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Stress, Appraisal and Coping in the Neonatal Intensive Care Unit: The Experiences of Parent Dyads

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Stress, Appraisal, and Coping in the Neonatal Intensive Care unit: The Experiences of Parent Dyads

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A dissertation submitted to the faculty of the Medical University of South Carolina in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Nursing.

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ABSTRACT

Problem: The hospitalization of their infant in the neonatal intensive care unit (NICU), regardless of the circumstances, is stressful and shocking. Parents find themselves unprepared and on an emotional rollercoaster. Parents are at risk for depression, anxiety and PTS- the effects of which can be lasting and can adversely affect the relationship between the parents in the dyad, and their ability to bond with, and parent their child. Parents have little influence over their circumstances and need information from staff in order to appraise their situation and determine how to cope.

Methods: A scoping review of parents' mental health in the NICU within the social ecological model, utilizing the Arksey and O'Malley framework, was conducted to establish the breadth of the problem. Then, an integrative review of qualitative studies of parents' experiences in the NICU within the transactional theory of stress and coping utilizing the Whittemore and Knafl framework was conducted. Finally, a descriptive qualitative study examined the experience of parent dyads in the neonatal intensive care unit, using the transactional theory of stress and coping as a framework.

Results: The scoping review of parents' mental health in the NICU included 26 studies and revealed that this distress is a cluster of symptoms (anxiety, acute stress, in some cases depression) that is eased or exacerbated by multiple factors, at multiple levels of the SEM. The integrative review of qualitative studies of parents' experience in the NICU included 16 studies and resulting themes included emotional upheaval and faith, and subthemes of the NICU environment and learning to parent, as factors that affect how parents appraise and cope with stress, and whether or not they adapt successfully. In the final qualitative descriptive study, nine themes from eight dyad interviews emerged and were categorized within the six domains of the transactional theory of stress and coping. The major themes were: Deeply Distressing, Unexpected and Unprepared, Expecting to Hear and Be Heard, Becoming Parents, Stronger Together, Support is Key, Parents Want Better Communication, and Adjusting to the NICU.

Implications for Practice and Research: Support from professionals and family, and clear and consistent communication from the treatment team helped alleviate parents' anxiety about their infant. Research regarding the impact of a NICU hospitalization on the relationship between parent dyad members, specifically longitudinal studies, may lead to a better understanding of the long-term effects of this specific stressor on parents.

Keywords: neonatal intensive care unit, NICU, parents, experience, psychological distress, qualitative

INTRODUCTION

1. OVERVIEW

The hospitalization of one's infant in the neonatal intensive care unit (NICU) is a stressful experience for parents. Neonatal intensive care unit admissions transpire when an infant is born prematurely, has complications that require intense nursing care, or is acutely ill. Premature birth is the leading cause of death of infants in the United States (1, 2). Fifteen million infants are born prematurely each year (3), affecting 1 of every 10 infants born in the United States (2, 3). In general, parents have the hope of a healthy pregnancy and expect to leave the hospital with their newborn. When this is not the case, a NICU hospitalization due to illness or prematurity may be traumatic for some parents and may cause psychological distress or may alter or impair parenting.

Parents in the NICU are at increased risk for psychological distress, including depression, anxiety, acute stress, and/or posttraumatic stress, each of which can be lasting and have negative impacts on the individual parent and the relationship between the parents, the ability to bond with and nurture their infant, and child development (4-10). Up to 70% of mothers in the NICU have postpartum depression (4, 11-14), compared to 11.5% in the general population (15). As many as 37.5% of fathers in the NICU have been found to have depression (13, 16), and one study found fathers had a 33% risk of posttraumatic stress disorder (17).

Given the risk for psychological distress, the unmet needs of parents, including restrictions on visiting and lack of meaningful communication with NICU staff (18), are problematic added stressors. Parents have described the following reasons for being dissatisfied with a NICU hospitalization: a lack of information provided by NICU staff to parents, the inability to provide care for their child (19-21), perceived negative attitudes of health care personnel (20, 22), and dissatisfaction with services received or recommended while their child was hospitalized in the NICU (17, 22-24). To better understand the issues facing parents in the NICU, it is important to examine their experiences and how parents cope with the hospitalization of their infant. Learning about the experiential and coping differences between parents, and the effects of the stress of the NICU hospitalization on their relationship with each other are areas infrequently explored in prior studies. Addressing these gaps has the potential to inform development of future support services for this population.

The specific aims of the dissertation study were to:

- **Aim 1: Describe the experience of having a child in the NICU and how parents cope with the experience.** This was accomplished by interviewing 8 dyads of parents of infants who had been hospitalized in the NICU; parents were interviewed together as a dyad and individually, for a total of 22 interviews (one couple was lost to follow up prior to the individual interviews).
- **Aim 2: Identify experiential and coping differences, if any, between mothers and fathers or non-birth mothers.** Dyadic and individual interview data were analyzed to compare the experiences of parents in the dyad.

- **Aim 3: Examine the effect, if any, that a NICU hospitalization has on the parent dyad relationship.** Semi-structured dyadic and individual interviews included inquiry about the effect of the NICU hospitalization on the parents' relationships.

The aim of the dissertation study was to provide a better understanding of the experiences of parents in the NICU, and to provide a foundation for future studies informed by data from parents to guide the assessment and provision of psychosocial services and support during this vulnerable time (9, 25). Future studies on this trajectory can inform the need for interventions for parents to mitigate the occurrence and severity of parental psychological distress and improve the NICU experience. These interventions may impact the care of parents with hospitalized children, allow for the earlier identification and treatment of psychological distress in both parents, and decrease the negative effects on parents and children from untreated illness or poor NICU experiences. Results from the dissertation study will guide the design of future studies with this population, and guide development, testing, and refinement of interventions to improve parents' experiences in the NICU.

2. BACKGROUND AND PROBLEM STATEMENT

The hospitalization of an infant in the neonatal intensive care unit (NICU) is a highly stressful experience for parents, and it is critical to understand these experiences to address the unmet needs of parents and provide appropriate psychosocial support. Parents are fearful that something may go wrong during the hospitalization (26), or that they may ultimately suffer the loss of their infant (27). Having an infant in the NICU makes it difficult for parents to carry out typical parenting activities and roles for both first-time parents and those with other children (8, 17, 28, 29). In addition, parents find the NICU hospitalization frustrating because they feel that it renders them helpless (21). For those who have a premature infant in the NICU, the conceptual idea of parenthood is disrupted (11) due to truncating of the pregnancy and subsequent feelings of loss, grief, and anxiety (29) associated with pre-term birth. Life-threatening illness and an unknown prognosis or outcome for infants in the NICU is distressing to parents (30), and the resulting increased risk for adverse outcomes or long-term illnesses is also of concern (31), as infants who survive an early or traumatic birth often face chronic health problems and developmental and intellectual delays. With the rising incidence of NICU admissions in the United States for term and preterm infants (32), it is vital to gain new knowledge about the experiences of parent dyads in the NICU to better understand their individual and combined needs and provide psychosocial support. Whereas studies have shown that mothers in the NICU are at risk for postpartum depression and anxiety, and emotional dysregulation has been subjectively reported in both parents, research was required regarding the joint experience of parents to understand how the NICU experience affected parents' relationships and subsequent coping abilities.

