

EXPLORING PARENT EXPERIENCES WITH EARLY PALLIATIVE CARE
PRACTICES IN THE NEONATAL INTENSIVE CARE UNIT

by

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ABSTRACT

The anxiety and uncertain outcome of an admission of a seriously ill infant to the neonatal intensive care unit (NICU) can cause great stress for parents. This stress can lead to decreased quality of life and poor mental health outcomes including anxiety, depression, and posttraumatic stress disorder (PTSD), which NICU parents suffer from at higher rates than parents of well infants. Palliative care (PC) is an approach to care that aims to maintain the quality of life for a person and their loved ones by emphasizing value-based decision-making, management of distressing symptoms, and family-centered care. Early implementation of PC emphasizes shared decision-making, care planning, and support for coping with distress. Evidence from pediatric, adult, and perinatal literature supports the use of early PC, but barriers to implementation exist, and NICU PC literature focuses exclusively on end-of-life. Evidence is needed about these three early PC practices from NICU parents in order to develop a parent-centered program of early PC.

The purpose of this study was to explore parent experiences with shared decision-making, care planning, and coping with distress during their child's NICU admission. Qualitative descriptive methodology was used, and strategies of reflexive journaling, peer debriefing, and data audits were used to enhance trustworthiness. Participants were recruited online through email and social media sites of a parent organization. Sixteen individuals participated in semi-structured interviews using videoconferencing technology. Participants also completed an online survey to supply demographic information and describe relevant characteristics of their infants to contextualize the qualitative data and describe the sample. Qualitative data was analyzed with a

conventional content analysis approach by coding important phrases and abstracting these to overarching themes.

Parents' descriptions of shared decision-making contained three key aspects of their experience: gathering information to make a decision, the emotional impact of the decision, and influences on their decision-making. In experiences with care planning parents described learning to advocate, having a spectator versus participant role, and experiencing care planning as communication. The key themes expressed regarding parental coping were exposure to trauma, survival mode, and a changing support network. These findings provide practicing clinicians with key areas for improvement: providing more support and collaboration in decision-making, true engagement of parents in care planning, and supporting peer support and interaction in the NICU environment. Implications for research include exploring parent experiences with early PC practices with a more ethnically and culturally diverse sample. Researchers may also further this research by developing and evaluating programs of PC emphasizing early intervention not limited to infants with a terminal diagnosis. Parents' use of social media should be studied further due to its emerging use as a tool for peer connection and support in the NICU. Limitations of this study include a lack of diversity in sample race or ethnicity and marital status. This study provides a beginning foundation for the work of implementing early PC in the NICU from a parent-centered perspective, emphasizing communication and the building of relationships between parents and clinicians, and parents and researchers to achieve this goal.

CHAPTER I: INTRODUCTION

The following chapter will clarify the problem of poor mental health outcomes for parents with infants in the neonatal intensive care unit (NICU) by describing the environment of the NICU, the stress experienced by parents in that environment, and potential negative outcomes of that stress. An approach to care that may mitigate these poor outcomes will then be proposed, based on theoretical concepts of the relational self and interpersonal nursing care. Finally, the purpose and aims of this dissertation will be presented.

The birth of a child is often an exciting and profound event for a family. When complications arise either during or after birth that lead to a baby's hospitalization in the NICU, fear and uncertainty can overwhelm a parent's excitement and lead to negative postpartum experiences rather than happy ones (Shaw, Bernard, Storfer-Isser, Rhine, & Horwitz, 2013). The normal birth process is interrupted, and the ideal paradigm of the "healthy baby" is no longer a reality. The anxiety and uncertain outcome of a NICU admission can cause great stress for parents (Ahn & Kim, 2007; Busse, Stromgren, Thorngate, & Thomas, 2013; Greene et al., 2015; Miles, Funk, & Carlson, 1993; Peebles-Kleiger, 2000). Length of stay in the NICU is typically much longer than other areas of intensive care, and a baby's condition may be tenuous for a long period of time, with no guarantee of a good outcome. Even if a baby is not in critical condition, parents must cope with the loss of the normal birth and healthy baby experience they likely imagined, while adjusting to a new stressful environment, a new parenting role, and a new NICU culture and language (Bouet, Claudio, Ramirez, & Garcia-Fragoso, 2012). This set of stressors, which are usually universal among parents in the NICU, create an increased risk for anxiety, depression, and posttraumatic stress that can range from acute to chronic and have long-term

effects on both parent and child (Christiansen, Elklit, & Olf, 2013; Greene et al., 2015; Kong et al., 2013; Miles et al., 1993; Treyvaud, Lee, Doyle, & Anderson, 2014). Reducing parental stress in the NICU is key to mitigating these poor outcomes and may be accomplished through quality nursing interventions.

Background and Significance

Parental Stress in the NICU

The problem of parental stress in the NICU is complex. Exposure to stressors, coping capacity, resilience, social support, and perceptions of stressors are different for each parent, and there is no theory that specifically addresses the unique context of parenting in the NICU.

Parental stress in the NICU is unique because parents are coping with not only the stress of their child's hospitalization but also the stress and potentially traumatic events of a birth that did not go as expected (Miles et al., 1993; Peebles-Kleiger, 2000). Though there is no unifying theory that explains parental stress in the NICU, it is a phenomenon that has been widely studied and related to both acute and long-term negative outcomes for families (Bouet et al., 2012; Busse et al., 2013; Melnyk et al., 2006; Miles et al., 1993; Peebles-Kleiger, 2000; Turner, Chur-Hansen, Winefield, & Stanners, 2015).

There is a varied body of literature that provides some empirical evidence for causes of, influences on, and mitigators of parental stress in the NICU. One exemplar of this research is the development of a tool known as the Parental Stressors Scale: NICU that measures parental perceptions of, and perceived severity of various potential stressors that occur in a typical NICU environment (Miles et al., 1993). The PSS: NICU tool was developed using experiential knowledge and data from parents. This tool has been used in many studies to measure parental

perceptions of stressors and possible effects of interventions on those perceptions. This tool frames parental stress as an effect of the high intensity and unpredictable environment of the NICU and identifies three categories of potential stressors: sights and sounds of the unit, parental role alteration, and infant appearance and behavior (Miles et al., 1993). Studies conducted using this tool often find that parents report the loss of their parental role as the most distressing part of the NICU experience (Baia et al., 2016; Bouet et al., 2012; Turner et al., 2015). While this tool is the standard for evaluating NICU-related stress in parents it does not address other socioeconomic, familial, and work-related stressors that may further affect parental stress and ability to cope during their child's hospitalization (Dudek-Shriber, 2004).

Consequences of Parental Stress

The reduction of parental stress in the NICU is a reasonable goal on its own, but the toll it takes on parent and family quality of life can be severe. The gravest consequence of unmitigated stress in the NICU is the deterioration of a parent's mental health, which can affect the way they bond with their child, their family relationships, and their own self-efficacy in caring for their fragile infant (Busse et al., 2013; Callahan & Borja, 2008; Feeley et al., 2011; Roque, Lasiuk, Radunz, & Hegadoren, 2017). The most common mental health outcomes reported for these parents are symptoms of anxiety, depression, and posttraumatic distress, all of which are significantly worse when compared with other parents of newborns who were not admitted to the NICU (Greene et al., 2015).

Anxiety and depression. Postpartum depression (PPD) is a common phenomenon in parents who have recently experienced the birth of a child (Centers for Disease Control and Prevention, 2018), and the problem of anxiety and depression in NICU parents has been studied

for many years. Parents whose infants are born more prematurely, have greater severity of illness, or have a history of a mental health disorder are commonly more at risk for developing these symptoms throughout the NICU stay, but there is some evidence to suggest that other risk factors may be relevant though minimally studied (Roque et al., 2017). Symptoms of elevated depression and anxiety can be 2-4 times greater in NICU parents than in other parents of newborns, with elevated anxious symptoms being more prevalent than elevated depressive symptoms, at 55% and 33% respectively in a study conducted by Greene and colleagues (2015). Parents may not meet the diagnostic threshold for a clinical depressive or anxious disorder, but these symptoms are still distressing and may affect parents' relationships with their child.

Depression in these parents, especially mothers, can be further complicated by postpartum changes that may contribute to an increased risk for depression (Schiller, Meltzer-Brody, & Rubinow, 2015). Mothers have been more widely represented in most studies on NICU-related anxiety and depression, but studies that include fathers do demonstrate that they are also at risk (Helle et al., 2015; Kong et al., 2013). Though symptoms of anxiety and depression often decrease throughout length of stay in the NICU (Greene et al., 2015), they can affect outcomes far beyond discharge; for example, higher levels of maternal anxiety in the NICU have been associated with lower fine motor outcomes in their infants at 20 months of age (Greene, Rossman, Meier, & Patra, 2018).

Posttraumatic stress. Admission of a child into the NICU has been conceptualized as a traumatic event (Peebles-Kleiger, 2000), and posttraumatic stress (PTS) and posttraumatic stress disorder (PTSD) are not uncommon among NICU parents (Karatzias, Chouliara, Maxton, Freer, & Power, 2007). Symptoms of PTS are found in 25% of parents with children in the NICU

compared to 3% of mothers with term infants in a postpartum setting (Greene et al., 2015; Zerach, Elsayag, Shefer, & Gabis, 2015). A recent study has reported much higher rates of PTSD, as many as 60% of mothers, and 47% of fathers (Aftyka, Rybojad, Rosa, Wrobel, & Karakula-Juchnowicz, 2017). Unlike symptoms of anxiety and depression, severity of PTS often remains constant throughout the NICU stay and persists post-discharge (Feeley et al., 2011; Greene et al., 2015). Common PTSD symptoms reported by parents are hyperarousal or sensitivity, flashbacks to trauma, and avoidance of the NICU location or staff (Roque et al., 2017). Mothers with PTSD tend to exhibit more avoidant coping behaviors than mothers without PTSD, such as denial, restraint, and mental and behavioral disengagement (Aftyka et al., 2017). These findings are particularly concerning due to the vast body of evidence supporting parental presence in the NICU for improving infant and parent outcomes (Pineda et al., 2018; Reynolds et al., 2013; Vohr, 2019).

Some of these mental health consequences are affected by brain chemistry and hormonal changes, but changes in social support networks, disruption in parental role, and environmental stressors present in the NICU can contribute to symptom exacerbation and potentially evolve into a clinically significant disorder (Bouet et al., 2012; Miles et al., 1993; Turner et al., 2015). Symptoms of anxiety and depression in NICU parents have been affected by targeted education for parents, enhancing the parents' feelings of control through increased participation in the infant's care, and improving perceptions of social support from healthcare team members (Enke, Oliva, Miedaner, Roth, & Woopen, 2017; Lee, Wang, Lin, & Kao, 2013; Melnyk et al., 2006; Mendelson, Cluxton-Keller, Vullo, Tandon, & Noazin, 2017; Morey & Gregory, 2012; Smith, Steelfisher, Salhi, & Shen, 2012). Despite this, these interventions have had fairly low effect

sizes and are commonly delivered in isolation from other potentially effective interventions. Cognitive behavioral therapy has also been used to improve mental health outcomes in parents (Mendelson et al., 2017; Shaw et al., 2014; Shaw, St John, et al., 2013), but adequate resources to deliver this type of specialized psychological intervention are not often available. Perhaps what these interventions have been missing is a framework of care that is directed at improving aspects of quality of life (QOL), such as stress and mental health, and can guide intervention development from a comprehensive, holistic approach.

Theoretical Perspectives

There are no theories within nursing ontology that adequately represent or reflect all aspects of parental stress in the NICU. Theories can help frame a problem and provide concepts on which to focus interventions or study, so lack of a theory can make studying and addressing a problem more challenging because a grounding framework for conceptualizing the problem is not available. In approaching the problem, however, personal worldviews influence the way researchers explore problems themselves and solutions to those problems. Two philosophical and theoretical perspectives that influenced the ideas in this dissertation are described in the following sections. Because the relationship between the parent and their child in the NICU is an essential element in understanding parental stress, both of the following perspectives hinge on the importance of relationships and the sharing and respect of feelings and experiences.

Feminist Perspective

Feminist philosophy and theory is an area of critical philosophical inquiry that focuses primarily on the construct of gender, gender expression, and societal subjugation of the female gender (Alcoff & Kittay, 2007; Friedman & Bolte, 2007; Lindemann, 2007; Sherwin, 2008;

Tong & Williams, 2016). Feminist philosophers take a critical view of philosophical traditions and societies that exalt culturally masculine traits such as independence, dominance, hierarchy, and autonomy, while treating culturally feminine traits and concerns such as community, sharing, emotion, connection, trust, and intuition with patronization or even outright disdain (Alcoff & Kittay, 2007; Tong & Williams, 2016). There are many different branches of feminist theory, each with unique views on issues relating to gender and peoples' experiences in the world (Tong & Williams, 2016). Theories from some branches of feminist philosophy are considered care-oriented because they address the role of all persons in caring for others, and what responsibilities people should have and to whom. Many of these theorists have identified family relationships, specifically mother and child relationships, as the foundation for caring relationships in other areas of the family and in society (Tong & Williams, 2016). The reason these ideas are so relevant to the problem of parental stress is that the parent-child relationship is often altered by the NICU experience, and repair to this relationship should be a primary concern for those wanting to reduce parental stress. Feminist philosophers also ascribe value to emotional and social intelligence, and the bodily knowledge and experience of individuals (Tong & Williams, 2016). This is respectful of the idea that all parents' experiences with stress are different, that their coping capacity is likely affected by emotional and social factors, and that their perspectives and experiences must be elicited and respected in order to help them. These values along with the value of relationships are also demonstrated by the concept of the relational self.

The relational self is a concept based on "the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and

shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity” (Mackenzie & Stoljar, 2000, p. 4). A person’s relationships can be of great support in times of illness and stress (Coppola, Cassibba, Bosco, & Papagna, 2013; Veenstra, 2002). Positive or healthy familial relationships and friendships increase a person’s social capital, meaning they have a greater pool of social resources to draw from when they need support. Valuing relationships and inherent responsibilities to and effects of those relationships is a key concept in feminist philosophy. A specific example of this concept is relational autonomy, which is a more authentic view of autonomy than the strictly principled and individualist view that prevailed in the past several decades (Berkhout, 2012; Jennings, 2016; Ruhe, De Clercq, Wangmo, & Elger, 2016; Walter & Ross, 2014).

Relational approaches to any concept focus on the roles that social context and interpersonal relationships play in decision-making and agency (Jennings, 2016; Mackenzie & Stoljar, 2000; Marway & Widdows, 2015; Ruhe et al., 2016; Walter & Ross, 2014). This concept of an autonomy that is an expression of a person’s agency in terms of their holistic self is termed relational autonomy. The relational view of autonomy is consistent with nursing philosophy, seeing the person as inseparable from his or her social, cultural, environmental, and historical contexts, rendering a completely unbiased, exclusively rational ethical decision not only impossible but undesirable (Cole, Wellard, & Mummery, 2014; Marway & Widdows, 2015). When considering parents, specifically in terms of their relationship to and responsibility for their critically ill infants, it is essential to consider a philosophy in which this relationship is valued and its influence over all aspects of the parents’ life is recognized.

Human-to-Human Interaction Theory

Interpersonal nursing theories also ascribe value to the development of therapeutic relationships with people in need of care. Joyce Travelbee's Human-to-Human Interaction Theory (Travelbee, 1964) places interpersonal interactions at the center of the nursing process. Her theory was developed from a concern she perceived to be a trend in nursing that nurses were being trained against expressing sympathy toward their patients, and cautioned against showing too much kindness (Travelbee, 1964). Worried that the essential humanity of nursing was being eroded by tasks and cool professionalism that did not fulfill the essential function of the nurse, she outlined her theory of human-to-human interactions. The goal of nursing in this theory is to help a person cope with suffering and find meaning in the experience of suffering by forming an interpersonal relationship with them and reaching a true rapport (Meleis, 2018), as explained in the following.

Travelbee theorized that there are five phases to the nurse-patient relationship, each with specific tasks that must be completed before the relationship attains the interpersonal closeness needed for the nurse and patient to achieve their goals. The first phase is the *original encounter* during which both nurse and patient need to recognize each other's humanity underlying their professional relationship (Travelbee, 1966). Next, the nurse and patient transcend their roles and recognize their *emerging identities* by continuing their recognition of each other's humanity and uniqueness. A phase of *empathy* follows, during which the patient may share more about their thoughts and experiences of suffering, but the nurse remains apart and they do not share feelings. Next, the distance between the nurse and patient closes and they do share feelings and experiences, resulting in *sympathy*. Sympathy does not mean the nurse places an emotional

burden on the patient, but that they each share authentic and personal feelings and experiences, creating a shared vulnerability that is more human than professional (Travelbee, 1964). This distinction between empathy and sympathy is extremely important to Travelbee:

There is a warmth, an urge to action in sympathy that is not present in empathy. The empathetic person can perceive another's distress, identify its source.... But the sympathetic person *feels* another's distress; he is touched and moved by it and actively wants to do something to alleviate it. (1964, p. 69)

An essential part of sympathy, in Travelbee's view, is the call to action, and it is this desire for action that differentiates the empathy and sympathy phase in this relationship development. The last phase of this relationship is the achievement of *rapport*, a natural culmination of all prior phases, and both nurse and patient are able to perceive, share, and communicate about the feelings, thoughts, and experiences that will help them reach the goal of coping with suffering (Travelbee, 1966).

Suffering is a major concept in Travelbee's theory, and she defines it as a feeling of discomfort, transitory to chronic, mild to extreme, and considers the worst kinds of suffering to manifest as despair or apathetic indifference (Meleis, 2018, p. 247). According to Travelbee, the relationship between nurse and patient is the process by which the nurse is able to help the patient, and this relationship must be personal, not superficial. Once the nurse and patient reach the rapport phase of their relationship and are able to share and perceive each others' life experiences and stories of suffering, the nurse can understand what is necessary to help the person cope with however they are suffering and help them find meaning in their suffering if they are unable to do so alone. Ultimately, Travelbee states that the goal is for the person to find hope despite their suffering (Meleis, 2018).

This goal is particularly congruent with a palliative approach to care; the coping with, alleviation of, and finding meaning in suffering is the ultimate goal of palliative care (PC) as well (National Institute of Nursing Research [NINR], 2011). *Palliative care is a holistic approach to care that improves QOL by treating distressing symptoms of life-threatening or serious illness, and addressing emotional, spiritual, and cultural needs of the entire family* (Catlin, Brandon, Wool, & Mendes, 2015; National Consensus Project for Quality Palliative Care [NCP], 2018; NINR, 2011; World Health Organization [WHO], 2015). The tenets espoused in Travelbee's theory are relevant throughout the continuum of PC, whether early in diagnosis, approaching health, or approaching death. Although the meaning of suffering may change, and people may have to adapt their hopes to the circumstances that they find themselves in, the therapeutic relationship and its assistance in coping with suffering is always relevant. Her propositions all point toward the same beliefs that interactions between people who see each other as individuals and recognize each other's humanity are the only way to achieve relief of suffering, and denying this interpersonal need causes more suffering (Travelbee, 1964). The emphasis on communication and sharing of the self-espoused in this model is also congruent with essential components of PC, especially with parents who are not necessarily experiencing physical suffering but may be emotionally and spiritually suffering a great deal. Travelbee understood that the interpersonal interaction between a nurse and patient is the essential work of nursing, and her emphasis on relief of suffering and hope as the goal of the nursing process supports the goals of PC.

Palliative Care to Reduce Parental Stress

The suffering of NICU parents may be eased through the early initiation of PC in the NICU. Traditional PC has often been directed at older adults and people with terminal illness, but rather than waiting to initiate PC when death is imminently anticipated, *early initiation of PC* at time of diagnosis or soon after has been more effective in improving outcomes in other populations, even in people with serious illness that is not considered life-limiting (Lieberman, Song, Radbill, Pham, & Derrington, 2016; Maloney et al., 2013; Scibetta, Kerr, McGuire, & Rabow, 2016). Advances in neonatal healthcare have led to more infants *living* with serious illness in the NICU rather than dying in the first days or weeks of life. Research on neonatal PC is limited by an almost exclusive focus on EOL care and a lack of data about successful implementation (Conway-Orgel & Edlund, 2015; Kain, 2011; Leuthner & Pierucci, 2001; Quinn & Gephart, 2016; Samsel & Lechner, 2015; Younge et al., 2015). The potential benefits of improved quality of life, comfort, and mitigation of parental distress are crucial motivators to promote implementation of early neonatal PC.

