaning associated with the NICU experience.

### **Definitions**

*Cognitive Impairment:* Difficulty learning, remembering, concentrating, and/or making decisions that are important to daily functioning (U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2011).

*Co-researchers:* a purposeful sample of individuals who have experienced a particular phenomenon (Sultan, 2019). Due to the nature of heuristic inquiry, participants become co-researchers to help the researcher engage in self-and other exploration of a shared phenomenon.

*Explorative reflexivity:* the reflective and reflexive processing of an experience, primarily done through journaling or documentation (Sultan, 2019).

*Neonatal Intensive Care Unit (NICU)*: a nursery in a hospital designed to provide resources and medical intervention to newborns (American Academy of Pediatrics, 2019). There are four levels of NICUs (Levels 1-4) that provide specific levels of care based on the medical require required to sustain a newborn's life.

*Neurodevelopmental disorders (NDDS)*: childhood-onset disorders that can lead to a variety of developmental impairments such as intellectual disability, autism spectrum disorder, Rett syndrome, tuberous sclerosis, and fragile X syndrome (Srivastava et al., 2019). NDDS can impact individuals in many ways. Individuals with NDDs may experience difficulties related to cognition, self-help, communication, and motor control (Srivastava et al., 2019).

*Posttraumatic Stress Disorder (PTSD)*: a mental health condition that can occur following the experience of a traumatic event or circumstance (American Psychiatric Association, 2023). PTSD can also occur when a traumatic event has been witnessed. Symptoms associated with PTSD can include intrusive thoughts, avoidance, alterations in cognition and mood, and/or alterations in arousal and reactivity (American Psychiatric Association, 2023).

*Perinatal Asphyxia*: a condition that can occur during childbirth marked by a lack of blood flow to or from the fetus (Gillam-Krakauer et al., 2023). Perinatal asphyxia can result in neurological impairment.

*Premature or preterm*: newborns born prior to 37 weeks' gestation are considered preterm neonates and are at an increased risk of requiring medical interventions in the NICU (Talisman et al., 2022).

*Psychological distress*: any non-specific symptom of depression, anxiety, or stress that adversely impacts mental health (Viertiö, et al., 2021).

### **Assumptions**

There were two main assumptions that were critical to the meaningfulness of the study. The first assumption was that participants would be willing to openly discuss a potentially traumatic lived experience in detail with someone with whom they are unfamiliar. A heuristic inquiry depends upon the willingness of co-researchers to engage in self-exploration and introspection to facilitate an understanding of the essence of a shared human experience (Djuraskovic & Arthur, 2010).

The second assumption for the study was that I would be able to immerse myself completely into the study, introspect, reflect, make meaning, re-live traumatic experiences, and connect with co-researchers about their deeply personal experiences. Moustakas (1990) identified the first step in heuristic inquiry as identifying with the focus of inquiry. This involves achieving complete connection with the experience (Djuraskovic & Arthur, 2010). I engaged in reflexive journaling to help distance myself from my thoughts and the experience and to help myself maintain the course of the study. Furthermore, I took breaks from the experience through incubation. Incubation is a phase in heuristic inquiry that serves as a designated break, allowing the researcher to become detached from intense immersion and inner workings of the study (Djuraskovic & Arthur, 2010).

### **Scope and Delimitations**

Heuristic methodology was chosen as the research design for the proposed study because it allowed for the most in-depth exploration of the phenomenon. Heuristic inquiry incorporates social constructivism, constructivism, and phenomenology to create an autobiographical approach to qualitative research design (Moustakas, 1990). Heuristic inquiry is an introspective, reflexive, experiential, embodied, and holistic approach to research that requires the researcher to immerse themselves into their work and develop a connection with co-researchers to make meaning of a phenomenon (Sultan, 2019). Due to the nature of the study and the role of the researcher, the scope of heuristic inquiry is broad.

I chose constructivism and social constructivism as theoretical frameworks based on the assumption that knowledge and experiences are interconnected and socially constructed by a group of people (Creswell, 2009). To facilitate transferability, I utilized thick descriptions. Sultan (2019) affirmed that thick descriptions involve clear communication of the research process to increase transparency and transferability. While the study was unique and required the researcher to have intimate connection to the phenomenon, thick descriptions and transparency will allow for future replications of the study, should researchers choose to explore the phenomenon in greater depth.

### **Limitations**

While not considered a vulnerable population, parents who have had a newborn that required care in the NICU environment have likely experienced some degree of psychological distress. For this reason, accessing participants was a challenge. By

conducting interviews about the lived experience of parents, I asked parents to re-live a potentially traumatic experience they may not have been ready to discuss in great detail. I overcame this challenge by using empathy to relate more fully to their experience and compassion by not pressuring them to provide responses if they were uncomfortable. While every parent's experience was different, there was common ground amidst a shared hardship. To help parents manage intense emotions, flashbacks, intrusive thoughts, or distress, I used the Qualitative Research Distress Protocol (QRDP) as a guide and identified mental health resources within geographic proximity in the form of contact information for mental health providers. I also communicated to co-researchers that I was willing to help find them resources in the community that would best fit their needs should they experience distress or flashbacks that cause unease.

Another limitation involved the subjective nature of heuristic inquiry. Heuristic inquiry is based upon flexibility, as there are few limitations placed on data collection and analysis (Djoraskovic & Arthur, 2010). This limitation required the researcher to exercise discipline in separating oneself from the co-researchers during the data collection process enough to allow the co-researcher to tell their story. Due to the nature of heuristic inquiry, it is not uncommon for researchers to over-identify with stories, examples, and the overall experience of each co-researcher. While doing so, it can become difficult for the researcher to manage their own thoughts and feelings (Djoraskovic & Arthur, 2010). To overcome this limitation, I utilized active listening to capture the meaning of the experience for each co-researcher, rather than collude their experience with my own. In the same vein, researchers conducting heuristic inquiry must

be mindful to mitigate their own biases, as those can influence the study, the interpretation, and the findings (Djoraskovic & Arthur, 2010). I remained open to the notion that co-researchers had opinions and experiences that differed from my own. I worked hard to ensure that I did not seek to confirm my own experiences as I deciphered potential themes that emerged from the raw data and maintained an open mind to the unique experiences of all co-researchers.

Mitigating limitations that arise due to the subjective nature of subjective inquiry can often prove to be difficult, as the researcher is not only the instrument used to collect data, but also the party responsible for analyzing the data (Florczak, 2021). Furthermore, developing an intimate relationship with co-researchers is integral in constructing a universal experience between the co-researchers. To manage these challenges, it is important that the researcher balances their involvement. More specifically, qualitative researchers must appear indifferent as to not influence the responses of co-researchers, but also immersed in the co-researcher's experience to maintain trust and rapport (Florczak, 2021). One strategy that has been identified to facilitate the balance between the two states of being is called centering. Centering is defined as maintaining a watchful eye for any potential influence on the co-researcher (e.g., nonverbal communication such as facial expressions and body language) and a reminder to remain in the present moment and open to the experiences of co-researchers (Florczak, 2021).

An additional limitation or challenge that arose was the arousal of intense emotions from a traumatic NICU experience. To conduct a heuristic inquiry, one must have experienced the phenomenon being studied. While conducting interviews,

transcribing, and identifying themes, I spent a significant amount of time listening to the lived experience of others and reliving my own experience. I overcame this challenge by engaging in reflexivity and journaling throughout the experience. I also allowed myself to “feel” the experience of the co-researchers. When they cried, I cried. When they conveyed excitement and joy as their newborn achieved milestones, I felt a sense of joy as well. Furthermore, I ensured adequate self-care practices were implemented. To mitigate any bias that arose from the arousal of intense emotions during data analysis, I utilized a third party, or a researcher who is knowledgeable about both the theory and methodology to serve as an unbiased advisor.

### **Significance**

This study is significant in that it allowed both mothers and fathers with newborns in the NICU to give voice to their experience and how the stressors of the NICU have manifested in their lives. If the lived experience of both mothers and fathers is not fully understood, healthcare providers and mental health professionals cannot provide the best care for families of newborns receiving life-saving medical care. Newborns receive the most care while in the NICU, however, they are not the only individuals experiencing some form of trauma.

The goal of this study was to facilitate positive social change for parents, healthcare professionals, and the community. Results of this study will inform parents of coping mechanisms and strategies that will help them not only withstand the stressors of the NICU, but cope with the adversity in a more productive manner. This study will facilitate positive social change by informing mental health professionals and healthcare

providers of resources and avenues of care necessary for parents. It is standard practice for a social worker to establish a connection with each child and family in the NICU. While social workers are able to provide information on community resources, they are not equipped to provide mental health care or therapeutic services for parents. Results of the study will influence NICU practices to adopt or develop in-house resources designed to target the psychological needs of parents who are in the midst of a difficult experience. Furthermore, emotional support has been found to be an integral factor in protecting the resilience of individuals who are dealing with stressful situations (American Psychological Association, 2022). Results of the study highlight the importance of promoting parental support groups to mitigate the potentially adverse mental health symptoms that often co-occur with an experience such as an admission to the NICU. In addition, this study will help the community by increasing the standard of care given to parents who have newborns in the NICU. Furthermore, results of the study can be used to influence future research pertaining to the differences in symptomology experienced by mothers and fathers in the midst of stressful experiences to better understand the unique needs of each and identify adaptive coping behaviors and psychosocial support resources.

### **Summary**

I have used constructivism, social constructivism, and the transactional model of stress and coping as theoretical frameworks to guide the methodology of the study. Researchers have identified a need for additional qualitative research to better understand the lived experience of mothers and fathers with newborns in the NICU. I chose heuristic inquiry as a qualitative phenomenological approach to the research question. Heuristic



methodology allowed me to select co-researchers who have experienced the same phenomenon, develop connection, and make meaning of the phenomenon.

Current literature lacks studies that explore the lived experience of parents with newborns in the NICU in an in-depth manner that allows for a rich narrative of the essence of the experience. Findings from the study will contribute significantly to the body of knowledge that currently exists. Moreover, results of the study will inform mental health professionals about the lived experience of parents and increase the standard of care at NICUs locally and nationally. Chapter two provides the background of constructs related to psychological distress and the NICU that were explored in addition to the theoretical and conceptual frameworks that were used to guide the study.

## Chapter 2: Literature Review

### **Introduction**

Parents who have newborns that require medical intervention in the neonatal intensive care unit (NICU) following birth are at an increased risk of experiencing psychological distress (Loewenstein, 2018). Psychological distress is defined as any non-specific symptom of depression, anxiety, or stress that adversely impacts mental health (Viertiö, et al., 2021). The experience of a NICU admission can impact the health and wellbeing of parents and caregivers both instantaneously and long-term. An admission to the NICU can adversely affect many facets of parents' lives including the transition to parenthood, family dynamics, spousal relationships, and parent-child attachment (Loewenstein, 2018). Researchers have focused on examining the relationship between the NICU and the mental health of parents in a quantitative manner (Dickenson et al., 2020). Less research, however, has focused on exploring the lived experiences of NICU parents in a qualitative manner. Previous qualitative research has mainly focused on understanding the experience of mothers with newborns in the NICU (Ocampo et al., 2021). Fathers also experience psychological distress when their newborn is admitted to the NICU. The present study seeks to fill a gap in the research, as there have been limited qualitative studies conducted to understand the lived experience of both mothers and fathers with newborns in the NICU.

Qualitative research is important to the field of psychology because it allows the researcher to identify, explore, understand, and explain the human experience in a way that quantitative research does not (Cleland, 2017). The five qualitative approaches to

inquiry include ethnographic research, narrative research, phenomenology research, grounded theory research, and case study research (Cleland, 2017). Each approach is designed to help the researcher better understand a phenomenon.

After completing an extensive review of the literature, it was concluded that additional qualitative studies exploring the lived experience of mothers and fathers with newborns in the NICU are necessary to assist researchers, policy makers, and healthcare professionals ensure the appropriate standard of care is afforded to parents with newborns in the NICU. It was also determined that, to date, there have been no heuristic inquiry studies conducted exploring the nature and meaning of the NICU experience for parents. A heuristic inquiry is a specific phenomenological approach to qualitative research that was pioneered by Clark Moustakas (Mihalache, 2019). Heuristic inquiry is used by researchers to understand and make meaning of a phenomenon (Mihalache, 2019). Most phenomenological approaches are phenomenon-centered, meaning they are designed to help researchers better understand a specific phenomenon. Heuristic inquiry, however, is a person-centered approach to qualitative research. Rather than remove the personal experience of the researcher, heuristic inquiry requires the researcher to directly engage in the process of self-discovery in attempt to understand the complexities of a deeply personal experience (Mihalache, 2019). Thus, the researcher's experience plays a vital role in enhancing the exploration of a phenomenon.

The purpose of this heuristic inquiry was to understand the lived experience of mothers and fathers with newborns in the NICU. The "lived experience," a cornerstone of phenomenological human science, refers to an immediate consciousness that is given

meaning through reflection (Van Manen, 2016). Dilthey (1985) likened lived experience to a fulfillment of the soul and a breath of meaning. Therefore, it is our reflections that provide meaning to a lived experience. Lived experiences are subjective in nature and unique to the individual. While heuristic inquiry is based upon the researcher's experience of a phenomenon, it requires the engagement of other participants who have experienced the same phenomenon (Mihalache, 2019). Communication between the researcher and the co-researchers, self-searching, and personal reflection allow for meaning making and understanding (Moustakas, 1990). This heuristic inquiry incorporated the experiences of the researcher with the experiences of co-researchers to produce a full descriptive account of a life-changing experience (Mihalache, 2019). This specific type of qualitative study empowered individuals to lend voices to their story, which allowed for the transcription of rich, meaningful data (Creswell, 2013). The integration required for such a rich depiction of a phenomenon allowed the researcher to discover the underlying meanings of the experience.

There are various dynamics of the NICU that shape the experience for both mothers and fathers. This chapter has been divided into nine main sections. The first section includes the literature search strategy, followed by the theoretical foundation and conceptual framework. The next section, Neonatal Intensive Care Unit (NICU) details common medical complications that can occur at birth as well as complications associated with preterm neonates. The section that follows details the distress associated with the immediate separation between parents and their newborn when the baby is physically taken from labor and delivery to the NICU. The next section describes the

NICU environment and NICU discharge, two unique experiences for parents with newborns admitted to the NICU. The following sections comprise the literature review of research pertaining to the lived experiences of parents who have had children who required medical intervention post-natal and stay in the NICU. First, the lived experiences of parents are outlined in detail, followed by accounts of maternal mental health and paternal mental health. Researchers have concluded that the NICU experience is unique to all parents. The final section of Chapter 2 is a conclusion of the literature review and support for the present study addressing gaps in the current literature.

### **Literature Search Strategy**

A thorough review of the literature was conducted using three databases accessed through the Walden University Library. The databases chosen for the literature review were ERIC, SAGE Journals, and APA PsychInfo. The Boolean operators and keywords used to search the literature included “NICU,” or “Neonatal Intensive Care Unit;” “Lived Experience;” “Parents,” or “Caregivers,” or “Mother,” or “Father;” “Mental Health” or “Mental Illness;” “Wellbeing” or “Well-Being” or “Quality of Life,” “Preterm Birth” or “Preterm Birth Complications;” “Parenting Stress” or “Parental Distress;” “Posttraumatic Growth” or “Coping” or “Coping Strategies” and “Qualitative” or “Phenomenology” or “Heuristic Inquiry” with appropriate variations. The databases included in the search were accessed through the Walden University Library.

Google Scholar was used in addition to the databases accessed through the Walden University Library to identify pertinent articles. To ensure the most current literature was accessed and included in the literature review, the articles included in this

dissertation are articles dated between 2018 and 2023. A few articles published prior to 2018 were included in the literature review because they were novel, provided important insight into the experience, or related to the theoretical and conceptual frameworks used to ground the study. Peer-reviewed articles were utilized to maintain the quality of the dissertation and ensure appropriate validity.

### **Theoretical Foundation**

#### **Constructivism**

Heuristic inquiry is a humanistic research methodology focused on the lived experience of an individual or group of individuals. Heuristic inquiry is often influenced by several theories, to include specific theories proposed by Edmund Husserl, the originator of phenomenology; Martin Buber, an existential philosopher; and Abraham Maslow, a humanistic psychologist who believed that individuals are motivated to fulfill their life's potential (Nevine, 2020). The constructivism theory, also referred to as cognitive constructivism, is based on the belief that individuals create their own understanding of the world through reflection on personal experiences (Akpan et al., 2020). This theory is founded upon the idea that we construct our own knowledge through curiosity, exploration, and assessing our knowledge (Wnet, 2004). As such, individuals are constantly creating and discerning meaning from their experiences and the environment around them.

The constructivism theory is closely related to social constructivism, another theory used to ground the current study. Social constructivism posits that individuals are inherently driven to pursue an understanding of the world around them (Creswell, 2013).

Through this pursuit of understanding, individuals create subjective meanings of their lived experience (Creswell, 2013). While initially proposed by Les Vygotsky as a learning theory, the underpinnings and core tenants of social constructivism can be utilized as a framework to understand the human experience (Akpan et al., 2020). Social constructivism postulates that language and culture play an integral role in the way individuals perceive the world around them (Akpan et al., 2020). Knowledge and experiences are interconnected and socially constructed or co-constructed by a group of people. A heuristic inquiry is based upon the lived experiences of the researcher and the co-researchers aiding in the study. Researchers most position themselves in the research to interpret and construct meaning through personal and cultural factors (Creswell, 2013). The lived experiences of parents with newborns in the NICU, then, is understood by exploring the experience of the researcher, as well as the uniquely constructed experiences of each co-researcher.

### **Transactional Model of Stress and Coping**

In addition to constructivism and social constructivism, the transactional model of stress and coping was utilized as a framework for the present study. The transactional model of stress and coping was developed by Lazarus and Folkman in 1984 and is based on the notion that a stress response is influenced by the appraisal process of an individual (Lazarus & Folkman, 1984). When faced with a stressor, an individual evaluates the relevance of the stressor (i.e., the primary appraisal) and the resources they possess to overcome the stressor (i.e., the secondary appraisal). The primary and secondary appraisals directly impact the coping strategies an individual utilizes to overcome the

stressor (Obbarius et al., 2021). The coping strategies implemented directly impact the stress response, health, social functioning, and wellbeing of the individual (Lazarus & Folkman, 1984).

When faced with a stressor such as the uncertainty of an infant's health or the realization that medical intervention in the NICU is imminent, an individual first assesses the relevance of the stressor. This is the primary appraisal. The primary appraisal is also when a parent determines whether or not the stressor they face poses a threat (Lazarus & Folkman, 1984). Following the assessment of the threat is the secondary appraisal. The secondary appraisal is a parent's evaluation of the resources available or coping strategies at his or her disposal for managing the threat (Lazarus & Folkman, 1984). Resources may include perceived social support, spirituality, financial support, experience, or mental fortitude. If a parent perceives a situation as a threat and identifies they do not have the resources or coping strategies available to effectively manage the threat, the body's stress-response can shift into overdrive. This can result in high levels of anxiety, increased heart rate, racing thoughts, catastrophic thinking, increased muscle tension, feelings of guilt, sadness or anger, fatigue, and avoidance.

The stress experienced by mothers and fathers is impacted by various coping mechanisms that either mitigate or alleviate distress and improve mental wellbeing or exacerbate the stress and negatively impact wellbeing (Brelsford & Doheny, 2020). To survive the NICU experience, parents engage in both secular and nonsecular coping strategies. Both include both adaptive and maladaptive strategies of dealing with the stressors experienced (Brelsford & Doheny, 2020). This concept is important in relation



to understanding the lived experience of parents with newborns in the NICU because the NICU often incites spiritual struggles that challenge parents' beliefs about themselves and about parenting (Brelsford & Doheny, 2020).