3. GAPS IN KNOWLEDGE

Despite the statistics reported in prior studies supporting psychological distress in parents of infants hospitalized in the NICU, the ensuing effects on the parent dyad relationship and differences between how mothers and fathers cope are often not discussed. This is significant because of the negative impact psychological distress may have on parent relationships, parent-infant bonding, and parental roles. Differences in the development of parental psychological distress within the context of the NICU experience suggest that fathers develop more active coping mechanisms, but that the rate of postpartum depression in men is likely underestimated (33). Fathers are at risk for developing psychological distress, yet few studies have been conducted to examine the effect of the NICU hospitalization on fathers and any ensuing development of depression, anxiety, or posttraumatic stress (17, 33-35). No studies were identified that explored the experiences of non-birth mothers, adoptive parents, or those who used a surrogate in the NICU setting.

The National Perinatal Association and the associated mental health workgroup recommended screening parents of high-risk infants for emotional distress and embedding mental health professionals in the NICU (9, 25, 36). However, those recommendations are not always translated to practice and it is unknown how many NICUs in the United States have screening or intervention programs for parents in the NICU who may be experiencing psychological distress. Many studies have examined and measured the mental health and psychosocial status of parents with infants in the NICU (9, 11, 25, 37-47), and studies have explored the experiences of mothers or fathers in the NICU individually (13, 48-53). Few studies, however, have described the personal experiences of a NICU hospitalization for the parent dyad and examined their specific needs as a couple in the context of the parents' ability to cope with stress. Moreover, few studies have compared the differing experiences between parents in a dyad, the effect of a NICU hospitalization on their relationship, and their subsequent perceived ability to parent their child. Thus, a significant gap remains in the literature regarding parents' experiences in the NICU, a gap the dissertation study was designed to address. Previous studies with parents of infants in the NICU were based on individual perspectives and focus groups, and parents were not interviewed together as a dyad (54-58). The need for further research into the effects of the NICU hospitalization on the parental relationship and the benefits of family-centered care has been cited in the extant literature and the dissertation study sought to meet that need (59). Research comparing parents' experiences in the NICU between parent dyad members can elucidate parents' perceptions of the NICU experience, their reflections of the effects of that experience on the other parent, and the impact of those experiences at the individual and dyadic levels (60). When birth mothers, fathers, and non-birth parents of infants hospitalized in the NICU are properly assessed, appropriate intervention strategies can be developed and offered.

4. DESIGN AND METHODS

The dissertation study used a qualitative descriptive design (61, 62) to explore the experiences of both parents regarding their infant's NICU hospitalization. The differences and similarities of parents' experiences, the subsequent effects of the NICU hospitalization on their relationships, and their parenting styles were specific areas of inquiry. Participants were recruited from two level II NICUs in the northeast United States. Parent dyads of infants with a length of stay of at least 2 weeks were invited to participate in the study. Parents who met the inclusion criteria and gave informed consent were interviewed together as a dyad and then individually. Each interview was between

30 and 75 minutes and the follow-up interviews were conducted within 2 weeks of the dyad interview. After the first (dyad) interview, parents were asked to complete a demographic survey to provide a description of the sample. The survey took less than 10 minutes to complete. Interviews were conducted in private conference rooms at each NICU. Interviews were recorded, transcribed word for word, read and re-read for content, checked and re-checked for accuracy, and examined for similarities and differences between parents. Data analysis began after the dyad interview, continued through individual interviews, and remained concurrent to data collection throughout the study until data saturation or informational redundancy was achieved and no new themes emerged (63). Through content analysis, an accurate description of parents' experiences in the NICU was rendered.

5. KEY CONCEPTS

The key concepts of stress, cognitive appraisal, and coping are described as part of the theoretical framework below.

6. THEORETICAL FRAMEWORK

The transactional theory of stress and coping (64-66), originally published by Lazarus and Folkman in 1984 (67), provided the structure for manuscript 2 and the original research described in manuscript 3 and the subsequent organization, analysis, and synthesis of the results of the integrative review and qualitative descriptive study. The transactional theory of stress and coping is a cognitive theory of the person-environment relationship in the context of the stress response (64). Parents have individual responses to stressful situations, as individual factors influencing appraisal will affect parents' responses to a NICU hospitalization (68):

Situation Factor Affecting Stress in NICU	Example
Novelty	No previous experience with a NICU hospitalization
Predictability	Awareness of potential NICU hospitalization
Event uncertainty	Likelihood a NICU hospitalization will impact parents' appraisal or cause confusion about the meaning of a NICU hospitalization
Imminence	Amount of time before birth are parents aware of possible NICU hospitalization
Duration	Length of hospitalization
Ambiguity	Lack of clarity about the situation
Timing	In relation to the life cycle

Cognitive appraisal includes primary and secondary appraisal (65, 66, 69-71). Primary appraisal is the person's feeling about the meaning of the event (i.e., a NICU hospitalization) as traumatic, optimistic, difficult, etc. It is how parents interpret the stimuli they are presented with and how they categorize it as immaterial or as a threat (70). Secondary appraisal is the assessment of coping resources and choices in the situation, or controllability of the stressor (72); it is how parents determine the coping skills they have available to them, and if these skills are sufficient to deal with the NICU hospitalization (70).

Coping is the key process in the model; coping abilities affect parents' views of the stressor, and determine their reactions (70). Coping strategies are varied in the model and categorized into specific styles within two processes: emotion-focused coping and problem-focused coping (65, 66, 69-71). Within the process of emotion-focused coping, strategies include: focusing on encouraging aspects like small improvements the infant has made; self-controlling by hiding one's feelings to maintain emotional control; escape avoidance using wishful thinking; accepting responsibility by managing one's guilt through self-criticism; and distancing by refusing to acknowledge or think about the situation, or accepting the situation as fate (71). Problem-focused coping skills are utilized when parents seek social support from family, friends, and NICU staff, and include information seeking behaviors or seeking professional help for their own mental health. Lau and Morse (2001) posit parents utilize different coping methods at different phases of the stress experience, often feeling angry, powerless, and frightened in the early stages of hospitalization, and in later stages, information-seeking behaviors and social support are better utilized (70, 71).

Emotion- and problem-focused coping can ease or hinder the coping process (68). Effective problem-focused coping allows management of the environment causing the distress and effective emotion-focused coping by regulating the emotional response to the stressor (67). Ineffective emotion-focused coping may impede subsequent problem-focused coping, and Lazarus and Folkman (1984) describe ineffective problem-coping cycles of information seeking that intensify emotional anguish and interfere with emotion-focused coping mechanisms. The appraisal of a stressful situation will affect coping abilities, and the ability to cope with one's circumstances affects the outcome for parents as successful adaptation, or maladaptation (negative adaptation).

Because there is constant interaction between parents and the environment, the process of appraisal, coping, and adaptation changes over time- what is a consequence at time one can be an antecedent at time two, caused by environmental or personal factors

(68). Limitations of this framework are addressed by Lazarus and Folkman who surmise that people want to know what is occurring in a stressful situation and what it means for them, but also tend to put a positive light on most situations (68), thus limiting how they describe and reflect on their experiences. The appraisal of a stressful situation and subsequent coping efforts, coping styles, and outcomes of coping or adaptations are key concepts of the theory, and the lens through which the parent experiences in the NICU are analyzed and evaluated through the qualitative data analysis process.