The lack of studies addressing neonatal PC from a parent perspective represents another significant gap in the literature. Parents play a key role in neonatal PC by acting as surrogate decision-makers, participating in care planning, and carrying the psychological, spiritual, and emotional burden of their child's critical illness (Catlin & Carter, 2002; Shaw, Stokoe, Gallagher, Aladangady, & Marlow, 2016; Willems, Verhagen, van Wijlick, & Committee End-of-Life Decisions in Severely Ill Newborns of Royal Dutch Medical Association, 2014). Because parents must adopt these roles on behalf of the infant, they should be considered co-recipients of neonatal PC to reduce the burden of their child's serious illness. Studies focusing on parental

decision-making in the NICU have proposed frameworks and preferences for parent decision-making but have focused on initiation or withdrawal of life support rather than continuous values-based decision-making (Allen, 2014; de Boer, van Blijderveen, van Dijk, Duivenvoorden, & Williams, 2012; Shaw et al., 2016). Similarly, studies have been conducted on parental support and coping but have not connected these elements to other critical interventions in a PC framework. *There is an urgent need for evidence regarding parent experiences with early PC in the NICU to determine the extent and quality of current practices of surrogate decision-making, involvement with care planning, and coping with emotional and spiritual stressors, with an end result of developing a parent-centered PC program for implementation in the NICU.*

TABLE 1. *Table of key terms.*

Key Terms	Definition
Anxiety	An emotion characterized by feelings of tension, worried thoughts and physical changes (e.g. increased blood pressure); people with anxiety disorders usually have recurring intrusive thoughts or concerns and may avoid certain situations or places (American Psychological Association, 2019)
Depression	Characterized by two or more of the following symptoms: persistent sad or empty mood, hopelessness, irritability, loss of interest in usual activities, fatigue, appetite changes, sleep alterations, difficulty concentrating or making decisions (National Institute of Mental Health [NIMH], 2018)
Early palliative care	Initiation of palliative care practices at the time of diagnosis of or recognition of a serious health condition likely to affect quality of life of a person or their caregivers
End of life (EOL)	The time of and time surrounding a person's death
Neonatal intensive care unit (NICU)	Inpatient intensive care unit that provides care for infants with acute health needs at time of birth or shortly after, whose conditions are often related to alterations in fetal development, birth, and/or newborn transition
Palliative care (PC)	A person-and family-centered approach focused on providing relief from the symptoms and stress of a serious illness with the goal of improving quality of life for both the patient and the family (NCP, 2018)
Parent	Any person primarily responsible for the care and rearing of a child and surrogate decision-making about the child, usually with a legal or biologically familial relationship
Postpartum depression (PPD)	A period of depression starting within 4 weeks of childbirth that may be exacerbated by changes in hormones, social support, and sleep patterns (NIMH, 2019)
Posttraumatic stress disorder (PTS)	A serious psychological condition occurring following exposure to a traumatic event (Vignato, Georges, Bush, & Connelly, 2017)
Posttraumatic distress	Psychological distress following exposure to a traumatic event, absent all criteria necessary for a diagnosis of PTSD

Statement of the Problem

Hospitalization in the NICU can cause infants and their parents to suffer physically, psychologically, emotionally, and spiritually (Baia et al., 2016; Busse et al., 2013; Peebles-Kleiger, 2000; Woodward et al., 2014). NICU parents exhibit symptoms of anxiety, depression, and posttraumatic distress in far greater numbers than parents who are not coping with a NICU admission (Greene et al., 2015). With approximately 320,000 infants admitted to NICUs in the United States per year (Harrison & Goodman, 2015) this represents a significant threat to the mental health and quality of life of this population. The disproportionate burden of anxiety, depression, and especially posttraumatic distress among NICU parents has only been recognized recently, therefore development of and consensus on best practices for improving these outcomes for parents with infants in the NICU is limited. PC has been used as a holistic approach to care aimed at maintaining quality of life and mitigating consequences of serious illness for patients and their loved ones. There is evidence that implementation of PC can improve patient and caregiver satisfaction, decision-making, and coping, especially when implemented early after a serious diagnosis (Levine et al., 2017; Salins, Ramanjulu, Patra, Deodhar, & Muckaden, 2016; Vadeboncoeur & McHardy, 2018). Essential practices associated with early PC in other populations are shared decision-making, care planning, and coping with distress. These practices are appropriate in the NICU population as well and are more relevant for the parents as caregivers than the infant patient. Parents may have experiences with these essential practices, but since PC has been used almost exclusively for infants close to death in the NICU, little is known about these experiences in the context of early PC.

Purpose of Study

The purpose of this study is to explore and describe parental experiences with parent-centered elements of early neonatal PC: shared decision-making, care planning, and coping with stress. These data are needed to develop an experiential understanding of early PC in the NICU, which will be integrated with theoretical and empirical evidence to inform intervention development. The long-term goal is to develop a family-centered neonatal PC program that emphasizes early intervention, parent-focused support, parent-integrated care planning, and a more universal application of PC to non-terminal patients. Implementation of such a program could be expected to reduce parent distress, increase parent satisfaction with care, and further promote the principles of PC in neonatal healthcare.

Specific Aim

The specific aim of this study is to describe parent experiences during their infant's hospitalization in the NICU with:

1. Surrogate decision-making and shared decision-making
2. Care planning
3. Coping with emotional, spiritual, and social stressors

The expected outcome of this study is a description of current parent experience with early PC practices in the NICU. Findings of this study will fill a critical gap in our knowledge of parent experiences with early PC and will provide foundational knowledge for the development of future neonatal PC interventions and programs. It may also lead to the identification of parental needs and requirements from an early neonatal PC program, which will provide essential

formative work for future development and testing of a family-centered early-intervention neonatal PC program.

CHAPTER II: REVIEW OF THE LITERATURE

This chapter contains a conceptualization of early PC in the neonatal population, including definitions of its key attributes, differentiation from end-of-life care, and a defense of its place as an essential element of modern care for neonates and their families. Due to the lack of early PC literature specific to neonates, a narrative review format is used to describe PC literature across the lifespan with a focus on early PC. Three essential early PC practices with relevance to NICU parents are derived from this literature: shared decision-making, care planning, and coping with distress. The state of the science on these three practices in particular are shared, with a focus on neonatal and pediatric patients and their families. Finally, strengths and limitations of the literature are outlined, emphasizing the need for evidence specific to early neonatal PC.

Literature Review Focus

The ability to relieve suffering in people who are seriously ill is perhaps the main commonality between all healthcare providers. While the push for longevity is also a primary concern of health technology, the reduction of suffering and thus ability to enjoy an acceptable quality of life is essential to make advances in longevity worthwhile. The World Health Organization (WHO) defines PC as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness” (WHO, 2015). While sometimes seen as being incompatible with any curative treatment, goals of PC are not contrary to curative treatment, rather PC is aimed at improving quality of life and relief of suffering to make curative treatments worthwhile (NINR, 2011). Despite increased awareness of PC in recent years, this awareness has emphasized end-of-life (EOL) and hospice

care and has neglected how PC may benefit a person in early stages of any serious disease. Consequently, the concept of *early PC* is not well-defined for any population or discipline (Chidiac, 2018). This is especially true in the newborn or neonatal population, where conditions commonly targeted for PC in adult and older pediatric populations are uncommon, and the challenges of seriously ill neonates are not readily understood outside the setting of the NICU.

Search Strategy

To collect evidence supporting the concept of early neonatal PC, multiple searches were conducted from 2016 to 2019, and the findings contain literature published up to April 2019. Searches were primarily conducted using PubMed and CINAHL databases, though some seminal articles were discovered through reference searching. Various combinations of keywords were used to find all relevant evidence depending on the focus of the search. Common keywords searched were: neonatal; neonate; NICU; palliative care; early palliative care; perinatal palliative care; pediatric palliative care; pediatric intensive care unit; family-centered care; palliative or hospice care; advanced care planning; palliative care consultant; decision-making; neonatal ethics; and end of life decisions. Article selection was limited to English-language only and evidence supporting implementation and interventions was generally limited to being published in the last 10 years, though exceptions were made for seminal or essential articles contributing to the field. All literature was published through either peer reviewed journals or well-known organizations such as the National Consensus Project for Quality Palliative Care (NCP).

Findings

Early hospices were places of rest and hospitality for travelers and for the ill, and alleviation of suffering from illness was largely conducted in homes (Dahlin & Mazanec, 2011).

Advances in healthcare changed cultural views of both health and death, as many previously untreatable or inevitable illnesses became treatable, curable, and preventable. Modern movements addressing care for the dying were spearheaded by nurses, first by Dame Cicely Saunders in England, then by Dr. Florence Wald in the US (Dahlin & Mazanec, 2011). Though Dame Saunders became a physician, she began her career as a nurse, and both she and Dr. Wald shared a deep distress over the insufficient treatment of their patients who were seriously ill. Both women led teams of interdisciplinary colleagues to developing the first modern hospices in their respective countries and increasing awareness about the need for hospice and PC in modern healthcare (Clark, 2004). Hospice and PC movements in current years owe a debt to these advocates for compassionate, holistic care. However, the determination of hospice care as exclusively for the dying, and the connotation of hospice as a synonym for rather than a branch of PC has led to a body of literature and culture of practice that is dismissive of the palliative needs of people who may not be dying but are still seriously or chronically ill and have similar needs to those who receive end-of-life care.

Differentiating Early Palliative Care

A universal difficulty across populations is in defining, quantifying, and measuring early PC. There is no single definition of early PC, and no shared understanding of how best to approach it in any setting (Chidiac, 2018). Most definitions of PC from major organizations, however, include a statement that PC should begin as early as possible after a serious diagnosis (NINR, 2011; WHO, 2015). Recently, the NCP was commenced to outline the delivery of quality PC and set standards of care for PC in the United States. Their work is organized into eight domains of PC (Figure 1) that should be addressed whenever a person is treated with PC,

and all but one of these essential domains of PC are applicable to any person in any stage of serious illness. This supports the definitions of PC as being appropriate for early intervention, regardless of age or anticipated proximity to EOL. In practice, however, PC is often not considered until a person is assumed to be near death or at high risk of death (Thompson, Knapp, Madden, & Shenkman, 2009). Evaluating evidence for early PC across populations describes benefits and barriers to early PC that will contribute to understanding how best to apply early PC to the neonatal population.

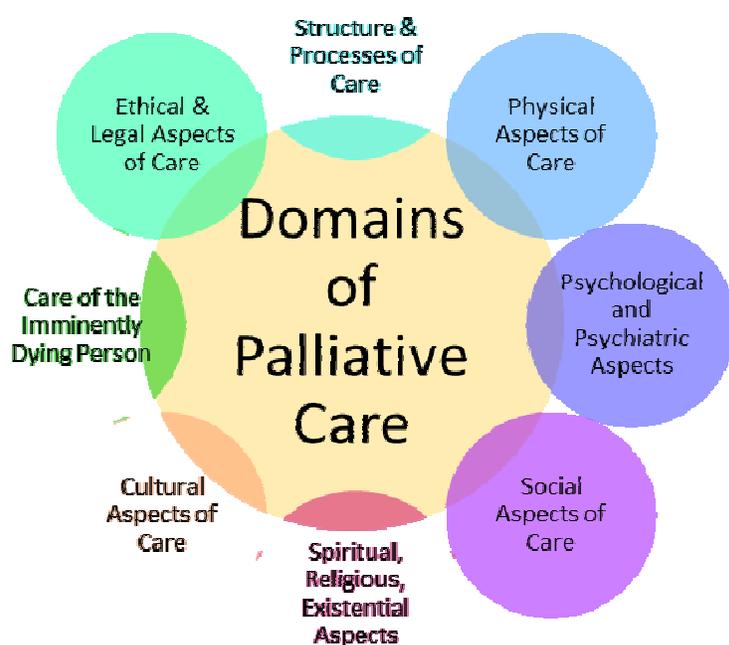


FIGURE 1. Domains of palliative care.

Early Palliative Care for Adults

The study and practice of PC is most prominent in the adult population, and this is also true for early PC. Adults with cancer and their caregivers perceived early PC as helpful, and

while they did not all express a need for PC services, none shared any harmful aspect or negative experience of early PC (Hannon, Swami, Rodin, Pope, & Zimmermann, 2017; Maloney et al., 2013). These adults described some benefits of early PC such as enhanced problem solving and coping, and positive feelings of empowerment and support. Adult PC is not free from the bias toward end-of-life that exists in neonatal PC; despite evidence that early PC intervention provides both benefits to patients and cost-savings, early PC is still underutilized (Scibetta et al., 2016). The usefulness of early PC for adults with chronic illness is gaining awareness, but also remains underutilized (Chidiac, 2018).

Early PC in adults provides both a model and a justification for early PC in the neonatal population. Consider two adults diagnosed with the same type and stage of cancer at the same time. Both have conversations with their healthcare team about their treatment options and make decisions that consider their individual circumstances and values. Both participate in programs designed to help them and their families cope with the serious diagnosis, and both require additional help for pain and symptom management during their treatment. After treatment, one person is in remission, and one person has died. The support provided to the survivor is not invalidated because of their survival, and evidence demonstrates increased rates of survival, decreased cost of illness due to lower utilization of healthcare services, and improved mental health outcomes for adults who had early PC intervention (Chidiac, 2018). If early PC intervention benefitted this adult cancer survivor, might early PC interventions benefit seriously ill infants and their families, even if they are not expected to die?

When applied to a case of two infants born at 23 weeks gestation, at the lower limit of viability with high risks for death and significant disability, this case also applies. Both of these

infants have an acceptable survival rate and would likely be offered a full range of interventions at birth, but their extreme prematurity leaves them vulnerable to many complications that may lead to acute or chronic disease and may cause death. If early PC addresses all domains of care other than physical care of the dying person, there is no reason to withhold this supportive care for these infants and their families simply because they are not expected to die. These infants will spend months in the stressful environment of the NICU, leaving their parents at risk for the negative outcomes associated with parenting in that environment.

Early Palliative Care in Pediatrics

Though serious and life-threatening illness is less common in children than in adults, pediatric PC is still an essential aspect of care. As with adults, the majority of referrals to PC service in the pediatric population are for children diagnosed with cancer, though children with serious congenital or genetic conditions are also often referred (Thrane, Maurer, Cohen, May, & Sereika, 2017). The literature addressing PC in children describes relatively late delivery of PC and emphasis on EOL decision-making, as in the adult literature. This persistent late delivery of PC exists despite evidence that both parents and children may benefit from and prefer earlier initiation of PC (Hendricks-Ferguson & Haase, 2018; Levine et al., 2017; Vadeboncoeur & McHardy, 2018). A study completed with pediatric intensivists found that EOL interventions and medical management were not what they would most like from a PC consult, but rather activities associated with early PC like care coordination between facilities and family support (Jones & Carter, 2010). Another study determining perceptions and appropriate timing of PC among pediatricians also described their persistent belief that PC was synonymous with hospice care and thus would delay a PC referral until a child's death was anticipated (Thompson et al., 2009).

Despite the relative lack of literature describing early pediatric PC to more traditional PC, there is evidence of benefits to early initiation of PC for children and their families. In children with serious chronic health conditions, initiation of PC was viewed as ‘very helpful’ by families and all would recommend it to similar families, even though their children were not expected to die (Lieberman et al., 2016). Though some needs of newborns and their families are quite distinct from the populations included in studies of pediatric PC, the emphasis on family decision-making and the family-centered nature of most early PC interventions mean these findings may also translate to neonatal PC.

Perinatal Palliative Care

The field of perinatal PC supports pregnant women and families whose unborn children have been diagnosed with a serious health condition that may lead to death before, during, or shortly after birth (Wool, 2013). Advancements in antenatal and fetal diagnostic testing and imaging over the past few decades have led to early diagnosis of serious fetal health problems during pregnancy rather than after birth. While a mere awareness of potential complications can be a useful decision-making tool after their child is born, families presented with a serious fetal diagnosis may suffer severe emotional distress, decisional conflict, and grieve the loss of the “normal” child and birth they anticipated (Cote-Arsenault & Denney-Koelsch, 2011). Perinatal PC programs have developed to address these needs by providing parents with information on their available options, providing emotional and psychosocial support, and guiding care planning regarding continuation of pregnancy, induction of labor, and PC during and after birth (Denney-Koelsch et al., 2016; Kiman & Doumic, 2014; Wool, 2013; Wool et al., 2016).

By definition, perinatal PC is primarily *early* PC, and is complementary to neonatal PC due to the age of the child and the feature of parental surrogates. Perinatal PC may be an entry point for infants and families who would also benefit from PC in the neonatal setting, such as infants with congenital abnormalities, who represent the highest rate of death in the neonatal period (Mathews, MacDorman, & Thoma, 2015). Though a relatively new field, perinatal PC has been incorporated into new programs emphasizing a continuum of PC throughout the lifespan, especially for children with conditions that are expected to be serious and chronic (Wool et al., 2016). Children with complex congenital heart defects, for example, may require multiple surgical procedures, extended hospital stays, and need a high level of health management during their lifetime. If these conditions are diagnosed before birth, perinatal PC specialists may work with families to help them understand their options for care delivery both before and after delivery, and connect them with valuable services and support organizations (Bertaud, Lloyd, Laddie, & Razavi, 2016). Since the goals of perinatal PC (i.e., decision-making, care planning, and family support) can be carried forward throughout pregnancy and into infancy, these goals can also be used as a guideline for early PC in neonates.

Early Palliative Care in the NICU

While other populations have a small amount of evidence addressing early PC, most literature addressing neonatal PC is focused exclusively on EOL care and infants who are expected to die imminently (Quinn & Gephart, 2016). EOL care is an important aspect of PC, and dying infants and their families certainly deserve the dignity and support that neonatal PC provides, but this narrow focus does a disservice to other infants and families needing support. An exclusive focus on EOL care limits and places barriers on the implementation and adoption

of neonatal PC. Clinicians may be hesitant to consult a PC team or initiate a PC protocol if it stands as a symbol of imminent death. Studies have found that both clinicians and parents do not want to feel like they are “giving up” on the infant, and clinicians fear that they will be forced to relinquish care or abruptly stop curative treatment if they initiate PC (Kain, 2006, 2011; Kain, Gardner, & Yates, 2009; Martin, 2013; Wright, Prasun, & Hilgenberg, 2011). When PC symbolizes death, it may be less effective and underutilized. It also fails to address the needs of parents whose infants are seriously ill but are not considered likely to die. When PC is initiated early in a disease process, the focus shifts from death to decision-making, social and cultural family support, setting value-based goals, and building relationships between clinicians and families.

Parents as Primary Recipients of Neonatal Palliative Care

Family is an important aspect of PC in any population, but an infant’s parents are an integral part of neonatal PC. Parents act as surrogate decision-makers, navigate the complex healthcare system, and bear the emotional, spiritual, and psychological burden of their infant’s illness. While the focus of neonatal PC is always on upholding the human dignity of the infant, many PC interventions traditionally directed at the person with illness must be directed at the infant’s parents because they carry these burdens of illness for their infant and are ultimately responsible for their infant’s care (Catlin et al., 2015; Mancini, 2011; Widger & Wilkins, 2004). This is especially true for early PC, where goals are not necessarily related to alleviation of physical symptoms but on more complex cognitive and social processes (i.e., decision-making, care planning, and coping). Even in adult PC, a person’s family would be included in these aspects of care; in neonatal care, the patient is unable to actively participate in this care, so the

role is assumed by the child's parents. When considering PC priorities, they should be viewed at least equally to the newborn, and perhaps in greater need of supportive care.

Shared Decision-Making

An essential part of PC at any stage of illness is decision-making. Decisions regarding resuscitation orders and life-prolonging treatments such as enteral feeding and mechanical ventilation are commonly associated with PC, but decisions regarding curative treatment options, location of care, choice of caregivers, and symptom management options are also common (NCP, 2018). Historically, healthcare providers had paternalistic attitudes toward their patients, and most healthcare decisions were made unilaterally by a physician with little input from the person most impacted by the decision (Beauchamp & Childress, 2013). In the past several decades, however, a shift has occurred that has led to more autonomous healthcare decision-making, which for neonates means that critical decisions are often left up to parents (Kon, 2011). This shift from paternalism to complete autonomy has not been entirely beneficial for parents, who have demonstrated a continued need for guidance and expert opinion from healthcare providers when making critical decisions (Allen, 2014; Rosenthal & Nolan, 2013; C. Shaw et al., 2016; Weiss, Barg, Cook, Black, & Joffe, 2016).