Brelsford and Doheny (2020) collected data from 185 parents of premature newborns, to include one hundred thirty-one biological mothers, fifty-two biological fathers, and two nonbiological fathers. Self-report questionnaires pertaining to the NICU experience, spiritual struggles, depression, anxiety, stressors specific to the NICU, and wellbeing (Brelsford & Doheny, 2020). Brelsford and Doheny (2020) found a positive correlation between spiritual struggles (e.g., the meaning in life) and general worry, despair, and an unstable sense of wellbeing. Parents who reported experiencing symptoms of depression and anxiety also reported experiencing spiritual struggles in the months following NICU discharge. Part of parents' struggle with the meaning of life involves blame and guilt surrounding the reason behind their newborns' NICU stay and health prognosis, which leads to a greater impairment of their mental wellbeing. Furthermore, the results of the study highlight the importance of understanding the unique experience of the NICU, to include spiritual aspects that can serve as adaptive coping mechanisms for parents as they navigate an incredibly difficult season of their life (Brelsford & Doheny, 2020). The study relied on self-report measures. The authors were not able to ask study participants follow-on questions about their spiritual struggles and the blame and doubt parents placed on themselves. It was recommended that future studies include deeper probes into parents' spiritual lives to understand how worldviews influence the lived experience. The current study allowed for more in-depth

conversations with co-researchers about their worldviews and the meaning of the NICU experience.

Utilizing the transactional model of stress and coping as a theoretical framework provided valuable insight into the way an individual creates understanding and meaning through a stressful experience. It cannot be denied that an admission to the NICU is a source of stress for parents. The researcher and co-researchers all experienced the same phenomenon: an infant admitted to the NICU for medical intervention. According to the transactional model of stress and coping, the stress response experienced by an individual, however, is greatly influenced by their appraisal of the stressor (Obbarius et al., 2021). It was hypothesized that the primary appraisals will lead to distinct, unique experiences for the researcher and all co-researchers. It was also hypothesized that the primary and secondary appraisals influence how parents make meaning of the phenomenon.

## **Conceptual Framework**

### **Seven Processes of Heuristic Inquiry**

The conceptual framework chosen to guide this study was heuristic inquiry. There are seven processes outlined by Moustakas (1990) that are used to guide the journey of the researcher in the quest for meaning and understanding: identifying with the focus of inquiry, self-dialogue, tacit knowing, intuition, indwelling, focusing, and internal frame of reference. Identifying with the focus of inquiry is intimately related to the ability to immerse oneself into the research question and fully engage with the experience (Djuraskovic & Arthur, 2010). Identifying with the focus of inquiry is a prerequisite to

connecting with the experience of others. Self-dialogue occurs when the researcher journals or documents certain thoughts, feelings, memories related to the phenomenon. An integral part of self-dialogue is tacit knowledge. Tacit knowledge is the term used to describe knowledge that seems impossible to explain (Djuraskovic & Arthur, 2010). It is often associated with a 'gut feeling' or premonition that can only be felt and understood by the individual. Through self-discovery, tacit knowledge can become explicit, giving rise to greater meaning and a more universal understanding of a phenomenon. In addition to self-dialogue and tacit knowledge, intuition is an important component of the heuristic inquiry process. Moustakas (1990) claimed that intuition is not only important, but a vital component in the search for knowledge. Intuition allows the researcher to develop perception, perspective, and understanding. It also allows the researcher to experience illumination. Indwelling refers to the process of turning inward to gain insight (Djuraskovic & Arthur, 2010).

The focusing process occurs when the researcher brings portions of the experience that existed outside of consciousness, back into consciousness (Moustakas, 1990). Finally, the internal frame of reference, as Moustakas (1990) stated, serves as the base for all knowledge. The researcher must honor the essence of his or her experience, thoughts, feelings, perceptions, and meanings (Djuraskovic & Arthur, 2010). These processes are unique to heuristic inquiry as they emphasize the creative approach to research and inquiry. The research process must be genuine, fluid, and flexible (Sultan, 2019).

### **Six Phases of Heuristic Inquiry**

Heuristic inquiry consists of six phases: initial engagement, immersion, incubation, illumination, explication, and creative synthesis (Sultan, 2019). The initial engagement marks the first encounter with a topic through a deeply personal experience with the potential for universal significance. It serves as the main question of the study and is central researcher's quest for self-reflection and self-searching (Mihalache, 2019). My first-born son was born at 33 weeks' gestation. He was immediately taken from the Labor and Delivery wing of the hospital to the NICU for medical intervention. He received life-saving care in the NICU for 42 days prior to discharge. Those 42 days were some of the most difficult days of my life. They profoundly shaped who I am and how I show up for my son as his mother. A few years later, my second child was born at 36 weeks' gestation. He was admitted to the NICU for seven days. While my experience was different following the birth of my second child, it left a profound imprint on me, nonetheless.

As of 2018, NICU admission rates had risen from 6.62% of births in the United States to 9.07% (National Center for Health Statistics, 2018). Nearly 1-in-10 births in the United States results in an admission to the NICU. Sultan (2019) stated that a phenomenon or experience that is felt so deeply often serves as the topic of inquiry that has chosen its researcher and becomes the connection between the internal and external experiences by which the research has already begun to take place. These profound experiences started my journey toward self-reflection and meaning making and served as the basis for the study.

Following the initial engagement, the next step of heuristic inquiry is immersion. Immersion is the process of connecting fully with the phenomenon or topic of inquiry (Sultan, 2019). The process of immersion allows the researcher to connect with the totality of the experience through curiosity, openness, reflection, openness, and vulnerability (Moustakas, 1990). This phase is marked by a shift in perception. When the researcher becomes fully immersed, the perception shifts from looking at a phenomenon, to looking at the world (e.g., people, places, readings, natures, etc.), from within it (Mihalache, 2019). Complete immersion in self-dialogue, reflection, and interviews with co-researchers can cause the recurrence of intense, potentially traumatic memories to be drawn to the forefront of the mind. While immersion is a necessary component of heuristic inquiry, it requires the awareness and knowledge of when to pause.

Complete immersion into the totality of the experience allows for incubation, the third phase of the heuristic process. Incubation permits for the cultivation of insight and integration (Sultan, 2019). Incubation is best described as a temporary retreat from the weight of the study (Mihalache, 2019). At times, detachment from the process may be necessary. The NICU experience has been identified as a period of tremendous stress, psychological distress, and emotional vulnerability. Conjuring up emotions associated with the memories of the NICU can be intense and difficult. The process of incubation is twofold: it allows the data that has been uncovered by the researcher to permeate and incubate while also giving the researcher a break from active self-discovery (Mihalache, 2019). Stages of immersion and incubation are often used to offset one another.

Illumination is the fourth phase of heuristic inquiry. Illumination is defined as an awareness or the unearthing of greater understanding (Douglass & Moustakas, 1985). During this phase of research, themes become illuminated (Djuraskovic & Arthur, 2010). Illumination is not a process that is planned, rather it occurs naturally in the form of revelations and hidden meanings (Mihalache, 2019). Illumination is marked by intuition and tacit knowledge, two processes outlined previously that help guide the journey of the researcher.

Following illumination is explication. Explication involves examining the themes that arose during the illumination phase of the heuristic inquiry process (Djuraskovic & Arthur, 2010). During this phase, the researcher often recognizes the distinct qualities of the lived experience that make it unique and life-altering. The pieces of the puzzle begin to form a single picture during this phase. Creative synthesis is the final phase of heuristic inquiry. This phase involves the integration of data obtained through interviews with the co-researchers with the themes identified during the explication phase (Moustakas, 1990). Creative synthesis often takes the form of a narrative depiction of the human experience (Djuraskovic & Arthur, 2010).

## **Literature Review**

### **Neonatal Intensive Care Unit (NICU)**

#### ***Medical Complications at Birth***

The birth of a child is a stressful experience for many parents. The potential for complications and the stress surrounding the unknown can seem endless for parents anticipating the arrival of a new baby. Stalled labor, perinatal asphyxia, congenital

anomalies, infections, difficult births, and problems with the umbilical cord are merely a few unforeseen complications that can occur during childbirth (Brelsford & Doheny, 2020; Kazemi et al., 2020). Many complications can result in an immediate admission to the NICU. There are also many co-morbidities such as genetic syndromes, cardiac disease, lung disease, gastrointestinal diseases and neurological diagnoses that require extensive surgical interventions following birth (Nelson et al., 2022). When newborns require immediate medical intervention, surgery, or medication, they are often admitted directly to the NICU so that neonatologists and other medical professionals can monitor their condition with around-the-clock care.

### ***Preterm Neonates & Complications***

Medical intervention immediately following birth due to complications or other medical circumstances can occur when an infant is born full-term (e.g., 40 weeks' gestation) or preterm. Newborns born prior to 37 weeks' gestation are considered preterm neonates and are at an increased risk of requiring medical interventions in the NICU (Talisman et al., 2022). While complications, co-morbidities, and infections can lead to preterm birth, most preterm births occur spontaneously (World Health Organization, 2023). There are three classifications of preterm newborns based upon gestational age. Newborns born at less than 28 weeks' gestation are considered extremely preterm, newborns born between 28 weeks and 31 weeks, 6 days are considered very preterm, and newborns born between 32 and 37 weeks are considered moderate to late preterm (World Health Organization, 2023). According to the U.S. Centers for Disease Control and

Prevention (2022) 10% of newborns born in the United States are born prematurely each year.

Many preterm newborns face health complications that can cause both short-term and long-term medical concerns (Mayo Clinic, 2023). Short-term complications can include problems relating to breathing, the heart, the brain, temperature control, blood, metabolism, and the immune system. Preterm babies often face difficulty breathing because their lungs are not fully developed. As such, it is not uncommon for premature newborns to experience respiratory distress syndrome (Mayo Clinic, 2023). It is also not uncommon for premature newborns to experience problems related to their blood (e.g., anemia and jaundice). Many preterm newborns have either not developed enough red blood cells, or their blood may contain an overabundance of yellow-colored substance called bilirubin, which causes an infant's skin and eyes to appear yellow (Mayo Clinic, 2023). Since a preterm infant's immune system was not afforded the opportunity to develop fully prior to birth, many preterm newborns are at a greater risk of developing infections or illnesses.

Long-term complications associated with premature birth can include cerebral palsy, difficulty learning, vision problems, hearing problems, dental problems, and behavior and mental health problems. For instance, premature newborns are more likely to experience attention deficit hyperactivity disorder (ADHD) than newborns who are born following a full-term birth (March of Dimes, 2019). Attention deficit hyperactivity disorder is a neurodevelopmental disorder. Symptoms often appear between the ages of three and six and continue through adolescence and adulthood (Shaw et al., 2023).



Attention deficit hyperactivity disorder can be very debilitating for children, as it impacts many areas of functioning (e.g., interpersonal relationships, school achievement, and self-esteem) (American Psychiatric Association, 2022).

Retinopathy is a vision problem that is also more likely to occur and therefore impact premature newborns. Retinopathy is an eye disease that develops when an infant's retina does not fully develop (March of Dimes, 2019). Retinopathy can result in long-term vision problems. In addition, preterm newborns may also sustain long-term health conditions such as asthma that impact them throughout their lives (Mayo Clinic, 2023).

Both short and long-term complications following a pre-term birth can significantly alter the trajectory of an infant's life. Research shows that over fifty percent of babies discharged from the NICU require special education due to various forms of neurodevelopmental disability such as cerebral palsy, blindness, hearing loss, or an intellectual disability (Msall et al., 2017). Medical advances have significantly decreased premature infant mortality. Unfortunately, many newborns do not survive the complications of a preterm birth (World Health Organization, 2023). According to the World Health Organization (2023) the leading cause of death in children under five years of age both in the United States and globally is prematurity. The Centers for Disease Control and Prevention estimates that the infant mortality rate in the United States was 5.4 deaths per 1,000 live births in 2021 (Centers for Disease Control and Prevention, 2021). While there are risk factors associated with preterm birth, the cause is not always clear.

## **Immediate Separation**

Parents are typically unprepared for a spontaneous preterm birth or a planned birth with unforeseen complications. Both often require an admission to the NICU for medical intervention. A newborn requiring medical care in the NICU can present as a unique challenge and an additional stressor for parents. Mothers often remain in the hospital for two to three days following an uncomplicated birth in most Western countries (Jones et al., 2021). In other countries, the duration of time a mother spends at the hospital is even less. In England, for example, 20% of women are discharged the day they give birth, and 38% are discharged the day following (Jones et al, 2021). This means the mother and her newborn are released from the hospital and able to start embarking on their next chapter of life at home. For families with infant's requiring care in the NICU, however, the transition is much different.

When babies are born that require immediate medical intervention, parents often feel a sense of loss as their baby is quickly removed from their possession and cared for by medical staff. The first hour of a newborn's life is often referred to as the "golden hour." There is an innate need for both a mother and her newborn to be close (Patriksson & Selin, 2022). Kangaroo care, often referred to as skin-to-skin contact, is recommended by many medical professionals as the gold-star standard method of enhancing "togetherness." Skin-to-skin contact is when there is contact between a naked infant and a parent's bare chest, often in the prone position (Patriksson & Selin, 2022). Skin-to-skin contact has been found to be a beneficial method of establishing togetherness for both mothers and fathers and their infant. Oxytocin is released during skin-to-skin contact,

reducing stress for both the newborn and the parent (Patriksson & Selin, 2022). There are also many additional benefits derived from skin-to-skin contact. Skin-to-skin promotes attachment, facilitates sleep, increases feelings of love, enhance breastfeeding after birth, and stabilize infant heart rate, blood pressure, and breathing (Patriksson & Selin, 2022).

Newborns who require additional medical care are often transferred to the NICU within two hours postpartum (Patriksson & Selin, 2022). This removes the opportunity for a mother to fully experience the “golden hour” or establish skin-to-skin contact. When parents visualize the first few moments of their newborn’s life, they often imagine holding their child in their arms, admiring the true miracle of life. Many NICU parents, however, have reported feeling extreme disappointment in the moments following childbirth, as their expectations do not match their new reality (Gundogdu et al., 2022). Parents have also reported feeling helpless with no sense of control in the moments immediately following childbirth as their newborn is removed and placed under medical care (Afyka et al., 2020; Gundogdu et al., 2022). For many parents, feelings of helplessness are merely the tip of the iceberg. Many parents also report feeling lonely and isolated as they watched their newborn vanish from sight (Afyka et al., 2020; Nelson et al., 2022).

Patriksson and Selin (2022) conducted an observational study during a four-month span at a hospital in Sweden. Data was collected in three different units: the labor ward, the maternity ward, and the NICU. Despite the researcher confirming the importance of skin-to-skin contact following childbirth, parents with infant's requiring care in the NICU included in the study experienced the most separation from their

newborn for various reasons. When the newborns were transferred to the NICU for medical intervention, they were separated either immediately following birth or within two hours postpartum (Patriksson & Selin, 2022). While there were instances that mothers required medical observation or rest herself due to complications or difficult births, other separations occurred due to deficits in organization, infrastructure, and resources (Patriksson & Selin, 2022). Regardless, many mothers with newborns observed in the study were not afforded the opportunity for immediate bonding with their infant. While the study was qualitative, it was an observational study. As such, rich, detailed data detailing the experience of mothers or fathers was not provided. This study allowed both mothers and fathers to give voice to their story and the impact of immediate separation from their infant.

### **NICU Environment**

There is an initial shock associated with the NICU experience that illuminates the intensity of a life-altering event such as childbirth (Brelsford & Doheny, 2020). Depending upon the length of stay, the exposure to certain aspects of the NICU environment such as noise, lights, and infections, can lead to a greater susceptibility of complications (Kirby et al., 2007). Such complications can lead to intellectual developmental delays, vulnerability to the development of chronic illness, impaired cognitive functioning, and neurodevelopmental disorders such as attention deficit hyperactivity disorder (ADHD), depression, anxiety, and/or autism spectrum disorder (ASD) (Fu et al., 2023).

The NICU environment can be overwhelming for parents. Machines, medication, medical jargon, and an uncertainty of the infant's prognosis can all lead to adverse psychological outcomes (Dickinson et al., 2020). The NICU is often noisy, and it is not uncommon for parents to experience communication difficulties with NICU staff (Galea et al., 2022). Additionally, parents can be separated from their infant for extensive durations of time. Parents are often not prepared to view a physically ill infant and can experience elevated distress when that infant is their own (Clotney & Dillard, 2013, Galea et al., 2022). Preterm newborns who are more fragile require more advanced care, which can force parents to shoulder caregiver roles they feel unprepared and unqualified to take on (Galea et al., 2022). These caregiving responsibilities can become exacerbated by the increased stress parents are already forced to endure.

The physical environment of the NICU can vary by facility or level of NICU. Level I NICUs are designed to operate as well newborn nurseries and provide resources to stabilize newborn newborns born prior to 35 weeks until they are transferred to a higher level of care (American Academy of Pediatrics, 2019). Level II NICUs can provide special care for newborns born after 32 weeks' gestation who are moderately ill and are not anticipated to require extensive care. (American Academy of Pediatrics, 2019). Level III NICUs can provide sustained life support and care for newborns born prior to 32 weeks' gestation. Level IV NICUs are traditionally regional NICUs that maintain a full range of medical interventions, subspecialists, surgeons, and anesthesiologists (American Academy of Pediatrics, 2019). Some NICUs are designed as multi-room experiences where multiple neonates and their families all share a single

space. Other NICUs contain private patient rooms that provide a more secure, intimate experience and facilitate bonding between parents and their infant (Barton et al., 2021). The physical environment of the NICU can have profound effects on parents. A qualitative study conducted by Barton et al. (2021) found that fathers of newborns in multi-room environments reported a significant increase in anxiety as they found themselves worried about the health and wellbeing of newborns and families aside from their own.

### ***NICU Discharge***

Hospital discharge is another experience unique to parents with newborns in the NICU. Parents are often taught how to care for their newborns; however, it is far less common for medical professionals to address the mental health needs of parents (Galea et al., 2022). For NICU parents who have an increased risk of developing symptoms of anxiety and depression, discharge from the NICU can serve to heighten the experience of those symptoms. Parents reported experiencing care-related anxiety due to feeling as though they were inadequate or unprepared to care for their infant (Gundogdu et al., 2022). Subthemes that emerged from a qualitative study conducted by Gundogdu et al. (2022) included fear of unmet care requirements, confidence, and a need for counseling. More specifically, parents expressed feeling as though they did not have the skills necessary to care for their premature infant and a fear as though they will unintentionally harm their newborn (Gundogdu et al., 2022). While the study produced valuable qualitative data, most study participants were mothers. Only four fathers were included in the study, limiting representation of fathering experiences. Additionally, researchers

focused more on examining parents' experience with the hospitalization process rather than their experience in the NICU. It was recommended that future studies explore parents' NICU experience. Data for the study conducted by Gundogdu et al. (2022) was collected in a state hospital in Turkey. Parental experiences in the United States may differ due to many factors such as medical care, values and beliefs, and mental health history. This study focused on the parents' experience rather than the parents' experience of the hospitalization process.

### **Parental Mental Health**

The lived experience of the NICU varies for every individual. Risk factors, protective factors, length of stay, medical diagnosis, and perception of social support are all factors that can influence the constructed experience of both mothers and fathers. In addition to the traditional worries of childbirth, parents with newborns born prematurely or in need of medical intervention often have additional thoughts about worst case outcomes such as death (Gundogdu et al., 2022). Parents can experience a heightened sense of fear, uncertainty, and even fatigue while attempting to manage the additional stress of the NICU and a medically fragile infant. Clinically significant levels of depression, anxiety, stress, and acute trauma were reported by 4-26% of parents within the first two weeks of a NICU admission (Dickinson et al., 2020).