7. OVERVIEW OF MANUSCRIPTS

Manuscript 1: In a scoping review of the literature conducted in 2016 (73), the PI described the intrapersonal characteristics of parents of infants hospitalized in the NICU and how these characteristics affected their interpersonal relationships with the other parent or family members and subsequently impacted their perceived support. These interpersonal relationships also affected the behavior or emotional status of the parents individually. Cohabitation was found to be a possible determinant of parent mental health status; not living with the child’s father was found to be a risk factor for development of postpartum depression in low-income women with very low birth weight infants, and support from the infant’s father mitigated risk of depression in one study (74). Conversely, two studies demonstrated marital status, specifically being married, was an indicator of increased maternal stress and higher levels of depressive symptoms (8, 28). One study found a decreased perception of family cohesion was associated with depression at 1-month post discharge (26), and the findings of another study indicated nearly all mother and most father participants experienced symptoms of posttraumatic stress that can negatively affect family processes, such as parenting behaviors and child development (20). Relationships and interactions at the institutional level were reciprocal; if families did not feel as though they were receiving enough or the right kind of information in the NICU, they became dissatisfied, angry, or upset. This affected the parents at the intrapersonal and interpersonal levels and affected the relationships the parents had with the NICU staff, which impaired communications among all parties.

Manuscript 2: The PI conducted a follow-up integrative review in 2017, submitted to the *Journal of Perinatal and Neonatal Nursing* (75), of published qualitative studies in which the following major themes were identified: panic sequence, violated cognitive schema, emotional upheaval, regulating emotions, social support, faith, managing the NICU, and adjusting. The PI identified no studies that used both individual and dyadic interview methods to collect data, which would have allowed for triangulation (the use of two or more approaches in the same study) and the ability to compare parents’ experiences within the dyad. Although all studies in the review included mothers and fathers as participants, there was scant comparison of the differing experiences of these two groups and the effect of a NICU hospitalization on the parents’ relationships and their subsequent perceived ability to parent their child. Further, fathers were underrepresented, comprising only 38% of study participants in the sample. The PI identified no published studies that included non-birth parents and/or same-sex couples in the sample. These findings informed the dissertation study which proposed to address gaps in knowledge of the shared experience of a NICU hospitalization for parent dyads, as well as identify any differences noted between and among parents in their perceptions of the hospitalization experience.

Manuscript 3: The results of the dyadic analysis of the IRB-approved study, "The experiences of parent dyads in the neonatal intensive care unit," are presented in this manuscript. This study used a qualitative descriptive design in which dyadic and individual interviews were conducted with each member of the parental dyad to examine the experience of having a child in the NICU and how parents describe coping with the experience. Themes were categorized and analyzed within the six domains of the transactional theory of stress and coping. Major themes to emerge were: Deeply Distressing, Unexpected and Unprepared, Expecting to Hear and Be Heard, Becoming Parents, Stronger Together, Support is Key, Parents Want Better Communication, Parents Do Not Know How Much More They Can Take, and Adjusting to the NICU. Key findings include the subtheme we are different and major theme Stronger Together, the difference between coping methods of mothers and fathers, and their perceptions of the effect of the NICU hospitalization of their infant on their relationship with each other. Results of the analysis of the individual interviews of the mothers and the individual interviews of the fathers will be presented in separate, future publications.

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Parent Psychological Distress in the Neonatal Intensive Care Unit Within the Context of the Social Ecological Model: A Scoping Review

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Abstract

Background: NICU parents are at risk for psychological distress and impaired mental health, and statistics related to parent psychological distress vary.

Objective: To determine the scope of literature regarding the mental health and psychosocial well-being of parents in the NICU.

Design: A scoping review within the Arksey and O'Malley framework and the SEM was undertaken to answer, "what factors contribute to parent's mental health in the NICU?" A systematic review of the literature was performed using the PRISMA methodology.

Results: Common socioeconomic factors and infant and parent characteristics may place parents at a greater risk for developing distress. History of mental illness, family cohesion, birth trauma, altered parenting role, gestational age, birth weight and severity of prematurity/illness emerged as themes.

Conclusion: Further research is required to provide a standard for the screening and assessment of parents' mental health and psychosocial well-being during a NICU hospitalization. The experiences of non-birth parents' in the NICU should be explored to examine the effects of the hospitalization on all types of parents.

Keywords: neonatal intensive care unit, anxiety, depression, stress, parent

PARENT PSYCHOLOGICAL DISTRESS IN THE NEONATAL INTENSIVE CARE UNIT WITHIN THE CONTEXT OF THE SOCIAL ECOLOGICAL MODEL: A SCOPING REVIEW

The hospitalization of one’s child in the neonatal intensive care unit is a stressful experience for parents. Neonatal intensive care unit (NICU) admissions occur when a neonate is born prematurely, has complications that require intensive nursing care, or is critically ill. Life-threatening illness and an unknown infant prognosis following a NICU admission are distressing to parents (Pinelli, 2000). The resulting increased risk for adverse outcomes or long-term illness is also of concern for parents (Lasiuk, Comeau, & Newburn-Cook, 2013). Parents are fearful that something may go wrong (Hawes, McGowan, O'Donnell, Tucker, & Vohr, 2016), or that they may ultimately lose their baby (Misund, Nerdrum, & Diseth, 2014). There are varying forms of psychological distress experienced by parents in the NICU such as depression, anxiety, acute stress, and/or posttraumatic stress. For example, postpartum depression (PPD) in mothers of infants hospitalized in the NICU is as high as 40% (Greene et al., 2015; Kim et al., 2015; McCabe et al., 2012) and posttraumatic stress disorder (PTSD) in fathers as high as 33% (Busse, Stromgren, Thorngate, & Thomas, 2013).

The available literature reveals a relationship between NICU hospitalization and parent psychological distress that is associated with several moderating variables like length of stay and birth weight (Al-Akour, Khassawneh, Mohammad Jaradat, & Khader, 2014; Bergström, Wallin, Thomson, & Flacking, 2012; De Magistris, Coni, Puddu, Zonza, & Fanos, 2010; Garfield et al., 2015; Hatters Friedman et al., 2013), as well as other factors associated with the medical fragility of a neonate. Although the relationship between a NICU hospitalization and parental psychological distress is established, there is no guideline or algorithm that informs assessment, psychological, or psychiatric treatment of parents who have infants hospitalized in the NICU (Shaw et al., 2014). In addition, statistics vary on the prevalence of parental psychological distress and its contributing factors, likely due to the different tools used to screen parents (Vasa et al., 2014).

Screening of parents of high risk infants for emotional distress is recommended, as is embedding mental health professionals in the NICU (Hall et al., 2015; Hynan, Mounts, & Vanderbilt, 2013; Hynan et al., 2015), but those strategies are not always translated to practice. The aim of this inquiry is to synthesize what is currently known about psychological distress in parents of infants hospitalized in the NICU and to analyze the results within the context of the Social Ecological Model (SEM) (McLeroy, Bibeau, Steckler, & Glanz, 1988; Stokols, 1996) in order to gain a greater understanding of the complexities associated with parents' mental health status during infant hospitalization and, thus, inform clinical practice.