Shared decision-making has emerged as a prominent, ethical framework for decision-making regarding health, and is accomplished when a person or family and their healthcare provider make decisions in a partnership (Kon, 2010). Shared decision-making requires honest estimations of consequences, and clear communication of options their and consequences (Kon, 2010). Though early neonatal PC may not require parents to make life or death decisions, shared decision-making may still be utilized as a model to guide parents in decisions regarding surgical

intervention, plan of care, and pharmacological approaches. Encouraging parents to collaborate actively in decision-making can help them regain a sense of control and affect feelings of parental role fulfillment (Peebles-Kleiger, 2000). The degree to which parents may want to or feel capable of participating in decision-making may depend on individual parent characteristics, the emergent nature of the decision, and the potential for long-term consequences following a particular course of action (Shaw et al., 2016; Weiss, Xie, Cook, Coughlin, & Joffe, 2018; Wyatt et al., 2015). Implementing shared decision-making can be challenging for practitioners, however, and they may not understand how best to give guidance to family members acting as surrogate decision-makers (Richards et al., 2018).

Care Planning

Care planning and *advance* care planning are hallmarks of early PC. Ideally, care planning evolves from the shared decision-making process, a natural progression from a discussion of values, hopes, and expectations with a person experiencing serious illness or that person's surrogate. The main distinction between shared decision-making and care planning in neonatal PC is that care planning is more goal-oriented and may not revolve around a central decision. *Advanced* care planning generally relates to planning for advanced disease and may be relevant at EOL, such as advanced directives and living wills (Hoerger et al., 2018). Advanced care planning in the NICU describes parental decision-making regarding do-not-resuscitate status, and acceptable resuscitation interventions (Beecham et al., 2017). Since these advanced care planning topics largely relate to EOL, they are less likely to be helpful in an early PC timeframe. Instead, care planning in early neonatal PC may be viewed broadly in terms of

determining a plan with overall goals of healthy development, symptom management, and timely discharge, which are goals that are ideally shared by both parents and the healthcare team.

With the rise of family-centered care in NICUs, parents are encouraged to be involved in all aspects of care (Gooding et al., 2011; Raiskila, Axelin, Rapeli, Vasko, & Lehtonen, 2014; Thomas, 2008). But the extent to which parents are welcome or encouraged to be involved in their child's care varies between NICUs, and may only include activities that exemplify "normal parenting" (i.e., skin-to-skin holding, diapering, bottle/breast feeding). This is an improvement on attitudes toward parental involvement prevalent during early decades of neonatal care but encouraging parents to participate in activities of care without collaborating with them in decision-making and encouraging their guidance of the plan of care is not true family-centered care. Some efforts have been made to involve parents in care planning by inviting them to participate in routine rounds made by the healthcare team where the infant's plan of care is discussed, and a course of action decided (Harris, 2014; Kelly et al., 2013). Current evidence, however, has exposed the tokenism that often characterizes this kind of parental involvement in care planning and decision-making (Axelin, Outinen, Lainema, Lehtonen, & Franck, 2018).

Family conferences provide another opportunity for parents to engage in care planning. These meetings are often convened when a serious decision is being considered or when the healthcare team has poor prognostic or diagnostic news to share with the family. As with rounds, family conferences tend to place parents in the role of a passive participant rather than an active guide of discussion and may act more as forums for formal updates by the healthcare team rather than an environment for collaborative decision-making and care planning (Boss, Donohue, Larson, Arnold, & Roter, 2016). These conversations may not truly serve parents' needs as

healthcare team members generally speak more about functional and health needs rather than quality of life, which is a primary concern for parents (Boss, Lemmon, Arnold, & Donohue, 2017). Estimations and perceptions of prognosis often differ between clinicians and parents after such conferences, with clinicians often presenting a more optimistic view than they truly believe (Boss et al., 2017). These sub-optimal attempts at family-centered care planning are not benign; rather, they may give NICU teams a false sense of being inclusive of family while perpetuating a culture of token parental involvement that invites parents to a table that is still headed and dominated by the healthcare team. Including care planning as an essential part of a parent-centered framework for early PC in the NICU, and re-orienting the care planning experience toward true collaboration with parents is a critical step in providing family-centered PC.

Support for Coping with Distress

Supporting parents during a stressful NICU admission is an element of early neonatal PC that has been addressed in existing literature. It is well-understood that having a child in the NICU, even with non-critical illness, is distressing for parents (Baia et al., 2016; Bouet et al., 2012; Busse et al., 2013; Greene et al., 2015; Turner et al., 2015; Woodward et al., 2014). This distress can be so significant that it leads to increased risks of anxiety, depression, and posttraumatic distress in NICU parents, even after their child leaves the hospital (Agius, Xuereb, Carrick-Sen, Sultana, & Rankin, 2016; Kim et al., 2015; Segre, McCabe, Chuffo-Siewert, & O'Hara, 2014; Treyvaud et al., 2014).

Though NICU care providers are likely aware of this parental distress, there are not any standard interventions across NICUs, and available services such as hospital-supported peer groups, mental health service availability, and parent-focused programs vary widely including

many institutions with no formal support (Coppola et al., 2013; Huenink & Porterfield, 2017; Melnyk et al., 2006; Smith et al., 2012). There is no universal approach to parental support, and because parents are not direct patients, there may be barriers to providing formal mental health support for them as caregivers. Bereavement support when a child is expected to die or after a child dies is a common feature in most NICUs, but providers are not necessarily trained to provide support for parents whose children do not meet such narrow criteria. A common function of early PC in other populations is to address the distress caused by the *diagnosis* of a serious illness, and to facilitate healthy coping in the person and their family (NCP, 2018). Because of the significant consequences of NICU-related distress in parents, relieving or ameliorating this distress should be viewed as a priority in all neonatal PC.

Strengths and Limitations of Prior Research

The evidence supporting PC across populations to improve QOL is abundant, so much so that national and international organizations support PC and have created guidelines for practicing it (NCP, 2018). Much of the most rigorous evidence, however, is found among adult populations with specific diagnoses. The primary limitation of the evidence presented in this chapter is that it was not found in the NICU population, whereas the evidence supporting neonatal PC is limited by its focus on EOL rather than comprehensive or early PC. There are few highly rigorous studies, such as randomized controlled trials, that have been conducted evaluating patient and family outcomes after early PC interventions, and only a few of these can directly inform PC for the parents of neonates. Moreover, the varied definitions of early PC, limited description of interventions involved in early PC, and inconsistent descriptions of family involvement continue to limit the applicability of the evidence, especially across populations.

Summary

The importance of early initiation of PC for people enduring serious illness is slowly being recognized by healthcare providers across populations. Despite this, minimal literature exists to concretely define and provide outcome measures for early PC in any population, which makes comparing outcomes and developing an early PC model difficult. This difficulty is more significant in the neonatal population because a strong bias toward equating PC with EOL and hospice care restricts the concept of PC to a model that does not allow for early intervention, even though this has proven beneficial in other populations. Parents of seriously ill newborns may especially benefit from early intervention because they bear all but the physical aspects of the illness for their child and are consequently at high risk for poor mental health outcomes such as depression, anxiety, and posttraumatic distress. The constructs of shared decision-making, care planning, and support with coping presented here are congruent with early PC practices in other populations but have to be explored as complementary constructs within a model of neonatal PC. It is essential to conceptualize and promote early initiation of PC for all seriously ill infants in the NICU to ameliorate the suffering of these infants and their families, and to evaluate whether early PC delivers on the promises it has hinted at in other populations. Since so little is known about how parents currently experience these practices in the NICU, experiential data from parents is needed to fill this knowledge gap.

CHAPTER III: METHODS

This chapter contains details of the research methods used to address the problem described in the previous chapters. The purpose and aims are restated to reorient the chapter toward research design and method. The need for a qualitative approach to the problem and the methodology of qualitative description are described. A detailed description of the research setting, sampling strategies and frame are followed by the methods used for data collection, management, and analysis. The strategies used to uphold rigor and trustworthiness are outlined. The conclusion of the chapter includes a discussion of the risks and benefits to study participants and the plan used to help protect those participants from risks to their wellbeing or privacy.

Purpose and Aim

The purpose of this study was to explore and describe parental experiences with parent-centered elements of early neonatal PC: shared decision-making, care planning, and coping with stress. The specific aim of this study was to describe parent experiences during their infant's hospitalization in the NICU with:

1. Surrogate decision-making and shared decision-making
2. Care planning
3. Coping with emotional, spiritual, and social stressors

Study Design

To fulfill the purpose of this study, an exploratory qualitative approach was chosen to explore parent experiences of caring for a seriously ill child in the NICU. This approach helped identify whether parents encounter early PC practices in the NICU, and if so what the essential aspects or desired aspects of those practices are. Early PC for neonates is an innovative concept;

very little is known or has been studied examining what early PC looks like for neonates and their families. A *quantitative* design was not appropriate for this study because the features of early neonatal PC have not yet been identified, so valid measures of the phenomenon are not available. Quantitative designs require measures or instruments that can be reliably and validly applied to fulfil the study's purpose. Metrics applied at this stage would be best guesses, and content validity of such instruments would be difficult to support because the essential characteristics of early neonatal PC are not known.

The methodology of qualitative description was used to fulfill the purpose of this study. When very little is understood about a phenomenon, as with this proposed concept of early neonatal PC, qualitative description allows the researcher to explore the experience of interest without excessive interpretation that may not help in identifying the 'facts' of the experience (Sandelowski, 2000; Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016). Qualitative description is bound by less structure than other qualitative methodology, which makes it ideal for such an exploratory purpose; it is defined individually according to purpose, theory, and context, and is best understood through descriptions of data collection and analysis that are unique to each qualitative descriptive study (Sandelowski, 2010).

Setting

The focus of this study is not a particular region or institution, but rather common or general NICUs in the US. Recruitment and data collection for this study both occurred online. Participants were recruited through email and social media networks targeting NICU parent organizations, and data was collected through online videoconferencing interviews and online surveys.

Sampling

A combination of two purposeful sampling methods – maximum variation and stratified purposeful sampling – were used in this study. In qualitative descriptive research, participants are typically gathered using purposeful sampling (Sandelowski, 2000). The purposeful sampling strategy includes a sampling frame of participants whose data can contribute to the aims of the study (Coyne, 1997; Patton, 2002). Qualitative researchers are not necessarily concerned with the ability to generalize findings to a wide population, but it is essential in an exploratory study to find participants who are deep wells of information and can provide detailed, meaningful descriptions of their experiences (Creswell, 2013). Sandelowski (2000) suggests that maximum variation sampling, a variant of purposeful sampling wherein heterogeneous cases are sought out to gather a broad range of experiences, can be used to great effect to enhance transferability, especially if little is known about the subject. Similarly, when defined characteristics of participants are known to exist, such as sex or diagnosis, stratified purposeful sampling may be indicated. This method is used to predetermine these essential case criteria and ensure that all necessary data are collected from participants who fit the case criteria (Creswell, 2013).

By combining maximum variation sampling and stratified purposeful sampling strategies, parents with a wide range of experiences were recruited, including those whose experiences were ideal for application of early PC and traditionally underrepresented in neonatal research. For example, since fathers are historically underrepresented in NICU-based research, recruitment and data collection was not completed until multiple fathers had participated and comprised at least 25% of the sample. This required targeted recruitment of fathers after several parents had been recruited, which will be discussed in subsequent sections.

Participants were recruited from a population of parents who previously had at least one infant admitted to a NICU. The estimated sample size was 12-20 parents, and individual interviews were ultimately conducted with 16 participants. Data saturation was reached after these 16 parents had been interviewed, when new participants provided consistently repetitive data that confirmed previous major findings but did not add new or unique findings that contributed to major themes (Saunders et al., 2018). To obtain enough data to fully explore early PC experiences in depth and breadth, the concept of data salience, ensuring the concept of interest is explored in depth, was also considered in determining whether more participants needed to be recruited (Weller et al., 2018).

Inclusion Criteria

To participate in this study, only individuals who fit the following criteria were recruited:

1. 18 years or older
2. Able to speak and read English
3. Had an infant admitted to a NICU whose discharge date or date of death is within three years prior to the time of recruitment
4. Had an infant whose length of stay in the NICU was at least two weeks, unless the infant was deceased during the NICU stay or was discharged with hospice care

Adolescent parents under age 18 were not included in this study. Due to their developmental stage, the cognitive function, social status, relational autonomy, and coping ability of these parents may be very different from adult parents and may affect study results by greatly increasing heterogeneity in the participant group. The purpose of the maximum limit of three years since the NICU stay was to help ensure that participants could remember their experiences

enough to recall and provide authentic responses. Parents with previous NICU experience occurring more than three years in the past may be less likely to recall events relevant to the interview. The length of stay criterion was an effort to ensure moderate infant acuity level, without excluding parents whose children were so seriously ill that they died or were transferred into hospice care at less than two weeks. These parents would likely be candidates for early PC interventions in the NICU.

Exclusion Criteria

Individuals who fit the inclusion criteria were considered ineligible to participate if any of the following criteria also applied:

1. Lack of involvement in the infant's care during the NICU stay due to any circumstance
2. Had experienced the death of their child within six months from the time of participation
3. Unable to comprehend or respond to verbal interview questions

The first exclusion criterion excluded parents who, due to their limited involvement in the child's care, likely had very little experience with the early PC practices that were the focus of the interview. Parents were considered to have had limited involvement if they were incarcerated during their child's NICU stay, relinquished their parental rights within one week after birth, or were unable to visit their child at all during their hospitalization. These specific circumstances are rare, and the parents' visitation record was not otherwise quantified or questioned. The second criterion excluded parents who were in early stages of bereavement and may have

become too distressed by participation in the study. The last criterion was a necessary exclusion of parents who were unable to participate in the chosen method of data collection.

Recruitment Methods and Consenting

Initial participants were recruited from the parent advocacy community, specifically the Premie Parent Alliance (PPA) group. The PPA is a coalition of parent-led advocacy and support groups that have an active online and community presence and are mostly comprised of parents who have had children in the NICU. Permission to distribute recruitment information to members was obtained through the PPA Standards and Review committee, and their social media liaison posted recruitment information. Members of this organization were reached by email and posts to the group's members-only Facebook group page. Refer to Appendix A for this and all following recruitment information and documents. The recruitment email and social media posts directed parents to a link to an eligibility survey that allowed them to submit their email address if they fit eligibility criteria and were interested in participating. Parents that did not meet eligibility criteria were directed to a page thanking them for their interest; information about bereavement resources were included on the page viewed by parents who did not fit eligibility criteria due to their child's recent death. Parents who responded positively to all inclusion criteria and negatively to exclusion criteria viewed a screen confirming their eligibility and provide details about the study. The bottom of this page included a place to enter and submit their email address if they were interested in participating. The PI viewed responses to this survey daily and initiated email communication with interested participants. Potential participants were able to correspond with the PI by email or phone to ask any questions or discuss the process before agreeing to participate. Initial participants were asked to pass on

recruitment information to any other parents they thought would be interested in participating, and some parents reposted the link to the eligibility survey in other parent social media groups on their own. The initial information was reposted after two weeks of recruitment to remind parents of the opportunity, and a further post was released with messaging specifically targeting fathers and encouraging them to participate.

After agreeing to participate and setting an interview date, potential participants were sent a unique link to an electronic consent document hosted on Qualtrics, the secure data collection site utilized by UA College of Nursing. The PI ensured this consent document had been completed before sending a separate unique link to the demographic survey and the link to complete the interview. At the beginning of the interview, the participants were asked to indicate their consent verbally to ensure participation was voluntary. Copies of these electronic consent documents were uploaded to the secure UA Box Health site in a folder marked “CONFIDENTIAL” and will be retained for six years per UA policy.

Data Collection

The primary method of data collection in this study was semi-structured interviewing, which combines the structure of a guided interview with the responsive openness of an open interview (Kallio, Pietila, Johnson, & Kangasniemi, 2016). The method of data collection in qualitative description depends greatly on the subject and context of study. As with other qualitative methods, interviewing is the most commonly used strategy for data collection in qualitative description because it is often the best way to obtain narratives that detail the experiences of interest to the researcher (Sandelowski, 2000). Approaches to data collection in qualitative descriptive studies vary; some researchers approach problems from a theoretical or

conceptual perspective, which affects how they guide interviews and the elements of experience they consider most important (Sandelowski, 2000, 2010). Since the conceptual framework of EPC has been proposed as part of the study purpose, interview questions focused on exploring parent experiences with shared decision-making, care planning, and coping with distress. Parents were also asked, however, to share anything that they considered essential to understanding their experience so that vital aspects of their experience are not overlooked.

Parents participated in one semi-structured interview lasting no more than two hours. Interviews were conducted using a pre-constructed guide (Appendix B) containing questions designed to elicit responses focused on the aims of the study, but participants were free to respond in an open way and the PI followed up with important responses that did not ascribe to the guide. At the beginning of each interview, participants were asked to share their NICU story. Questions about experience were open and general, such as “Tell me your baby’s story,” and “Tell me about your best day in the NICU.” These opening questions allowed the parent to share the most important aspects of their experience and provided the PI with potential avenues for future questioning. Following this discussion, parents were asked to recall specific experiences with shared decision-making, care planning, and coping with distress. Questions relating to these topics were more focused and direct. Examples included, “Tell me about a serious decision you had to make in the NICU,” and “What helped you most in coping with the NICU experience?” The goal with these questions was to answer the primary aims of the study: to describe parent experiences specific to early PC practices. (Appendix B to view the interview guide.)

The secondary method of data collection was quantitative in the Demographic and Infant Characteristics Survey (DICS) (Appendix C). After participants completed the online consent

document, they were given a link to complete this survey. The PI reminded parents during the interview to complete the survey, but there was one non-respondent. Demographic data included variables of age, sex, ethnicity, marital status, education, socioeconomic status, and employment status. Child-related variables were also collected and included gestational age at birth, birth weight, length of NICU stay, whether living, and number of infants admitted to the NICU. To help contextualize the chronic serious illness among the infant population, the survey also included a question regarding number of hours of home nursing per week for which the child qualified. These quantitative elements provided context for participant responses and allowed description of the study sample with relevant detail to evaluate how transferable these results may be to a different population.

Data Management

Data collection in this study produced four forms of data: audio and video data from online interviews, online survey data, written transcripts of the audio interview data, and handwritten interview notes. All data except for the interview notes were obtained and stored in a digital format; no physical copies of identifiable data exist.

Protection of Data Confidentiality

Data was comprised of audio recordings, interviewer's notes, and transcripts of audio from the interviews. Audio and video data were recorded through the secure virtual meeting software Zoom. The purpose of using video during the interviews was to simulate an in-person interview through face-to-face interaction, but participants were able to turn off video recording if they did not want their image recorded. Video data was not strictly necessary for analysis, but recording of audio data only was not available on the Zoom platform. Only the PI had access to

this audio and video data. Recordings were transcribed by Landmark Associates Inc., a well-known and secure transcription service. Interview transcripts were uploaded into Atlas.ti qualitative data analysis software. All project files were saved to the UA Box Health cloud storage service for retention and file transfer between the PI and her committee members. Only the PI and her dissertation committee members had access to the folder holding these files. Interview notes were stored in a secure lockbox in the PI's home office and were also scanned and uploaded into Atlas.ti; these notes did not include any unique participant identifiers. Audio and visual recordings were deleted after confirming accuracy with the written transcripts. Transcripts will be retained for six years or until this dissertation study is completed and approved by the committee, whichever comes later. At that time, recordings and paper copies will be shredded using industry standards.

Protection of Participant Privacy

All participant contact information handling was performed by the PI who has experience in maintaining data confidentiality. Interviews took place online using private digital meeting technology. During these interviews the PI was in a private location and participants were free to choose their own meeting location. The participants were not aware of others' participation unless they chose to disclose that information. The PI and her dissertation committee members have completed the CITI online training in human research subject protection. The primary objectives of the training are to: (a) provide the historical framework for current regulations governing the protection of human subjects; (b) summarize the ethical principles that guide research with humans and illustrate how those ethical principles are applied in human subjects research; (c) discuss the investigator, staff, and institutional roles and responsibilities in

protecting human subjects; and (d) explore the evolving issues related to human subjects research. The PI and her dissertation committee members have been involved in numerous research projects that were successfully accomplished in terms of human subjects' protection.

Sharing Results with Participants

To provide follow-up and a feeling that their contributions were useful and contributed to a larger purpose, participants may be interested in reviewing a summary of the study results. The consent document included a section requesting permission to store the participant's email address if they were interested in receiving this summary. When data analysis is complete, a summary of the results will be sent to interested participants. Data included in the summary will not be identifiable or ascribable to specific participants and will be written with consideration toward a stakeholder audience.