While medical advances have significantly increased the survival rate of high-risk neonates over the past few decades, the additional stress experienced by parents can have both long and short-term effects (Erdei et al., 2021). The added stress can significantly impact their mental health, wellbeing, and close relationships (Loewenstein, 2021).

Loewenstein (2018) conducted a scoping review using of the social ecological model (SEM) as a framework to determine the breadth of literature connecting the mental health and wellbeing of parents with an infant admitted to the NICU. The NICU, an environmental stressor, was found to influence the mental health of parents on several levels within the SEM framework to include intrapersonal factors and interpersonal factors (Loewenstein, 2018). Intrapersonal factors include parent and infant characteristics, history of mental illness, birth trauma, birth weight, and gestational age (Loewenstein, 2018). Interpersonal factors include family cohesion, parent romantic relationships, marital status, gender difference, and social support (Loewenstein, 2018). Sixteen of the twenty-three studies included in the scoping review were conducted outside of the United States. Moreover, all 26 studies included in the scoping review utilized quantitative methodologies to examine the impact of the NICU on the psychological wellbeing of parents. Five qualitative studies met inclusion criteria for the scoping review. Due to the small number of qualitative studies, they were omitted from the review. Loewenstein (2018) identified that exploratory research, particularly about the experience of fathers with newborns in the NICU, is necessary to gain a better understanding about parental distress following a NICU admission.

Galea et al. (2022) conducted a scoping review of the literature in attempt to assess research related to the mental health of parents with infant in the NICU following discharge. The results of the review confirmed previous research highlighting the profound impact a NICU admission has on parents while their infant is hospitalized as well as after they have been discharged. Galea et al. (2022) found that anxiety,



depression, trauma symptoms, and elevated stress are only a few of the mental health issues experienced by NICU parents. Moreover, symptoms experienced by parents are often interconnected. Parents who experience mental health symptoms such as anxiety are more likely to also experience symptoms of depression or post-traumatic stress disorder (PTSD) (Galea et al., 2022). Perhaps more concerning is the link between high anxiety and psychopathology (e.g., post-traumatic stress disorder (PTSD) and mood disorders such as anxiety or depression). Parents who experience heightened anxiety are more likely to also experience or develop stress-induced psychopathology (Galea et al., 2022, Weger & Sandi, 2018).

The scoping review conducted by Galea et al. (2022) consisted of 59 articles. Of the studies included, 18 were longitudinal prospective studies, 10 were cross-sectional studies, seven were randomized controlled trials, four were quasi-experimental studies, three were mixed-methods studies, and three were secondary analyses of pre-existing datasets. Furthermore, five articles were literature reviews and four were informative papers. Of the 59 articles included in the scoping review, only two studies were qualitative in nature. Recommendations for future research included exploring the lived experience of NICU parents utilizing qualitative methodology (Galea et al., 2022). Most of the research included in the scoping review was focused on the impact of the NICU on mothers. The authors recommend that future studies include both parents. This study incorporated the lived experience of mothers and fathers.

In addition to anxiety, depression, and trauma, guilt and grief have been documented as emotions experienced by parents with newborns in the NICU (Dickinson

et al., 2020). While feelings of guilt and grief tend to be more fluid and transient, feelings associated with anxiety, depression, and trauma tend to remain high when compared to parents who give birth to term babies for at least six months (Dickinson et al., 2020). Dickinson et al. (2020) conducted a prospective, prevalence-based study using quantitative data from participants located in Queensland, Australia. Results indicated that twenty-two percent of mothers and four percent of fathers experienced clinically significant symptoms associated with depression, twenty-seven percent of mothers and eleven percent of fathers experienced clinically significant symptoms associated with anxiety, twenty-four percent of mothers and thirteen percent of fathers experienced clinically significant symptoms associated with stress, and fifteen percent of mothers reported clinically significant acute trauma symptoms within the first two weeks of the child's admission to the NICU. The symptoms experienced by parents did not completely dissipate following discharge. Twenty-one percent of mothers met criteria for generalized anxiety disorder three months following discharge, seven percent of mothers met diagnostic criteria for major depressive disorder three months following discharge, and six percent of mothers met diagnostic criteria for post-traumatic stress disorder three months following discharge (Dickinson et al., 2020).

The lived experience of parents in the NICU differs significantly. Lundqvist et al. (2018) conducted a qualitative study that included six parent couples located at a NICU in Sweden. The study was a descriptive phenomenological study. The authors interviewed participants after they were discharged from the NICU. Lundqvist et al. (2018) determined that mothers experienced an increase in physiological reactions that

led to significant loneliness and guilt tied to mothering roles and maintaining a relationship with their partner. Fathers, on the other hand, were found to experience more conflicts related to balancing the demands of their spouse, family responsibilities, and employment challenges (Lundqvist et al., 2018). According to Lundqvist et al. (2018) many parents included in the study presented as though they were unaware of their partner's needs, and there were topics that were often avoided or rarely discussed. Hames et al. (2020) also found that an admission to the NICU significantly impact perceived relationship quality between mothers and fathers. Parents endorsed experiencing lower relationship quality between admission and discharge and reported an increase in stress due to a discomfort in discussing the experience with their partner (Hames et al., 2020). The differences, when left unresolved, can lead to detrimental familial relationships.

The notion that the NICU is a vulnerable and challenging environment was confirmed by a study conducted by Lundqvist et al. (2018) who found that the stress faced by each parent negatively impacts the spousal relationship. The qualitative study was part of a larger quasi-experimental study that was conducted over a two-year span. While sixty mothers and fifty-eight fathers were included in the original study, the parent couples who were chosen for the phenomenological study were included because they provided the most robust narratives of NICU experiences. Fathers included in the study were Swedish men (Lundqvist et al., 2018). The mothers included in the study were born in several Scandinavian countries, all with differing values and beliefs. Each participant was interviewed one to two weeks following NICU discharge at the same hospital in Sweden. As such, the circumstances described may have influenced the

phenomenological description of the study (Lundqvist et al., 2018). This study included co-researchers from NICUs in multiple states, which provided greater diversity in data collection.

While there are many sources of stress that impact both mothers and fathers, one in particular is the perception of a newborn's illness as well as prognosis and treatment options. Hames et al. (2020) conducted a quantitative study that included 84 parents with infant's admitted to a Level II NICU in New Zealand. Results indicated that parents share similar stress trajectories throughout the NICU admission. More specifically, the stress experienced by both mothers and fathers decreased significantly from admission to discharge. When mothers believed their baby's condition was chronic long-lasting and doubted treatment efficacy, they reported experiencing higher levels of stress (Hames et al., 2020). Fathers experienced higher levels of stress when they perceived less control of the situation. More specifically, fathers experienced higher levels of stress when their infant was born at a younger gestation (Hames et al., 2020).

The study conducted by Hames et al. (2020) was the first to examine risk factors of parental stress at two important transition points of a NICU stay: admission and discharge. Moreover, findings from the study highlight the important role parental beliefs and perceptions about their infant's illness have on their mental health between the markers of hospital admission and discharge. These results can provide valuable insight to NICU staff and may serve to alleviate distress experienced by parents. Results of the study are likely not generalizable due to participant recruitment. All participants were recruited from a highly specialized teaching hospital New Zealand. Moreover, there were

only 20 fathers who participated in the study compared to 64 mothers. According to Hames et al. (2020) much less research has focused on paternal stress. Future studies should include the experience of fathers, as there are often feelings of hopelessness and confusion attached to a NICU admission (Hames et al., 2020). The authors also recommend between-group analysis to examine the relationship between the duration of NICU admission and distress risk factors (Hames et al., 2020). This study included narrative accounts that detailed in-depth descriptions of emotional and physical experiences of fathers with newborns in the NICU.

### ***Maternal Mental Health***

When expecting mothers imagine labor, delivery, and the birth of their child, rarely does their imagination include an environment filled with medical equipment and life-saving intervention apparatuses (Nelson et al., 2022). For mothers, this can lead to the experience of intense emotions and significant emotional distress. Mothers with infant's admitted to the NICU for less than two weeks had 19% greater odds of developing a clinically significant mental health diagnoses such as anxiety or depression (Beck et al., 2022) when compared to mothers whose newborns were not hospitalized in the NICU. Furthermore, mothers whose newborns were hospitalized for longer than two weeks had 37% higher odds of developing a mental health diagnosis when compared to mothers whose newborns were not hospitalized in the NICU following birth (Beck et al., 2022). Longer NICU stays were also correlated with a greater risk of developing anxiety and/or depression. The study confirmed that the odds of maternal mental health diagnoses increase when an infant is hospitalized in the NICU (Beck et al., 2022). While women

who identified as Black, Hispanic, and Asian were admitted more often to the NICU, more women who identified as White received mental health diagnoses (Beck et al., 2022).

The study conducted by Beck et al. (2022) included 533,080 women who delivered babies between 2010 and 2018. Data was obtained using Clinformatics Data Mart Database (CDM), a database that includes statistically deidentified health claims from all 50 states in the United States. The authors utilized the database to identify postpartum women who gave birth between 2010 and 2018. All women in the database were enrolled in employer-based health plans. The privately insured sample of mothers may not accurately reflect the association that exists between race and ethnicity and postpartum mental health (Beck et al., 2022). Moreover, due to the methodology, researchers could not address the causes of the mental health diagnoses, (Beck et al., 2022). Additionally, the study does not address differential rates of mental health diagnoses between races or ethnicities (Beck et al., 2022). Qualitative research was recommended to better understand the causes of mental health conditions.

One potential cause of maternal mental health diagnoses may be related to an inability to control a wide range of emotions experienced following NICU admission. Nelson et al. (2022) conducted a phenomenological qualitative study that included eight mothers with newborns in the NICU. The study was designed to explore the lived experiences of mothers who had newborns admitted to the NICU for at least one month. The study yielded five themes: the unanticipated journey, an emotional rollercoaster, a

mother's lost voice, roadblocks to mothering, and an unexpected layer to occupations related to mothering tasks (Nelson et al., 2022).

Overwhelmingly, mothers discussed the fear and concern they experienced for their preterm infant. Mothers reported they were unable to process all that was happening due to the fear of the unknown (Nelson et al., 2022). Mothers also stated the vast contrast of the emotions experienced often led to exhaustion. Mothers stated that they experienced significant sadness or fear, but, at the same time, experienced great pride in the strength of their babies (Nelson et al., 2022). They also reported experiencing distress due to various roadblocks they experienced. Newborns in the NICU often require significant medical care, which means doctors, nurses, and specialty occupations such as occupational therapists and physical therapists provide medical intervention. Mothers reported feeling as though they did not have the opportunity to care for their own infant (Nelson et al., 2022).

The study conducted by Nelson et al. (2022) allowed for the collection of rich data through multiple semi-structured interviews. The study also included a diverse population of mothers to include a Black mother, an older mother, and a young mother. Conversely, the study did not include fathers. It was recommended that future research include the lived experience of fathers. It was also recommended that future studies should consider families whose newborns were admitted to the NICU for less than one month, as their lived experiences may yield different thematic insights. This study included both mothers and fathers whose newborns have been admitted for varying durations ranging from one week to over 100 days.

Guilt is an emotion that many NICU mothers report experiencing. Specifically, NICU mothers have reported experiencing an extreme sense of guilt due to beliefs that their actions played a role in causing premature birth (Gundogdu et al., 2022). Mothers with newborns in the NICU are also at a greater risk of developing postpartum depression (PPD) (Galea et al., 2022). The immediate separation can also prove to be a very difficult experience for mothers to endure. Mourning and grief are not uncommon experiences for mothers with newborns in the NICU, as some mothers have reported feeling inadequate and unable to protect their newborn from pain and suffering (Gundogdu et al., 2022).

Mothers have also reported heightened anxiety about breastfeeding. The feeding schedule in the NICU is regimented and scheduled, making a mother's ability to breastfeed increasingly difficult. In addition, many newborns in the NICU can require feeding tubes. An inability to breastfeed as anticipated can become a source of additional stress for mothers who desire to breastfeed, as they are often relegated to a breast pump (Gundogdu et al., 2022). Nelson et al. (2022) also found that mothers reported feeling unheard as NICU staff cared for their infant. Moreover, medical jargon is common speak between members of the medical community but can lead to distress when mothers do not understand information pertinent to caring for their infant.

### ***Paternal Mental Health***

The NICU experience is unique to each parent. To date, most of the research has focused on the experience of mothers with newborns in the NICU (Dickinson et al., 2020). While the NICU can have a profound impact on mothers, the NICU can be a life changing experience for fathers as well. Results of previous research has supported the



notion that the NICU experience has the potential to impact the bonding that occurs between and parent and their infant (Barton et al., 2021). Additionally, fathers have reported a loss of control, both physically and emotionally (Barton et al., 2021). Fathers have also been found to experience symptoms associated with trauma, depression, and anxiety (Dickinson et al., 2020). Paulson and Bazemore (2010) conducted a meta-analysis review of paternal depression and found that fathers with newborns in the NICU reported depression rates of 10.4% immediately prior to and after birth, with elevations reported 3-6 months following birth.

While many mothers are robbed of an opportunity to establish skin-to-skin contact and an immediate bond with their newborn, fathers can also experience significant distress in the moments following childbirth. Barton et al. (2021) found that fathers reported experiencing immense sadness in not being able to touch or hold their baby right away. In addition, they reported difficult experiences coping with the immediate disappearance of their newborn. Barton et al. (2021) conducted a phenomenological qualitative study designed to explore the lived experiences of six fathers whose newborns were admitted to the NICU following childbirth. As part of their narratives, all six participants emphasized the profound experience of separation from their newborn. “You have two pieces of your heart laying on a table,” and “Watching and not even being able to touch your child right away... it’s hard” were two statements mentioned by participants in the study (Barton et al., 2021, p. 208).

The results of the study conducted by Barton et al. (2021) confirm that the NICU experience is a traumatic, stressful, and anxiety-inducing for fathers. The study

contributed to a growing body of research by shedding unique insight into a phenomenon. Fathers reported feeling as if they had no control or access to their own child (Barton et al., 2021). It was recommended that future studies continue to explore the experience of fathers following a NICU admission. In addition, it was recommended that future studies include fathers who anticipate a NICU admission, as the study conducted by Barton et al. (2021) included only fathers whose newborns were spontaneously admitted to the NICU. The present study will extensively capture the experience and perceptions of fathers with newborns in the NICU, building upon the study conducted by Barton et al. (2021). The present study will also include the experience of mothers, adding to the richness of the narrative.

### ***Long-Term Impacts***

The stress caused by the NICU experience has been found to impact parents for months and even years post discharge (Brelsford & Doheny, 2020). While the trajectory of symptoms associated with mental health disorders has been shown to decrease around the time an infant is discharged, there is sufficient evidence to suggest they are still present (Dickinson et al., 2020). When compared to parents of term babies, psychological distress such as anxiety, depression, and trauma, have been found to remain elevated for up to six months post birth (Dickenson et al., 2020). Anxiety, depression, and posttraumatic stress are only a few of the residual effects the NICU experience can cause (Brelsford & Doheny, 2020). The NICU experience has also been found to negatively impact family functioning for up to seven years after a preterm infant who was born at 32 weeks' gestation or earlier (Dickenson et al., 2020).

When parents with newborns in the NICU experience psychological distress, anxiety, depression, and trauma, they are at a greater risk of developing posttraumatic stress disorder (PTSD), especially if early intervention is not received (Galea et al., 2022). While such mental health symptoms can be treated and managed, they can escalate to more serious health issues and mental health disorders if left untreated. In a study conducted with 20 pairs of parents of preterm newborns, ninety percent of mothers and sixty-five percent of fathers exhibited clinically significant levels of depression during the NICU hospitalization, while eighty percent of mothers and sixty-percent of fathers exhibited clinically significant levels of depression one-year post-discharge (Salome et al., 2022).

The novel study conducted by Salome et al. (2022) was the first to research psychophysical wellbeing in mothers and fathers with newborns in the NICU during the first year of the baby's life. Researchers found that mothers experienced more mental and physical health challenges compared to fathers both during the NICU stay and at a one-year-follow-up visit (Salome et al., 2022). More specifically, mothers exhibited more symptoms related to anxiety and post-traumatic stress disorder (PTSD) when compared to fathers at a follow-up visit (Salome et al., 2022).

The longitudinal nature of the study allowed researchers to ascertain valuable gender-specific insight into parental psychophysical wellbeing post-discharge. While the study provided valuable insight, it was not without limitations. The authors identified that the quantitative study included a small sample size and a large drop-out rate. Moreover, there was not a control-group of parents of full-term newborns. The study relied on self-

report measures. It was recommended that more qualitative research is needed to further explore gender-specific differences in psychophysical wellbeing following discharge from the NICU. This study relied on detailed narrative accounts of both mothers and fathers following discharge from the NICU rather than self-report questionnaires.

### ***Adverse Health Behaviors***

The psychological distress experienced by parents can lead to adverse health behaviors. Dickinson et al. (2020) found that eighteen percent of parents reported consuming harmful levels of alcohol within the first two weeks of NICU admission. Compared to mothers, fathers engaged in significantly more alcohol use. Fourteen percent of parents endorsed consuming harmful levels of alcohol at a three-month follow-up (Dickinson et al., 2020). Alcohol use among fathers remained more elevated than alcohol use among mothers. There were 114 parents included in the study. Sixty-nine participants were mothers, and forty-five participants were fathers. Of the 114 participants included in the study, three met diagnostic criteria for suicidality (Dickinson et al., 2020). All were deemed low risk.

This study confirms the prevalence of psychological distress experienced by mothers and fathers with newborns in the NICU immediately following admission as well as at a three-month follow-up. While results yielded valuable information about the psychological function of mothers and fathers, data was obtained at a regional NICU in rural North Queensland, Australia. Participants in the study included many families from low-income households (nearly one third of study participants) (Dickinson et al., 2020). Moreover, nearly half of the parents who participated in the study had not obtained a high

school diploma. As such, rural parents were found to experience lower levels of psychological distress when compared to parents of higher socioeconomic status. Due to the participant demographics, findings may underestimate the prevalence of distress experienced by parents with newborns in the NICU and may limit generalizability of the findings (Dickinson et al., 2020). It was recommended that future research should include participants who represent a more generalizable sample population. Participants in this study represented a socioeconomic status that more accurately reflects the general population.

### ***Post-traumatic growth***

While there is substantial research highlighting the adverse impact a NICU hospital admission can have on the mental health and wellbeing of parents, there is less research focused on posttraumatic growth. Posttraumatic growth is a term used to describe positive psychological changes that occur after an individual copes with adverse or difficult life stressor (Bayarami et al., 2023). Aftyka et al. (2020) conducted a quantitative study that involved 82 parents whose children were hospitalized in the NICU. Results indicated that both mothers and fathers experienced some form of posttraumatic growth such as a higher sense of self-worth and effectiveness, a change in self-perception, feeling like a better person, an increase in confidence in themselves and their capabilities (Aftyka et al., 2020; Bayarami et al., 2023). Aftyka et al. (2020) found that women experienced more posttraumatic growth than men, likely due to the use of religion as a coping strategy. Women are more likely to seek out emotional or spiritual support in times of crisis and trauma. This research affirms the importance of emotional

support, healthy coping strategies, and psychological support for both men and women enduring difficult circumstances. The authors of the study recommend future research on posttraumatic growth to identify protective factors that facilitate positive change in a difficult situation (Aftyka et al., 2020). Participants in this study were given the opportunity to discuss coping strategies, transformative experiences, and posttraumatic growth.