There also is a need to understand the social determinants of parents' mental health and psychosocial well-being in the NICU in order to ensure their access to appropriate assistance and services (Braveman, Egerter, & Mockenhaupt, 2011). The SEM proposes that the combined influence of parent characteristics and environmental features interact to impact outcomes (Bronfenbrenner, 1994). This scoping review summarizes the existing research regarding the assessment and prevalence of parental psychological distress in mothers and fathers of NICU infants and addresses salient gaps in the literature by examining and analyzing the varying forms of psychological distress in parents of infants hospitalized in the NICU, and contributing factors, within the SEM framework. This is significant because parent psychological distress can lead to perinatal mood and anxiety disorders or other mental health impairments that, if left untreated in the postpartum period, can increase the risk for suicide or self-injury, infanticide, decreased parent-infant bonding and attachment, negative effects to the parent's romantic relationship, and negative effects on child development (Hynan et al., 2013; Johannsen et al., 2016; Kim et al., 2015; Manning, 2012; Parker, 2011; Penny, Friedman, & Halstead, 2015; Rogers, Kidokoro, Wallendorf, & Inder, 2013). Analysis of the results within the SEM will allow clinicians to examine the social determinants of mental health and psychosocial functioning of parents in the NICU, in order to develop appropriate interventions for the targeted level of the model.

Theoretical Framework

The SEM focuses on the environmental causes of behavior and environmental interventions for those behaviors (McLeroy et al., 1988). Stokols (1996) stated that "the environment can act as a stressor exerting detrimental effects on people's mood…as a result of their exposure to uncontrollable demands" (p. 284). In this case, the NICU is the environmental stressor, and the detrimental effects are mood and anxiety disorders in the mothers and fathers of pre-term, hospitalized infants. The five levels of analysis in the SEM framework include intrapersonal factors, interpersonal factors, institutional factors, community factors, and public policy (McLeroy et al., 1988). Intrapersonal factors are characteristics of the individual persons, in this case, the parents and the infant. Interpersonal processes, the second level in McLeroy's SEM, include social supports, specifically for parents of hospitalized infants in this context. Institutional factors that may contribute to parent psychological distress at the third level of the framework will be examined as results are analyzed, including the NICU microenvironment and the hospital environment, as discussed and described in the reviewed publications. Community factors may be local support groups and national advocacy organizations. The last level of the SEM is public policy, the domain containing social advocacy and national organizations that advocate and lobby for parental rights. Analysis of the literature within respective levels of the SEM framework will inform clinicians of the intra- and interpersonal effects parents may experience while their child is hospitalized, and how best to target interventions.

Methods

A scoping review is a type of study that provides information about the relevant literature in a field, and addresses the need for further exploratory research, including a full systematic review (Colquhoun et al., 2014; Grant & Booth, 2009). The scoping review allows for mapping of key concepts and visualization of the range of available literature (Arksey & O'Malley, 2005). The primary method of search and review is broad. Arksey and O'Malley (2005) suggested a framework that includes 6 stages: 1. Identify the research question, 2. Identify relevant studies, 3. Select studies, 4. Chart the data, 5. Collate, summarize and report the results, and 6. An optional consultation exercise (Arksey & O'Malley, 2005). Additional steps were appended afterward for clarification (Colquhoun et al., 2014; Levac, Colquhoun, & O'Brien, 2010). The scope of this review is limited to literature that quantifies and defines parent's mental health status through use of psychometric measurements and does not include the optional consultation with NICU-parent stakeholders.

The keywords "neonatal intensive care unit, NICU, anxiety, depression, distress, posttraumatic stress disorder, parents, mother, father, postpartum depression, coping skills, mental health, and psychosocial functioning" were searched with Boolean phrases in all the available EBSCOhost databases (235 results) (Table 1, Appendix A). A PubMed search of the terms neonatal intensive care units, parents, and anxiety using Boolean phrases yielded 161 results. That initial search was conducted in the fall of 2016. Studies were excluded if they were published prior to 2011; did not discuss the parental effects of a NICU hospitalization; focused on infant outcomes, breastfeeding, substance abuse, peer support, discharge from the hospital, critical illness, biomarkers, pregnancy, family centered care, policy, or the death of an infant; or were letters to the editor. Publications prior to 2011 were excluded because a systematic review written in 2010 examined the prevalence and risk factors for depression in postpartum women of low birth weight infants (Vigod, Villegas, Dennis, & Ross, 2010). This review includes studies that focus on other types of psychological distress; in addition to depression, studies that examine anxiety and posttraumatic stress are also included. Studies that include fathers in addition to mothers are also reviewed in this manuscript, as opposed to the analysis by Vigod et al. (2010), which examined depression in mothers only. The remaining articles were assessed for eligibility, and 26 manuscripts are charted, analyzed, synthesized, and discussed in this review. The flow of studies utilizing the PRISMA methodology (Moher, Liberati, Tetzlaff, & Altman, 2009) is illustrated in Figure 1 and summarized in Table 2 (Appendix A).

Results

Twenty-six studies formed the sample for this review. All studies are quantitative; the small number of qualitative studies found (n=5) led to their exclusion. One mixed-methods study is included. Of the remaining twenty-six quantitative studies, only one is a retrospective design, the others are all prospective, and nine of those are longitudinal, over varying timeframes. Nine studies are from the United States, eight are European, three each from Asia and Australia/New Zealand, two from the Middle East and one each from Canada and Africa. Many studies had similar results with common themes. Figure 2 depicts the factors of the NICU environment and the associated overlapping variables that cause parent psychological distress within the context of the SEM. Theoretical frameworks or conceptual models were not discussed in any of the studies that are included in the review, although many studies had similar results, which produced common interpretations. The themes that emerged from this scoping review were examined within the constructs of the SEM and categorized into and synthesized within the SEM levels of analysis (Figure 2).

Intrapersonal Level

Findings at the intrapersonal level of the SEM reflect key characteristics of the parents, including a previous history of mental illness, as well as infant characteristics such as weight at birth (Table 3). Hawes et al., (2016) found that women with a previous mental health diagnosis were 2-3 times more likely to have an Edinburgh Postnatal Depression Scale (EPDS) score ≥10 and to develop PPD. A history of mental illness, including depression, anxiety, and posttraumatic stress is associated with greater posttraumatic stress disorder and postpartum depression in NICU parents (Bergström et al., 2012; Garfield et al., 2015; Hawes et al., 2016; Helle et al., 2016; Vasa et al., 2014). Mental illness and mental health disorders include a history of substance misuse and depression or anxiety during or after a previous pregnancy (Helle et al., 2016; Vasa et al., 2014). Helle et al. (2015) posit men develop more active coping mechanisms, but that the rate of PPD in men is likely underestimated if the same cut-off for assessment (with the EPDS) is used for mothers and fathers, as the cut-off for men is generally lower.

Seven of the studies discussed birth trauma as a major contributor to parental distress (Table 4). The researchers found that having a child in the NICU causes parents to find it difficult to carry out normal parenting activities and roles (Alkozei, McMahon, & Lahav, 2014; Busse et al., 2013; Rogers et al., 2013; Woodward et al., 2014); parents found the hospitalization frustrating because it rendered them helpless (Goutaudier, Lopez, Séjourné, Denis, & Chabrol, 2011). Further, having a child prematurely "violates a mother's cognitive schema" (Greene et al., 2015, p. 369); the mental representation of what motherhood is expected to be is disrupted due to the truncating of the pregnancy and subsequent feelings of loss, grief, and anxiety (Woodward et al., 2014) associated with pre-term birth.