Data Analysis

Qualitative description does not have a prescribed method for data analysis, rather the guiding principles of analysis are to remain close to the data, preserve participants' own words, and use minimal interpretation (Sandelowski, 2000). Sandelowski (2010) clarifies, however, that a recitation of data without interpretation or analysis is not acceptable; it is necessary to identify important data, discover patterns or themes in data, and synthesize results. Content analysis is commonly used to achieve this goal (Hsieh & Shannon, 2005; Willis et al., 2016). Narrative inquiry of this kind while having several underlying purposes, can be used to understand major events and the effect of those events on the parents. Researchers conducting conventional content analysis look across all the data to identify the common issues that recur, and identify the main themes that summarize all the views collected (Hsieh & Shannon, 2005). This starts with

assigning codes, which are descriptive words or short phrases, important phrases that represent major ideas within the data (Saldana, 2016). The researcher then further abstracts these codes into themes by collating codes that represent similar or related ideas (Hsieh & Shannon, 2005; Willis et al., 2016). Data analysis techniques can evolve throughout data collection and analysis phases as new information is discovered, so a certain flexibility in analytic methods is beneficial (Sandelowski, 2000). For example, affective coding strategies specifically identify values or emotions within the data, so data about experiences with these concepts as central areas of importance may be valuable to code using these methods (Saldana, 2016).

A conventional content analysis was used to analyze the qualitative data. The PI read through each transcript and assigned codes to important phrases to categorize the raw data. Most codes were inductive meaning that they were derived from the data itself and not prescribed a priori to analysis, though some a priori deductive codes were used at the beginning of analysis matching the major concepts of the study aims (Saldana, 2016). Codes were continuously re-defined throughout the data collection and analysis phases as new data was collected and analysis revealed new information. Codes were further categorized into themes, and some connections between codes and themes were established in networks. The final product of this qualitative analysis is a set of overarching themes for each EPC concept (i.e. shared decision-making, care planning, and coping) that describe both parent experiences with them and their relationships to each other. Dr. Crist was a resource for the PI throughout qualitative analysis, providing oversight and guidance on coding, synthesis, and interpretation. Dr. Gephart acted as a second reader during preliminary analysis to help reduce bias and maintain rigor. The PI, Dr.

Gephart, and Dr. Crist held multiple videoconferencing meetings to discuss major points of analysis and to help refine proposed themes.

Data from the demographic survey and infant characteristics survey was analyzed using descriptive statistics. Frequencies, means, and ranges were calculated as appropriate for the measure. Though this data could not necessarily be statistically correlated to qualitative results, analysis of these variables helped describe the study sample, particularly the ethnic and socioeconomic diversity of participants and their NICU experiences. Understanding the sample diversity was useful in relating the findings to other literature, determining possible limitations and creating a detailed description of the sample to determine transferability as described below.

Rigor and Trustworthiness

Qualitative researchers are concerned with representing the truth of what is being studied. Unlike quantitative research, however, the philosophical underpinnings of qualitative research dictate that finding a *single objective truth* is not only not the goal of qualitative research, but may be impossible, so criteria for rigor in quantitative methods is not applicable to qualitative methods. Lincoln, Lynham, and Guba (2011, p. 120) pose a definition of validity in relation to qualitative research in the form of a question: “Are these findings sufficiently authentic... that I may trust myself in acting on their implications?” This definition is suitably clear and action-oriented in a way that is appealing to researchers whose work is intended to influence practices or policies, such as nurse scientists. Though helpful in conceptualizing rigor in qualitative research, specific criteria are still useful, especially for research novices. The qualitative validity criteria posed in seminal work by Lincoln and Guba (1985) and termed *trustworthiness* remains standard, though others have posed similar criteria in intervening years (Creswell, 2013). There

are four main criteria of trustworthiness: credibility, transferability, dependability, and confirmability. Specific approaches to strengthen trustworthiness and uphold rigor in the proposed study are described in Table 2.

TABLE 1. *Methods to establish rigor.*

Trustworthiness Strategy	Trustworthiness Criterion	Purpose	Specific Strategy	Phase of Study
Member check/ community engagement	Credibility	Returning the analysis to the people experiencing the phenomenon to check for the “ring of truth” in the interpretation of the essential meaning of the experience (Lincoln & Guba, 1985)	Present summary of findings to interested participants and request feedback regarding degree to which their experiences are reflected	Data analysis
Peer debriefing	Credibility	Identify potential sources of bias, areas of “blindness” in analysis or faults in coding strategies (Morse, 2015)	Meetings held at regular intervals with committee members to share data and decisions regarding coding and analysis	Data analysis
Thick description of study sample	Transferability	Provide a thorough description of the participants to determine how transferable results are to other populations	Collect demographic and infant specific data and report descriptive statistics	Data collection, data analysis
Data audit trail	Dependability Confirmability	Establish a record of observations during interviews that can be reviewed by co-analysts	Keeping field journal of notes written during and after interviews	Data collection, data analysis
Reflexivity	Confirmability	Understanding the PI’s place within the phenomenon (Enosh & Ben-Ari, 2016); recognizing assumptions, prior knowledge and experience, and bias to assess and reflect on how the former may affect findings	Personal journal to reflect on personal beliefs about PC practices in the NICU and parent inclusion in practices	Design, data collection, data analysis

Credibility

Credibility refers to the truth-value of the results, the desire to present an authentic representation of the participants’ experiences (Lincoln & Guba, 1985). The method of member checking was used to support the credibility of the results. Member checking is a process in which results are taken back to participants to determine whether they are representative of the

felt experience (Lincoln & Guba, 1985). This method is somewhat controversial because it can invalidate experiences that are not particular to the participants who perform member checking (Morse, 2015), but for the purpose of this study it was helpful to conceptualize common themes between participants and it also facilitated parent engagement in the research process.

Participants were asked at the end of interviews whether they would be willing to participate in a member checking session, and three participants responded to requests for this follow up. Member checking was conducted with a relational approach, re-establishing relationships with the participants in an informal way, discussing findings with them while asking them to think about whether the findings reflected their experiences or they had something different to add. These meetings took place on the same videoconferencing technology used for the interviews. All three participants involved in this process agreed that the major findings were reflective of their experiences, though they did add context and clarity to the way the findings were described, and were eager to share further stories that reflected the findings.

Peer debriefing is another strategy to ensure credibility that was completed during this study. During peer debriefing, a colleague with knowledge to understand the work and the context of the work but with more impartial views on the subject reviews the analysis and data audit to identify any important data missed by the PI or interpreted with apparent bias (Morse, 2015). The PI conducted meetings with Drs. Gephart and Crist at multiple points during analysis, explaining key elements of the data and discussing analysis process, including emerging codes and themes.

Transferability

Transferability describes the degree to which the results are transferable to people other than the participants (Lincoln & Guba, 1985). Most philosophies supporting qualitative research do not support the concept of universal or generalizable experiences, but most methods of qualitative analysis include attempts to find commonality among their data. The most commonly recommended method for addressing transferability is to provide a thick description of the participants, their circumstances, demographics, and any other information that researchers consider would be relevant for others attempting to determine whether results would apply to their own populations of interest (Lincoln & Guba, 1985; Morse, 2015).

A thorough description of the study sample was obtained by collecting demographic and infant characteristic data across participants, which helped determine transferability. The maximum variation and stratified purposeful sampling strategies were also chosen to increase transferability by increasing the heterogeneity and thus representativeness of the study sample. Where possible and relevant, additional descriptive details about participants are included.

Dependability

Dependability is a challenging concept in qualitative research. Lincoln and Guba (1985) relate it to the quantitative concept of reliability or consistency, but these concepts are not supported by the naturalistic paradigm that guides qualitative study. The human researcher is the instrument in qualitative research, and constantly changing perspectives, experiences, and understandings lead to a constantly changing human instrument that is inconsistent by nature. It is more important to promote dependability by providing an understanding of the state of this human instrument and decisions made during analysis.

An audit trail was maintained to establish dependability. An audit trail is essentially a detailed record of data analysis including raw data, coding methods, approaches to data abstraction, and any notes on process, especially at points of interpretation (Lincoln & Guba, 1985). This not only provides documentation for the researcher to defend later claims against the dependability of their results, but it also ensures that decisions made during analysis are thoughtfully considered. This was accomplished by using tools within the Atlas.ti analysis software to preserve records of raw data, codes ascribed to the data, connections and relationships made between codes, and qualitative analytic memos detailing rationale behind theme creation. These were reviewed with Drs. Crist and Gephart during data analysis to increase dependability of the findings.

Confirmability

Confirmability addresses a particular challenge often posed to qualitative researchers, which is the degree to which results are unaffected by bias. Because qualitative analysis necessarily involves interpretation, and the methodology of qualitative description does not require negation of researchers' perspectives to perform analysis, it is not expected nor completely desirable for the results to be devoid of the researcher's perspective (Lincoln & Guba, 1985). The maintenance of an audit trail as described to promote dependability can also be used to demonstrate confirmability. Though no formal data audit will be conducted during this project, an audit trail is available as discussed in the previous section if committee members have concerns about bias in the study results. The PI also kept a reflexive journal, a commonly recommended strategy (Lincoln & Guba, 1985), to create an internal audit that encouraged self-awareness of perspectives and biases during analysis. Entries kept in this reflexive journal

covered thoughts and emotions about the data during collection and analysis, as well as questioning of assumptions and conscious biases.

Ethical Considerations

This study required collecting data from parents whose children had been hospitalized with a serious illness or condition, since these parents were likely to have experienced EPC practices in the NICU. Recognizing that these parents are at higher risk for anxiety, depression, and posttraumatic distress, the psychological and emotional risks of discussing potentially distressing or traumatic events were the most serious risks posed to the study participants. The reliving of the potentially distressing events of their child's hospitalization may have cause psychological distress, and parents with posttraumatic distress may have been triggered by the discussion of these experiences. A plan for managing parent distress during interviewing and referral to appropriate support services was developed and is outlined in the following section.

Risks and Costs to Participants

The most significant risks that this study posed to participants were the psychological and emotional risks of discussing potentially distressing or traumatic events. The reliving of the potentially distressing events of their child's hospitalization may have caused mild emotional and psychological distress; moderate distress was considered unlikely and did not occur. Parents with posttraumatic distress may have been triggered by the discussion of these experiences.

At the beginning of each interview, participants were asked if they were ready to share the story of their child's hospitalization in the NICU. The participants were reminded that they had the right to pause the interview and ask for a break or request to terminate the interview at any time without penalty. After signing the consent, each participant was sent a list of parent

support resources that they could access after the interview if they needed extra support. This list included NICU parent support organizations that emphasize peer support and provide support specific to the NICU experience (Appendix D). Participants were not asked directly about particularly distressing events (e.g., a child's death, struggles with depression or post-traumatic distress), but parents did bring up and discuss these topics. At any point during the interview, if participants appeared overwhelmed by emotion or distress, the PI offered to pause the interview for a five-minute break, but this only occurred once during data collection and the participant was able to progress without desiring a break.

Withdrawal of participants. Individuals had the option to withdraw without penalty or repercussions from the study at any time. This included withdrawing from the recruitment process or the interview. Three potential participants were recruited in addition to the 16 who completed the study, but they did not respond to email contact with the PI after their initial response. There were no risks associated with abrupt withdrawal from the study, and no participant chose to withdraw after signing the informed consent document.

Cost to participants. Participants were required to access a computer with audio or video conferencing ability or a telephone, but it was assumed that participants already had access to these technologies without utilizing further financial resources. Interviews lasted from 40-120 minutes with an average length of 66 minutes and were not repeated, so their time burden was minimal. Those who participated in member checking were asked to spend no more than 1 hour reviewing the results with the PI to provide their feedback.

Benefits to Participants

There was no direct benefit to participants in this study. Parents who participated may have considered this as an altruistic opportunity to help future parents who were once in their situation. In preliminary work, parents expressed that they found meaning and satisfaction in contributing toward research that may make life better for future NICU parents and families. Participants were offered \$50 Target gift cards as a gift to demonstrate respect for their time and effort. Gift cards were sent by mail after the interview was completed.

Summary

A qualitative descriptive methodology was used to describe parental experiences with parent-centered elements of early neonatal PC: shared decision-making, care planning, and coping with stress. Parents who had a child in the NICU were recruited through parent groups in the online parent advocacy community and provided descriptions of their experiences through qualitative interviewing. They also provided demographic information and standardized data regarding their child and the NICU stay to provide context to qualitative responses and describe the study population. The greatest potential risk to participants in this study was the psychological effect of recalling possibly painful or traumatic memories of their child's hospitalization, but the PI is not aware of any ill effects experienced by participants. Qualitative data was analyzed using conventional content analysis, wherein valuable phrases and ideas were assigned code names representing the concept they reflected, and these codes were further collated into themes. These themes provided an overarching understanding of the parents' experiences with each early PC practice and thus fulfilled the purpose of the study and prompted

further research questions leading toward the long-term goal of a parent-centered early PC program for the NICU.

CHAPTER IV: FINDINGS

This chapter will detail findings of the study conducted as described in the previous chapter. The study sample is described using data from the demographic and infant characteristics survey. Qualitative findings about the concepts of interest are presented. Findings express themes of what parents experienced, according to the three main concepts of shared decision-making, care planning, and coping with distress. Themes of shared decision-making include information gathering, emotional impact of decision-making, and influences on decision-making. Themes of care planning were learning to advocate, spectator versus participant roles, and care planning as communication. Themes of coping contained more sub-themes due to the breadth of data shared regarding coping experiences. These themes were exposure to trauma, including posttraumatic distress symptoms, traumatic triggers, and minimalization and rationalization; survival mode; and a changing support network, including sub-themes of a new NICU family, family stress, and parent peer support.

Sample Characteristics

Sixteen parents were interviewed for the study (Table 3). The sample was comprised of 12 mothers and 4 fathers. One participant did not complete the demographic survey. The majority of participants were married (N = 12), one mother was single, and one unmarried couple living together was interviewed separately. All parents had completed post-high school education, with 12 completing Bachelor's degrees and two completing Master's degrees. Most parents were employed in full-time positions outside the home (N = 9), although two described full-time positions in self-employment, and three described themselves as caregivers or

homemakers. Annual household income varied, but about half of participants earned at least \$75,000 per year.

TABLE 3. *Parent demographics (N = 16*)*

		N (%)
Age (mean)		33.7 (SD 4.8)
Sex	Female	11 (74.4)
	Male	4 (26.6)
Marital Status	Married	12 (80)
	Living w/ partner	2 (13.3)
	Single	1 (6.7)
Race/Ethnicity	White, non-Latinx	15 (100)
Education Completed	Associates degree	2 (13.3)
	Bachelor's degree	11 (73.4)
	Master's degree	2 (13.3)
Employment	Homemaker/Caregiver	3 (20)
	Self-employed	2 (13.3)
	Part time	1 (6.7)
	Full time	9 (60)
Annual Household Income (\$)	20-34,999	1 (6.7)
	35-49,999	2 (13.3)
	50-74,999	4 (26.7)
	75-99,999	5 (33.3)
	>125,000	3 (20)
# of children		1-4 (1.53)
> 1 NICU infant		6 (40)

* 15 completed demographic data

Parents reported data on 20 infants who had been admitted to the NICU for at least two weeks (Table 4). Four parents had twins in the NICU at the same time, and two parents experienced NICU admissions following separate pregnancies. The average gestational age was 27.8 weeks with an average birth weight of 1393 grams. The infants had an average length of stay of 72.3 days and the primary diagnosis for all infants was prematurity, although some had

secondary diagnoses related to congenital disorders (e.g., epiglottal fistula) or complications of prematurity (e.g., inguinal hernia, chronic lung disease). Eight infants comprised four twin pairs, with the remaining 12 infants resulting from singleton pregnancies. Only one child was eligible for home nursing care at the time of the interview, indicating persistently complex care needs.

This child received 24 hours of home nursing care per week.

TABLE 4. *Infant characteristics (N = 20*)*

	Mean (range)
Gestational age (weeks)	27.8 (23 – 36)
Birth weight (grams)	1393 (540 – 3100)
Length of Stay (days)	72.3 (18 – 165)

* 1 non-respondent, 1 duplicate response excluded

Experiences with Decision-Making

Decisions described by parents fell into three categories: therapeutic plan of care, feeding plan of care, and daily care. Therapeutic plan of care decisions related to surgical or invasive procedures and medication therapy to address clinical diagnoses. The most common surgical decision described was the placement of a gastrostomy tube (GT) for poor feeding, unsafe feeding, or gastroesophageal reflux. Treatment of patent ductus arteriosus (PDA) was discussed by parents who all indicated that they had been presented with three treatment options: surgical closure by ligation, pharmaceutical therapy with NSAIDs, and “watchful waiting.” For the parents in this study, this was a decision presented to them that they described as “never having to make” since each of their infants’ PDAs resolved without treatment. Parents also described being asked to make decisions regarding hernia repair and jaw distraction, though these decisions related to how and when to complete the procedure rather than whether to complete it at all. Few parents recalled being asked about resuscitation at delivery or during the NICU stay. During

anteartum consultation resuscitation was discussed with a few parents, but they stated that resuscitation at delivery was based on gestational age limits set by the NICU team and was not offered as a choice.

Feeding plan of care decisions revolved around breastfeeding, pumping milk, and receiving donated human milk. Exclusive breastfeeding was offered as an option to a few parents, but none of the parents in this study chose to feed by exclusive breastfeeding. Some parents did choose and advocate for partial breastfeeding, and some decision-making was influenced by practical concerns when a mother's supply was limited, or she had to return to work. One mother described deciding how to distribute her milk when her infant required more than was available:

They would ask me what I wanted to do with the milk that I pumped. Do I want to do half and half? Do I want to do a little bit each feeding? What do I want to do with it?

The most common decisions that parents described related to their infant's daily care, such as holding, involvement in bedside cares, personalization of their infant's physical environment, and selection of nursing or physician care. These decisions offered them control in an environment where they often felt powerless and without control over what was happening to their child. Although not as impactful on their infant's health status as perhaps a surgical procedure could be, these decisions were made more constantly by parents who described the decisions as having an impact in helping them develop their confidence and their ability to bond with their baby. Parents' descriptions of shared decision-making contained three key aspects of their experience: gathering information to make a decision, the emotional impact of the decision, and influences on their decision-making.

Gathering Information to Make a Decision

Decision-making was an individual process for each parent depending on the situation's urgency, severity, resources available, and parents' personal characteristics. When parents had time to prepare, they often sought additional information to help inform their decision-making. Parents gathered information by researching online or in published material, reading stories from other parents, and eliciting advice and multiple opinions from NICU staff. Some parents were aware that this was their typical decision-making style and described relying on those same methods in making decisions for their infant. One mother described her need to research all of her options to feel confident in her decision-making:

I'm the sort of person who researches the crap out of everything. I need to know all the details and all the options so that I can make a decision. Then once I've made that decision, I know that it's the right decision for me. It's the best possible option. That's it. Because I've looked at all of the options. (A_14)

Parents conducting research apart from the NICU team often connected with online resources, which were easily accessible and provided a wide array of information. They did not always describe in detail the sources of the information they were seeking, but some mentioned looking in social media groups and parent blog posts. Parents seeking information on the Internet expressed knowing that those resources were not always reliable or applicable to their child, but it is unclear how that affected their decision-making. This knowledge may have led some parents to avoid online resources to help inform decision-making, as one parent expressed: "*I stayed off the Internet. I learned that the hard way. The nurses would tell me stay off the Internet.*" (E_7)

Some parents who were connected to online parent communities sought advice or testimonial information from parents who had endured similar situations. Parents did not describe having direct conversations with other NICU parents to discuss decisions, but rather

gathered information from online sources including blog posts and parent communities. This online information gathering from other NICU parents was not the only source of information sought for decision-making but supplemented other sources of information. Although this could expose parents to conflicting information, one mother described her experience as helping confirm her decision:

I remember when they mentioned the GT, I had looked it up and I found...a post that was someone asking about it, and every single comment was someone being like, 'My only regret is that I didn't do it sooner. I didn't want it to happen and I pushed the doctors and we waited...and it's the best thing that ever happened for my kid.' I was sold on that right away. As soon as I read it, I was done. (K_1)

This peer advice was helpful for parents who often felt that nobody but other NICU parents could understand their perspective or the experience they were going through.