### **Conclusion**

When an infant is admitted to the NICU for medical intervention following birth, parents experience a tremendous amount of stress. The NICU experience can alter the trajectory of parents' lives, as research has shown they can experience both short and long-term adverse effects. Parents experience many forms of psychological distress, to include depression, anxiety, acute stress, and posttraumatic stress (Loewenstein, 2018). Many preterm births occur spontaneously and without precipitating factors. This experience often leaves parents shocked and unprepared for the NICU journey and the emotional rollercoaster they are bound to endure (Patriksson & Selin, 2022). While mothers and fathers both experience distress, the experiences of each parent can differ greatly. Quantitative research has confirmed the impacts of a NICU admission on the mental health of mothers and fathers. More research is needed, however, to fully understand the lived experience of mothers and fathers with infant in the NICU (Loewenstein, 2018).

### **Addressing the Gap**

At present, there is limited qualitative research regarding the lived experience of parents with newborns in the NICU. Based on results of an extensive literature review of current research, it has been identified that researchers have primarily focused on the experience of mothers with newborns in the NICU (Barton et al., 2022; Nelson et al., 2022). Few studies have explored the lived experience of fathers with newborns requiring medical intervention immediately following birth (Barton et al., 2022). The experience of navigating the NICU is not the same for any two parents. To understand the profound impact a NICU admission can have on all members of a family, it is imperative to understand the lived experiences of both mothers and fathers (Thomson et al., 2023).

Future qualitative studies about the lived experience of NICU parents are recommended to provide a more robust, detailed narrative of the NICU experience and to supplement current quantitative research (Loewenstein, 2018). Heuristic inquiry is a qualitative methodology that allows for in-depth exploration of the subjective experience and the overall essence of the experience (Moustakas, 1990). To date, there has not been a qualitative heuristic inquiry conducted to explore the lived experience of both parents with newborns in the NICU.

Heuristic inquiry provides a unique research perspective that connects the researcher to a phenomenon and allows for the construction of meaning (Djuraskovic & Arthur, 2010). Many researchers have relied on self-report measures to collect data about the impact of the NICU on parents' mental health (Brelsford & Doheny, 2020). Heuristic inquiry allows for the collection and integration of rich, meaningful data through

informal conversational interviews. Moreover, heuristic inquiry allows researchers to understand a phenomenon more fully and in greater depth. This study was conducted by me, the researcher, and included eight participants who served as co-researchers. Each participant is the parent of a newborn who has required medical intervention in the NICU. This study gave voice to the integrative perspective of a unique human experience.

In chapter 3, I have presented the research methods and the analysis strategy I utilized to address the current gap in the literature.



## Chapter 3: Research Method

### **Introduction**

The purpose of this heuristic inquiry was to understand the nature and meaning of the lived experience of parents with newborns in the Neonatal Intensive Care Unit (NICU). The intent of the study was to explore the subjective experience of the phenomenon using a purposeful sample of mothers and fathers who have had a newborn that required medical intervention in the NICU. Furthermore, my focus was to provide a platform for mothers and fathers to give voice to their experience and provide detailed insight into the various ways the profound experience of a NICU admission has manifested in their lives. I sought to identify coping strategies that have helped parents manage the stressors associated with the NICU, inform mental health professionals of resources that will facilitate posttraumatic growth, and increase the standard of care given to parents with newborns in the NICU.

In Chapter 3 I have discussed the research design and rationale, role of the researcher, methodology, issues of trustworthiness, ethical procedures, and provide a summary of the main points of the chapter.

### **Research Design and Rationale**

The primary research question was: what is the lived experience of mothers and fathers with newborns in the neonatal intensive care unit (NICU)? The primary concept of the study was the essential nature of the human experience and the meaning attached to the phenomenon. The impact of the NICU on psychological distress, wellbeing, and parent-infant attachment has been studied, primarily through a quantitative lens.

There have been qualitative studies conducted exploring the lived experience of mothers with newborns in the NICU. Research detailing the lived experience of fathers with newborns in the NICU, however, is much scarcer. Experts in the field recommend continued exploration of father's experiences (Barton et al., 2021; Hames et al., 2020; Nelson et al., 2022). Moreover, it is recommended that future studies explore the lived experience of NICU parents through qualitative research to provide detailed narratives and shed insight into the NICU experience (Galea et al., 2022; Lundqvist et al., 2018; Thomson et al., 2023). Future research is also recommended to explore parents' experience as a couple (Gundogdu et al., 2022).

Heuristic investigation allows for the exploration of a subjective experience of a phenomenon using the researcher as an integral component of the study. Heuristic research, then, allowed for a more in-depth exploration of the NICU experience for both mothers and fathers, effectively filling the gap that currently exists in the literature. To date, this study is the first heuristic investigation conducted to highlight the unique subjective experience of the primary researcher and coresearchers, establish connections between narratives, and intertwine meaning and understanding to a shared phenomenon between members of the research team (Sultan, 2020).

The research approach utilized was heuristic inquiry. While heuristic inquiry is one of the lesser-known phenomenological approaches to qualitative research, heuristic inquiry has been used by a variety of researchers spanning many domains. A heuristic inquiry is a type of qualitative study that is exploratory, introspective, reflexive, humanistic, authentic, creative, and discovery oriented (Moustakas, 1990). Heuristic

inquiry was developed by a humanistic psychologist named Clark Moustakas. Moustakas was driven to create a process that could help researchers explore the subjective nature of a human experience and derive meaning (Moustakas, 2015). Moustakas explored his own personal phenomenon using heuristic inquiry and subsequently explored the phenomenon in others. Thus, the goal of heuristic inquiry is to understand the unique experiences of the researcher and other members of the research team (Sultan, 2019).

Heuristic inquiry has been used in clinical psychology, education, anthropology, sociology, medicine, counseling, art therapy, and psychotherapy (Blau, Bach, Scott, & Rubin, 2013; Kenny, 2012). Heuristic inquiry differs from many qualitative research designs, primarily due to the role of the researcher. It is often assumed in qualitative research that the researcher has a personal commitment to the phenomenon being studied. In heuristic inquiry, however, the researcher must become immersed as the main focus of the research (Brisola et al., 2016).

I used the six phases of heuristic inquiry as a roadmap to guide the research design and data collection process. Moustakas (1990) described the processes involved in heuristic inquiry as identifying with the focus of inquiry, internal dialogue, tacit knowledge, intuition, indwelling, focusing, and an internal frame of reference. Heuristic inquiries provide unique challenges for the researcher, as heuristic inquiries are grounded in personal experience. As part of the immersion process, the researcher must disengage from the desire to find a specific outcome and instead adopt a learner mindset guided by curiosity and vulnerability (Moustakas, 1990). While imperative for a researcher to connect to the experience, it is also important to manage the interplay between one's own

experience and the experiences of the co-researchers. Through the illumination process, a deeper understanding often emerges for the researcher that may unintentionally evoke emotions, past trauma, or other concerns. As such, it is important for the researcher to exercise boundaries, reflexive bracketing, and self-care.

In addition to the six phases, there are seven processes that are central to heuristic inquiry. The seven processes include identifying with the focus of inquiry, self-dialogue, tacit knowing, intuition, indwelling, focusing, and internal frame of reference.

(Moustakas, 1990). The seven processes facilitate exploration and a creative approach to self-reflection, inquisition, and meaning making. I utilized the seven processes to discover meanings, the essence of the phenomenon, and to build connection with the co-researchers. The phenomenon explored in this study was profoundly personal and has influenced the values, beliefs, and decisions parents have adopted. I know first-hand the influence the NICU experience has had on my life, my relationships, and my ability to parent my children.

### **Role of the Researcher**

A heuristic inquiry involves exploring the living experience using the researcher as an integral part of the study. To explore the subjective experience of a phenomenon, heuristic researchers focus their work on the interaction between their own lived experience and the lived experience of others who have experienced a similar phenomenon (Moustakas, 2015). As such, the role of the researcher in a heuristic inquiry is to move through the phases of initial engagement, immersion, incubation, illumination,

explication, and creative synthesis outlined by Moustakas (1990). The overall role of the researcher is to develop a more intimate understanding of the central question.

Due to the nature of heuristic inquiry, participants of the study have been referred to as co-researchers. This approach eliminates any power differences that may have existed and facilitated open, honest, and transparent narrative accounts by all participants. Additionally, heuristic research is relational and reflexive in nature. As such, heuristic researchers must remain completely immersed and part of the study (Sultan, 2018). Researcher biases, beliefs, and values are tied to the process of the research. This can make it difficult to create and maintain appropriate relational boundaries with co-researchers. To address this concern, I engaged in explorative reflexivity to inform ethical decision making and maintain appropriate boundaries with the research team (Sultan, 2018).

The subject matter I asked the co-researchers to revisit did provoke previously experienced trauma or thoughts that may led to intense emotional experiences related to anxiety, depression, guilt, and sadness. Prior to the interview, I informed participants that they can pause the interview at any moment, ask to move forward to another question, or express their emotions with no fear of judgement. I identified mental health support services located in geographic proximity to each of the participants and encouraged the use of mental health services if the interview causes the resurgence of psychological distress. These resources are found in Appendix 1.

In addition to considering the psychological wellbeing of the co-researchers, I took great care in considering and managing my own thoughts and emotions. A heuristic

inquiry requires the researcher to engage in copious amounts of self-reflection, which requires rigor, integrity, and emotional availability (Brisola & Cury, 2016). Moreover, the researcher must be open to one's own experience. This openness allows the participants to open him- or herself to contribute to the deepening and understanding of the experience (Brisola & Cury, 2016). As such, the researcher carries a heavy weight and a significant responsibility throughout the investigation. Self-care practices and reflexive journaling were necessary for me to prioritize throughout the study to lessen the heaviness of the process.

## **Methodology**

### **Participant Selection Logic**

Participant selection plays an integral role in heuristic inquiry. According to Moustakas (1990) there is not a specific number of participants required for heuristic inquiry, but rather a range of participants. Each participant must have their own unique experience of the phenomenon (Brisola & Cury, 2016). Moreover, all participants must be willing to enter into a dialogue with the researcher. I identified three criteria for inclusion in the study. Co-researchers must (a) be a parent of a newborn who required medical care in the NICU; (b) be discharged from the NICU; and (c) speak English. Furthermore, the study required participation from both mothers and fathers. As such, an equal number of mothers and fathers were selected for inclusion in the study.

I identified one exclusion criteria for my sample. Parents were excluded from the study if their newborn was still receiving medical care in a NICU environment. Parents with newborns currently in the NICU were excluded from the study because they are in

the midst of a difficult experience and have not had adequate time to process or reflect on the meaning of the phenomenon.

I recruited eight participants that became co-researchers of the study. Purposeful sampling was used to recruit participants, as is often used in qualitative research to both identify and select participants that will provide valuable, rich accounts of the phenomenon being studied (Palinkas et al., 2016). Purposeful sampling involves deliberately selecting individuals that will help the researcher obtain the information necessary to answer the research question (Ravitch & Carl, 2021). While Moustakas (1990) identified ten to fifteen participants as an ideal number of participants to achieve profound depictions of the experience, the number is fluid. Sultan (2019) noted that, since data collection from each co-researcher is analyzed before an interview with another co-researcher, the number of participants included may change. I used saturation to determine the number of participants needed for the study. Creswell (2013) defined saturation as the point in a study that data is deemed to yield no new insight. I analyzed participant data prior to interviewing more participants and checked findings for saturation prior to continuing data collection (Sultan, 2019).

Participants were recruited using digital flyers posted online in various NICU support groups on the social media platform Facebook. The digital fliers were posted in Facebook support groups created for NICUs located in Colorado, Missouri, Iowa, Texas, and North Carolina. In addition, I coordinated a meeting with a Perinatal Nurse Navigator at a NICU local to Colorado Springs. The Perinatal Nurse Navigator is responsible for the coordination of the NICU Mentor Mom Program as well as the NICU Facebook Support

page. According to Moustakas (1990) it is important to recruit participants who are interested, committed, and willing to reflect upon their experience and communicate a rich narrative. The inclusion criteria for the sample was posted on digital fliers and posted in the Facebook support groups, which helped determine co-researcher eligibility. Exclusion criteria was noted on the digital fliers. The digital flyers can be found in Appendix A.

### **Instrumentation**

Data was collected using individual informal conversational interviews. Interviews were conducted using an online platform called Microsoft Teams using an interview guide of semi-structured interview questions. Interviewing is the most common method of data collection in heuristic inquiry for two reasons: (a) it is difficult to fully understand the essence of a phenomenon without understanding the participants who have experienced it, and (b) a heuristic inquiry is relational in nature (Moustakas, 1990). I met with each participant for approximately thirty minutes to one hour and conducted interviews utilizing a process called embodied relational interviewing. Embodied relational interviewing involves the inclusion of thoughts, emotions, sensations, intuition, memory, and perception into the interview process (Sultan, 2018; Sultan, 2019). Interviews were conducted with the mother and the father separately. In the one instance two participants were married, a joint interview was conducted with both parents. Gundgodu et al. (2022) recommended that future qualitative studies explore parents' experience as a couple.



The interviews were designed to feel informal, as the process is viewed as a collaboration to co-construct understanding (Sultan, 2019). Interviews conducted using Microsoft Teams were completed using a password protected conference room. The session was locked prior to the start of the interview to ensure privacy. I controlled the waiting room and allowed participants to enter the conference room when the previous participant has finished his or her interview and logged out of the platform.

A set of instructions specifically aligned with heuristic inquiry was developed to help the researcher prepare the co-researchers for the study (Moustakas, 1990). These instructions include informing the co-researchers about the purpose of the study, the research design, and the role of the researcher (Moustakas, 1990). Moreover, it is also recommended to communicate the following: (a) inclusion and exclusion criteria for participation, (b) expectations throughout the data collection process, (c) confidentiality and storage of data, (d) evaluation of findings, (e) rights of co-researchers, (f) contact information for the researcher, and (g) Institutional Review Board (IRB) contact information (Sultan, 2019). These guidelines were communicated to the participants prior to the start of the study and also confirmed during the interview.

Patton (2002) identified three approaches to heuristic interviews: informal conversational interview, general interview guide, and semi-structured interview. While Moustakas (1990) acknowledged informal conversational interview as the interview methodology most closely aligned with heuristic inquiry, it is not the most appropriate option for a formal study. As such, I have chosen to use semi-structured interviews. Semi-structured interviews involve utilizing a specific set of predetermined questions for

all co-researchers (Sultan, 2019). The flexibility of a semi-structured interview provided co-researchers opportunities to generate spontaneous discourse, naturally emergent dialogue, and in-depth reflection on questions that resonate more deeply. Probing questions were also used throughout the interview to aid in validity and increase the accuracy of understanding. All participants spent time reflecting on the experience and answered all questions with honest, rich detail.

The first question, “Please describe your experience as a parent with a newborn in the NICU in as much specific detail as possible,” was broad in nature, and was designed to serve as a starting point that allowed each co-researcher to begin describing the deeply meaningful experience in a way they felt comfortable. Additional probes such as, “What was the environment like?” and “What was the most difficult situation you endured?” were designed to help co-researchers reflect and explore the experience more deeply and guide the conversation if the co-researcher experienced difficulty expressing what the experience was like. Additional questions were designed to inquire about the mental health, coping strategies, self-care practices, and overall impact of the experience. I informed participants that they could stop the interview at any time, should intense emotions resurface following in-depth self-reflection. The pre-determined questions can be found in Appendix B.

Embodied relational interviewing is the specific interview method that was used to collect data in an informal and conversational manner. Embodied relational interviewing involves the inclusion of thoughts, emotions, sensations, intuitions, memory, and perception (Sultan, 2019). Sultan (2019) has outlined several key concepts associated

with embodied relational interviewing such as (a) being open and interested, (b) creating an agenda, but remaining flexible, (c) opening with a brief, informal conversation, (d) inviting the co-researcher to participate in deep breathing or some form of relaxation exercise, and (e) engaging in embodied relational listening.

Given the nature of the study and the potential that the interview itself would likely cause co-researchers to re-live a potentially traumatic experience, I developed preparatory strategies to address distress. I utilized the Qualitative Research Distress Protocol (QRDP). The QRDP is a participant-centered tool that helps participants or co-researchers navigate distress during the data collection process (Whitney & Evered, 2022). The QRDP is a guide to help the researcher respond to participant distress and minimize any countertransference that may occur (Whitney & Evered, 2022).

Furthermore, I identified mental health support services within geographical proximity to co-researchers. While it was important to address the potential for distress among co-researchers, it was also important for me, the researcher of a heuristic inquiry, to effectively manage the potential to experience my own distress. In addition to reflection and self-care, I maintained a journal of my thoughts, emotions, and any other noteworthy experiences throughout the data collection and data analysis process and took breaks when necessary.

### **Procedures for Recruitment, Participation, and Data Collection**

Data was collected from mothers and fathers who have had newborns that required medical intervention in the NICU. Following approval from the Institutional Review Board (IRB), I recruited participants from Colorado, Iowa, Missouri, Texas, and

North Carolina utilizing digital flyers posted in NICU support groups on Facebook. Once participants opted in for the study, I contacted them in person, via telephone, or on Microsoft Teams. Reviewed the purpose of the study, inclusion criteria, and the process of data collection (e.g., 60-minute informal interviews), expectations for data collection, confidentiality, contact information for myself, and IRB contact information. When participants agreed to become co-researchers of the study, I scheduled them for individual interviews. All interviews were conducted using the online program Microsoft Teams. Interviews lasted anywhere from thirty to sixty minutes. Data collection for heuristic inquiry has no definitive timeline (Sultan, 2019). Decisions about ceasing data collection are determined based upon an assessment of need (e.g., saturation has been reached or a co-researcher has withdrawn from the study) (Sultan, 2019).

Each participant completed a consent form (Appendix B). Consent was obtained via email. When consent was not obtained prior to the interview process, it was obtained at the time of the interview via recorded oral consent. Each session was recorded. In addition, I recorded my own observational notes. Participants were reminded about the importance of anonymity. I communicated that the final manuscript will be void of any personally identifiable information such as names, information pertaining to demographics that could be used to identify a co-researcher, and other personal details such as stress addresses or email addresses (Laryeafio & Ogbewe, 2023). Once the interview was completed, each participant was debriefed. Data will be retained in a secured location to protect the confidentiality of participants for five years prior to it being destroyed.

### **Data Analysis Plan**

Once an interview with a co-researcher was completed, it was organized and prepared for analysis. Heuristic inquiry requires the researcher to become intimately familiar with the content (Sultan, 2019). To do so, complete immersion was required. Moustakas (1990) established the following guidelines for complete immersion in preparation for data analysis: (a) vertical and horizontal reading of observational notes and interview content and (b) vertical and horizontal listening and viewing of audio and video recordings. The terms vertical and horizontal refer to a deep and broad understanding of the data (Sultan, 2019). It may be necessary to listen to audio and video recordings multiple times to achieve complete immersion and an intimate understanding of the uniqueness of each co-researcher (Sultan, 2019).