Low (<2500g), very low (<1500g), or extremely low (<1000g) birth weight of the infant have been shown to affect parental development of mood and anxiety disorders in several studies (Al-Akour et al., 2014; Chang et al., 2016; Greene et al., 2015; Helle et al., 2016; Ukpong, 2011). Gestational age at birth correlates with an increase in PPD and anxiety symptoms in mothers of infants hospitalized in the NICU (Al-Akour et al., 2014; Chang et al., 2016; Kong et al., 2013; Misund et al., 2014; Ukpong, 2011); however, one study did not find significant correlations between infant gestational age and scores on the psychometric tools utilized to assess parent psychological functioning (Busse et al., 2013). In three studies, prolonged mechanical ventilation significantly correlated with increased anxiety and stress levels (Al-Akour et al., 2014; Chang et al., 2016; Rogers et al., 2013). Most of the studies excluded parents of infants who had a terminal or congenital illness. Thus, this review does not include parents who may have increased psychological distress due to a life-limiting illness. Intrapersonal factors such as higher anxiety levels and depression are related to the extent of prematurity (Pace et al., 2016) and illness severity of the infant (Alkozei et al., 2014); birth weight, gestational age, and respiratory status are all indicators and determinants of NICU hospitalization and thus, are determinants of parents' mental health status.

Interpersonal Level

Cohabitation may determine parental mental health status. Not living with the child's father was found to be a risk factor for development of PPD in low-income women with very low birth weight infants and support from the baby's father was identified as a factor in mitigating risk of depression in one study (Garfield et al., 2015).

Alternatively, two studies found that marital status, specifically being married, was an indicator of increased maternal stress and higher levels of depressive symptoms (Alkozei et al., 2014; Rogers et al., 2013). The differences in the development of parental distress between men and women with respect to the NICU experience were discussed in several studies (Busse et al., 2013; Candelori, Trumello, Babore, Keren, & Romanelli, 2015; Helle et al., 2015; Pace et al., 2016). In the studies that included fathers, men were found to have lower scores on measures of anxiety and depression, but the lower scores often met the threshold for further screening for parent psychological distress. Hawes et al (2016) found that a decreased perception in family cohesion was associated with depression at 1-month post discharge, and Yaman & Altay (2015) found that nearly all the mothers and most fathers experienced symptoms of posttraumatic stress which, the authors speculated, could negatively affect family processes, such as parenting behaviors and child development (Table 4). Mothers and fathers are both at risk for development of psychological distress and impaired mental health, but their experiences are different. Interpersonal factors and processes include the relationship between the parents, the parents’ relationships with other friends and family, and the social support the parents accept and receive.

Institutional, Community and Public Policy Levels

Parenting behaviors and family processes may be affected by the NICU itself. Hospital rules and regulations can all contribute to parent psychological distress at to the SEM. The NICU as an environment contributing to parental distress was the overarching theme within the institutional domain, and several studies discussed nuances of the NICU environment specifically. In those studies, the emergent themes were the lack of information from NICU staff to parents, the inability to provide care to their child (Al-Akour et al., 2014; Goutaudier et al., 2011; Yaman & Altay, 2014), perceived negative attitudes of health care personnel (Kong et al., 2013; Yaman & Altay, 2014) and services received or recommended while their child was hospitalized in the NICU (Busse et al., 2013; Jubinville, Newburn-Cook, Hegadoren, & Lacaze-Masmonteil, 2012; Kong et al., 2013; Montirosso et al., 2014). Screening for parent psychological distress, such as depression, anxiety, acute stress disorder and/or posttraumatic stress disorder, while the infant is in the NICU was the ultimate recommendation of 2 studies. Screening of parents in the NICU is within the institutional, community, and public policy domains, and is the overall implication for nursing practice (Cherry et al., 2016; Shaw et al., 2014) (Table 5).

Discussion

The NICU environment is stressful for parents, and this stressor affects them at the individual, interpersonal, institutional, and community levels of the SEM. The SEM is a reciprocal model because variables and processes can cross domains and overlap. The intrapersonal characteristics of the parents can affect their interpersonal relationships with the other parent or family members, thus impacting the support they perceive or is given to them. In return, interpersonal relationships may affect the behavior or emotional status of the parent at the individual level. Relationships and interactions at the institutional level are also reciprocal. If families do not feel they are receiving enough information, or the right kind, they may become dissatisfied, angry, or upset at the situation. This can affect the parents at the intrapersonal and interpersonal levels, and it may also affect the relationship the parents have with the NICU staff, impairing communications with all parties. This exemplifies why this model is well applied as the theoretical framework for measuring parents' mental health. The interaction and interdependency between parents and their environment can determine parents' mental health status and psychological well-being (Stokols, 1996). Many aspects of the NICU hospitalization cross the domains of the SEM. Characteristics that are unique to the parent, and those unique to the infant fall within the intrapersonal level of analysis. Intrapersonal factors such as altered parenting role, history of mental illness, birth trauma, preterm birth, and parents' fear due to the critical illness of their child can affect the development of parent psychological distress. Parents' individual responses to stressors occurs at this level of the SEM.

The emergence of birth trauma as a theme was somewhat unexpected relative to parent psychological distress in the intrapersonal domain of the SEM. Birth trauma is defined as injury to the infant during delivery in medicine; yet for the purposes of this review, birth trauma is the alternative definition: a traumatic experience for the parent. Birth trauma is the subjective experience of the mother who gave birth; an "emotional rollercoaster" for parents and fears of what may go wrong (Hawes et al., 2016) and a traumatic event for families (Jubinville et al., 2012).

Altered parenting role is also affected by the Institutional level of this model, as the NICU is the primary reason for the altered role. Parents expect to be discharged with their child, yet because of one or several circumstances, their newborn must remain behind, hospitalized in the NICU. Parents are thus unable to perform normal parenting activities as they had expected or envisioned during the pregnancy. This concept is also related to the concept of pre-term birth, as the ultimate cause of the NICU hospitalization in many cases. Another of the most common themes to emerge is the correlation between birth weight, specifically low birth weight, earlier gestational age, and pre-term birth and/or its complications, thus identifying the infant characteristics that contribute primarily toto parental distress. Birth weight, gestational age, and mechanical ventilation are all infant characteristics or consequences that are seen in pre-term births. Pre-term birth and subsequent NICU hospitalization may also potentiate stress in couples, further contributing to parent psychological distress.

Unresolved parenting and spousal roles in the NICU may continue when the infant is discharged and contribute to stress, as can the limited communication parents may have with each other while they are in the NICU (Manning, 2012). Parents of children with cancer or other chronic conditions have been shown to be at greater risk of marriage or relationship termination, and the same may be inferred of NICU parents (Manning, 2012). While prevention of preterm birth is optimal, it is not always possible, so informing parents, and including them in their infant's care is imperative. Intrapersonal factors are the most numerous in the literature, thus requiring the development and administration of most interventions at this level. Continuing care for preexisting mental illness, counseling for birth trauma, and interventions aimed at assisting parents to cope with the stress of a NICU hospitalization may be effective at this level of the model.