Parents also relied on trusted relationships with nurses and other NICU staff to provide them with alternative opinions and seek advice about the decision. Many parents were able to name specific staff members in various roles who they turned to for information, but they also reported asking any staff member they could as long as they felt comfortable speaking with them. Parents described relying on the expertise and trust developed between them and staff members to gather information that was informed by experience, individualized, and delivered by someone who cared about their infant.

We actually leaned on his primary nurses...we're getting told this from the doctors, and that's fine, but you [the nurse] have been here in the unit for 20-plus years. You've seen good stories, bad stories. What do you say? We took a lot of their opinions to heart... 'cause the nurses ...were absolutely outstanding and extraordinarily knowledgeable. (T_19)

Parents were often introduced to the decision in conversation with a member of NICU staff, and many described pros and cons of options being discussed. They did not describe guidance

offered during these initial conversations, rather parents had to elicit guidance and advice from staff if they desired it. This information gathering from staff often occurred in informal settings at the bedside during routine care rather than formal care conferences or family meetings.

Emotional Impact of Decision-Making

Parents also experienced varied emotions during and after the decision-making process. Uncertainty was the most common emotion surrounding decision-making. Reasons for uncertainties varied with each situation, but commonly parents expressed not feeling that they understood the situation and the complexity of their child's condition enough to make a completely informed decision. This could be increased in situations when parents perceived uncertainty within the healthcare team. One parent shared her uncertainty influenced by perceived uncertainty within her child's team:

I think there was uncertainty within the team and then one doctor wouldn't mention it at all so then we were like, oh, maybe he doesn't need the surgery. Then another doctor would come on and say, 'What are you doing about the hernia surgery?' We were like, 'Okay. We don't really know.' (E_7)

For some parents, uncertainty did not end once a decision was made. The persistent uncertainty of the future and need to balance their child's complex care challenges made some parents question their decision. One parent did not express decisional regret but rather uncertainty that the choice she had made was the right one in the long-term: *"I don't know if I have caused long-term issues...because I refused that. At this point, we have still not had surgery to address it. We've almost made it. Hopefully, we'll make it."* (S_9)

Many parents discussed their experience with decisions that did not feel like real decisions due to the perceived lack of options available or presented to them. This perceived

illusion of choice could be frustrating for some parents, as a parent described in this exchange with a physician:

“I haven’t gotten a say about anything that has happened to my kid in this NICU...I signed consent forms, but if I didn’t sign ‘em, you’d call [child services] on me. I don’t actually have a choice. None of this has been up to me. I have to ask when I can hold my kid. Are you kidding me?” (K_1)

This lack of control over decision-making distressed parents who experienced it, leading some to not necessarily question choices they made, but resent the situation in which they were placed.

Knowing what I know now, I hate how much I felt like I didn’t have a choice. It felt like they were telling me, ‘If you don’t do this, your kid’s gonna die and it’s gonna be on you.’ I don’t think that that’s true. (K_1)

Some parents were distressed by the burden of responsibility placed on them in making decisions that they felt unprepared to make. These parents felt that they did not have the clinical knowledge and expertise required to make the right decision on behalf of their child. One parent who was asked about treatment for a PDA said:

I called my parents and cried. I said, ‘I can’t believe they’re gonna make us choose this.’ That’s exactly what I did on the way home. I said, ‘I cannot believe this is happening. They’re asking us what we would do.’ ...I remember the conversation clear as day. I said, ‘This is barbaric. How do you make a parent choose this?’ (E_7)

Many parents expressed this distress with the burden of responsibility placed on them, usually expressing that they did not feel they understood enough about the consequences of their options or their child’s condition to make an informed decision. A fear of making the wrong decision accompanied this burden for some parents, as one parent describes:

You don’t wanna make the wrong decision. You just want somebody to tell you what to do...they could’ve told me a million times the pros and cons, and I still would not have been comfortable making the decision because I don’t know that you ever can be. (E_7)

There were decisions, however, that parents described in more positive terms. Smaller decisions related to daily care of their child, such as when and how to hold or feed, or how involved to be

in bedside care gave parents a sense of control. Parents described these smaller care decisions as being critically important in developing their confidence and reconnecting to their parental role:

The nurses were very good about putting smaller decisions in our hands. Things that might not feel like they made a big difference, but they really did, like putting things in his crib, giving him his own stuff, like bedding and things. Which really made it feel less like you were in a hospital. (D_20)

Another parent expressed the same sentiment, emphasizing how a particular nurse put these small decisions in their hands and facilitated their involvement and feelings of control:

[One nurse] was just super laid back. Do whatever you wanna do. You wanna put the babies both in one little bassinet...and take pictures, do it. You wanna hold them both? Do it. You wanna give them a bath, do it. You wanna start without me, this is the time to do it. You do it is kind of her philosophy. That made me feel involved in their care. (C_15)

Influences on Decision-Making

Parents expressed various motivations and influences on their decision-making, the most overarching being a desire not to cause harm and to do what was best for their infant. Quite often when parents expressed feeling no choice or alternative in the decision they were asked to make, the reality was that the alternative to the decision they made was too harmful to their child for them to consider, so from their perspective there no was decision to be made.

Most of his early decisions weren't really decisions, for the most part. It was like, 'Well, we can do this thing or not do this thing. If we don't do this thing, he's probably going to die.' Which isn't really a decision to be made. (D_20)

Not all decisions were so dire, but parents still were influenced by the desire to keep their child from harm. Avoiding harm by avoiding the most invasive intervention, often surgery, was a common sentiment among parents presented with that option. *"I guess in my gut I probably would've thought about the medication first, the least invasive intervention."* (E_7) For some

parents, however, a more invasive surgical intervention was not always a last resort. Sometimes this desire to do what was best for their child manifested in a desire for their child to come home.

They also ended up getting GTs placed because they weren't eating...that was what finally allowed us to bring them home was getting GTs put in...hospital policy wouldn't allow discharge with an NG tube, so we could either stay in the hospital and see if they'd eat and hope, or get the GT and go home. We had the g-tubes done. (A_14)

Though these parents were all presented with different decisions and chose different outcomes, the main influence on their decision-making was the drive to do the best for their child.

In addition to gathering information from the healthcare team, parents' trust in the NICU staff and others involved in their child's care was a major influence on their decision-making.

For the most part, with the decisions, it just felt like I was mostly deferring to other people's expertise...it was really hard to argue with a lot of the stuff, too, because he was so small...I was very much of the mindset of, we'll go with what you [the team] wanna do. (D_20)

Parents also described the desire to trust the expertise of the team but also for their opinions and thoughts to be heard if they had them. One parent eloquently expressed this idea:

Essentially...I wanted their decision making with honest consideration of my input. That was the most important thing to me. Ultimately, you're the expert, but I need you to consider items X, Y, and Z. As long as I feel like I'm being listened to on that and you are considering it, I'm gonna be okay with what you ultimately decide. (D_20)

Decisions were not always positively influenced by the healthcare team. When team members expressed conflicting opinions, one parent expressed doubt about the choice they would make:

It went back and forth for a two-week time period...some doctor would say, 'Just do it here and get it over with.' Another doctor would say, 'You're better off going to another hospital.' We didn't really know what to do. (E_7)

Just as emotional turmoil caused by team uncertainty affected parents' emotional experience with decision-making, the same uncertainty could change their own decision-making process, and some parents described this leading to a delayed decision, or continuing uncertainty.

For some parents, their autonomy in decision-making was limited by practical concerns and conflicting responsibilities. This mother who had been attempting to breastfeed said:

I had to go back to work, so that I'd have time off when they came home, so I wasn't there as often as I had been. I had to make the decision to start introducing bottles... (S_10)

Other parents shared similar restrictions on their autonomy due to conflicting responsibilities, which led them to make different decisions than they might have otherwise. Responsibilities such as returning to work, caring for other children or family members, and continuing to provide basic needs for themselves all had to be weighed when making a decision. These practical influences often resulted from compromises parents had to make, decisions balancing the demands of life outside the NICU while considering other influences such as NICU team input and doing what was best for their child.

Experiences with Care Planning

Parents described varied experiences and roles with planning care for their infants in the NICU. Active involvement in care planning was connected with advocacy and speaking up, but more passive spectating roles were also described. There were formal and informal processes for planning care, and various interactions with clinicians that either welcomed or deterred parents from participating in care planning. The following themes emerged from experiences with care planning: learning to advocate, spectator versus participant role, and care planning as communication.

Learning to Advocate

Parents overwhelmingly described advocacy and care planning as something they learned to do over time as they became more knowledgeable about their infant, NICU routines, and

normal expectations. Almost all parents expressed that at the beginning of their child's stay they knew little about the NICU and were overwhelmed and unsure of the NICU environment.

There was not a time that I felt unwelcome there, but...I was a first-time mom, not really knowing what I was talking about and feeling that I barely knew him as a person. I was his mom but didn't feel that way. I didn't really speak up enough, and I didn't really know what it was like to advocate for him then. (K_13)

Because parents lacked confidence in their own knowledge at the start of their child's NICU stay, many did not feel they would have been able to meaningfully participate in care planning even if they had been invited to: *"I don't know that we would've known what to ask about progression of care either. I think we probably felt more like spectators because we didn't know any better."* (E_7)

Over time, as parents expressed greater confidence in their own parental role and knowledge about their child, and had observed clinicians planning their child's care, they felt more able to speak up and begin to advocate for their own needs and those of their child. This often took the form of asking questions, requesting clarification, and expressing opinions or observations when they were elicited. Sometimes clinicians invited active parent participation later in the child's stay by eliciting information, as this parent shared:

Once she got a little bit older it was, do I think that that plan is good, like increasing her milk if I thought she could tolerate it...they'd ask me if I thought so. They'd ask if I saw any difference in her that maybe the nurses hadn't seen. (J_16)

Many parents also described others who mentored or coached them in advocacy, encouraging them to ask specific questions or informing them that certain options were available to them such as the concept of a family conference. NICU nurses often took on this role, using their expertise and more frequent interactions with parents to offer this help:

There was one nurse in particular, my daughter ended up developing really severe reflux and she was instrumental, she gave us information on what to ask the next day at rounds and about different medications and things like that that she knew had worked for other babies... (C_2)

Another parent shared a similar experience of a nurse informing her about the concept of a family conference, which was common among other parents' experiences as well:

I was really upset about something, or I wanted answers about something. I don't even remember what it was, but it was one of his nurses was like, "You should ask them for a care meeting." I didn't even know it was a thing I could do, and so, a lot of the times that I did end up advocating or talking through stuff, it was with nurses and not really with the doctors. (K_1)

Parents were usually unfamiliar with options or methods for more formalized care planning and usually discovered the information in passing rather than as part of a standardized orientation to processes in the NICU. Others, both staff and fellow parents, provided more general encouragement, leading parents to feel more confident in their role as their child's advocate.

They were encouraged that speaking up was acceptable and at times necessary.

I voiced my concerns, and [the nurse] told me, 'Say something. That's your baby. You're his mother, and you are his first line of defense because he can't defend himself. If you are concerned, or if you don't understand, or you don't agree, say something. They might not agree with what you have to say, but at least you know you voiced it. At least you know you stood up for [him].' When she put it that way... I'm that type of person where I won't necessarily defend myself, but if it's someone in my family, I'll go ham on somebody messin' with my family. When she put it that way, 'You have to stand up for [your baby]' that's when I did. I started saying, 'Well, what does that mean?' and 'Why are you changing it now?' and 'What are we doing to address this?' (S_9)

Some parents also were coached in advocacy by other NICU parents, both in their NICU and in online parent communities. Parents who had been in similar situations may suggest questions to ask of the team, or provide parents with examples of care options available that they had experienced in their own child's stay. For example, several parents noted that they did not know that family conferences or meetings were possible until they heard about them from another

parent, or that they were able to request primary nursing care: *That was how I found out about advocating for the nurses that were on her service, was through those [Facebook] groups.*

(S_15) Another mother was unaware of the concept of a family conference until 3 months into her child's stay after talking to another parent who had requested one. Some parents were never fortunate enough to experience this sort of help in learning advocacy; one mother expressed that she was still learning, and learning on her own:

No one taught me how to do that and I'm still learning how to do that because it's so far of a reach for me as a person to do things like that – to speak up. It's easier to do it when it's for your kid. It's harder to do it for yourself. I'm still learning a lot about that.
(K_13)

Learning how to navigate care planning came easier to parents with prior experience in NICU or the hospital system in general. Parents who had had a previous NICU experience expressed that it was easier to advocate and be involved in care planning during the subsequent stay because they already understood the process: *“Generally speaking, I think it was easier [the second time] because I found my voice right away. I knew what I was advocating for. I knew what I was looking for.”* (E_5) One parent who was a cancer survivor and was familiar with the complexities of care planning took notes when present for rounds.

I always took notes during my oncology and radiation oncology visits, and so that was something I did...if I wouldn't have had cancer, I might not have known to do that, or I might not have been prepared to have that ready with me that first day when we were going to the NICU. (N_6)

For many parents, advocating on behalf of their child connected them to their parental role and allowed them to feel like they were an integral part of their child's care. Many parents expressed that they did not always truly feel like their child's parent, especially at the beginning of their NICU stay. Learning how to advocate over time, growing in confidence and knowledge, was

essential to their growth as a new parent. As one parent eloquently expressed, advocating for her child was what made her feel like a parent, a unique role that she could occupy when she doubted her worth as a parent.

I think researching and doing all that stuff became a way for me to have some semblance of control and to feel like I had some say, or at least that I would know what was going on. It made me feel like I could do something for him, 'cause for a really long time, I felt like I couldn't do anything for him. I couldn't keep him in my body. I couldn't grow him safely. I did pump for him for six months, but I couldn't breastfeed him. I couldn't hold him when I wanted to hold him. It became the thing that I could do for him that no one else could do for him 'cause no one else—we had amazing nurses and they were great advocates. They taught me how to be an advocate, but no one will ever advocate for your kid as hard as you will, and I think that I learned that and that became the thing that I grabbed onto and was like, 'This is what I'm gonna do for him 'cause it's all I can do and no one else is gonna do it if I don't.' (K_1)

Spectator versus Participant Roles

Parents did not describe environments either completely hostile to or inclusive of their involvement in care planning. Rather, what was more common was parents describing a spectator role, in which they had access to care planning conversations but were not empowered to actively participate, versus a participant role, which enabled them to have more input and control over care planning. These two roles were often discussed in the context of daily rounds, which was the most common type of formal care planning described. Most parents expressed that they were able to be present during rounds, though some were not able to do more than be present. When this was the case, parents assumed the role of spectator – observing information sharing and care planning by the interdisciplinary NICU team, but without active interaction. Some parents were content with taking this spectator role:

I'd say that they let us be involved as much as we wanted to be. That was good. Just be able to stand there and listen to them all talk about what's going on, ideas and decisions and stuff. Yeah, that was nice to be involved with that for sure. (M_19)

Understanding their child's current goals and challenges by receiving updates from their child's bedside nurse or another care team member was consistent with their expectations to have access to all relevant information about their child. Another parent expressed that she felt welcome and able to participate in rounds, though she mostly spectated:

I usually had had a chance to talk to their nurse for the day and find out what was going on. Then sometimes I would just ask the nurse questions I had, and then they would bring it up in rounds or help me remember what I was gonna ask. Mostly I just listened. (S_10)

This ability to witness care planning in action and receive updates on their child's status and plan of care was sufficient for some parents.

Other parents, however, did not necessarily have the access to care planning or the role in care planning that they wanted. A few described barriers to their participation in rounds, such as rounds taking place very early in the morning or while the NICU was closed to parents.

I missed out on the doctor a lot. The doctor rounded super early in the morning. Super early. Like between 6:00 and 7:00 a.m. I have two older kids that go to school, and I have to bring to school, so very rarely would I catch the doctor. (C_15)

Even some parents who were able to be present during rounds expressed that they didn't feel that rounds were beneficial for them. "*When they would go and do their rounds, I would listen to the nurse report to the team, and then they would do their thing, and I just felt like a spectator really.*" (E_5) She further described her experience of spectating at rounds:

I remember the neonatologist would make their rounds with the team of people, and I didn't even feel like they would talk to me at that point. I just felt like they were sort of reporting on my baby, the nurse was having a conversation with them, and they would just kind of move on. (E_5)

One parent, after experiencing rounds for the first time expressed frustration with his perception of the team ignoring his presence at the bedside and speaking over his head, but then explained:

[the doctor] was great. After she was done, she came back and she ended up saying, 'Listen. I apologize. I knew you were sitting there but we had to do this 'cause that's our rounds, and we have to get through everybody...I wanna explain to you everything that was said,' and she did. (T_19)

This experience was redeemed in the parent's eyes by the physician returning to the bedside and discussing the plan of care with him, but even this physician admits that rounds is a healthcare team-oriented process, not a family-centered process. Another parent, having a similar realization about the intention of rounding in her child's NICU questioned the purpose in being present at rounds:

...it just seemed pointless. I sat there, and they were like, 'Okay, this is the update...' I'm like, 'Okay, I knew all that.' I didn't really have any questions for the doctor, so I was like, 'Okay, I'm not doing this anymore.' I chose to only attend rounds a couple times because they didn't feel beneficial to me. (S_15)

This parent felt keenly that rounds were not for her benefit because the extent of her involvement was the ability to ask questions, and she did not have any. Most parents in this study expressed that they were updated regularly, so when rounds consisted simply of updates they did not learn anything new and were not encouraged to keep participating in rounds.

There were parents who described more active participant roles in their child's care planning. Often this was later in their child's stay, as discussed in a previous section, when they had gained confidence and knowledge to feel able to advocate for the plan they wanted for their child. Active participation, as defined by the parent, generally led with the NICU team outlining a plan and the parent having the ability to negotiate a different one if they desired it.

It was less of an update than, "Here is what our plan is. Do you have any concerns with it from here?" They would lay it out beforehand. Then if we had an issue with something, I feel like we were given time to let them know and say that we did or didn't want something. (D_20)

Occasionally, actively participating parents would take the initiative to speak up or approach a team member when they felt their child was not making progress. One parent who had experience in planning care for their own complex illness described one such experience:

It felt like there wasn't really much improvement going on in those last couple week...we weren't getting anywhere, and so we basically requested a meeting with a NICU director to lay out a plan versus just kind of, 'Oh. We'll just see how it goes tomorrow.' (N_6)

This kind of forthright participation was uncommon among parents; however, as discussed in the previous section, it was not uncommon for parents to initiate conversations with NICU team members to express their wishes for the plan of care. Other parents described participating by negotiating with their child's team to come to a compromise on goals or treatment plans to develop a plan that was acceptable to all care team members, including the parents. Spectator and participant roles were not always static, and some parents described assuming different roles at times, especially as they grew more confident and as different providers were available and encouraging of their participation in planning their child's care.

Care Planning as Communication

The work of care planning for parents was accomplished primarily through communication with their child's healthcare team. When asked how they were able to participate in changing or influencing their child's plan of care, all parents described having a discussion with one or more NICU team members. Often, these initial care planning conversations were informal, occurring during the normal course of their child's care and not part of a formal process such as interdisciplinary rounds or family conferences. One parent who felt very involved in her child's care planning expressed that most of her participation in care planning took place during informal discussions the plan of care with her child's physician:

I definitely got to a point where I felt comfortable going to the doctor where they were sitting and being like, “Hey, when you have a minute, I have a question for you,” and talking to them, but we didn’t have formal care meetings except I think we had one one time. (K_1)

For most parents, advocating for a change in the plan of care or being involved in the plan of care ultimately meant communicating with a physician, nurse practitioner (NP), or physician’s assistant (PA), since they were usually responsible for directing the plan of care. Experiences with these conversations were varied; some parents had very positive experiences, such as this mother who expressed anxiety at speaking to her child’s physician about attempting bottle feeding in a NICU encouraging exclusive breastfeeding:

[The doctor] just looked at me and he was like, ‘You’re her mom. If you wanna give it a try, let’s try it.’ He was 100 percent supportive. I remember thinking, ‘Why didn’t I talk to him sooner?’ (E_5)

Another parent appreciated a physician’s effort to keep her informed, accommodate her schedule, and speak one-on-one when it was convenient for her:

[The doctor] just sat right down on the couch and started talking to me. It was during the time that I was holding her, and he just sat right down, crossed his legs, and just like a conversation at home. He especially would make a point when he wanted us to know something or wanted to get feedback, he would communicate it with nurses, and we would find a way to meet when it was convenient for both of us. It didn’t just have to be that rounds in the morning. I did feel like I was being involved, and I felt like I had a role in it. Luckily, it was more on my schedule, and I appreciated that. (S_15)

Parents had both positive and negative experiences communicating with all members of the healthcare team. Many expressed a feeling that individual providers were better at communicating than others:

Some provided more education for us and some...I think they just wanted to talk because they were super smart and would then say things that we didn’t understand and then somebody would have to come back to us and then explain what he was talking about. (E_7)

Another parent, when asked how involved she felt she was in planning her child's care stated: *I think it also depends on who was on for that day, 'cause it definitely differs from person to person. (C_2)* When parents perceived providers as dismissive of their concerns or in a hurry, they were reluctant to participate more actively by asking questions or sharing input.