Each interview transcribed and summarized. As a member of the research team, my intent was to transcribe the data myself, as data analysis is an ongoing process that begins once data collection begins (Sultan, 2019). Microsoft Teams was selected as the platform to conduct the interviews because it was designed with a built-in transcription feature. Other professionals or data transcription services do not have familiarity with the topic, the experience, or the co-researchers (Sultan, 2019). As such, I engaged in a process called embodied relational transcription. Sultan (2019) defined embodied relational transcription as a transcription strategy challenged by the researcher that is embodied, multidimensional, holistic, reflexive, and member checked. An embodied relational approach allows the researcher to use language as a vehicle to describe and convey the holistic experience of the co-researchers and connect cognition with

physiology and physical experiences. Following each interview, I immediately downloaded the transcript of the interview and read through each line, ensuring an accurate account of the co-researcher's dialogue was captured while the interview was fresh in my mind.

Constructivism and social constructivism, two of the frameworks that underpinned the study, were integral to data analysis. The essence of social constructivism is that an individual's reality is constructed based upon the subjective meaning-making of personal experience or a specific phenomenon (Ponterotto, 2005). The core component of social constructivism is that both cognition and experiences are interconnected as well as socially constructed through multiple realities of subjective experience (Creswell, 2009; Sultan, 2019). To successfully capture the meaning of the NICU experience for parents with newborns who have been admitted to the NICU, a comprehensive and subjective reality must be constructed between the co-researchers. By nature, a heuristic inquiry is a collaborative experience between the researcher and his or her co-researchers. Analyzing the data through the lens of constructivism and social constructivism allows for experiences of the researcher and co-researchers to become universal (Sultan, 2019).

To ensure accuracy in co-researcher narratives, I ensured verbatim accounts were transcribed. In addition to exact dialogue exchanges between the co-researchers and myself, I transcribed observational notes about emotional expressions (e.g., facial expressions or tears), socially-relationally based changes (e.g., changes based upon relational interactions such as empathy), and spiritual changes (e.g., honoring experiences

that hold deep meaning) (Sultan, 2019). Once the interviews were transcribed, the participants each received a summary. This allowed participants the opportunity to ensure accuracy.

Data analysis for heuristic inquiry differs from data analysis for most qualitative studies. Data analysis for heuristic inquiry does not involve line-by-line transcription (Sultan, 2019). Data analysis for heuristic inquiry focuses more on giving equal value to all content provided by co-researchers to identify and generate themes. Moustakas (1990) outlined the following recommendations for data analysis: (a) obtain data from one co-researcher at a time (b) fully immerse into the data (c) allow adequate time for rest and incubation (d) return to data to identify essential themes (e) begin data collection with another co-researcher (f) gather individual depictions and resume immersion, incubation, and reflexivity (g) return to raw data, select two or three data sets from co-researchers, and formulate themes and (h) develop a creative synthesis.

Once the transcriptions are obtained and finalized, Sultan (2019) recommends full immersion with the recording and notes taken during the interview to not only listen to what the co-researcher has said, but to connect with silence, laughter, emotions, and the lived experience. While analyzing the transcripts, I focused on three components: content, context, and interrelationships. The content of raw data included responses from the co-researchers directly related to the research question, responses through discussion not directly related to the research question, and specific phrases, images, and examples verbalized by the co-researchers (Sultan, 2019). The context of raw data includes interpersonal and intrapersonal dynamics as well as sociocultural dynamics (Sultan,

2019). Focusing on these three components facilitated meaning-making and provided an organizational framework for identifying themes. To aid the analysis process, NVivo 14 software program was used.

Deciphering themes is an integral part of the data analysis process. The interview transcripts should be analyzed holistically, rather than in groupings of words or phrases (Sultan, 2019). A holistic approach to data analysis facilitates the identification of big picture patterns. Sultan (2019) suggests utilizing reflection questions as well as the seven processes and six phases of heuristic inquiry, notes, and personal reflections, to see the data, live the data, and identify emerging themes. An openness to words, phrases, or nuanced descriptions of the phenomenon are also important in identifying significant themes from the interview transcriptions.

Following theme identification and the illumination process, there are four methods of heuristic theme explication. The four methods are individual depictions, composite depictions, exemplary portraits, and creative synthesis (Sultan, 2019). Individual depictions involve a holistic illustration of each co-researcher's experience. Composite depictions involve the integration of the co-researchers' experiences. Exemplary portraits include demographic information about co-researchers (Sultan, 2019). Finally, creative synthesis involves the process of transforming raw data to a creative manuscript capturing the essence and meaning of the lived experience.

### **Issues of Trustworthiness**

According to Lincoln and Guba (2008) trustworthiness is an important component of a research study, as it speaks to the evaluation of the study's worth. Trustworthiness



involves establishing four specific components. The four components include: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 2008).

### **Credibility**

Participants were interviewed using an online platform called Microsoft Teams. As I interviewed participants, recorded my observations and incorporated those observations into data analysis. Shenton (2004) suggests triangulation as a method of ensuring internal validity in qualitative research. Triangulation was achieved by incorporating both interview and observable data. I also implemented member checks following data analysis and transcription. Member checks ensure the accuracy of the data by allowing participants to review whether their words match their intention (Shenton, 2004).

Credibility is also established using reflective commentary Shenton (2004). Reflexivity is an integral component of heuristic inquiry. Heuristic inquiry relies on the researcher's ability to reflect on the complexities of another's experiences as well as their own experiences (Sultan, 2019). Throughout the data collection and data analysis processes, I engaged in reflective commentary using reflective note taking and journaling.

### **Transferability**

Transferability, or the ability for a study's findings to be applicable to other contexts, was facilitated using thick descriptions. Sultan (2019) affirmed that thick descriptions involve clear communication of the research process to increase transparency and transferability. Clear, detailed descriptions of the sampling procedure,

theoretical, and conceptual framework, and findings of the study will allow future researchers to apply aspects of the study to other populations or contexts (Sultan, 2019).

### **Dependability**

Dependability is an important component of qualitative research. After extensively reviewing the literature, it was determined there was a gap that required further study. Based on the gap and authors' recommendations for future research, it was determined that a heuristic inquiry was the approach best suited to answer the research question. I outlined and described the methodology used for the study as well as the data analysis techniques implemented in detail so that the work can be repeated by future researchers (Shenton, 2004). I ensured transparent audit trails to establish dependability.

### **Confirmability**

Due to the subjective nature of heuristic inquiry, the researcher's personal biases, attitudes, values, and experiences can influence interactions with co-researchers and data analysis. To quell any potential biases or countertransference experienced during data collection, I engaged in reflectivity. I kept an introspective journal to record my biases, values, beliefs, attitudes, and perspectives throughout the data collection and data analysis processes (Sultan, 2019).

### **Ethical Procedures**

Approval was obtained through the IRB at Walden University prior to proceeding with data collection. Participants were recruited for the study using digital fliers posted online in NICU support groups in Iowa, Colorado, Missouri, Texas, and North Carolina. I am a member of a support group called "NICU Graduates" that was created as a support

group for parents who have had newborns that required medical intervention in the NICU at Cantura St. Francis Hospital in Colorado Springs, Colorado. I am also a member of the NICU Mentor Mom Program serving as a mentor to NICU moms in Greater Colorado and Kansas. I contacted colleagues in these groups and organizations to aid in publicizing the study.

Individuals who were interested in participating in the study contacted me directly. Written informed consent was obtained prior to the initial interview. In the event consent was not obtained prior to the interview, it was obtained at the time of the interview. The consent process ensured that participants understood that they have the right to participate or opt out of the study at any time (Sultan, 2019). Obtaining proper consent was also an important step in maintaining confidentiality. Consent is a useful tool to provide assurance to co-researchers that their names will not appear in any publication, to include reports, articles, or presentations (Laryeafio & Ogbewe, 2023).

Prior to the interview, I informed participants of the following: (a) inclusion and exclusion criteria for participation, (b) expectations throughout the data collection process, (c) confidentiality and storage of data, (d) evaluation of findings, (e) rights of co-researchers, (f) contact information for the researcher, and (g) IRB contact information (Sultan, 2019).

Interviews were conducted using the platform Microsoft Teams, a secure online platform. Interviews were conducted using a private conference room with waiting room features activated. This ensured that that all participants remained private from one another. I communicated to all participants that they had the option of withdrawing from

the study at any time without fear of negative repercussion. Furthermore, I reiterated the importance role anonymity played in the study. I communicated to co-researchers that information collected would be barren of personal details such as address, email, name, or other information pertaining to demographics that could be used somehow to identify a co-researcher (Laryeafio & Ogbewe, 2023). Ensuring the protection of co-researchers' identities helped to protect their privacy and maintain confidentiality that aligns with ethical standards. Participants were also informed that they would not be compensated for participating in the study.

Following data analysis, transcripts were shared with the co-researchers to ensure accuracy in their narrative. Transcripts with redacted personal information have also been shared with my committee members. The names of the co-researchers and their newborns have been de-identified to ensure confidentiality and privacy. The interview data and observations will be saved for five years. After five years, data will be destroyed by deleting digital files and shredding paper materials.

Heuristic inquiry is deeply personal and relies on in-depth reflection on the parts of the researcher and co-researchers. As such, it was important for me to uphold core ethical principles relating to the rights, dignity, worth, and wellbeing of the co-researchers who agree to participate in my study (Sultan, 2019). Interview questions triggered intense affective reactions and traumatic memories, which is not uncommon when using methodology such as heuristic inquiry (Adler & Adler, 2002; Fogel, 2009). This was discussed with participants prior to the start of the interview. I utilized the Qualitative Research Distress Protocol (QRDP) during the interviews to help me remain

attuned to the psychological needs of co-researchers and mitigate the potential for countertransference should distress arise (Whitney & Evered, 2022). Furthermore, I located professional resources available in geographic proximity to participants should they need mental health support following the interview. I also engaged in researcher reflexivity throughout the data collection process to ensure that I was mindful of the potential for the experience of personal distress, as full emersion was required throughout the heuristic inquiry process.

### **Summary**

In this chapter, I identified the qualitative design that was most appropriate to answer the research question, which was Moustakas' (1990) heuristic inquiry approach. I discussed in detail my role as the researcher. The role of the researcher is much different in heuristic inquiry methodology, and it was important to outline the integral role that I played as a catalyst of the integration of meaning-making that took place throughout the study. I outlined the methodology, to include the strategy I employed to recruit participants as well as the strategy I used to obtain informed consent and interview participants. I discussed specific issues related to trustworthiness: credibility, transferability, dependability, and confirmability. Furthermore, I outlined ethical considerations accompanied with conducting a heuristic inquiry. Chapter 4 provides a summary of my data and subsequent findings.

## Chapter 4: Results

### **Introduction**

Parents who give birth prematurely or who have newborns that require medical intervention in the neonatal intensive care unit (NICU) are at an increased risk of experiencing psychological distress (Loewenstein, 2018). The experience of a NICU admission can impact the health and wellbeing of parents and caregivers both instantaneously and long-term. To date, there have been no qualitative heuristic inquiry studies conducted to explore and understand the lived experience of parents with newborns requiring medical care in the NICU. The purpose of this heuristic inquiry was to understand the subjective meaning and lived experience of mothers and fathers with newborns in the NICU. The “lived experience,” a cornerstone of phenomenological human science, refers to an immediate consciousness that is given meaning through reflection (Van Manen, 2016). The study was guided by one research question. This was as follows:

#### **Research Question:**

What is the lived experience of mothers and fathers with newborns in the neonatal intensive care unit (NICU)?

The following section of this chapter discusses the study setting, including the demographic details of participants. Next, a discussion of data collection and data analysis procedures is provided. The chapter also discusses how trustworthiness of data was established. This is followed by the presentation of results. The chapter ends with a summary.

### **Setting**

The co-researchers in this study were parents whose newborns required medical care in the Neonatal Intensive Care Unit (NICU). Specifically, their newborns received treatment in NICUs located in Colorado, Missouri, Texas, North Carolina, and Iowa. The NICUs are part of healthcare facilities or hospitals within the aforementioned states. Newborns born prematurely are often admitted to the NICU due to medical complications. Overall, NICUs are nurseries within a hospital that offer around-the-clock care to newborns who are born prematurely or who require specialized medical care (Loewenstein, 2018). The co-researchers in this study were not influenced by any personal or organizational conditions. Thus, the interpretation of the study results was not influenced by personal or organizational conditions.

### **Demographics**

A total of eight co-researchers were included in this study. Each of them was a parent of a newborn who required medical care in the NICU. Furthermore, each parent's child or children had been discharged NICU, and all co-researchers spoke English. To effectively fill the gap in the literature, an equal number of mothers and fathers were included in the study; that is, four mothers and four fathers. The co-researchers represented a wide range of geographic proximity, as their newborns were admitted to NICUS in the following states: Colorado, Iowa, Missouri, North Carolina, and Texas. All participants identified themselves as white. Guided by social constructivism, and the notion that knowledge and experiences are interconnected and socially constructed or co-constructed by a group of people, co-researchers were selected based upon duration of

NICU admission (Creswell, 2013). The shortest NICU admission was eight days, while the longest was 120 days. The earliest gestation, in weeks, when a parents' baby was born was twenty-five weeks, and the latest was thirty-eight weeks, which is considered a full-term birth.

As the researcher, I was aware of each of the co-researchers' real names. It was important to maintain confidentiality and anonymity. As such, a pseudonym was used to identify each co-researcher. Specifically, an alphanumeric pseudonym was created for each of the eight co-researchers, and this was used instead of their actual names. The pseudonyms were as follows: Co-Researcher 1 (CR1), CR2, CR3...CR8. The use of pseudonyms ensured that their identities remained protected. Table 1 shows the demographic details of the co-researchers.

**Table 1**

*Participant Demographics*

<b>Participant pseudonym</b>	<b>Gender</b>	<b>Race</b>	<b>Gestation at Birth</b>	<b>Length of NICU Admission</b>	<b>Important Family Dynamics</b>	<b>Geographic Location</b>
Co-researcher 1	F	White	38 weeks	8 days	Firstborn	Missouri
Co-researcher 2	M	White	33 weeks & 36 weeks, 2 days	42 days & 7 days	Firstborn	Colorado
Co-researcher 3	M	White	35 weeks	8 days	Firstborn	Missouri
Co-researcher 4	M	White	25 weeks, 6 days	105-110 days (girl) & 120 days (boy)	Firstborn twins	North Carolina
Co-researcher 5	F	White	35 weeks, 6 days	13 days	Second born	Iowa
Co-researcher 6	F	White	32 weeks, 4 days	28 days	Firstborn	Texas
Co-researcher 7	M	White	34 weeks	21 days	Second born	Colorado
Co-researcher 8	F	White	25 weeks	110 days	Firstborn	Colorado

*Note.* Demographic characteristics of co-researchers



### **Data Collection**

Following IRB approval, social media flyers were posted in NICU support groups on Facebook, an online platform, as was described in Chapter 3. Parents who were interested in participating in the study contacted me directly, and a subsequent interview was scheduled. Data was collected from four mothers and four fathers who had newborns that required medical intervention in the NICU. Interviews were immediately transcribed as part of the immersion process. Following the eighth interview, it was deemed that saturation had been met.

Saturation is unique to qualitative research as there are no statistical analysis methods, confidence intervals, or other metrics to report (Guest et al., 2020). To determine saturation, I began by identifying broad themes as I interviewed co-researchers and immediately reviewed the interview transcript. I continued the process of identifying themes and similarities and weighed each piece of new data against the information and themes that had already been identified (Guest et al., 2020). To ensure a range of different experiences, I selected co-researchers who had newborns requiring various durations of NICU admissions, ranging from eight days to 120 days. As I transcribed the seventh and eighth interview, I noticed that novel themes were ceasing to emerge. Additionally, eight interviews allowed for an even number of interviews to be conducted with both mothers and fathers.

Informed consent was obtained from each participant via email from participants. For those who could not provide consent prior to the interview process, the consent was obtained at the time of the interview via recorded oral consent. Co-researchers were

reminded about the importance of anonymity. Owing to the sensitive nature of the topic of the study, I ensured that the final manuscripts did not include any personally identifiable information including names, information pertaining to demographics that could be used to identify a co-researcher, and other personal details such as stress addresses or email addresses, as recommended by Laryeafio and Ogbewe (2023). This ensured that participant privacy and anonymity were maintained.

All eight semi-structured interviews were conducted using Microsoft Teams, an online platform used for private meetings. A semi-structured interview guide was used as a template for conducting the interviews. The semi-structured interview guide consisted of open-ended questions and prompts to further the discussion if necessary. Interviews were conducted over a period of two weeks. The duration of the interviews ranged from 22:16 minutes, which was the shortest interview and was conducted with CR3, to 52:51 minutes for the longest interview, which was with CR4. Table 2 shows the details of each interview that was conducted with each participant. The details include the length of each interview, interview location, and number of single-spaced transcript pages. The average number of transcript pages and average interview duration are also provided.

**Table 2**

*Details for the Semi-Structured Interviews*

<b>Participant Pseudonym</b>	<b>Interview Location</b>	<b>Duration (Minutes)</b>	<b>Number of Pages (Single-Spaced)</b>
Co-Researcher 1	Microsoft Teams	30:13 minutes	36
Co-Researcher 2	Microsoft Teams	23:21 minutes	20
Co-Researcher 3	Microsoft Teams	22:16 minutes	15

Co-Researcher 4	Microsoft Teams	52:51 minutes	34
Co-Researcher 5	Microsoft Teams	32:38 minutes	53
Co-Researcher 6	Microsoft Teams	40:12 minutes	54
Co-Researcher 7	Microsoft Teams	27:13 minutes	21
Co-Researcher 8	Microsoft Teams	50:55 minutes	68
<b>Total</b>		<b>278.19 minutes</b>	<b>301</b>
<b>Average</b>		<b>34:77 minutes</b>	<b>37.625</b>

*Note.* The eight semi-structured interviews had average duration of 34:77 minutes.

The default Microsoft Teams recorder was used to record the interview sessions. During each interview, I recorded observations about participants' tone of voice, emotions conveyed, processing pauses, and points of emphasis. Microsoft Teams was also used to transcribe the interviews. Following each interview, I downloaded the transcription and ensured an accurate, verbatim narrative was captured. The recording was only completed after permission from the co-researcher was obtained. Once transcription for each interview was complete, it was sent to the participant for validation.

The process of immersion continued following the interview and transcription to determine when saturation was met. While additional participants expressed interest in participating in the study, saturation was obtained after eight interviews were conducted. Participants were recruited from five states, to include Colorado, Iowa, Missouri, North Carolina, and Texas.

During each interview, probing questions were asked. Probing questions allowed for the elicitation of additional information beyond an initial response. Probing questions were used when there was a pause in dialogue or when further exploration about the participant's experience was deemed as important. No unusual circumstances were noted

during the interviews. After completing an interview, participants were debriefed. Data is stored in a secure location to protect the confidentiality of participants, where it will remain for five years prior to it being destroyed.

### **Data Analysis**

In this study, data analysis was performed in a manner consistent with the steps outlined by Moustakas (1990). To aid the analysis process, NVivo 14 software program was used. Data analysis for heuristic inquiry is different from data analysis for other qualitative studies as it does not involve line-by-line transcription (Sultan, 2019). Instead, data analysis for heuristic inquiry is mainly focused on giving equal value to all content provided by co-researchers to identify and generate themes (Sultan, 2019). Data analysis in heuristic inquiry is an ongoing process that starts as soon as data collection begins (Sultan, 2019). Thus, in this study, data analysis started when the collection of data began. Moreover, when analyzing the gathered data in this study, my focus was to give equal value to all information provided by each of the eight parents in order to discover themes.

The following steps outlined by Moustakas (1990) were followed: (1) initial engagement, (2) immersion, (3) incubation, (4) illumination, (5) explication, and (6) creative synthesis. The six steps, as Moustakas (1990) pointed out, draw the researcher into higher states of understanding and focus. In addition, they are both reiterative and recursive throughout the heuristic inquiry process (Sultan, 2019). They are described below.