The concepts of altered parenting role and birth trauma can cross into the interpersonal domain. The individual responses of the parents may be intrapersonal aspects of the model, but the effect of this deviation from what was expected may also affect interpersonal relationships. Family cohesion in the face of this adversity is a requirement, or the impact of the NICU hospitalization can negatively affect the family process and parenting of other children (Yaman & Altay, 2014). This occurs within the interpersonal domain of the SEM, and interpersonal relationships are important sources of influence in health-related behaviors (McLeroy et al., 1988). The experience of both parents is important to consider, yet the history and experience of fathers relative to pre-term birth or hospitalization of a child in the NICU is not often discussed in the literature. Gender differences, or the different experience and incidence of distress in fathers and mothers, is a concept that has been identified as a gap in the literature and in need of further research to provide information on the prevalence, type, and interventions for distress experienced by fathers of infants hospitalized in the NICU (Busse et al., 2013) thus impacting the interpersonal level of the SEM.

The NICU environment is the most impactful institutional factor; the rules and regulations of the NICU and hospital at large greatly influence the perception of families and their experience during their child's hospitalization. The staff of the NICU are an important aspect of the environment, and the way patients and their families are treated and how they are given information about their child's condition can add to the stress of the experience, if the parents do not feel adequate support from the nursing staff (Gueron-Sela, Atzaba-Poria, Meiri, & Marks, 2013; Kong et al., 2013). This overlaps with the interpersonal domain of the model; the development of a therapeutic relationship with the NICU staff rather than an adversarial one can change the NICU experience for parents. Screening for parent psychological distress is in the community and public policy level of the SEM, as is paid maternity leave, paternity leave, and family medical care leave. Shaw et. al (2014) noted that consensus guidelines for screening this high-risk population of NICU parents are absent, signifying a need at the community and public policy levels. Screening and intervention programs may be developed at the local NICU level and the health-system level, and such programs may be mandated or regulated through local and national legislation and/or clinical practice guidelines to improve parents' experiences and parental mental health outcomes in the neonatal intensive care unit.

Exemplars exist in various NICUs; many implement some type of screening program, some NICUs implement intervention programs to reduce depression in NICU mothers (Bernard et al., 2011; Horsch et al., 2015; Segre, Chuffo-Siewert, Brock, & O'Hara, 2013; Wu et al., 2007), while other NICU focus on empowering parents (B. Melnyk et al., 2001; B Melnyk, Crean, Feinstein, & Fairbanks, 2008; B. M. Melnyk et al., 2006), however, the literature did not reveal a routinization of screening or assessment protocols for parent psychological distress in the NICU.

The implications for practice are clarified by examining the effects of a NICU hospitalization on parents within the context of the SEM. Screening programs and the availability of mental health professionals are the first step in promoting the mental health and psychological well-being of parents. Consideration must be given to the intrapersonal characteristics of parents and their interpersonal relationships when assessing parents and planning interventions. The quality of interactions between parents and the NICU environment are also essential and may need to be examined and altered to improve parents' perceptions of their NICU experience. Clinicians are advised to implement family-centered, supportive initiatives that create a therapeutic environment in the NICU for parents.

Limitations

A limitation of this study is the one-person reviewer model. For the current study, publications focused on interventions for parents in the NICU; studies were excluded if they did not use a psychometric scale to measure distress (Figure 2). Restricting the review to publications written after 2010 may also constitute a limitation; the systematic review conducted in 2010 by Vigod, et al., focused solely on depression in mothers and, thus did not examine other types of parent psychological distress, or the other half of the parent dyad. Thus, the scope may not have been sufficient to identify all significant gaps in the literature and the areas of greatest need for further study. More than half of the studies in the review (n=16) occurred outside the United States, thus making it difficult to generalize the results to the U.S. population, due to the variations in hospital rules and restrictions across countries and cultures. Despite these limitations, the results of this review are instructive for psychiatric nurses caring for diverse populations in increasingly integrated settings.

Conclusion

Parent psychological distress is a cluster of symptoms, together or individually, that are exacerbated or caused by the hospitalization of one's child in the NICU and are mediated or moderated by factors that can be assessed within the framework of the SEM. This study identified several gaps in the literature and in practice. Both exploratory and experimental research are required to further this discussion and expand the treatment of parents with psychological distress secondary to the hospitalization of their child in the NICU. Several studies recommended the need for further research on the incidence, experience, and symptoms of fathers of infants hospitalized in the NICU, as well as interventions for those men. Overall, there is a scarcity of literature about the effects of a child's NICU stay on the father or other non-birth parents in scholarly publications. When fathers or non-birth parents of infants hospitalized in the NICU are properly identified and assessed, appropriate intervention strategies can be developed. Future research is needed to identify and measure the outcome of screening and interventions to lessen the incidence and severity of parent psychological distress symptoms, in particular, studies to determine the most precise measurement of parent psychological distress in the NICU. Future qualitative studies would add an increased understanding of the lived experience of NICU parents and give greater descriptive meaning to the quantitative data.

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Appendix A

Table 1. Results of search on EBSCOhost platform.

PsycINFO (73)	Academic Search Premier (37)	MEDLINE (35)	CINAHL Complete (27)	CINAHL Plus with Full Text (27)	Health Source: Nursing/Academic Edition (14)
Consumer Health Complete – EBSCOhost (7)	Psychology and Behavioral Sciences Collection (7)	Vocational and Career Collection (4)	Education Full Text (H.W. Wilson) (3)	Professional Development Collection (1)	Agricola (0)
Alt HealthWatch (0)	Newswires (0)	Applied Science & Technology Full Text (H.W. Wilson) (0)	Computer Source (0)	Criminal Justice Abstracts with Full Text (0)	eBook Collection (EBSCOhost) (0)
ERIC (0)	European Views of the Americas: 1493 to 1750 (0)	Fuente Académica (0)	Funk & Wagnalls New World Encyclopedia (0)	GreenFILE (0)	Health Source - Consumer Edition (0)
History Reference Center (0)	Library Literature & Information Science Index (H.W. Wilson) (0)	Library, Information Science & Technology Abstracts (0)	MAS Ultra - School Edition (0)	MasterFILE Premier (0)	Middle Search Plus (0)
Military & Government Collection (0)	Newspaper Source Plus (0)	Primary Search (0)	PsycARTICLES (0)	Regional Business News (0)	Religion and Philosophy Collection (0)
Science Reference Center (0)	Teacher Reference Center (0)	Web News (0)	AHFS Consumer Medication Information (0)	American Doctoral Dissertations, 1933 – 1955 (0)	eBook Academic Collection (EBSCOhost) (0)