Often, parents expressed negative experiences with communication not when they had a negative interaction with a team member, but when they were not told information that they perceived as important. One mother shared this common experience:

One thing I'm bummed about is how much they didn't tell me. When he went to get his surgery...when I had that long conversation with the doctor—that was when they were like, 'Oh, they're gonna do an MRI,' and I was like, 'Why?' They were like, 'Oh, he probably has neurological stuff going on.' It was just like they didn't say it that whole time and I don't know if they assumed that I knew or they didn't wanna tell me, but it took me by surprise. (K_1)

Another parent was told her child had had CPR at delivery months into her NICU stay while she was completing a survey and a nurse corrected her statement that her child had never had CPR:

[my daughter] had to be resuscitated 'cause her heart stopped, which I didn't learn about until a couple of months in. Nobody told me that. Nobody told my husband that. He didn't know. Yeah. That was not a fun thing to find out randomly one day. (A_14)

Parents could only speculate whether they thought this information was held from them deliberately, or was simply forgotten in the course of daily care, but at least one parent who expressed understanding the balance between being over-informed and under-informed said:

There were definitely times where there was seemingly an information gap, and I'm not sure what the balance is with that is. There's always a time where there's too much information and it gets the mind racing...But I just got that feeling a couple of times where it was, 'You guys know something that I don't,' and I'm not liking that part. I wanna know what's going on with my son. (T_19)

Experiences with Coping

Coping was the parents' main topic of discussion during interviews, and their responses were varied and complex. The analysis, therefore, is presented with more breadth than experiences with the other two concepts. No parent described being either fully done coping with the NICU experience or having no awareness of having coped with it. Individuals expressed a wide range of coping mechanisms, often relying on their usual methods of coping with stress, but finding that their new role of parent and caregiver changed the ways in which they related to their old ways of coping, presented new challenges to overcome, and affected their relationships. The key themes expressed regarding parental coping were: exposure to trauma, survival mode, and a changing support network.

Exposure to Trauma

Anxiety, worry, fear, and trauma was present in each parent's NICU experience. Even good moments, like seeing their child for the first time, could be marred with the visual trauma of seeing unfamiliar medical equipment around and on their child: "*honestly, one of the best and worst days was the first time seeing him because seeing him hooked up to everything was devastating.*" (S_9) Hearing alarms indicating drops in heart rate, oxygen saturation, or other condition changes were also frightening; as one parent expressed, "*Every time the alarms went off your heart would stop.*" (E_7). Intentionally alarming, this kind of sensory trauma could interrupt a previously calm moment, leading parents to be more on their guard.

Those are some scary moments that you watch those numbers and you hear those sirens or those beepers go off...we would sleep there, stay pretty late and start falling asleep, and those buzzers would come into your dreams sometimes...that was a scary feeling, just hearing those going off. (M_19)

The emotional trauma of seeing their child in such a vulnerable, unexpected, and unfamiliar conditions was also significant, and parents expressed anxiety about their child's future and prognosis. Parents described this trauma lessening with time, often as they grew more familiar with the NICU environment and understanding what was normal for their child, but with exposure to this trauma and continuing anxiety, it is not surprising that parents also described feelings of posttraumatic distress.

Posttraumatic stress symptoms. Though not all parents described feeling like they had or had been diagnosed with PTSD, many of them expressed some of the symptoms associated with posttraumatic distress. The most prevalent of these was avoidance. Parents described avoidance behavior such as not being able to look at photographs of their child in the NICU, blocking out negative memories, and avoiding visiting or doing activities in the NICU. One parent described his partner showing him pictures of their child when he was in the NICU:

There are a lot of things that are a lot harder for me than they are for her. She'll always be like, 'Oh, look at this picture of him in the NICU. He just came out.' I'm like, I can't really look at that picture 'cause it just makes me feel horrible. It makes me just think of how bad I felt all the time and how scared I was and worried about everything, all the time. For her, it's just, 'Oh, look at our little guy.' (D_20)

Parents described their partners as avoiding thinking about or talking about emotions from their NICU stay as well, though these could not be corroborated with participants' partners.

Avoidance behavior was also described as occurring in family members, as this parent recalled:

I had a talk with my mom...I realized one day that she was completely ignoring everything. She was sitting there and she was supporting me, but she didn't interact with [the baby]. I'm like, 'Mom, don't you wanna read your granddaughter a book?' She admitted to me later, 'I can't get more involved or attached because if something happens, I have to be there to pick up the pieces for you.' That was heartbreaking because I'm like, 'Mom, if something happens, don't you wanna have had the interaction with her?' (S_15)

Hypervigilance and hyperarousal, having a heightened sensitivity to stimuli and constant awareness of the environment to sense for recurrence of the threat, was also described by some participants:

I would hear alarms when they weren't going off. I had really, really bad hyperarousal and would just flinch and jump at everything 'cause I was always ready to run into action and take him to the ER...(K_1)

This was also described as “waiting for the other shoe to drop,” especially described after discharge from the NICU. Parents were used to thinking of their children as sick or fragile, so after coming home, some parents were anxious that their child would become sick again and they would have to go back to the hospital. This led parents to feel anxious even or especially when their child was healthy, increasing their stress unnecessarily, as this parent described:

I call it waiting for the other shoe to drop. Because we've been so lucky with [the baby], because she hasn't had so many issues, I am constantly in a state of, 'How is that possible? When is something gonna come up? When are we gonna get the bad news?' (S_15)

The same parent described her visceral reaction on seeing the area code for the hospital listed when receiving a call:

We're always dreading and kinda waiting for that phone call, especially in the early days when we didn't know what was going to happen...Luckily they were very conscious of that, so if they did call about something, they would always start with, 'Everything's fine,' but the terror when you saw it, because it was a hospital, I didn't give the whole number. It just gave the area code, and so whenever a call would come through that said 515, the terror, your heart would start beating really fast, and it was like, 'Oh no, what's this?' (S_15)

Avoiding or forgetting important memories is another possible sign of posttraumatic distress that was expressed by parents, but it is unclear whether experiences were forgotten due to trauma and avoidance or due to the passage of time and accumulation of other memories. Reminders of the trauma experienced in the NICU had been triggered in almost all parents. Often unexpected,

these triggering events could have detrimental effects to parents' mental and physical health. One parent described her feelings while watching a TV show with a premature birth subplot:

There was a scene where she's laying in a hospital bed with her hands folded on her stomach, and she's been told that her water has broken and they're just waiting for results. I saw that and it just honestly made me sick to my stomach, because that was me. That was me laying there in the hospital bed waiting to find out what was gonna happen next. That's why I have to say yes, I'm dealing with it fine, but there are times when things come back, and it's just like, 'Oh man, that's kinda heavy.' (S_15)

Minimization and rationalization. Minimizing the struggles of their own experience and rationalizing that “other parents had it worse” was extremely common among participants.

You're surrounded by people who are looking at you like you should be fine, and you should just move on? 'Nothing happened to you. You're fine. He was only in there for a month. That's okay.' I even was doing that, like, rationalizing. Like, he was only in there a month. I know NICU babies who are in there for four...but four or a month, it's still watching your kid in the hospital. (S_9)

After sharing stories of struggles and worries, parents would often minimize their own emotions, quick to assure the interviewer that they understood that their baby was not the sickest, or that it they were lucky. This may be a source of resilience for some parents, however, as it allowed them to feel grateful for the good things they were experiencing with their child and gave them perspective on their struggles in the context of other parents.

Like I said, yes, I had trauma. My son was in the NICU, but he was still relatively healthy compared to a lot of other NICU babies. It became to the point when I would talk to my other NICU neighbor, and I would have to tell myself, 'Dude, she has two babies. One literally just had hernia surgery at 30 weeks gestational age. Came out five weeks ago.' I would have to...calm myself down, everything's going to be okay. (A_4)

When self-driven, this minimization of their trauma or promotion of gratitude could be positive, but when coming from an external source parents felt hurt by comments either minimizing or otherwise invalidating their experience of having a child in the NICU. This was a common experience for parents, describing interactions with acquaintances, co-workers, and even friends

and family who did not understand or were uncomfortable with the struggle that parents had been through.

At work, I don't know that anyone knew why I was out for so long. I tried to be relatively vocal about it and be like, 'Well, this is what we went through,' and a lot of people would come back with me with, 'Well, he's home now, so all's good.' That's not the case. A lot of people minimized what we went through. (K_13)

Comments attempting to soothe or provide some misguided element of positivity to the parents' experiences were not just unhelpful but hurtful, as this parent describes:

A lot of people said stupid stuff. 'Oh, don't worry, he won't remember this.' That was my favorite. 'He won't remember any of this' or it was 'well, you didn't have to go through your whole pregnancy in the summer' ...somebody called me lucky because I didn't have to get fat and pregnant in the summertime. (E_7)

Although likely unintentional, these comments could lead parents to minimizing or rationalizing their own feelings, or at least feel a lack of support from the people with whom they had been vulnerable and shared their experiences.

Survival Mode

When asked how they coped with the NICU stay, many parents described “*just trying to survive*” (K_1). This meant focusing on the tasks they needed to do to get through each day rather than assessing their emotions about the NICU stay: *I was on autopilot, I feel like, for a lot of it and just was in survival mode. (C_2)* Day to day life in the NICU combined with the continued stressors and responsibilities of everyday life was often too overwhelming to do more than what was required to get through the day. This left parents little time to consider their own feelings and worries about the NICU stay and often resulted in parents de-prioritizing self-care, even while recognizing that it was important. One such parent regretted in retrospect that she had

not taken or not felt able to take the time to process her emotions about her role as a mother until well after her child's NICU stay:

I internalized all that [feelings], which, I think, caused a lot of issues for me down the line. Now I can talk about it and things like that, but once he finally came home, it was all about him still – as it should be...I wish I had dealt with those things at the time because I just kind of pushed them to the side. (K_13)

A consequence of this survival mode in the NICU was that many parents described delayed processing of their emotions, fears, and trauma related to their child's NICU stay. Taking part in this study demonstrated their willingness to speak about their NICU experience, but many of them said they had only recently reflected on their experience and had an awareness of their emotions:

I feel like I'm just now getting to a point where I can talk about [the NICU]. Sometimes things will come up that surprised me. I wasn't aware I was feeling that way or something. I rocked one of the babies to sleep and was just carrying him upstairs to bed, and it just hit me, 'Wow, we are finally doing what I thought this was gonna be like when I found out I was pregnant.' (S_10)

As this parent described, feelings about the NICU could be conjured up both intentionally or unintentionally, through small triggering moments or through therapeutic interventions. But many parents described still coping with or struggling with aspects of their child's NICU stay despite it being years in the past for some.

Part of this survival mode that also delayed parents' processing, according to them, was their focus on receiving and transmitting information to others, especially providing updates to loved ones. Delivering factual information to family and friends was a way of coping, and perhaps a way to avoid dealing with the emotions of the situation by dealing only with the medical facts:

Talking about it all the time was another way to not dig too deep into it almost, 'cause I was talking about it, but it was like talking about it from the medical perspective and giving everybody a medical update... (K_1)

Gathering and disseminating information and focusing on medical problem solving was a coping mechanism for some parents, leading them to feel more informed and more in control of their child's healthcare; but the emphasis on facts and objective data about their child distanced parents from their emotional, relational connection to their child.

A Changing Support Network

Social support was a complex topic for parents in this study. Some felt very supported by others, their family, friends, NICU staff, and other parents, but some expressed having little or no support. The most common feature of social support among all parents was how much their NICU experience changed their support network in positive and negative ways. Parents came to trust, rely on, and feel reassured by NICU staff, so much so that many of them described supportive nurses, physicians, and other providers as part of their family. Where a new family was being formed, sometimes previous supportive familial relationships became stressful, and parents were not as able to open up emotionally to family as they had been. They also found themselves part of a new group – NICU parents – where they were able to find advice, commiseration, and celebration of their children with an understanding of the challenges they had already endured. These changes to their social network were all occurring in the context of developing a relationship with their new hospitalized infant, coping with the loss of a normal pregnancy and postpartum experience, and trying to maintain their daily lives.

No one really knew how to act. No one knew that when they asked, 'How were his stats today,' that made me feel more abnormal. That they weren't, 'Oh, can I see pictures,' but they were just like, 'Did he gain weight?' Things like, 'Is he home yet?' And no one really knew that that's not helpful. (K_13)

New NICU family. Overall, members of NICU staff, particularly nurses, were described as being a critical support for parents, so much so that they “*became part of the family.*” Parents were forced to leave their children in the care of NICU staff, and this mutual care for their infant fostered trust and respect, as long as parents felt competent, compassionate, and respectful care from NICU staff members in return. These relationships were nurtured by compassionate caring on behalf of the staff member, particularly demonstrated through conversation and the nurses’ dedication to the welfare of the child. One parent described such an experience, and even maintaining a close relationship after the NICU:

There was one nurse in particular, and I'm still Facebook friends with her now. The biggest thing that comes to mind is there was one day that I was really upset about something. I don't know what it was now, but I was really upset about something, and...she came in to do one last check before her shift was over, and she saw how upset I was. She came in after her shift was over, after she had clocked out, and sat and talked with me. (S_15)

This parent was touched by the nurse’s willingness to talk with her and comfort her even though her working hours were over and she was taking time out of her own life to do so. This reaction was humanizing and strengthened the bond between this parent and the nurse, leading them to continue a relationship outside the NICU. Other parents described similar experiences, moved by a simple but powerful experience of a nurse, physician, or other NICU staff member having an unhurried conversation with them. Parents also expressed positive feelings about and developing relationships with nurses that went “above and beyond” in their work, making sure to care for them as parents as well as taking care of their baby, as this parent describes:

[the nurse] pulled over a seat from somewhere else—one of the nice rocking chairs...and she drags it right over and she goes, ‘Come here, sit. You are my patient right now, too. Sit there, shut up, don’t do anything.’ All right. Do I really look that bad? She comes back with a glass of water. She says, ‘Don’t say a damn word. There’s not supposed to be any liquids back here.’ I’m sitting there, and she has a little heart-to-heart with me going, ‘So

how much have you been sleeping?’ Oh, last night, I didn’t sleep at all. I was just restless. ‘Okay. Kick your feet up. You’re right here next to him. I’ll get you a blanket. Get some sleep. Then when your wife comes down here to switch with you, go home.’ (T_19)

Things that nurses did to make parents feel more connected to their babies, especially creating keepsakes or contributing to special memories were also described as a great support.

[the nurse] took the time to make these little Happy Thanksgiving cards from the babies, so that was really, really special, too...it’s not just a part of caring for the medical needs of the babies. She considered doing something special for the family. (A_14)

For some parents, support from the NICU staff became more meaningful than support from other trusted relationships, because parents knew that nurses had the knowledge and experience to accompany statements of caring, comfort, and reassurance.

They were able to make us feel like family, and because of that—because of the support that was there and their experience, that helped. That helped a lot more than—in my opinion, it helped a lot more than our actual family being there and going, “It’s gonna be all right.’ (T_19)

Parents even described personal relationships with some of their NICU staff that were maintained after their child’s discharge from the NICU.

Some of his nurses now are my friends and they applied to the home nursing company that supplies his nursing, and two of his NICU nurses take care of him at home, so they’re still very much in our lives and are definitely people that I probably have the most in-depth conversations with about [my baby] and all of his medical stuff, trying to figure it all out. (K_1)

Many parents expressed that they would not have been able to make it through their child’s NICU admission without NICU nurses. Developing relationships and leaning on them as a supplement or surrogate family support seemed to be essential for their coping experience.

Altered family support. Though family members offered support for NICU parents, parents expressed that they found themselves unable to relate to family members in the same way after their child’s NICU admission. Technically, family members were not entirely

unsupportive; when most parents were asked who they leaned on for support in the NICU they were able to list family and friends and discuss ways in which they felt supported. But where this support had once met their needs and social and relational contexts had been easily understood, after their child's NICU admission things had changed. One parent with a large family support network expressed that her family was not able to relate to her experience as a NICU parent, but they were able to offer practical support to help maintain life outside the NICU and reduce the burden of errands or household tasks:

I think [my family] struggled to connect with any experience that I was having at the hospital itself, but I felt like their way of making up for that was like, we'll take care of everything else, like, your lawn will mowed and all those sorts of things. That was really helpful because being able to come home and be like, 'Oh, look, someone packed four lunches for me, and they're just sitting in my fridge, and I grab one tomorrow when I go to the NICU.' (E_5)

Sometimes parents found family members to be an added source of stress. This stress sometimes emanated from parents having to manage other family members' behavior in the NICU, particularly related to visiting and interacting with the baby:

I mean it was to the point where I literally had to tell my mom, 'You cannot smoke before coming in here. You just can't.' She's like, 'Why not?' I'm like, 'You put that baby on your chest, and you just had a cigarette, and now he's inhaling all the nicotine that is on your clothes.' Still, to this day, doesn't understand...I hate to say it's like do you pick and choose the battle between your son's health and that relationship? I don't know. (A_4)

Another parent spoke about her family member's inability to follow advice about appropriate stimulation and neurodevelopment for her premature baby, causing tension between them:

[the nurses] always would talk to us about one stimulation...either talk softly or touch her back, but don't touch and rub her back...they would hand her to my mother-in-law, and the next thing you know, she would be rocking, rubbing her head, singing to her, and she would just be plummeting in every [vital sign], and I'm thinking, 'Ahh!' It was just every natural instinct that a grandma had, she would do, and that was so hard...with [my second NICU infant], I never went to the NICU at the same time as my in-laws. I would always

schedule them to drop by and visit while I would go out because it was too hard for me to be in a room with her...it was too hard for me to be that close to it. (E_5)

Other parents expressed that their family members' avoidance of the NICU or their child was distressing: *My mother-in-law is a nurse, and seeing my daughter, she worried that she wasn't gonna make it, so it was hard for her to be around. So, how do you think we feel that that's our life right now? (C_2)*

Some of parents' inability to relate to their old support networks stemmed from their own changing role and identity, not only as a parent but as the parent of a sick child, and others'

One of the hard things about talking about it and dealing with it is that you don't wanna feel like it's the only thing about you...People always ask, and they genuinely care about how he's doing...You don't really wanna say, 'This is all I deal with all the time. If we could just talk about, literally, anything else for a minute.' It's hard to do that when people legitimately care, and they want the best for you. They wanna know how they can help. There's just not a lot that they can do. To me, that was, by far, the hardest thing to cope with and deal with. (D_20)

Parents often understood the well-intentioned motivations of loved ones' behavior, even if they did not feel supported by the behavior. They usually qualified a statement about unsupportive or negative interactions with family and friends by offering an expression of understanding or compassion for the other person. This sensitivity to the position and feelings of others caused parents to modify their behavior at times to either preserve relationships or affect the emotions of others. Being a burden to their family, and even their partner, was a concern, and this contributed to some parents' feelings of being unable to share authentic emotions or unwillingness to talk:

You just stopped crying because then people just didn't want you to cry anymore...Every time I cried I think my dad's heart probably broke into a million pieces. Then I'm trying not to cry because I don't want my dad to be upset and my mom didn't know what to say...really you're trying to hold it together for everybody, but you're basically dying inside. (E_7)

Parent peer support. Despite support from family and friends, parents expressed that the only people who could really understand what they were going through were fellow NICU parents. The experience of having a hospitalized newborn that was much more fragile than babies they were used to seeing, that often came into the world in rushed worry, and who they had to ask permission to touch, hold, and talk to was so unique that only other parents could truly understand, despite support from others.

Talking to somebody who didn't experience it was not very helpful. I mean I love my family, but nobody got it really. I think my husband would say the same thing. If you didn't experience it yourself, it was very hard to either talk to somebody else about [it] or have them understand. (E_7)

One parent described the refreshing feeling that came from finding a former NICU parent who did understand her perspective, someone who would be able to interpret her words without her needing to explain the complex NICU environment:

When you go back to work and everybody's like, 'How's the baby?' ...you're like, 'It's good.' You tell stories and it's like you don't get it, you don't get it...Then when you hit somebody who does [know what it's like], you're like oh my god, we can actually talk about [bradycardia] episodes, and we can talk about things that happen. (A_4)

Many parents found a haven of understanding and solidarity in online communities for parents of premature babies and NICU babies. The integration of social media sites such as Facebook, Instagram, and Twitter over the past decade into everyday life of many adults has opened up opportunities for parents separated by distance to connect through the shared experience of a NICU admission.