#### **Step 1: Initial Engagement**

Initial engagement is where the researcher becomes one with the phenomenon of focus, and notices synchronizations, where theme is expressed (Moustakas, 1990). It serves as the main question of the study and is central researcher's quest for self-reflection and self-searching (Mihalache, 2019). The initial engagement served as the catalyst for this study because it was the first encounter with a deeply meaningful experience, or the phenomenon being explored. My children were both admitted to the NICU after childbirth. My oldest son was born at 33 weeks' gestation and spent 42 days in the NICU. Similarly, my second-born son was born prematurely and spent seven days in the NICU. While the NICU admissions were different in duration, they both shaped my life significantly.

### **Step 2: Immersion**

The second phase of data analysis in heuristic inquiry is the immersion phase. Immersion involves fully connecting with the phenomenon through curiosity and reflection (Moustakas, 1990; Sultan, 2019). In this step, I immersed myself fully into the collected data. Furthermore, I introspected, reflected, re-lived traumatic experiences, connected with co-researchers about their deeply personal experiences, and made meaning from the data. By fully immersing myself with the recording and notes taken during the interview, I was able to listen to what each co-researcher communicated and connect with silence, laughter, emotions, and the overall lived experience.

While immersing myself into the transcripts and my observational notes, three main components were the subject of focus: content, context, and interrelationships. The content of raw data included responses from the co-researchers directly related to the

research question, responses through discussion not directly related to the research question, and specific phrases, images, and examples verbalized by the co-researchers (Sultan, 2019). The context of raw data included interpersonal and intrapersonal dynamics as well as sociocultural dynamics (Sultan, 2019). Focusing on these three components facilitated meaning-making and also provided an organizational framework for identifying themes. The immersion process allowed me to connect with the totality of the experience through curiosity, reflection, openness, and vulnerability, as recommended by Moustakas (1990). Complete immersion in self-dialogue, reflection, and interviews with co-researchers resulted in the recurrence of intense, traumatic memories that were drawn to the forefront of the mind. Responses from the co-researchers were used to create codes as shown in

**Table 3**

*Codes and Corresponding Quotes from Co-Researchers*

<b>Codes</b>	<b>Quotes</b>
PTSD	CR6: “I think I probably had some undiagnosed postpartum anxiety. I’m not sure if this would be true PTSD”
Caring nurses	CR4: “Some of the nurses were amazing were there and were present and were very focused and caring.”
Task-oriented	CR6: “I was very task oriented and that moment like, OK, I’m doing everything for [my baby].”
Supportive staff	CR3: “But like I said, the staff there was so, so supportive”

*Note.* Codes were created from co-researchers’ quotes

**Step 3: Incubation**

Incubation is a temporary pause from the weightiness of the study (Mihalache, 2019). The incubation process is twofold. First, it allows the data that has been uncovered by the researcher to permeate and incubate, and secondly, it gives the researcher a break from active self-discovery (Mihalache, 2019). This study required many pauses and periods of rest during the incubation phase. Djuraskovic and Arthur (2010) posited that incubation is a phase in heuristic inquiry that serves as a designated break, allowing the researcher to become detached from intense immersion and inner workings of the study. This phase also allowed for greater clarification as I was able to clarify various patterns and ideas that were emerging from the data. Perhaps most importantly, the incubation phase allowed me reset mentally and emotionally following interviews, as some of the co-researchers interviewed discussed traumatic experiences in great detail.

**Step 4: Illumination**

Illumination refers to an awareness or the unearthing of greater understanding (Moustakas, 1990). Themes become illuminated in this stage (Djuraskovic & Arthur, 2010). Illumination occurs naturally in the form of revelations and hidden meanings, as it is not a planned process (Mihalache, 2019). This step is marked by intuition and tacit knowledge. In this study, I deciphered themes during the illumination phase. A vital part of the data analysis process entails deciphering themes (Moustakas, 1990). The researcher analyzed the interview transcripts holistically, rather than in groupings of words or phrases, as recommended by Sultan (2019). A holistic approach to data analysis facilitated the identification of big picture patterns and themes. Furthermore, an openness

to words, phrases, and nuanced descriptions of the phenomenon were crucial in identifying significant themes from the interview transcriptions. Table 4 shows the themes that were discovered in the data. The themes were formed by combining related categories, which had been created by combining related codes.

**Table 4**

*Identified Themes*

<b>Themes</b>	<b>Categories</b>	<b>Codes</b>
NICU staff mostly supportive and reassuring but others were less caring	Supportive and reassuring staff Less caring staff	Caring nurses, supportive doctors, lack of confidence in nurse, empathetic nurses, rude doctor, insensitive nurses
Spousal and familial support were important	Spousal support Familial support	Support from spouse Support from sister Support from in-laws Support from parents Support from husband
Experienced stress, trauma, depression, PTSD, and postpartum anxiety at NICU	Trauma and stress PTSD and anxiety Depression	PTSD, stressful situation, traumatic birth, anxiety, depression
Lack of mental health checkup, education on coping with anxiety, and follow-up after discharge	Lack of mental health checkup and coping strategies Lack of follow-up	No coping strategies, no discharge information about getting therapy, no follow-up after NICU, no mental health checks at NICU, no support after discharge, no support in therapy
Became more grateful, empathetic, and patient, and felt humbled as a result of the NICU experience	Grateful and empathetic Patient and humbled	Be more patient, felt humbled, felt more grateful, became more empathetic

*Note.* Fives themes were identified in the data.

**Step 5: Explication**

Explication occurs when the researcher examines themes that arose as a result of immersion, incubation, and illumination (Moustakas, 1990). In this study, I completed the



explication step of data analysis by carefully examining each of the five themes that arose from the data. The themes were examined to ensure that themes did not contain overlapping ideas or expressed the same overarching idea. Moreover, this step allowed for the assurance that sufficient data from interview transcripts supported each theme. There are four methods of heuristic theme explication, including individual depictions, composite depictions, exemplary portraits, and creative synthesis (Sultan, 2019). Individual depictions in this study involved a holistic illustration of each co-researcher's experience. Composite depictions involved the integration of the co-researchers' experiences. Exemplary portraits included demographic information about co-researchers (Sultan, 2019). Demographic details of each of the eight co-researchers has been provided in the 'Demographics' section of this chapter.

### **Step 6: Creative Synthesis**

This step involves transforming raw data to a creative manuscript capturing the essence and meaning of the lived experience (Moustakas, 1990). Creative synthesis also involves the integration of data obtained through interviews with the co-researchers with the themes identified during the explication phase (Moustakas, 1990). Creative synthesis often takes the form of a narrative depiction of the human experience (Djuraskovic & Arthur, 2010). A narrative depiction of the human experience of the co-researchers is provided in the 'Results' section of this chapter and includes verbatim quotes from the participants.

### **Evidence of Trustworthiness**

Trustworthiness is an important component of a research study. This is because it speaks to the evaluation of the study's worth (Lincoln & Guba, 1985). Trustworthiness involves establishing four specific components. The four components include: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). These are discussed in the following sub-sections.

#### **Credibility**

The first essential component of trustworthiness that was established was credibility. This component, as Lincoln and Guba (1985) pointed out, refers to a measure of the truth value of qualitative research. In this study, credibility was established through triangulation as data were gathered through two different sources, namely semi-structured interviews and observations. According to Shenton (2004), triangulation is a method of ensuring internal validity in qualitative research. The researcher in this study interviewed the co-researchers via Microsoft Teams meetings. While conducting the interviews with participants, my observations were recorded and incorporated into data analysis. Thus, triangulation was achieved by incorporating both interview and observable data. Credibility was also established through member checks. I implemented member checks following data analysis and transcription. Member checks ensured the accuracy of the data by allowing participants to review whether their words matched their intention (Shenton, 2004). All the eight co-researchers verified that the data gathered from them through interviews were accurate.

Moreover, credibility was established using reflective commentary. Reflexivity is a vital aspect of heuristic inquiry. Heuristic inquiry relies upon the ability of the researcher to reflect on the complexities of another's experiences as well as their own experiences (Sultan, 2019). Throughout the processes of data collection and data analysis, I engaged in reflective commentary using reflective note taking and journaling.

### **Transferability**

The second essential component of trustworthiness that was established in this study was transferability. This is understood as the degree to which the findings of a qualitative research could be applied to other settings, populations, and/or contexts (Lincoln & Guba, 1985). To enhance transferability in this study, the thick descriptions were utilized. Sultan (2019) affirmed that thick descriptions involve clear communication of the research process to increase transparency and transferability. Detailed descriptions of the research process have been provided in Chapter 3 of this dissertation. Furthermore, clear, comprehensive descriptions of the sampling procedure, theoretical, and conceptual framework provided in Chapter 3 and the thorough descriptions of findings of the study in Chapter 4 will allow future researchers to apply aspects of the study to other populations or contexts.

Thick descriptions of the co-researchers have also been provided to further enhance transferability, which are as follows. The co-researchers included parents of newborn babies who required medical care in the NICU, whose babies were discharged from the NICU, and the parents could speak the English language. Additionally, the participants included both mothers and fathers. They resided in the states of Texas, North

Carolina, Missouri, Iowa, and Colorado. By gathering data from the eight co-researchers by means of semi-structured interviews, I obtained detailed narratives that allowed for a greater understanding of the lived experience of mothers and fathers with newborns in the NICU.

### **Dependability**

Dependability was the third aspect of trustworthiness established in this study. Dependability ensures that the research can be repeated by using the same content, methods, and participants to produce similar results (Shenton, 2004). To ensure dependability, I outlined and described heuristic inquiry, the methodology chosen for this study, in great detail in Chapter 3. Chapter 4 contains the detailed data analysis techniques that were utilized to identify themes that emerged from the interviews (Shenton, 2004). Chapter 5 provides an evaluation of the study's effectiveness and a reflection provided by the researcher (Shenton, 2004). Furthermore, transparent audit trails have been established and kept in a secure manner.

### **Confirmability**

The final aspect of trustworthiness that was established in this study was confirmability. Lincoln and Guba (1985) mentioned that confirmability entails proving that the study is neutral and was not influenced by the researcher's biases or assumptions. Confirmability was enhanced by avoiding researcher biases. Heuristic research is generally subjective in nature (Sultan, 2019). In this study, the researcher's personal biases, attitudes, values, and experiences might have been influenced thorough the course of the study and following interactions with co-researchers. To quell any potential biases

or countertransference experienced during data collection, I engaged in reflectivity. I kept an introspective journal to record my biases, values, beliefs, attitudes, and perspectives throughout the data collection and data analysis processes.

In addition, confirmability was enhanced through member-checks. Each of the eight interview participants was allowed to confirm that my interpretations of their data accurately reflected their views, perspectives, and experiences. Lastly, confirmability was enhanced through the expert panel review of the interview guide, as well as through the field test.

## Results

The purpose of this study was to understand the lived experience of mothers and fathers with newborns in the NICU. The results are presented in this section. The findings are presented comprehensively. The results are organized by themes. In total, five themes emerged from the analyzed. Table 5 provides a summary of the themes.

**Table 5**

*Research Question and Theme*

<i>Research Question</i>	<b>Themes used to address the research question</b>
<b>RQ1:</b> What is the lived experience of mothers and fathers with newborns in the neonatal intensive care unit (NICU)?	<p><b>Theme 1:</b> NICU staff mostly supportive and reassuring but others were less caring</p> <p><b>Theme 2:</b> Spousal and familial support were important</p> <p><b>Theme 3:</b> Experienced stress, trauma, depression, PTSD, and postpartum anxiety in the NICU</p> <p><b>Theme 4:</b> Lack of mental health checkup, education on coping with anxiety, and follow-up after discharge</p>

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**Theme 5:** Became more grateful, empathetic, patient, and felt humbled as a result of the NICU experience

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*Note.* Five themes addressed the research question

### **Research Question 1**

The following was the research question for this study: *What is the lived experience of mothers and fathers with newborns in the neonatal intensive care unit (NICU)?* This question was answered by five themes that were discovered in the analyzed interview data. These included: (1) NICU staff mostly supportive and reassuring, but others were less caring; (2) spousal and familial support were important; (3) experienced stress, trauma, depression, PTSD, and postpartum anxiety in the NICU; (4) lack of mental health checkup, education on coping with postpartum anxiety, and follow-up after discharge; and (5) became more grateful, empathetic, and patient, and felt humbled as a result of the NICU experience. These are discussed below:

#### ***Theme 1: NICU Staff Mostly Supportive and Reassuring but Others Were Less Caring***

Data supporting this theme were drawn from seven out of the eight co-researchers. As per the findings, while most of the NICU staff (to include nurses and doctors) were reassuring and supportive, a few others proved to be less caring. CR1 talked about the NICU nurses being great people, saying, “I cannot say enough great things or praise about Mercy Hospital and the NICU nurses. They were true angels.” CR3 indicated that the nurses were very supportive, saying:

So they were very supportive on letting us, you know, see her and kiss her for the first time before they took her back. But uh, the nurses were amazing, and they

were very informative, and they talked to, talked us through everything because, you know, that was our very first child.

CR1 spoke about how the nurses were supportive and caring, saying:

They were open to answering all my questions. They even provided advice for me as a parent saying, you know what, skip one of the overnight wake windows while you're here. We're gonna take care of her. You just get rest.

CR2 noted that the nurses and doctors were very reassuring. He said:

I definitely felt better after speaking to the doctors and the nurses. I just knew that I truly believed from day one that everything was gonna be OK after getting there and talking to the doctors and being reassured that he was okay, they were helping him to the best of their ability.

CR5 spoke about an experience with a less caring and rude doctor. This participant stated:

There was [a certain doctor], sorry if that is incorrect to say, but he was, he was like kind of rude to me. And I remember we were getting ready to go home. And [my baby] just needed to be circumcised, and this doctor used two small, it's called a gomco when they, like, circumcise. So, they nicked [my baby] and he started bleeding really bad. And I remember getting, like, really upset with this doctor because he blamed [my baby]. He said your son's penis is too big for our instruments.

CR4 talked about having a regrettable experience with a nurse who was left to look after CR4's child, but the child later on developed complications. This participant said:

My spouse and I to this day like she has regrets. She regrets leaving.

Everything was good. We left. We weren't confident in the nurse.

It was one of the nurses that we were like, oh, we're not sure and that, you know, [our baby] had major complications the day that we left. Like that night it was bad. And so that's when a lot of other bad things happened.

In summary, the first theme suggested that mothers and fathers with newborns in the NICU interacted with nurses and doctors who were largely supportive and reassuring. Co-researchers indicated that NICU staff provided care for the newborn and the family. Furthermore, many co-researchers discussed the trust and faith they placed in the neonatologists, neonatal nurse practitioners, and NICU staff to care for their newborn. Co-researchers also noted, however, that there were NICU doctors and nurses who were less supportive or empathetic. On a couple occasions, co-researchers indicated that there were a few doctors and nurses they did not trust or who had seemingly made medical mistakes when caring for their newborn. This theme was supported by data from seven interview participants. The theme helps to answer the research question.

***Theme 2: Spousal and Familial Support Were Important***

All eight co-researchers contributed to this theme. The findings showed that support from family members as well as from the spouse was integral during the NICU experience. CR1 talked about assistance from his sister, saying, “my sister kind of helped me out.”



CR4 indicated that he got familial support from his mother, father, and spouse's relative. He noted, "My mom and dad would like call, text, and ask how are they doing? My spouse's sisters, my spouse's mom, everybody checking in."

CR6 spoke about assistance from her mother as well as from her spouse. She stated, "My mom was kind of taking on the role of taking care of me. And then my husband would kind of do the same thing. He'd be like, you need to eat a sandwich."

CR4 talked about wanting to help his wife to recover faster, saying, "I wanted to be a, you know, supporter of my wife, helping her through this, making sure she was okay, finding ways to get her recover." Similarly, CR3 noted:

So, for me, I was just like trying to gather as much information as I could and be like super supportive because I knew that actually she was going through, you know, a lot on her end. You know, she had hormones and everything that comes with having a baby. And then she had had a C-section. So, for me it's just, you know, I took on, you know, being supportive and transmitting information as I get it from a because I got to go see [our baby] right after. And I said they had to go prep [my wife] and get her. Take care of her before she could come over.

To sum up, the second theme indicated that mothers and fathers with newborns in the NICU found support from family members and from their spouses was very important during the NICU experience. All four of the fathers interviewed discussed, to some extent, their intent to lighten the mental, physical, and emotional load of their spouse and support them any way they could. Several co-researchers discussed the difficulty of not having family within geographic proximity. Those who did, described

the immense support they felt from their family and having a resource nearby to help them process the experience and provide support. Several co-researchers also indicated that the experience strengthened their marriage and provided them with the belief that, as a couple, they could survive any adversity. The theme was supported by data from all the eight participants. The theme addressed the research question. The next sub-section presents the third theme.

***Theme 3: Experienced Stress, Trauma, Depression, PTSD, and Anxiety in the NICU.***

All the eight co-researchers contributed to this theme. The theme demonstrated that the mothers and fathers with newborns in the NICU experienced trauma, stress, depression, post-traumatic stress disorder (PTSD), and postpartum anxiety. CR1 mentioned that the experience caused her anxiety. She stated, “As if I didn't have enough anxiety already. It gave me horrible anxiety and I think that just like I had said previously, not wanting to end up in the ICU again with her.” CR2 also talked about having feelings of anxiety, saying:

I was very anxious about what the kid, what our son, was going to look like and maybe the issues that he was going to have to battle being born so early, then getting there once again. Very, very anxious.

CR4 talked about experiencing stress, saying:

I showed the kids on FaceTime with my family to let them see them, which my spouse was very not comfortable with a lot because she didn't want people seeing them that way with the wires everywhere and they're being so tiny, especially

when things are bad. You never wanted to see them like that, it was also another stressor for me.

CR6 mentioned that she had anxiety and PTSD, saying, "I think I probably had some undiagnosed postpartum anxiety. I don't know if this would be true PTSD." Similarly, CR8 indicated that her spouse developed depression and PTSD from the NICU experience, saying, "I think with my spouse it's been harder because I think he has some PTSD and I honestly think that he has some depression, PTSD stuff going on from this and that he has not fixed yet.

CR2 indicated that the situation was stressful, saying, "If he [my son] was going to have any issues growing up far as brain function or muscle function or anything like that, that it was actually quite stressful, the whole unknown." CR4 spoke about traumatizing experiences, saying:

They check for the heartbeat. We were just praying to hear a heartbeat.

We were so worried. My spouse was in utter pain, like unbearable pain.

They had to, like, give her some sort of shot. I think it was morphine and something else and like it was just freaking awful. To be honest with you, like that experience was traumatizing for you know, an average person that cannot handle that well, and somebody with a lot of I guess capability for resilience and handling challenging adverse situations, it really requires somebody to have that skill set already.

CR6 spoke about, "trauma experience from when my water broke." CR8 also talked about trauma experiences, saying, "you're living the trauma and you're surviving

the trauma. And after the trauma is over, that's when you can start processing the trauma.”

In summary, the third theme indicated that mothers and fathers with newborns in the NICU experienced stress, trauma, depression, PTSD, and high anxiety levels. Many co-researchers acknowledged the “NICU” rollercoaster, a term often used to describe the wide range of emotions experienced throughout a NICU admission. Co-researchers indicated that during the NICU admission they were in “survival mode” simply attempting to manage the fear, panic, and stress that became part of their lives. Co-researchers reported experiencing psychological distress caused by many different facets of a NICU admission, including the fragility of their newborn, medical complications, separation from their baby, perceived nonsupport from NICU staff, and uncertainty. This theme was supported by data from each of the eight interview participants. The theme helped to answer the research question.