Author, Date	Study Purpose	Setting	Sample Description, Size (n)	Study Design	Data Collection Methods	Primary Outcome Variables	Scale Used	SEM Levels Addressed	Key Points	Comments
Al-Akour, Khassawneh, Mohammad Jaradat & Khader, 2014	To assess the effect of admission of infants to NICU on the psychosocial functioning of mothers, and to compare those mothers to mothers of healthy neonates	3 hospitals in Jordan	n= 75 NICU mothers, n= 75 non-NICU mothers	Prospective cohort design	Self-report and demographic questionnaires	Anxiety and depression	EPDS, STAI	Intrapersonal Interpersonal Institutional	• Anxiety on STAI significantly higher in NICU-mother group. • EPDS showed no difference between groups	• Mothers of smaller, sicker infants have increased anxiety, but depression levels are the same
Alkozei, McMahon & Lahav, 2014	To examine whether maternal or infant characteristics can identify mothers at risk for increased stress upon admission to the NICU	open bay NICU in Boston	n= 85 between 25-34 GA	Prospective cohort design	Self-report and demographic questionnaires	Maternal stress and depression	EPDS, PSS: NICU	Intrapersonal Interpersonal Institutional	• 52% mothers reported elevated levels of overall stress • 38% displayed depressive symptoms	• Marital status (married) a significant indicator • Distance from hospital a significant indicator
Bergstrom, Wallin, Thompson & Flacking, 2012	To investigate the incidence of PPD among mothers of infants cared for in the NICU and factor related to PPD onset at 1 and 4 months' post-discharge	2 NICUs in Sweden between 9/04-6/05	n= 133, 123 returned survey	Longitudinal cohort design	Self-report and demographic questionnaires	Incidence of PPD	EPDS	Intrapersonal Interpersonal Institutional	• 60% increased risk for PPD development when not offered counseling	

Busse, Stromgren, Thorngate & Thomas, 2013	To examine the relationship of stress, anxiety, depression, fatigue, and sleep disruption among parents of infants in the NICU	32 bed level 3 NICU	n=30; 22 females, 8 males	Exploratory design	Self-report and demographic questionnaires	Anxiety, depression, fatigue, and sleep disruption	PSS: NICU, PROMIS	Intrapersonal Interpersonal Institutional	• PSS score correlated with anxiety, depression, and sleep disturbance • NICU sights and sounds had no correlation • Alteration of parental role correlated with all • Infant appearance correlated with all except fatigue	• There is an increased risk for PTSD in fathers • Patterns of stress differ • LOS had no correlation
Candelori, Trumello, Babore, Keren & Romanelli, 2015	To explore fathers' experience of premature birth during the hospitalization of their infants compared to mothers	Italy	n= 64	Consecutive couples in prospective cohort design	Tools administered by a psychologist 10 and 20 days after birth	Anxiety and depression	EPDS, CLIP, STAI	Intrapersonal Interpersonal	• Mothers showed higher levels of depression and anxiety than fathers	• Focus on fathers
Chang, et. al, 2016	To assess prevalence of and risk factors posttraumatic distress in mothers of preterm infants	Taiwan	n= 102	Cross-sectional, prospective design	Self-report and demographic questionnaires with help of research assistant face-to-face	Posttraumatic symptoms	IES, CES, MPI	Intrapersonal Interpersonal Institutional	• IES scores higher in mothers of VLBW infants, ventilators, pre-term birth complications and those with neuroticism	• Depression and post-traumatic stress strongly correlated

									and depression - Prevalence of PTS symptoms 25.5%	
Cherry, et. al, 2016	To describe the development of a PPD screening program for the NICU and assess implementation	Oklahoma	n= 385	Convenience sample, prospective design	Self-report and demographic questionnaires	Depression	PDSS	Institutional	- 36% screen positive for depression - Additional 30% required a mental health referral	- Focused on implementing a screening program in NICUs
Garfield, et. al, 2015	To determine the risk factors for PPD in low-income women with VLBW infants	2 urban hospitals in Chicago, low-income communities	n= 113	Cross-sectional design, part of larger RCT, convenience sample	Retrospective data review from larger study	PPD, decreased paternal support	PPQ, NBRS, STAI, CES	Intrapersonal Interpersonal Community	- 47% had increased PPD symptoms - 33% had increased PTS symptoms	- Found lower mother/baby interaction in those with distress, failure to thrive, poor infant outcomes - Excluded infants on vents- possible weakness of study
Goutaudier, Lopez, Sejourne, Denis, & Chabrol, 2011	To explore the experience, coping and psychosocial consequences of premature birth post-delivery	S. France	n= 27	Mixed methods	2 questionnaires and a semi-structured interview	Experience of premature birth	EPDS, IES	Intrapersonal	- 78% symptoms PPD and/or PTSD	- Focus is more on the qualitative themes than psychometric scores

Greene, et. al, 2015	To compare the course and determine the predictors of elevated symptoms of depression, anxiety, and perinatal specific posttraumatic stress in mothers of VLBW in NICU	57 bed level 4 NICU in Chicago	n= 69	Prospective, longitudinal, part of larger NIH study on HM	Questionnaires administered by trained study staff	Psychological distress	PPQ, STAI, CES, PSS: NICU, LEC	Intrapersonal Interpersonal Community	• 65.6% mothers met cutoff criteria in at least one domain of stress	• Focus on perinatal specific PTSD • Preterm birth violation of preconceived notions of pregnancy • Screen across NICU hospitalization
Hawes, McGowan, O'Donnell, Tucker & Vohr, 2016	To examine association of maternal mental health at d/c, and 1-month post d/c	Rhode Island	n= 734	Part of larger study	Chosen prospectively, abstracted, scales administered at or prior to d/c	PPD	EPDS, FIPRE	Intrapersonal Interpersonal	• Mothers with prior mental illness and experiencing negative perceptions of self and infant at discharge at risk for depression	• 20% EPDS > 10 • Only 9% had EPDS > 14
Helle, et. al, 2015	To examine VLBW as a risk factor for PPD	Germany	n= 111 preterm, n= 119 term	Cross section of larger longitudinal study, prospective cohort design	Parents given questionnaires 4-6 weeks after birth and interviewed (SCID) by clinician	PPD	EPDS, BDI, SCID	Intrapersonal Interpersonal Institutional	• Risk of PPD 4-18 times higher in mothers • Risk of depression 3-9 times higher in fathers	• Most relevant risk factor is birth weight, followed by female sex, lifetime psychiatric disorder and low social support

Jubinville, Newburn-Cook, Hegadoren, Lacaze-Masmonteil, 2012	To examine mother's responses to the experience of having a premature infant in the NICU and to determine ASD	level 3 tertiary NICU in Canada	n= 40	Prospective cohort design	7-10 days after birth and 1 month after birth	Acute stress disorder	ASD, SASRQ, EPDS, SNAP	Intrapersonal Interpersonal Institutional	• 43% report significant depression • ASD diagnosis in 28% mothers • More than 40% experienced dissociation	• Different outcome variable than other studies
Kim et. al, 2015	To understand how postpartum posttraumatic stress disorder symptoms in mothers of high risk infants progress and what factors predict PPTSD	NICU in S. Korea	n= 130 NICU, n= 53 control	Prospective longitudinal cohort design	Self-report and demographic questionnaires at infant developmental follow-up visits	Postpartum posttraumatic stress	EPDS, PPQ, STAI	Intrapersonal Interpersonal Institutional	• Depression and anxiety symptoms in NICU mothers with PTSD significantly higher than NICU mothers with no PTSD, and controls	• If infant first born, controlled for other factors, delayed onset of PTSD
Kong, et. al, 2012	To investigate the prevalence of anxiety and depression in parents of hospitalized neonates and analyze the relationship with other factors	China	n= 400 fathers, n= 200 mothers	Cross-section, convenience sample	Self-report and demographic questionnaires in first week of infant hospitalization	Anxiety and depression	SAS, SDS, SSRS, PSS	Intrapersonal Interpersonal Institutional	• 20% of fathers and 24% of mothers had symptoms anxiety • 30.8% fathers and 35% mothers had depressive symptoms • Both significantly higher than normal population	• Social support found to be low • Lower educational level had higher depression and anxiety • Parents not allowed into the NICU to touch child in China