I couldn't believe that I met so many people on Instagram just by searching hashtags and things like that that, [who] I talk to regularly who have had experiences similar to us. Not just around us, but I have friends in Oklahoma and I have friends in Canada. All over the place, which is pretty crazy to connect with someone from so far away. (K_13)

Parents mostly described groups where parents would have an open forum to exchange advice, stories, and information about available resources, and find solidarity with other NICU parents:

I think [social media has] mostly been helpful with just seeing other preemies...knowing that they're on track with how they should be with other preemies compared to my friends' full-term babies. It's just completely different, and they don't really get it...Then if I have a specific preemie related question that my mom friends in person aren't gonna know about, I can ask it on there. Usually, get some responses that relate to our situation. (S_10)

Parents who were passionate about helping other parents also found social media a useful tool to connect parents to resources that might help them through the NICU experience:

I'm in a preeclampsia group, and every time I hear a new person with a preemie, I link 'em to my preemie group. I'm just like, 'Hey, I just wanna let you know this is a group I'm a part of. They give some great advice. They'll also give you some laughs. I know it's tough right now. You're not alone.' (S_9)

Participants in this study also recognized the need to sometimes filter information shared through social media, that “mom-shaming” and negativity existed, and they knew that they might have to take health advice with a grain of salt. Online communities also offered anonymity and distance for parents who wanted connection but perhaps did not have the social and emotional energy to interact with a fellow parent in real time and place, as this parent described:

If that support group was offered, I don't know if I would have wanted to talk to someone face to face, but if I can type to someone and get those same feelings out, you won't see my emotions and I'm a little bit more comfortable with that. Now I'm fine with talking to people face to face, obviously, but back then, I would much rather text someone or message someone on Facebook and connect that way... (K_13)

In many cases, online forums were the only place for parents to interact with peers because they had limited interactions with other parents who had babies in the same NICU during their stay. Inter-parent interactions were not often supported by staff, and parents felt mixed emotions about interacting with other parents while they were visiting their baby.

I'm just not that outgoing in the first place, so I found it hard to just strike up a conversation because you don't know what other people are going through...some people, you could tell, they could come [to the lunch room] scarf down their meal in two minutes and run back in, and other people would be out there with family and friends, and you don't wanna interrupt that either. I felt like that there wasn't a good opportunity. (S_15)

Parents were hesitant to intrude on other parents at their child's bedside, but were also uncomfortable with intruding on parents' break time, and perhaps feeling more emotionally exhausted and vulnerable in a new social environment. This could feel isolating or strange for parents who wanted to reach out and connect with other parents:

It was a weird dynamic with the other NICU moms I noticed. They had a common eating area, but nobody would talk to each other. You would just sit there and eat and then go back. The tables were like booths. Everybody would sit on the same side, so nobody was facing each other. It was just strange...you have all these people here that are going through the exact same thing and nobody would talk to each other. (S_10)

The same parent expressed that even though she found it strange that nobody talked to each other, she also hesitated to talk to other parents because her babies were doing relatively well and she didn't want to flaunt that to someone whose baby was not doing as well. Another parent expressed similar feelings, indicating that there was complex social navigation occurring with each decision to reach out to or remain closed off to their peers:

I didn't wanna talk to anyone whose kid was doing worse than mine 'cause that made me feel like shit and I was like, 'I am so overwhelmed, I can't feel empathy or have feelings about someone else's kid having a hard time. There's just nothing left in me to be sad about.' Then I didn't wanna be friends with anyone whose kid was doing better than mine 'cause it pissed me off, so there was no one to build a friendship with because I was just on such a roller coaster of emotions that none of it was a good fit for someone to talk to...' (K_1)

A few cases of parent interaction in the NICU stand out, however. One parent described working with other parents of twins to help change a policy that did not support holding twins together, something that these parents of multiples all felt strongly about:

We were waiting, I think, to scrub in one day, and I talked to the other mom...and I said, 'I'm so excited because I'm working with the nurses to try and be able to hold the girls together at the same time. Isn't that exciting?' She's like, 'That would be amazing. I've been dying to do that. I've been asking if I can do it, too.' I'm, like, 'They haven't let you, either? That's not right. This needs to happen.' (A_14)

Due to the advocacy of these parents, the policy against holding multiples together was changed to better support parents' emotional and relational needs. These encounters at communal parent spaces, such as sinks, lunch rooms, and pumping rooms, allowed brief interactions in a way that did not interfere with parents' time at their child's bedside and did not feel as intrusive. Another parent described how a small group of parents in her child's NICU came together and supported each other outside the NICU by hosting and attending crafting events:

We ended up forming our own little group outside of the main [Facebook] group and had scrapbooking nights...I didn't have a car when I was there – some of them would, if they had time they would take me with them to get groceries and we would...whenever craft stuff was on sale and we would just share with each other. Get pictures...and just sit and talk...now we have a Facebook group and we keep track of each other that way. (J_16)

These parents met each other through weekly crafting events hosted by child life staff at their children's hospital, and continued interacting in their online parent community. These examples demonstrate ways in which parents might be incentivized to come together and interact, provided that there was acceptable space and time for interactions between parents to occur.

Some parents had experiences of peer mentorship, both engaging with one as a semi-formal form of support, and helping other parents by becoming one themselves. One parent explained the benefit of having a support person who was not directly involved in their child's care or their family but was able to draw from their own experiences to

We were able to vent frustrations when we had them, voice concern when we had them, and [the peer mentor] was able to kind of pick from her own experiences with other families. 'I've seen this work,' or 'I understand that frustration. This is how that family

went through it. '...They're just a completely independent person who we were able to just be, like, 'Yeah, you know what? I'm having a shitty day. I'm gonna vent to you.' (T_19)

Parents were driven to become peer mentors largely because they wished they had had someone like them for support in the NICU and they wanted to help other families:

I'm still working through it. I did sign up to be a preemie parent mentor through Graham's Foundation because...it helps me to be able to talk through my story, but also I feel like I can be there for parents without being that rah-rah cheerleader, 'It'll be okay,' because I can't make those promises. I can't promise that everything's gonna be okay, but I can be there for those parents to listen when they've had a hard day or to celebrate when their baby is back to birth weight. I could be there for them to do those things and to be the person that I wish I had. (A_14)

Parents did not always find support from former NICU parents in the NICU or online. For some parents who were not involved with social media or interactive with others in the NICU, they found this support in already existing social networks or relationships. One father described his co-workers support after finding out his child was in the NICU:

Folks knew I was [on leave] because I had a premature kid and guys who had gone through the same kind of scenario—maybe not the exact same thing that we had gone through in terms of coming into the world, but had gone through the preemie process or gone through the NICU process—were coming up and saying—talking to me one-on-one and going, 'Hey, listen. I have a son that went through the NICU process. I know it sucks. You need anything, talk to me. It's scary. It's terrifying. You don't know what's going on, but look at my kid. He's running around here, and he came out premature.' (T_19)

Other parents also described previous friends and acquaintances reaching out to offer support and share their own NICU stories after finding out that the participant had a child in the NICU. This contact occurred both in-person and online through social media, depending on how the parent was currently in contact with the former NICU parent. Parents often welcomed this combination of peer support and previous acquaintance since it often meant they could see a way forward out of the NICU experience and know that there were other parents out there like them.

CHAPTER V: DISCUSSION

This chapter contains a summary of the findings discussed in the previous chapter, placing them contextually within current neonatal, pediatric, and palliative care literature. Implications of the findings for nurses, parents, and scientists are presented, emphasizing the need for parent wellness to be addressed with purpose rather than ad hoc, and for parent stakeholders to be involved in research and program development that is meant to support them. Future directions for this work are outlined, expressing the author's intention to use these findings as a foundation for the development of neonatal palliative care science to improve early intervention with parents of infants with non-terminal diagnoses. Limitations of the study are also addressed. The chapter concludes with a final discussion about parent experiences with early palliative care practices and the author's hope that continued research and practice deepens the relationships between those caring for infants in the NICU, clinical caregivers and parental caregivers alike.

Situating the Findings within Current Knowledge

Congruency within Existing Literature

The findings in this study are similar to findings in other studies of neonatal and pediatric decision-making indicating that parents are driven by doing what is best for their child, that they need to gather information from multiple sources, and that guidance is more appreciated when it feels individualized and caring (Allen, 2014). A theoretical framework of parents' ethical decision-making posed by Rosenthal and Nolan (2013) also highlighted parents' trust in the healthcare team, need for information, and communication as essential to their decision-making

capacity. Parents in this study expressed similar desires to truly share the burden of decision-making with their child's providers and have more guidance in making decisions for their child. Similar to parents in Weiss et al. (2016), parents wanted to be heard and have input on decisions that they related to their normal parenting role, such as feeding and holding, and decisions that affected the big picture of their child's care. On the other hand, when parents felt uncertain that they had enough knowledge or expertise to make a decision that they perceived as medically complex, such as which medication to use to treat a certain problem, they preferred the healthcare team to lead decision-making while keeping them informed (Weiss et al., 2016; Weiss et al., 2018). In this study, they did not appreciate feeling coerced or like they were simply being asked to formally agree with a plan that the team had already agreed on, but neither did they appreciate being presented with pros and cons and then left on their own to decide. Parents may prefer more collaborative or guided decision-making, especially for treatment options that are complex and have uncertain outcomes. The complex social nature of these findings support evolving ideas regarding the nature of decision-making as relational rather than completely data-focused and individualistic, emphasizing the social embeddedness of the decision, the decision-makers, and their influences (Walter & Ross, 2014).

The idea that there is a disconnect between the intention and practice of family-centered care has been commonly discussed in modern healthcare literature (Barry & Edgman-Levitan, 2012). Individual clinician approaches and beliefs about family-centered care may affect their ability to effectively practice it. Parents' impressions that their ability to engage in care planning and decision-making depended on the individual care provider present or in charge at a given time is also prevalent in the literature. Other researchers have identified variance in practice

around decision-making and care planning from physicians' perspectives (Richards et al., 2018). This team also suggested the need for a structured practice to determine parents' preferred roles, information desired, and preferences for care planning, which is often a function of early palliative care.

Parents' descriptions of rounding experiences in this study were similar to decision making and care planning styles described in the work by Axelin et al. (2018). They found varied styles of communication and decision-making during rounds, most commonly neonatologist-led or disconnected, with only one experience being described as collaborative with a parent. Parents in this study described similar experiences, with physicians and clinician's agenda driving the rounding process and the parent being invited in but treated as a spectator rather than a true participant. Simply allowing parents to be present during daily and interdisciplinary rounds may not provide opportunities for parents to engage in care planning. Other researchers have identified strategies for improving family engagement in rounds such as but parents may still feel out of place or intimidated to participate (Kelly et al., 2013). Having smaller plan of care discussions may be less intimidating for parents. The intended benefit of parental presence during rounding – to keep parents informed of every aspect of their child's care and to engage in collaborative care planning and decision-making – may not be achieved by simply allowing parents in to a process that does not adapt to their presence and is still dominated and driven by the healthcare team's needs. Other typical forums for care planning, such as formal family meetings or conferences centered on making a significant care decision, suffer from the same clinician-centric practice that often occurs in rounds (Boss et al., 2016). Physicians tended to dominate care planning conversations, mostly with medical knowledge and information rather

than inquiring about parents' opinions, values, or perceptions of their child's condition (Boss et al., 2016). The key to care planning for the parents in this study was that they felt their voices were heard and their wishes considered; a simple mission with seemingly complex and still elusive implementation.

Parents in this study clearly confirmed the now well-understood idea that the NICU admission of a child is a traumatic experience with which parents must cope (Peebles-Kleiger, 2000). The prevalence of mental health challenges among NICU parents, particularly anxiety and PTSD has been well-documented (Feeley et al., 2011; Greene et al., 2015; Kim et al., 2015; Lefkowitz, Baxt, & Evans, 2010; R. J. Shaw et al., 2014). Parents in this study described experiencing similar symptoms of posttraumatic stress, such as hypervigilance, avoidance, and hyperarousal. Challenges in addressing mental health challenges also corresponded with findings of this study in that parents may experience subclinical anxiety, depression, and PTSD (Busse et al., 2013; Greene et al., 2015; Segre et al., 2014), which should be considered when screening parents for these disorders. Coping with their child's NICU admission was more challenging for some parents than others, indicating that risk factors and resilience factors exist and may be predicted with further research (Kim et al., 2015). Other studies of NICU parents have emphasized parents' need for strong social support to help cope with the NICU stay as well (Huenink & Porterfield, 2017). Quite often researchers have sought to implement support programs that leverage the power of NICU staff support, particularly nurses, to improve parental outcomes but with mixed results (Ahern, 2013; Hall et al., 2015; Melnyk et al., 2006; Roque et al., 2017). The need to develop, investigate, and evaluate effective methods of social support is still present due to the changing nature of parents' interactions with others via social media and

the continued need to support parental coping despite the existence of interventions specific to this goal.

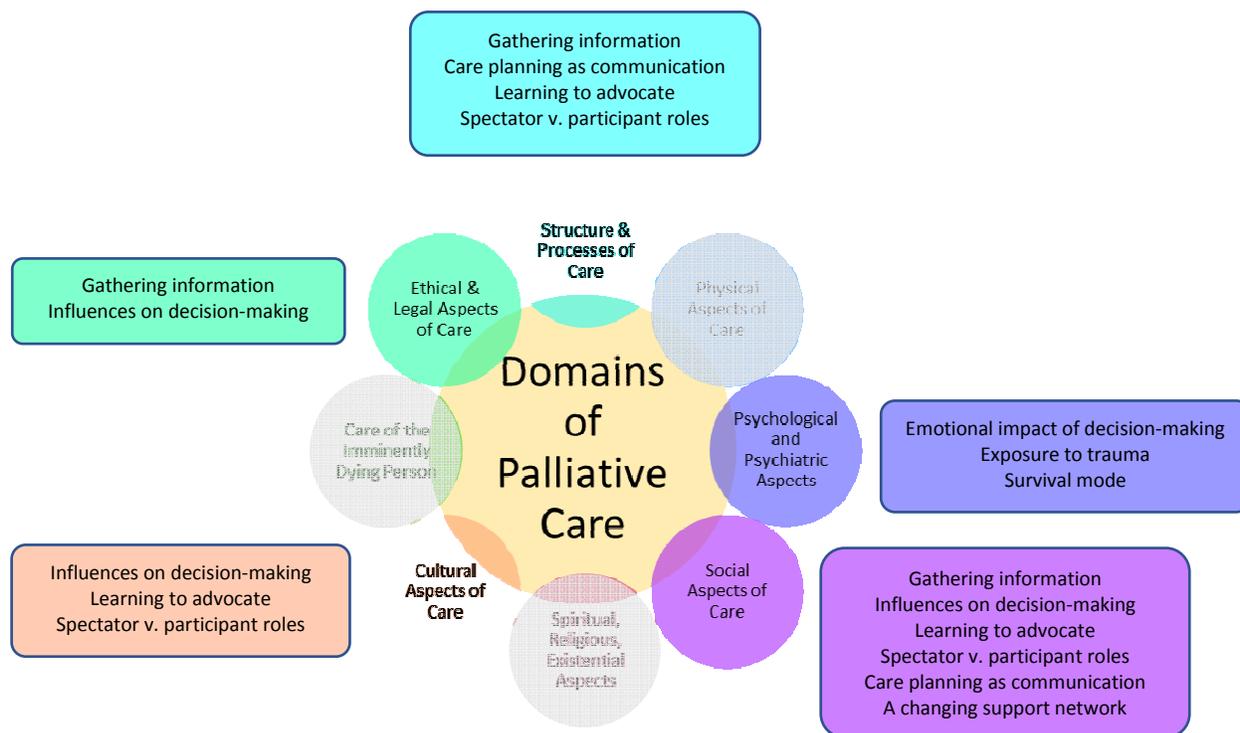


FIGURE 2. Findings in context of domains of palliative care.

These findings also fit within the domains of PC as outlined by the NCP (2018). Parents frequently discussed how they worked within and against the *structures and processes of care* in their child's NICU, often through formal procedures such as interdisciplinary rounds and family meetings. Parents were able to gather some information about decision-making using these rounding structures, but more often they described struggling to find their place in processes in place in the NICU. The nature of these structures, particularly rounding, affected how parents were able to participate in care planning, how they learned to advocate, and how they communicated their care planning desires to the team. These processes were not necessarily

facilitators or barriers to parent participation as a whole, but the way in which they were conducted and in which parents were made welcome within them did affect parent experiences.

Themes of coping fit well within *psychological and psychiatric aspects of care*. Exposure to trauma and how parents are able to cope with that trauma both affects and is affected by psychological factors such as a history of mental health challenges and pre-existing exposure to trauma (Greene et al., 2015; Roque et al., 2017). Survival mode was a primary method of coping and a psychological state in many parents' NICU experiences, but could alter processing of emotions later. And emotional impacts of decision-making could affect parents' psychological well-being, leading to feelings of distress and uncertainty. Parents took the responsibility of surrogate decision-making on behalf of their child seriously, leading them to consider *ethical aspects of care* by gathering information to make the most informed decision they could, and considering what was best for their child as a major influence on their decision-making.

Social aspects of care were very well represented in these parents' experiences. Almost every major theme contained social elements, indicating just how vital it is to understand and support the social experience of NICU parents. Determining which themes represented *cultural aspects of care* was difficult due to the relative lack of racial/ethnic diversity in the sample. It is possible that participants though varied geographically and socioeconomically, share cultural context by nature of their race and level of education. Ways of gathering information and the ability to form social bonds with NICU staff, for example, may have been different for parents with other cultural experiences.

Novel Findings

Decision-making processes and influences of parents have been studied, but often in the context of life-sustaining measures, resuscitation, and life-saving surgical procedures. This study contained a varied sample of parents who did not necessarily have life and death decisions to make, yet they still reported experiences with decision-making. Decisions about daily care, when and how to hold their infant, whether to breast or bottle feed, and decisions about treatment options such as whether or not to attempt medication treatment to prevent surgery, timing of surgical procedures, or pursuit of alternative therapies were perhaps not as serious as deciding whether to continue life-sustaining therapy, but they still had an effect on parents.

This study also highlighted that parents' experiences and methods of care planning may be quite different from the healthcare team's usual method of care planning. While interdisciplinary and daily rounds were mostly effective in updating and informing, parents were more likely to advocate and question the plan of care in individual conversations with nurses, physicians, NPs, and PAs. From a stakeholder-driven perspective, adapting a highly institutionalized, structured, provider-oriented process such as rounding to include parents may not be ideal; perhaps collaboration with parent stakeholders would lead to development of innovative methods of care planning that are truly oriented to the parent and family experience. Care planning that is individualized and based on compassionate, knowledgeable, and equitable communication may foster relationships between the parents and the care team, encouraging continued trust throughout the child's stay.

Limitations

The sample in this study was entirely non-Latinx white, and almost all parents were married. All the infants that parents discussed had prematurity as a primary diagnosis, so parents with seriously ill term infants may have different experiences. Since recruitment took place entirely online through parent communities, this sample may be more connected with the greater NICU parent community than the average NICU parent and more likely to use social media. Although parents were candid about negative experiences with NICU staff, they were aware that the interviewer was a NICU nurse and may have modified their responses. The PI was not known to any participants prior to the study, however, so there was no personal or professional connection to their child's care or their experiences.

Implications of Findings for Practice

The common thread of communication ran through all of the parents' experiences with shared decision-making, care planning, and coping in the NICU. Parents' desire for increased guidance and support during decision-making expressed the communicative and collaborative nature of truly *shared* decision-making. Care planning for parents occurred more often through small, daily conversations with their child's care providers rather than in large formal family conferences, or even during rounding. Parents were able to find agency in interactions that supported their role as their child's ultimate guardian and where they felt heard and cared for. And navigating their new social environment in terms of their new NICU family, their relationships with loved ones, and interacting with other NICU parents was a major element in their way of coping with their child's hospitalization. Developing staff communication skills and prioritizing therapeutic communication is not optional, it is essential in creating a family-

centered experience that will mitigate parent and family suffering. It was evident in the findings that the differences in parents' ability to participate in planning their child's care depending on the individual healthcare provider available is an unacceptable variance in practice. Providers must realize that the way they interact with parents and their willingness to communicate compassionately and empathetically is integral to their effective practice as clinicians. This may be a difficult charge in the meticulously controlled world of the NICU, to change perspective and cede some clinical power and control back to parents while providing them expert clinical knowledge and adapting approaches to communication based on individual needs in the moment. These are challenges that cannot be solved with a checklist or policy change, but rather a culture change wherein communication and parent experience are as equally vital to quality and practice improvement as changes in clinical practice.