***Theme 4: Lack of Mental Health Checkup, Education on Coping with Anxiety, And Follow-Up After Discharge***

Data supporting this theme were drawn from six out of the eight co-researchers. The findings indicated that according to the participants, there was a lack of mental health checkup at NICU, they were not provided with education on how to cope with post-partum anxiety during the NICU period. CR6 spoke about a lack of mental health checkup and mentioned that there needs to be some sort of mental health screening to identify people with conditions such as depression. This participant noted,

I think I would have been more forthcoming about it if there would have been a better mental health screen in place, not just for suicidal thoughts, because I definitely didn't have that aspect of like a postpartum depression that I feel like most of us women associate with. I wish there were better systems in place to check for a multitude of mental health issues after birth.

CR6 also talked about the need for education on coping with anxiety and how to identify PTSD. This participant noted:

I just kind of goes back to the mental health after just I guess coping on maybe this is what I wish for, you know, parents is after NICU. You discharge and maybe a NICU healthcare professional goes through signs to look out for postpartum anxiety or PTSD and how to cope with that and who the appropriate people are to reach out for that versus everything being about the baby and the car seat.

This participant also talked about the need for follow-up, stating, "I think I wish my doctor at my post follow up, and even while I was in the NICU, they didn't ever do any mental health checks on me."

Similar views were shared by CR8, who stated, "I do think that there should be some follow up for parents after the NICU, some sort of therapy, some sort of like processing, some sort of check."

Overall, the fourth theme showed that the co-researchers were never checked for mental health issues and were not educated on how to cope with post-partum depression. There was also no follow-up after discharge. Co-researchers highlighted that while they

experienced psychological distress during the NICU admission, there were no systems in place to ensure their mental health was stable. Several co-researchers noted that many symptoms associated with trauma are not present or are not processed during the experience itself, but manifest following discharge. Many co-researchers expressed a desire for mental health check-ins, therapeutic intervention, or follow-ups for mothers and fathers to help them navigate the NICU experience and their transition home. theme was supported by data from six interview participants. The theme answered the research question.

***Theme 5: Became More Grateful, Empathetic, Patient, and Felt Humbled***

Data from all eight co-researchers contributed to this theme. The theme revealed that the parents became even more grateful, empathetic, patient and felt humbled, as a result of the NICU experienced. Speaking about becoming more patient, CR1 noted:

It gave me more patience. I don't know how I would have been had she not been in the NICU. I find my old self probably would have gotten a little frustrated, a little impatient, but I find myself being more patient with her [my baby].

Similar views were shared by CR7 who noted:

And then also I think that uh, trying to let go of like the control factor that I tend to have on situations and wanting to like dictate a certain pace of things when it's like your 2-year-old is sick. You can't control how quickly he gets better. You just have to be patient and find ways to be more patient.

CR3 talked about being grateful for having a baby, saying,

I would be naive to think that after trying for so long and having a baby that I wouldn't have anxiety anyhow, but what it did is it made me, I think, even more appreciative and grateful for her, for my baby.

Likewise, CR2 stated, “it has definitely made me more like I said, more, thankful for our boys.”

This participant also spoke about being more empathetic, saying, “It just made me more empathetic, like I can truly empathize, even with some of my patients, like, even though maybe the scenarios are different.”

CR5 talked about being humbled by the experience, saying, “There were lots of micro premies there, like parents that had gone back to work because their babies were going to be in the NICU for months, so that that humbled me that we had this really scary experience.”

CR6 also talked about the experience being humbling, saying, “But then you go through something like that and realize something so precious can be taken from you in an instant. It's just really humbling.”

In summary, the final theme highlighted the posttraumatic growth that occurred as the mothers and fathers with newborns in the NICU became more grateful, empathetic, patient, and also felt humbled by the experience. All interview participants contributed to this theme and noted how the experience has given their lives meaning and shaped them in various ways. Co-researchers also highlighted the importance lessons they learned in not taking seemingly small things for granted, celebrating milestones big and small, and understanding that life is not guaranteed. The next section is a summary of Chapter 4.

## Summary

The purpose of this heuristic inquiry was to understand the lived experience of mothers and fathers with newborns in the NICU. The study was guided by one research question. Interview data from eight parents who had newborns that required medical care in the NICU were analyzed through data analysis for heuristic inquiry. Six steps were followed during the data analysis, including (1) initial engagement, (2) immersion, (3) incubation, (4) illumination, (5) explication, and (6) creative synthesis. Data analysis was an ongoing process that commenced when data collection began. To aid the analysis process, NVivo 14 software program was used. The research question was: *What is the lived experience of mothers and fathers with newborns in the neonatal intensive care unit (NICU)?* The findings indicated that according to the co-researchers, NICU staff were mostly supportive and reassuring but others were less caring, which was the first theme. The second theme revealed that spousal and familial support were important. The third theme showed that the co-researchers experienced stress, trauma, depression, PTSD, and postpartum anxiety at NICU. The findings also showed that there was a lack of mental health checkup, education on coping with anxiety, and follow-up after discharge, which was the fourth theme. However, the co-researchers became more grateful, empathetic, and patient, and felt humbled as a result of the NICU experience, which was the sixth theme. The research summary, implications, conclusions, and recommendations of the entire study based on these findings are provided in Chapter 5.



## Chapter 5: Discussion, Conclusions, and Recommendations

### Introduction

The purpose of this heuristic inquiry was to explore and make meaning of the lived experience of parents with newborns who required a medical intervention in the NICU. Research has shown that NICU parents are at an increased risk of experiencing psychological distress (Lowenstein, 2018; Dickinson et al., 2020). Parents have reported experiencing psychological distress such as anxiety, depression, guilt, postpartum anxiety, and posttraumatic stress (Thomson et al., 2023). There are many factors that can impact the experience of parents with newborns in the NICU such as the duration of an admission, the severity of their newborn's medical condition, or the NICU environment itself. Due to the complexities of a NICU admission, every parent's experience carries a different meaning.

Many quantitative studies have been completed to better understand the impact of a NICU admission on parents. Fewer qualitative studies, however, have been conducted to understand the meaning and the experience more fully. This study is the first heuristic inquiry aimed at exploring and understanding the lived experience for both mothers and fathers with newborns who have required medical intervention in the NICU following birth. The following research question was used to guide exploration: *What is the lived experience of parents with newborns in the NICU?*

The theoretical frameworks used to underpin the study were constructivism, social constructivism, and the transactional model of stress and coping (Creswell, 2013; Lazarus & Folkman, 1984). The six steps of heuristic inquiry were used as the conceptual

framework for the study (Moustakas, 1990). Using the data analysis process described in Chapter 4, five themes were identified. The five themes included: (a) NICU staff was mostly supportive and reassuring but others were less caring; (b) spousal and familial support were important; (c) experienced stress, trauma, depression, PTSD, and postpartum anxiety in the NICU; (d) lack of mental health checkup, education on coping with anxiety, and follow-up after discharge; and (e) became more grateful, empathetic, patient, and felt humbled as a result of the NICU experience.

### **Interpretation of the Findings**

#### **Parental Mental Health**

Researchers who have conducted both quantitative and qualitative research investigating the impact or experience of the NICU have determined that parents who have newborns requiring medical intervention in the NICU are at a greater risk of experiencing psychological distress (Loewenstein, 2018). Furthermore, researchers have identified that the experience of a NICU admission can impact the health and wellbeing of parents both instantaneously and long-term. To date, much of the research has been quantitative in nature. Qualitative studies have predominantly focused on the lived experience of mothers (Ocampo et al., 2021). Findings of this study confirm the psychological distress experienced by mothers and extend knowledge in the discipline by highlighting the distress experienced by fathers as well.

All eight co-researchers experienced psychological distress at some point throughout the experience. CR4 was a father whose spouse gave birth to twins at 25 weeks' gestation. He highlighted the distressing experience of the NICU, as he recalled

the time he was asked to think about comfort care (often referred to as palliative care) for his son. CR4 indicated that when he was asked to think about comfort care, it was one of the most traumatizing experiences he has endured. As he spoke about it, he took a moment to pause and cry. CR1 noted that the NICU experience has given her “horrible anxiety” and has caused her to become withdrawn to protect herself from the fear of another hospital admission should her daughter contract an illness. CR1 also provided insight into the anxiety experienced by many NICU parents to keep their newborns alive when they have been hooked up to machines required to help them survive. CR4 also discussed how his son stopped breathing and turned blue. He stated that he has never been so afraid and so scared in his life. CR5 echoed the same sentiment as she discussed how scary it was to see the doctors and nurses struggling to care for her son in a small hospital that was not equipped with the proper medical devices necessary for a baby born preterm. These descriptive accounts confirm and extend prior research findings that have found 4-27% of parents experience significant levels of depression, anxiety, stress, and acute trauma within the first two weeks of a NICU admission (Dickinson et al., 2020). All eight co-researchers recalled experiencing a substantial amount of stress, depression, or trauma, which may indicate that the percentage of parents who experience clinically significant levels of distress is actually higher than what has been reported.

The psychological distress experienced by parents extends beyond the NICU admission, as confirmed by many co-researchers. CR8 noted that her spouse had a much more difficult time navigating the NICU experience in the moment and beyond. She indicated that her daughter was born nearly five years ago and is certain that her spouse

has experienced post-traumatic stress and depression that he has not dealt with. She noted that the differences in how she and her spouse have managed or dealt with the experience has made things difficult between them at times. CR8 mentioned that even though her daughter is six months old, she is uneasy about taking her anywhere or allowing anyone to hold her because she has clung onto the fear she experienced while in the NICU. CR8 discussed ‘living the trauma and surviving the trauma’ while in the NICU and processing the trauma when the NICU experience is over.

The NICU experience is unique to each parent. Most research to date has focused on the experience of mothers (Dickinson et al., 2020). Fathers have been found to experience symptoms associated with trauma, depression, and anxiety, and a loss of control (Barton et al., 2021). Four fathers were interviewed for this study. In addition to experiencing psychological distress, all four fathers discussed responsibilities that weighed heavily upon them during the NICU admission. CR2 noted that when his son was in the NICU, he decided to take a year sabbatical from work to take care of him. CR4 discussed carrying the responsibility of financially supporting his family while his twins were in the NICU. He indicated that he had to figure out a way to continue working forty-hour work weeks. CR7 talked about assuming the role of caring for his two-year-old so his spouse could remain with their newborn as much as possible and taking care of the “behind the scenes” tasks. CR3 continued to work once his daughter was born. Fortunately, he worked at the same hospital, so he discussed how he was able to attend the early morning wake windows so that his spouse could sleep.

Furthermore, all four fathers interviewed emphasized that one of their primary roles was to provide support for their spouse. CR2 stated that his mission was to support his spouse through everything from pumping, taking milk down to the NICU, and making sure she had food. CR4 discussed how he wanted to support his wife by finding ways to help her recover. CR7 also indicated that he focused on making sure that his wife was fed and had everything she needed. CR3 discussed how his goal was to be super supportive, knowing that his spouse went through a lot during childbirth and was recovering from a cesarean section.

### **Medical Complications**

Research has shown that there are short and long-term medical complications associated with premature birth. According to Mayo Clinic (2023) many preterm infants experience short-term complications such as problems related to breathing (i.e., respiratory distress syndrome), the heart, the brain, metabolism, and the immune system. Many preterm infant's also exhibit symptoms consistent with jaundice, such as yellow-colored skin and eyes. Co-researchers 2, 4, 7, and 8 discussed short and long-term medical complications their newborns have experienced due to preterm birth. CR2 indicated that both of his sons required oxygen while in the NICU due to respiratory distress syndrome, which made it difficult to hold them. CR7 indicated that his son was immediately taken to the NICU for low oxygen and jaundice. He talked about how they were discharged with a portable kit used to treat babies with jaundice. The device ended up being a source of stress for the family, and CR7 indicated that his son was readmitted to the NICU due to a spike in bilirubin that causes jaundice.

Many newborns discharged from the NICU experience medical complications and disabilities. Research shows that over fifty percent of babies discharged from the NICU exhibit symptoms associated with cerebral palsy, blindness, hearing loss, or an intellectual disability (Msall et al., 2017). CR4, whose twins were born at twenty-five weeks' gestation, detailed the distressing experience of learning about and managing long-term medical conditions that arose as a result of preterm birth. He discussed how his four-year-old son has cerebral palsy, stages three and four brain bleeds on each side of his brain, complex hydrocephalus, and is unable to walk, stand, or support his own body. CR4 also mentioned that the term "mentally retarded" has been used by medical professionals to describe the cognitive ability of his son.

### **Immediate Separation**

Prior research has shown that parents with newborns who are immediately taken to the NICU following birth feel a sense of loss as their baby is quickly removed from their care (Patriksson & Selin, 2022). CR5 detailed how she gave birth to her son, who was immediately life-flighted to a hospital with NICU capabilities. Her son was physically removed from the hospital, and she was discharged a few hours later, forced to drive herself two hours to the NICU in Des Moines, Iowa alone. CR8 discussed how she gave birth to her daughter at twenty-five weeks' gestation. Her daughter weighed one pound, nine ounces at birth. She talked about how she did not have the opportunity to see her daughter for the first six or seven hours she was alive because her daughter was immediately placed in an incubator and brought to the NICU. She went on to discuss how, when babies are born that early, they cannot be held for seven days. CR1 stated that

she gave birth via cesarean section, and then immediately heard the nurses say they needed to take [her baby] to the NICU because she was having trouble breathing. CR6 discussed how she felt a sense of relief and gratitude as she was able to hold her son for a few moments following birth. The experience of the co-researchers supports prior research stating that many parents feel lonely and even isolated as they watch their newborn vanish from sight (Afyka et al., 2020; Nelson et al., 2022).

When new parents imagine the first few moments of their newborn's life, the image often features their baby in their arms. Researchers have found that NICU parents often experience disappointment as their expectations do not match their reality (Gundogdu et al., 2022). CR6 indicated that she finds herself becoming resentful when she sees the hospital photos where the family looks "perfect" knowing that she did not get the opportunity for those same photos. She stated that over time, she has realized that that is not her family's story, and her family's story is special.

### **NICU Environment**

This study confirms prior research findings that suggest there is an initial shock associated with the NICU experience (Brelsford & Doheny, 2020). Co-researchers 1, 7, and 8 discussed the shock they felt seeing their infant in the NICU environment. CR8 noted that she was "in shock" about what was going on and how little her baby was and detailed she did anything to "feel like a mom." CR1 discussed how her emotions changed quickly from feeling calm and at peace with her daughter's NICU admission to shock upon seeing the tubes running through her nose and mouth, all of the machines she was hooked up to, and the heel pricks that caused her daughter to scream. CR7 had a different

experience. He mentioned that in the state of Colorado, infants born at 37 weeks' gestation require one or two days in the NICU due to the altitude. Knowing that, CR7 stated that while the initial experience on the NICU floor was alarming with the buzzers and alarms chirping, once they were reassured that [their baby] was fine, the NICU became more of a waiting game than a stressful experience.

### **Support**

All eight co-researchers discussed the importance of support in some capacity. CR2 indicated that the staff was absolutely amazing. CR2 reiterated how the NICU nurses and doctors made him feel calm and assured him that his sons were going to be okay. He went on to discuss how the NICU staff was one of the biggest sources of support and comfort throughout the experience. CR3 talked about how the NICU staff helped him keep his emotions at bay so he could support his spouse. CR4 shed light on the complexities of support received at the NICU during a prolonged stay. While some doctors and nurses were incredible and supportive, he indicated that he and his wife knew which doctors or nurses were not as skilled, competent, or supportive. Furthermore, CR4 discussed the traumatic experience of a mismanaged medical procedure that could have resulted in his son's death. CR5 discussed how difficult it was when a NICU doctor blamed her son for a medical mistake. CR7 discussed the support he received from the NICU staff, and also highlighted the difficulty his family experienced because they did not have family within geographic proximity.



## **Posttraumatic Growth**

While detailed narratives given by the co-researchers support the research suggesting that parents of newborns in the NICU experience psychological distress, there was also substantial evidence that parents experience posttraumatic growth as well. Bayaarmi et al. (2023) has defined posttraumatic growth as positive psychological changes that occur following an adverse or difficult life stressor. Experiences of posttraumatic growth have been detailed as a higher sense of self-worth and effectiveness, a change in self-perception, feeling like a better person, and increased confidence in themselves and their capabilities (Aftyka et al., 2020; Bayarami et al., 2023). CR8 talked about how the NICU experience taught her the importance of celebrating everything and taking things moment by moment. CR1 discussed becoming more proud of her ability to not beat herself up and developing an ability to listen to others and view situations through the lens of optimism. The essence of social constructivism is that an individual's reality is constructed based upon the subjective meaning-making of personal experience (Ponterotto, 2005). All eight co-researchers discussed the various ways in which the NICU experience has changed their life and shaped who they are as a parent. Throughout the process of data collection and analysis, it was apparent that a NICU admission has a profound and lasting impact on the lives of parents.

Previous researchers have found gender differences in the experience of posttraumatic growth. Aftyka et al. (2020) found that women experienced more posttraumatic growth than men. That was not the case in this study, as all eight co-

researchers detailed various ways in which the NICU experience positively influenced their life, their belief in their abilities, and their perspective. CR2 indicated that he was most proud of his ability to provide support in really difficult moments and relying on his faith. CR4 indicated that he believes the situation strengthened his mental fortitude, ability to remain optimistic, and his marriage. CR3 discussed how the experience has made him more nurturing and patient.

### **Findings Relevant to Constructivism and Social Constructivism**

Constructivism and social constructivism served as the core underpinnings of the study. Researchers using constructivism and social constructivism actively seek to discover meaning through their own involvement in meaning-making (Creswell, 2013; Kim, 2014). These theoretical frameworks align with heuristic inquiry as the researcher is intricately involved in the study and the participants serve as co-researchers. Throughout the research process, from data collection to the interpretation of findings, I sought to make meaning of the collective experience of a group of people who have experienced the same phenomenon.

Overwhelmingly, co-researchers indicated how the experience changed their life. Seven of eight co-researchers discussed the various ways their experience with an infant in the NICU has shaped their lives, their parenting style, and their perspective on life. CR1 talked about how the NICU experience has encouraged her to love every step of the way with her baby. CR4 said the experience taught him that life is beautiful, and he has been strengthened by the incredible resilience of his children. CR6 noted that the NICU experience completely opened her heart to the realization that something so precious can

be taken from you in an instant. CR6 and CR8 both discussed how they are eternally grateful for the little things in life, never take anything for granted, and have learned to celebrate every milestone and every victory, no matter how big or small. After conducting the interviews, immersing myself in the transcripts, analyzing the data, and interpreting the findings, it was evident that the experiences of many of the co-researchers transcended the NICU admission itself, and have profoundly shaped who they are.

### **Findings Relevant to the Transactional Model of Stress and Coping**

The transactional model of stress and coping, developed by Lazarus and Folkman, was utilized as a lens to make meaning of the overall experience of parents with newborns in the NICU. In listening to the experience of the co-researchers, it was clear that the primary appraisal, or relevance of the stressor, and the resources they believed they possessed to overcome the stressor, known as the secondary appraisal, influenced the coping strategies implemented by parents (Obbarius et al., 2021). The influence of the appraisals and coping strategies can be seen in some way in all five themes that were identified during data analysis. Resources include perceived social support, spirituality, financial support, experience, or mental fortitude. All eight co-researchers discussed the ‘threat’ posed by the NICU experience itself, which serves as the primary appraisal, and the reliance on the NICU staff and spousal and familial support as resources to help them cope. Conversely, several co-researchers noted that the lack of mental health checkup, education to help cope with anxiety, and absent follow-up after discharge caused psychological distress in the form of anxiety, depression, and postpartum anxiety.