Though NICU providers have been encouraged to involve parents in rounding, it is clear that this initiative is not serving parents to the extent hoped. Parents in this study often expressed not feeling that rounds were for them, feeling that they were more spectators than participants. While keeping parents informed is vital, if this is the only place in which care planning is taking place, it may not be fully inclusive of parents. In contrast, parents who felt involved in planning their child's care often accomplished this outside the bounds of formal rounding and conferences. Informal conversations with nurses, physicians, NPs, and PAs were far more common. These informal discussions had the benefit of being accommodated on the parent's schedule, occurring in a one-on-one setting, and not requiring the parent to understand a specific process that could exist in a rounding environment. Parents spoke about these conversations as influencing the ultimate plan of care because they were able to share their opinions and concerns

with care providers, and grew in their confidence to do so over time. Clinicians should approach even brief and very informal conversations with parents as an opportunity to speak with parents about their child's plan of care, to determine if they have opinions or unmet needs, or if they have values or goals for which they wish to advocate. Each interaction with parents need not become an interrogation, but taking time to inquire about their feelings, life outside the NICU, or whether they have adequate support may all glean details relevant to care planning and clinicians must be able to listen deeply to understand when this is occurring.

NICU staff and administrators should consider how changing the built environment of the NICU might better support parents' needs, especially regarding privacy, having space to sit comfortably and interact with their child, and creating communal spaces for parents to interact away from the bedside. Parents named other NICU parents and former NICU parents as an especially helpful coping resource for them, but many did not have the opportunity to form bonds with other parents in their child's NICU. Parents who were able to develop relationships with other parents in their NICU often met during optional hospital-sponsored parent activities, giving parents a chance to interact in a low-pressure, low-risk environment where they did not have the social barriers of not wanting to intrude and respecting others' privacy. NICU staff may consider hosting such events, crafting days, social meals, interactive classes, not as an entertaining supplement to clinical duties, but as a professional imperative to encourage parent peer support and allow parents the physical and mental space to develop supportive relationships.

Findings of this study also have implications on the way in which NICU staff address mental health needs of parents. While PTSD and instances of anxiety and depression can be significant enough to require dedicate psychiatric care, parents often minimized their experiences

of trauma while describing themselves experiencing signs and symptoms of posttraumatic distress. Parents did not necessarily relate to the idea that they had been “traumatized” by their NICU experience, but many still reported coping with the experience many months later and experienced challenges with reminders of their child’s NICU stay. This sub-clinical experience of posttraumatic distress may be easily missed by common mental health screening tools because they do not fit the diagnostic criteria for anxiety, depression, or PTSD or do not relate to those diagnoses but yet they are still suffering. Parents may be too deep in survival mode and trying to defer processing emotional trauma while their child is in the NICU to take the time and mental energy necessary to seek or accept mental health support; it may take months or years for them to be ready to talk about and process their complex emotions. Implementing mental health care support in the NICU may help some parents but follow up with parents through early child development and providing continued opportunities to pursue counseling, therapy, peer support, and other forms of care may be effective at addressing challenges with delayed coping.

According to the participants in this study, NICU nurses have a huge impact on parents’ NICU experience. Parents repeatedly referred to their child’s nurses as a source of support, information, and encouragement. Most importantly to the future of palliative care practice in the NICU, nurses are an integral part of how parents communicate their wishes and values and how they participate in decision-making and planning their child’s care. Early palliative care in the NICU cannot happen without nurses. As the staff members most present with parents at the bedside and most likely to form strong bonds with them over the course of their child’s NICU stay, nurses should feel empowered to drive change from units who practice lip service of

family-centered care to units who communicate effectively and compassionately with parents and families and give agency over their child's care back to them.

Implications of Findings for Research

The intention of this study was to provide a parent-centered foundation for the development of an early palliative care program in the NICU emphasizing supporting parents in decision-making, care planning, and coping. These findings could be used to develop such a program by increasing understanding of what it is that parents actually experience and how they wish those experiences had been different. Research into the implementation and outcomes of such a program will be critical in determining whether it achieves intended outcomes of improved quality of life and mental health outcomes for NICU parents. Innovative changes to the environment of practice will likely have unintended consequences, both positive and negative. Integrating structured early palliative care with the cultural connotations of palliative care as an EOL concept, and emphasis on communication and relationship-building may affect workflow and unit culture in ways that change staff need for resources and support. Investigating both outcome measures and potential unintended consequences will be essential in determining successful implementation and areas for continued growth and improvement of the program.

The rapidly evolving environment of social media and parents' use of and engagement with it is a critical area of future exploration. The social phenomenon of being able to connect over large distances and interact with anonymity in a mostly public forum is an incredibly complex new venue for human interaction that is likely to have lasting effects on concepts of social interaction. Parents in this study mentioned using the internet for information gathering, connecting with other parents, and furthering their own advocacy, so it clearly plays a role in

many parents' experience of the NICU. Disruptive and culture-changing technologies can be challenging to study, often defying previously understood concepts and changing so quickly as to become outdated between study design and dissemination of findings. An area so relevant to parent experiences, however, must be investigated more deeply to increase researcher and clinician understanding of how this new method of information sharing and communicating positively and negatively impacts parents and other NICU family members.

Exploring these aims with a more racially and socially diverse group of parents may also reveal different findings or uncover nuance not present in this sample of non-Latinx white parents. Considering health disparities that exist among NICU infants and parents, efforts should be made to explore parent experiences from racial and ethnic minorities and parents without spousal support. Parents with term infants requiring a NICU admission may provide different perspectives, especially for parents who perceive stigma from their child's illness, as in cases of neonatal abstinence syndrome. Since these findings demonstrate the social complexities involved in early PC practices, parents with lower social capital or a different relational perspective may experience these practices differently and may need alternative or adaptive support.

Using other strategies for data collection such as handcrafts, scrapbooking, and arts-based methods that help parents with telling the story of their baby's life may enrich these findings and lead to development of interventions with more personal relevance to parents. Parents shared their thoughts and feelings about their experience in a largely narrative format, telling stories about their child's stay that demonstrated how they were feeling or a traumatic event, even if they could not articulate their own feelings. Narrative analysis methodology could be especially useful to analyze parents' experiences with learning to advocate, experiences that were described

as a journey of gaining confidence, knowledge, and increasing their parental bond. This qualitative methodology might be useful in determining the essential events in a parent's journey to becoming their child's advocate and determining how best to support parents through those various phases.

Above all, these findings demonstrate that parents must be included in research, intervention development, and programs that affect them. Stakeholder-engaged research approaches, commonly known as community-based participatory research, would help give voice to parents by placing them in positions of agency and even leadership within the research team (Barkin, Schlundt, & Smith, 2013; PCORI, 2015). As much as healthcare professionals can come to learn about the struggles and wishes of parents and families, ensuring that parent stakeholders have a respected voice alongside other experts allows collaborative efforts to truly be representative of the individuals most deeply impacted by the NICU experience. It is essential for researchers to nurture collaborative, respectful partnerships between parents and themselves, understanding the need to welcome parents into research environments and demonstrate that their input and engagement is valued (Black et al., 2018). While NICU parents have many vulnerabilities, their resilience in the desire to do what is best for their children, their hopes for the future, and their desire to help others should be leveraged to motivate their participation in work meant to improve the lives of NICU parents.

Conclusions

Parents are a critical stakeholder in neonatal healthcare, and their experiences reflect both struggles and triumphs. Their descriptions of life in the NICU demonstrate a clear need for improved support. Due to the EOL exclusivity of current neonatal PC, parents in this study were

not offered early PC, but they all had experiences with shared decision-making, care planning, and coping in which they wished for more support. This study and others describe these processes happening as a consequence of individual clinicians' willingness to support parents in these practices and are therefore subject to individual practice rather than a structured, consistent, and intentional approach to practice. Integration of early palliative care may provide this systematic yet individually adaptable approach to care. In true collaboration with diverse parent stakeholders, the responsibility to change NICU culture and practice to better support parents still weighs on the shoulders of NICU researchers and clinicians. It is no longer sufficient to believe that inviting parents into clinical spaces and processes is sufficient to fulfill the directive of family-centered care. Moving forward to respond to parents' stories of suffering requires an approach to care that emphasizes mitigation of suffering as the goal, and orients the goals of care to the perspective and experience of the suffering rather than the clinician. Work to destigmatize palliative care must begin now to counteract decades of avoidance of the palliative care approach due to its cultural and clinical relationship with death. Early integration of palliative care promises to answer parent needs for improved communication, collaborative and equitable decision-making, and support in their struggles of growing into their role as a parent and bonding with their critically-ill child. Hopefully, the imperative outlined here to continue the work of neonatal palliative care will inspire parents and clinicians to move forward together to create a nurturing and healing NICU environment for both child and parent.

APPENDIX A:
RECRUITMENT MATERIALS

E-mail and Social Media Flyer (parents will view this in their email or on social media)

Subject line (email): We Want YOU – For NICU Parent Research

Did your baby spend time in the NICU? Want to share your NICU story and help make the NICU experience better for future families? We want to hear it!

Answer these 6 short questions to see if you are eligible for our research study! *(link embedded)*

If you are eligible and would like to participate, you will complete an online interview with a nurse researcher to talk about your NICU experience. \$50 Target gift cards available for study participants!

An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Eligibility Survey (parents will view this page/survey after clicking the link above)

Thank you for your interest in our research - please answer the following questions to see if you are eligible to participate!

****Completing this survey does NOT mean you agree to participate in the research study****

1. Are you 18 years old or older? Yes/No
2. Have you had a baby in the NICU within the past 3 years? Yes/No
3. Was your baby in the NICU for at least 2 weeks? Yes/No
4. Did any circumstance keep you from visiting the NICU during your child's ENTIRE stay? (only respond Yes if you were unable to go to the NICU at all) Yes/No
5. Would you be able to participate in an interview with an English-speaking researcher? Yes/No
6. Are you currently grieving the death of any of your NICU babies that happened less than 6 months ago? Yes/No

Ineligibility Page – Default (parents will view this page if they are excluded for anything other than a child's death within the past 6 months)

Thank you for taking the time to fill out our eligibility survey and for your interest in our research study. Unfortunately, we are unable to include your valuable experience for this particular study, but we encourage you to look out for other opportunities to share your story.

Have a wonderful day!

Ineligibility Page - Bereavement (parents will view this page if they indicate they experienced a child's death within the past 6 months)

Thank you for taking the time to fill out our eligibility survey and for your interest in our research study. Unfortunately, we are unable to include your valuable experience for this study, but we encourage you to look out for other opportunities to share yours and your child's story.

We are sorry about the loss of your baby. Grief is one of the most difficult things we endure in life and can make you feel very alone. If you need support in helping you cope with your child's death, we encourage you to reach out for help. We suggest the following resource: [Dealing with Grief After the Death of Your Baby from the March of Dimes](#)

We wish you and your loved ones the best as you help each other through this challenging time.

Eligibility Page (parents will view this page if they meet inclusion/exclusion criteria)

Thank you for taking the time to fill out the eligibility survey and for your interest in the research study. Good news – your story is exactly what I'm looking for!

I am a graduate student completing my dissertation at the University of Arizona, and I have been a NICU nurse for 9 years. I believe the future of caring for our critically ill babies lies in bringing parents and clinicians together to develop and study new ways of making lives better for babies and families in the NICU. I am holding online interviews to explore parents' experiences in the NICU, specifically experiences with making decisions, planning your baby's care, and coping with the NICU stay. As a NICU parent, you have a wealth of information that even the most experienced NICU clinicians do not have, and I value your opinions.

This is a research study, so your participation is completely voluntary. Interviews will take place online via the Zoom virtual meeting technology (secure links to free software will be provided) and last no longer than 90 minutes. The virtual interview can be attended on computer, tablet, or mobile smartphone, and will require a stable internet connection. You will only be asked to attend one private interview, and you will be free to leave the interview at any time if you feel unable to participate further. If you agree to participate you will be sent a \$50 Target gift card and information on local and national parent support organizations regardless of your completion of the study. An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Please submit your email address below if you are interested or if you have further questions and I will get back to you within the next day or two! If you are not interested, you can simply close this web page. Thank you for your time!

APPENDIX B:
INTERVIEW GUIDE

General experiences and Opening Questions:

- *To begin with, I'd love to hear your baby's story. Tell me what you think is important for me to understand about your baby and your family.*

[Prompts: the day your baby was born? best day in the NICU? best "first"?]

Experiences with decision-making:

- *Sometimes parents have to make difficult time decisions such as whether to resuscitate in the delivery room to whether to have a certain kind of surgery. Tell me about decisions you had to make.*

[Prompts: emotions surrounding decision? Anticipated or unanticipated decision? How were you prepared to make the decision?]

- *Sometimes parents feel that they are not in control and aren't given the opportunity to make decisions on behalf of their child. Other times they feel that they are in control and are presented with many opportunities to make decisions. Tell me about a time when you felt this way.*

[Prompts: affect how you viewed yourself as a parent?]

- *How did other people support or not support your decisions?*

[Prompts: family/friends? Healthcare team? Other NICU parents? Religious community?]

- *Many parents find it hard to sort through all the things that go in to making decisions like these. Tell me more about the different aspects of your life that influenced your decision.*

[Prompts: balancing these factors?]

Experiences with care planning and goal-setting:

- *Tell me about your experiences working with the NICU team to plan your baby's care or setting goals for your baby.*

[Prompts: your influence on the care plan? Family meetings? Involvement in rounding?]

- *What did you find yourself hoping for when your baby was in the NICU?*

[Prompts: hopes change over time? Hopes change after birth?]

- *(If the infant died after withdrawal of life support or on hospice) Many parents make the same decision you did about the value of a comfortable life and death for your child.*

Without feeling like you have to justify your decision, tell me more about the value of comfort and how you considered your options.

Experiences with distress and coping:

- *Many parents describe life in the NICU as a roller coaster of emotions. Tell me about how you felt while your baby was in the NICU.*

[Prompts: any negative feelings you can name? any positive feelings you can name? how did you express these emotions? feelings differ from partner's? worst day in the NICU?]

- *Tell me about how you dealt with everyday stressors while your baby was in the NICU.*

[Prompts: other child care? Transportation? Personal health?]

- *Tell me what you did to cope during your baby's time in the NICU.*

[Prompts: self-care? Coping at home v. in NICU? Coping after the NICU?]

- *Tell me about any resources available in the NICU that helped you cope with your baby's stay.*

[Prompts: support/peer groups? staff relationships? chaplain or social worker?]

- *Tell me about the people, if any, you leaned on for support while your baby was in the NICU.*

[Prompts: partner? family? Friends? spiritual/religious support? Other parents? Social media groups? Mental health providers?]

Anything else you'd like me to know about your experience?

APPENDIX C:
DEMOGRAPHIC AND INFANT CHARACTERISTICS SURVEY

Questions about You**1. What is your age?** _____**2. What is your biological sex?**

Female Male

Prefer not to answer

3. Are you: (choose one response)

Single Married

Living with a partner

Divorced Widowed

4. How would you describe yourself? (may choose multiple responses)

American Indian

Asian

Black or African American

Hispanic or Latinx

White

Other _____

5. What is your current employment status? (choose one response)

Employed full time (40 + hours/week)

Employed part time (up to 39 hours/week)

Student Self-employed

Homemaker/Caregiver

Unemployed

6. Which of the following best represents your household's annual income? (choose one response)

Less than \$20,000

\$20,000 – 34,999

\$35,000 – 49,999

\$50,000 – 74,999

\$75,000 – 99,999

\$100,000 – 124,999

Greater than \$125,000

7. What is the highest level of formal education you have received (choose one response)

Less than high school

Some high school

High school diploma/GED

Associate's degree

Bachelor's degree

Master's degree

Doctoral degree/Professional degree (e.g.

MD, JD, DDS)

Questions about Your Baby

8. How many children do you have? _____

9. How many children live in the home with you? _____

10. Have you had more than one baby in the NICU?

Yes No

If yes, how many? _____

11. At how many weeks gestation was your baby born? _____

12. How much did your baby weigh at birth? (leave blank if you are not sure) _____

13. How long was your baby in the NICU? (approximate if you are not sure) _____

14. Is this baby living? Yes No

15. Is this child eligible for or does this child receive home nursing care? Yes No

If yes, how many hours? _____

Questions 11-15 will be repeated depending on parent answer to question 10

APPENDIX D:
PARTICIPANT RESOURCES

Parent Support Resources

Hand to Hold

A national non-profit organization focusing on peer and professional support of current and former NICU parents. They offer education and support materials through various visual and audio mediums, and they offer support online, by phone, and through online parent forums. Search for their podcast, “NICU Now” on your mobile device.

www.handtohold.org

Toll free: 855-H2H-NICU (855-424-6428)

NICU Helping Hands

This non-profit organization is run by former NICU parents and offers peer support and education. They also have developed a program for NICUs to help develop family-centered care models for hospitals that adopt the program.

www.nicuhelpinghands.org

Support 4 NICU Parents

A parent support site operated by the National Perinatal Association. Here you will find peer support and education on a wide variety of topics including managing life after the NICU and parent mental health.

www.support4nicuparents.org

Zoe Rose Foundation

A non-profit memorial foundation founded by a former NICU mom that contains valuable family resources including peer support, events, and education.

www.zoerose.org

888-963-7673

Preemie Parent Alliance

The Preemie Parent Alliance is an organization that networks many different parent advocacy groups. If you are interested in being involved in the parent advocacy community, this is a good place to start. They sponsor an annual parent-centered conference that discusses various topics pertinent to current and former NICU families.

www.preemieparentalliance.org

NICU parents experience a great deal of unanticipated stress that can take a toll on both your physical and mental health. NICU parents are at a greater risk for anxiety, depression, and post-traumatic stress disorder (PTSD) than parents whose babies were not in the NICU. If you feel like you haven't been yourself or you think you might be experiencing one or more of these common effects of being a NICU parent, please seek help through a local family or grief counselor or talk to your primary care provider.

APPENDIX E:
THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD APPROVAL
LETTER



Human Subjects
Protection Program

1618 E. Helen St.
P.O. Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
<http://rgw.arizona.edu/compliance/home>

Date: July 09, 2019
Principal Investigator: Megan Christine Quinn
Protocol Number: 1907776807
Protocol Title: Exploring parent experiences with early palliative care practices in the neonatal intensive care unit

Determination: Approved
Expiration Date: July 08, 2022

Documents Reviewed Concurrently:

Data Collection Tools: *DEMOGRAPHIC SURVEY.DOCX*
HSPP Forms/Correspondence: *MQuinn_IRB App_Revised.pdf*
HSPP Forms/Correspondence: *Quinn_IRB_list_of_research_personnel.pdf*
Informed Consent/PHI Forms: *Quinn DISSERTATION Consent.doc*
Informed Consent/PHI Forms: *Quinn DISSERTATION Consent.pdf*
Other: *INTERVIEW GUIDE.DOCX*
Other: *IRB_PPA Letter of Support_Dissertation_Signed.docx*
Other: *Parent Support Resources.docx*
Other Approvals and Authorizations: *Advisor Confirmation Email.pdf*
Other Approvals and Authorizations: *COI Certification Complete for 1907776807.msg*
Other Approvals and Authorizations: *Confirmation for Scientific Review and Department Review.pdf*
Recruitment Material: *RECRUITMENT MATERIALS.DOCX*

Regulatory Determinations/Comments:

- The project is not federally funded or supported and has been deemed to be no more than minimal risk.
- The project listed is required to update the HSPP on the status of the research in 3 years. A reminder notice will be sent 60 days prior to the expiration noted to submit a 'Project Update' form.

This project has been reviewed and approved by an IRB Chair or designee.

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted according to the approved protocol and the policies and guidance of the IRB.
- The Principal Investigator should notify the IRB immediately of any proposed changes that affect the protocol and report any unanticipated problems involving risks to participants or others. Please refer to Guidance Investigators [Responsibility after IRB Approval](#), [Reporting Local Information](#) and [Minimal Risk or Exempt Research](#).
- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office.

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