The stress experienced by mothers and fathers influences the coping strategies implemented. Researchers have found that parents engage in both secular and nonsecular coping strategies to help mitigate or alleviate distress (Brelsford & Doheny, 2020). Both types of strategies mechanisms include adaptive and maladaptive strategies. Brelsford and Doheny (2020 found a positive correlation between spiritual struggles and general worry, despair, and an unstable sense of wellbeing. When CR1's son was rushed back to the NICU moments before being discharged, he mentioned that he relied on his faith and a knowledge that whatever was going to happen was out of his hands. Similarly, CR4 detailed the experience as a "spiritual journey"

The psychological distress experienced by parents can lead to adverse health behaviors (Dickinson et al., 2020). In a study conducted by Dickinson et al. (2020) eighteen percent of parents reported consuming a significant amount of alcohol within the first two weeks of NICU admission. When co-researchers were asked how they coped with the adversity of the NICU or managed their mental health, no participants indicated that they consumed any type of substance in excess. On the contrary, all of the co-researchers endorsed the reliance on sources of support such as friends or family, exercise, or self-care strategies to cope. CR8 stated that when she was cleared by her doctor to exercise, she began to exercise as often as she could. CR2 talked about finding time to go to a gym to play basketball. CR7 discussed how he took his dog for walks every day to decompress and recharge. These findings disconfirm what has previously been found about the coping mechanisms implemented by families managing intense emotions and coping with challenges specific to the NICU environment.

### **Limitations of the Study**

While this study has provided valuable results and implications for future research, it was not without limitations. One of the limitations was accessing participants. This limitation was identified prior to data collection, as asking participants to re-live a traumatic experience was considered. On multiple occasions, participants reported that while their spouse would love to join the study as a co-researcher, they did not feel ready to discuss, in great detail, their experiences of the NICU. One of the goals of the study was to interview mothers and fathers separately, and then conduct a joint interview to explore the ways in which the experience influenced their relationship. Three of the co-researchers expressed hesitation about spousal participation. It was not in the best interest of participants' spouses to discuss an experience they had not fully processed. As such, only one couple was interviewed together. Prior research has indicated that the NICU experience can impact the relationship between the parents of a newborn requiring care. Not accessing parents for a joint interview means that the full experience and meaning of the NICU was not captured.

Another limitation involved the subjective nature of heuristic inquiry. This limitation required me to separate myself from the co-researchers during data collection and data analysis to mitigate my own beliefs and biases influencing the detailed narratives given by each co-researcher. I found myself over-identifying with emotions and experiences at times. Several co-researchers became emotional and even shed tears during the interviews, and I found myself experiencing similar emotions and physical reactions. I also found myself wanting to contribute to the narrative using my own

experience as the participant was responding to a question and had to remain deliberate in allowing the co-researchers to tell their own stories. Heuristic inquiry provides a unique challenge for the researcher, as it is often difficult to manage their own feelings (Djoraskovic & Arthur, 2010). To mitigate these challenges and ensure that I did not seek to confirm my own experiences as I analyzed the data, I journaled, took breaks, and centered myself. Centering has been described as an active attempt at remaining in the present moment and open to the experiences of the co-researchers (Florczak, 2021). While appropriate measures were taken, the role of the researcher in heuristic inquiry remains a limitation as there is no way to ensure a fully unbiased lens by which co-researchers' stories are interpreted, and findings are discussed, and recommendations are provided.

A third limitation was the homogeneity of the sample. All eight co-researchers included in the study identified as white. Such a homogenous sample may limit the transferability of findings to more diverse populations. Researchers have identified the presence of racial and ethnic disparities in neonatal outcomes due to factors such as systemic racism, and societal structures (Ravi et al., 2021). Ravi et al. (2021) assert that newborns who are Black, Hispanic, or American Indian are at an increased risk of receiving medical intervention in lower quality NICUs. Lower quality intervention and care can not only have detrimental impacts on the health outcomes of a newborn but can drastically influence the experience of parents. The homogeneity of the sample may have influenced the themes identified. For example, many of the co-researchers discussed the support they experienced from NICU staff and how that support served as a protective

factor of resilience. The lived experience of an ethnic minority parent in the NICU may be vastly different, as prior researchers have highlighted significant disparities. A vastly different experience, then, influences the totality of the experiential narrative, the themes identified, and the interpretation of findings.

### **Recommendations**

The findings of this study have highlighted a need for future research. Researchers have identified that the subjective experience of the NICU varies for every parent. The experience can also impact the relationship or marriage between a couple whose newborn requires medical care in the NICU. Gundogdu et al. (2022) identified a need for the exploration of parents' experience as a couple. While I hoped to interview more couples, the spouses of participants I did interview were not yet ready to discuss their experience due to lingering trauma or a discomfort in sharing their story. As such, this gap remains open for future research to explore the subjective experience of couples.

Additionally, while more is known about the symptoms of psychological distress experienced by mothers and fathers, less research has been focused on posttraumatic growth. As participants actively reflected on how the experience has influenced their lives, the existence of posttraumatic growth was palpable. Findings from this study can facilitate social change by encouraging future researchers to explore the experience of posttraumatic growth for parents with newborns in the NICU. Furthermore, Wang et al. (2023) conducted a quantitative study examining factors that influenced posttraumatic growth that included 217 parents of infants in a Chinese NICU. Higher levels of posttraumatic growth was observed in parents who reported a strong marriage. These

findings further support the need for qualitative studies exploring posttraumatic growth amongst parents as well as factors that influence posttraumatic growth for couples.

Constructivism, social constructivism, and the transactional model of stress and coping were utilized as theoretical frameworks to guide this study. Other approaches to a study exploring the lived experience of parents with infants in the NICU that may produce insightful data by incorporating a conceptual framework such as the social ecological model (SEM). Central to the SEM is the complex and reciprocal relationship between an individual, relationships, the community, and societal factors (Loewenstein, 2018). Loewenstein (2018) conducted a scoping review of literature related to NICU parents, psychological distress, coping skills, mental health, and psychological functioning and examined the themes that emerged from the review within the constructs of the intrapersonal, interpersonal, institutional, and community/public policy levels of the SEM. A qualitative study utilizing SEM as a framework may be beneficial in exploring parents' experience using the interplay between the four levels of the SEM.

### **Personal Reflections of the Researcher**

Heuristic inquiry is a qualitative methodology that allows for the researcher to play a central role in the research process. More specifically, the role of a heuristic researcher is to focus their work on the interaction between their own lived experience and the lived experience of those who have experienced a similar phenomenon (Moustakas, 2015). From start to finish, this study has been a passion project for me. Both of my sons required medical intervention in the NICU, and the collective experience has profoundly shaped and influenced my life.



This study has allowed me to give voice to mothers and fathers who have endured an experience very similar yet very different from my own. Many participants reached out to me following their interview to thank me for allowing them a space to share their story and to express excitement about the opportunity to ‘pay it forward’ to future mothers and fathers who will become devoted parents of NICU babies. As I listened to co-researchers provide detailed narratives of their experience, it was reaffirmed to me that humans are resilient. I listened to a father of twins tell a story about how doctors, nurses, and even his own parents encouraged him to think about keeping his son comfortable rather than pursue additional medical intervention because his life would be extremely hard. I listened to a mother who gave birth to a baby born at twenty-five weeks talk about how she was unable to hold her daughter for the first seven days of her life and often did anything and everything she could to simply feel like a mom. I smiled as I listened to parents talk about how proud they are of their children, and how they have embraced their unique stories. For hours, I listened to co-researchers’ stories and read through the interview transcriptions and felt both intense sadness that they endured such hardships and pride in the resilience and strength they demonstrated. Each co-researcher described their experience with such profound meaning (Creswell, 2013).

After reflecting on my own experience and the experiences of the co-researchers who shared their stories, I cannot help but hope for a time when parents do not have to be strong alone. Co-researchers’ accounts have confirmed that posttraumatic growth is possible following an adversity such as the NICU. How can posttraumatic growth be facilitated? What are the specific protective factors that can expedite the resolution of

distress or the trajectory of growth? What resources can be implemented that will help parents process the anxiety, the trauma, and the postpartum depression in the moment rather than years later? If distress is likely and growth is possible, determining resources, strategies, and intervention opportunities that can occupy the space between distress and growth must be a priority for medical and mental health providers in NICUS across the country and around the world.

### **Implications**

The implications for positive social change include a more comprehensive understanding of the meaning and subjective experience of the NICU for parents who have had newborns requiring care. An equal number of mothers and fathers willingly shared their experiences of both triumph and tribulation to provide a rich, detailed narrative of the experience of eight parents. Implications of positive social change also include informing parents of coping mechanisms and strategies that will help them withstand the stressors of the NICU and cope with adversity in an adaptive manner. Researchers have detailed a propensity for parents with newborns in the NICU to engage in maladaptive coping strategies (Dickenson et al., 2020). Many of the co-researchers discussed their reliance on adaptive coping strategies such as prosocial support, self-care, physical fitness, and faith. Furthermore, the collective experience of posttraumatic growth experienced by co-researchers should provide a sense of hope and comfort for parents who are currently enduring a NICU experience of their own.

Results from this phenomenological study can be used to inform medical and mental health professionals about the needs of parents caring for their newborns in the

NICU. Many co-researchers discussed the disappointment they felt when there were no resources afforded to them to help manage the distress they experienced while in the NICU and following discharge. Much of the attention is directed toward a newborn who may need assistance breathing, feeding, and surviving. While those types of interventions are life-saving and necessary, many co-researchers reported feeling as though they longed for mental health check-ins during the NICU admission and follow-ups post-discharge. Emotional support has been identified as a protective factor for individuals dealing with stressful situations (American Psychological Association, 2022). Results from this study confirm the importance of support in various forms. Many co-researchers discussed not knowing what the NICU experience entailed until they experienced it for themselves. Results from this study can be used to facilitate the development of emotional support groups online or in-person specifically tailored to NICU families.

### **Conclusion**

This heuristic inquiry explored the lived experiences of eight parents who had newborns that required medical intervention in the NICU following birth using the frameworks of constructivism, social constructivism, and the transactional model of stress and coping. Through introspection and self-reflection, co-researchers provided rich, detailed narratives of their experience as a parent of a newborn in the NICU. All co-researchers have created a subjective meanings of their experience in pursuit of understanding the world around them, the impact the experience has had on their lives, and how they have grown through adversity (Creswell, 2013). While enduring an admission to the NICU, parents experienced psychological distress in many forms (i.e.,

anxiety, postpartum anxiety, depression, and guilt). They also experienced posttraumatic growth. Co-researchers detailed various ways in which they grew stronger, their marriage grew stronger, they became more patient, more empathetic, and realized the importance of celebrating every victory, big or small. Co-researchers have made meaning of this experience and have used the experience as a guide to shape how they live their life and how they show up for their children. Participants have been transformed by the experience in meaningful and powerful ways.

This study confirmed that parents with newborns in the NICU are at an increased risk of experiencing psychological distress (Loewenstein et al., 2018). Co-researchers detailed the shock, trauma, and anxiety they experienced as they witnessed their newborn being kept alive by machines. Co-researchers discussed the hopelessness they felt when they were unable to touch their baby, or the guilt they experienced contemplating comfort or palliative care. What co-researchers found lacking, however, was any semblance of mental health checkups, education on coping with psychological distress, or follow-up appointments following discharge. Many co-researchers indicated that they have “unresolved” trauma from the NICU experience that they are still trying to process. While great measures are taken to care for newborns who are fighting for their lives, the same level of care must be offered for parents fighting right alongside their infant. The standard of care must be raised in NICUs across the country to prioritize the mental health of parents and caregivers trying to navigate the stressors of the NICU and the medical fragility of their newborn. As a parent who has experienced firsthand the fear, anxiety, and guilt that accompanies an admission to the NICU, it is my hope that the

results of this study will influence mental health professionals develop and implement protocols to ensure that the mental health of parents is prioritized during the NICU admission and following discharge.

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## Appendix A: Online Flyer

# PARTICIPANTS NEEDED

For a qualitative study exploring  
the **lived experience** of parents  
with Newborns in the Neonatal Intensive Care Unit (NICU).



There is a new study about the lived experience of parents with newborns in the NICU that will inform parents of effective coping strategies that will allow them to thrive rather than survive, inform mental health professionals about the specific mental health needs of parents, and improve the standard of care given to parents with newborns in the NICU.

For this study, you are invited to serve as a participant, describing your experience as a NICU parent.

**About the study:**

- One 60-minute interview (audio recorded)
- To protect your privacy, the published study will not share any names or details that identify you

**Participants Must Meet These Requirements:**

- Be a parent of a newborn who required medical care in the NICU.
- Be discharged from the NICU.
- Speak English.

This interview is part of the doctoral study for Abigail Bilyk, a Ph.D. student at Walden University.

Interviews will take place during February and March 2023.

Please message Abigail privately to let them know of your interest:

(p): (719) 301-9075

(e): Abigail.bilyk@waldenu.edu



## Appendix B: Interview Protocol

### **Background Information:**

The purpose of this study is to understand and make meaning of the lived experience of parents with newborns in the Neonatal Intensive Care Unit (NICU).

### **Procedures:**

Participants who agree to be co-researchers in the study will be asked to:

- Participate in a 60-minute interview.
- Provide feedback to the researcher about interview transcripts and emerging themes to ensure accuracy.

### **Voluntary Nature of the Study:**

Participation in the study is voluntary. There are no incentives to participate. If any participant decides to opt-out of the study, they will be allowed to do so at any time.

### **Risks and Benefits of Participating in the Study:**

Participation in the study is not without risk. Participants will be asked to re-live potentially traumatic experiences that may conjure distressing memories and emotions.

Participation in the study will not, however, pose a risk to participants safety or wellbeing. The potential benefits that may arise from participation in the study involve a better understanding of the lived experience of parents with newborns in the NICU. It will also provide valuable information so that medical and mental health providers can increase the standard of care given to parents with newborns in the NICU and lessen the odds of parents experiencing debilitating distress.

**Privacy:**

All information provided by participants will remain confidential. Identifiable information will never be published or utilized for any purposes aside from the research study. Any information that could potentially identify a participant will be masked and not included in any draft or final publication of the study. Data obtained throughout the study will be kept secure in a locked file cabinet. As required by Walden University, participant data will be kept for five years. After that time, data will be destroyed.

**Demographics:**

1. Gender/Race:
2. Geographic location and name and location of NICU
3. Year(s) of NICU admission (e.g., 2020).
4. Length of NICU admission
5. Important family dynamics (e.g., only child in NICU, siblings, etc.)

**Semi-Structured Interview Questions:**

1. Please describe your experience as a parent with a newborn in the NICU in as much specific detail as possible.

Possible Probes:

- a. What was the environment like?
  - b. What role did you take on during the NICU admission?
  - c. What was a typical day like?
  - d. What was the most difficult situation you endured?
2. How was your mental health during the experience?

3. How did you care for yourself during the experience?
4. How did you care for yourself following NICU discharge?
5. What impact has this experience had on your life?
  - Possible Probe:
    - a. How has this experience changed you?
    - b. How has this experience influenced your family?
6. What would you have done differently?
7. What are you most proud of after overcoming this experience?
8. How has the experience of having a newborn admitted to the NICU shaped you as a parent?
9. What are the long-term impacts you have seen following the NICU admission?
10. What advice would you give to other parents with newborns in the NICU?
11. Is there any additional information you would like to share with the researcher?

### Appendix C: Participant Consent Form

You are invited to take part in a research study about the lived experience of parents with newborns in the Neonatal Intensive Care Unit (NICU). This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part.

This study seeks 10-15 volunteers who:

- Are parent(s) of a newborn who required medical care in the NICU
- Discharged from the NICU
- Speak English

This study is being conducted by a researcher named Abigail Bilyk, who is a doctoral student at Walden University.

#### **Study Purpose:**

The purpose of this study is to explore, discover, and understand the underlying nature and meaning of the NICU experience for parents in order to facilitate positive social change.

#### **Procedures:**

This study will involve you completing the following steps:

- Take part in a confidential in-person or audio recorded phone interview (60 minutes)
- Review a typed transcript of your interview to make corrections if needed (email option available) (15 minutes)
- Speak with the researcher one more time after the interview to hear the researcher’s interpretations and share your feedback (this is called member checking, and it takes 20-30 minutes (phone option available)

Here are some sample questions:

- Please describe your experience as a parent with a newborn in the NICU in as much specific detail as possible.
- How was your mental health during the experience?
- How did you care for yourself during the experience?
- What impact has this experience had on your life?
- What are you most proud of after overcoming this experience?

#### **Voluntary Nature of the Study:**

Research should only be done with those who freely volunteer. So, everyone involved will respect your decision to join or not. If you decide to join the study now, you can still

change your mind later. You may stop at any time. The researcher will follow up with all volunteers to let them know whether or not they were selected for the study.

**Risks and Benefits of Being in the Study:**

Being in this study could involve some risk of minor discomforts. Volunteers will be asked to re-live a potentially traumatic experiences that may conjure distressing memories and emotions. With the protections in place, participation in the study will not pose a risk to participant safety or wellbeing. The potential benefits that may arise from participation in the study involve a better understanding of the lived experience of parents with newborns in the NICU. It will also provide valuable information so that medical and mental health providers can increase the standard of care given to parents with newborns in the NICU and lessen the odds of parents experiencing debilitating distress. In the event a volunteer experiences psychological distress, contact information for free or affordable mental health providers within geographic proximity will be provided. For volunteers in Colorado Springs, Colorado, Aspiring Minds Psychological Services (AMPS) will be available as a mental health resource. The contact information for AMPS is (719) 358-6806.

The aim of this study is to benefit society by allowing mothers and fathers who have had newborns requiring medical care in the NICU an opportunity to give voice to their experience. Furthermore, results of the study will inform parents of coping strategies that will help them manage stressors associated with the NICU, inform mental health professionals of resources best suited for parents with newborns in the NICU, and increase the standard of care given to parents who have newborns in the NICU. Once the analysis is complete, the researcher will share the overall results by emailing you a summary.

**Payment:**

There is no monetary payment for participation in the study.

**Privacy:**

The researcher is required to protect your privacy. In-person interviews will be conducted in a private room located at the Pikes Peak Library District – East Library, a public library centrally located in Colorado Springs, Colorado. The address is 5550 N. Union Blvd, Colorado Springs, CO 80918.

Your identity will be kept confidential, within the limits of the law. The researcher is only allowed to share your identity or contact information as needed with Walden University supervisors (who are also required to protect your privacy) or with authorities if court-ordered (very rare). The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. If the researcher were to share this dataset with another researcher in the future, the dataset would contain no identifiers so this would not involve another round of obtaining informed consent. Data

will be kept secure by password protections, data encryptions, and locked physical locations (e.g., a filing cabinet). Data will be kept for a period of at least 5 years, as required by the university.

**Contacts and Questions:**

You can ask questions of the researcher by phone and/or email. The researcher's phone number is (719) 301-9075. Her email is Abigail.bilyk@waldenu.edu. If you want to talk privately about your rights as a participant or any negative parts of the study, you can call Walden University's Research Participant Advocate at 612-312-1210. Walden University's approval number for this study is 03-04-24-1045228. It expires on March 3, 2025.

You might wish to retain this consent form for your records. You may ask the researcher or Walden University for a copy at any time using the contact info above.

**Obtaining Your Consent**

If you feel you understand the study and wish to volunteer, please indicate your consent by Replying to this email with the words, "I consent."