Misund, Nerdrum & Diseth, 2014	To explore the degree of psychological distress, anxiety, and trauma related to stress reaction in mothers of preterm infants and predictors of mental health problems	Norway	n= 29	Exploratory cohort design	Data collection by interview and chart review, blinded to demographics	Anxiety, depression, posttraumatic stress	IES, STAI, GHQ	Intrapersonal Interpersonal Institutional	• 52% mothers had posttraumatic stress responses • 28% mothers had depression • 17% mothers had anxiety	• Planned C-section predicted low anxiety scores
Montirosso, et. al, 2014	To investigate the extent to which level of quality of developmental care effects maternal stress and depression	Italy, 25 NICU units	n= 178	Cross-section observational design	Part of multi-center longitudinal study, consecutive recruitment, self-report scales	Maternal stress and depression	EPDS, PSS: NICU	Intrapersonal Interpersonal Institutional	• 54.3% depression in preterm group • 31.1% depression in control	• Study relates conclusions to infant pain management • Higher quality of care does not seem to mitigate depression
Mulder, Carter, Frampton & Darlow, 2014(Mulder, Carter, Frampton, & Darlow, 2014)	To evaluate the psychological reaction in parents whose infants were admitted to a NICU over the first 2 years of life	NZ	n= 226, control= 94	Prospective 2-year follow-up, longitudinal cohort, randomized	Clinical interview and self-report questionnaires at baseline, 9mths, 2yrs	Anxiety and depression	EPDS, HADS	Intrapersonal Interpersonal Institutional Community	• NICU fathers and mothers had higher rates of probable anxiety based on HADS at baseline • No significant differences with control at 9mths and 2 yrs.	• NICU parents more likely to have used antidepressants • Correlation b/w maternal psychological distress and infant scores on MDI • Authors feel that there is no difference in psychological distress after 2 years and parents should not "pathologized."

Northrup, Evans & Stotts, 2013(Northrup, Wootton, Evans, & Stotts, 2013)	To investigate potential associations between maternal characteristics, depression, and infant health conditions	Texas	n= 114	Cross sectional prospective cohort design	Self-report and demographic questionnaires	Depression	CES	Intrapersonal Interpersonal Institutional	• Depression rates b/w 20-50%	• Focused on those with infants who had serious health disorder and ELBW
Pace, et.al, 2016	To describe the trajectory and predictors of distress in parents of very preterm infants during the first 12 week after birth	Australia	n=113 mothers, n= 101 fathers; control 117 mothers, 110 fathers	Longitudinal, prospective follow-up cohort design	Self-report questionnaire every 2 weeks	Anxiety and depression	CES, HADS	Intrapersonal Interpersonal Institutional	• Rates of depression and anxiety in both parents 40-51% and never dropped below 20%	• Mean score and rates reduced over time in 12 weeks • Compared to control there were higher rates of depression
Rogers, Kidokoro, Wallendorf & Inder, 2013	To investigate whether demographics, maternal psychosocial and infant factors identified mothers of preterm infants at risk for PPD or anxiety at time of discharge	St. Louis, urban level 3 NICU	n= 73	Prospective cohort design	Self-report, demographic, and discharge questionnaires	Anxiety and depression	EPDS, STAI	Intrapersonal Interpersonal Institutional Community	• 20% mothers had clinically significant levels of depression • 43% mothers had moderate to severe anxiety	• Being married, parental role alteration and prolonged ventilation associated with increased depressive symptoms
Shaw, et. al, 2014	To identify potential risk factors associated with symptoms of depression, anxiety, and PTS	CA	n= 135	Prospective convenience sample	Data obtained from recruitment and screening for RCT	Anxiety, depression, stress	BDI, BAI, SASRQ	Intrapersonal Interpersonal Institutional Community	• 77.8% mothers screened positive on at least 1 measure	• Maternal sociodemographic characteristics were not useful in differentiating those who screened

										positive from negative
Ukpong, 2011	To investigate risk factors associated with psychological morbidity in mothers of preterm infants	Nigeria	n= 57	Cross-sectional, prospective design	Self-report and demographic questionnaires	Psychological distress	HADS, GHQ	Intrapersonal Interpersonal Community	• 36.8% mothers showed psychological distress • 19.3% mothers had depression • 12.3% mothers had anxiety	• Birth weight and GA predictors of psychological distress
Vasa, et. al, 2015	To assess the incidence, risk factors and management strategies for PPD in mothers of NICU infants	Chicago	n= 131	Prospective cohort design	Self-report and demographic questionnaires and urine drug screen	Depression	EPDS	Intrapersonal Interpersonal Institutional	• 19.1% at risk for depression	• PPD significantly increased in those who report substance abuse • History of depression and problems with pregnancy significantly associated with PPD, as is LOS
Woodward, et. al, 2014	To examine sources, predictors and child outcomes associated with NICU-related stress for mothers of very preterm infants	NZ, level 3 NICU	n= 133	Prospective, longitudinal cohort design	Self-report and demographic questionnaires interview by trained researcher	Maternal stress	EPDS, PSS: NICU, MBS, SRSS, EISI,	Intrapersonal Interpersonal Institutional	• Highest score in PSS in loss of role and infant appearance	• Perceived loss of parental role and being separated from infant are biggest stressors

Yaman & Altay, 2015	To examine PTS of parents in the NICU and differences b/w their stressors, the factors that affect PTS and parental experiences	Turkey, 2 NICUs	n= 66 sets of parents	Descriptive design	Self-report and demographic questionnaires	Posttraumatic stress	IES	Intrapersonal Interpersonal Institutional	• 81.8% of mothers and 66.7% fathers experience PTS	• sociodemographic factors had no bearing on PTS • Study did uncover common problems experienced by parents with NICU environment

Key for Table 2: **ASD**-Acute Stress Disorder; **BAI**-Beck Anxiety Inventory; **BDI**-Beck Depression Inventory; **CASP**-Critical Appraisal Skills Programme; **CES-D**-Center for Epidemiologic Studies Depression Scale; **CLIP**-Clinical Interview for Parents of High Risk Infants; **EIS**-The Elley and Irving Socioeconomic Index; **EPDS**-Edinburgh Postnatal Depression Scale; **FIPRE**-Fragile Infant Parent Readiness Evaluation; **GHQ**-General Health Questionnaire; **HADS**-Hospital Anxiety and Depression Scale; **HM**-human mil; **IES**-Impact of Events Scale; **LEC**-Life Events Checklist; **MBS**-Mother and Baby Scale; **MMAT**-Mixed Methods Appraisal Tool, **MPI**-Maudsley Personality Inventory; **NBRS**-Neurobiologic Risk Score; **NICU**-neonatal intensive care unit; **NIH**-National Institutes of Health; **PDSS**-Postpartum Depression Screening Scale; **PPD**-postpartum depression; **PPQ**-Perinatal Posttraumatic Stress Questionnaire; **PROMIS**-Patient Reported Outcomes Measurement Information System; **PSS**-Perceived Stress Scale; **PSS: NICU**-Parental Stressor Scale: NICU; **PTS**-posttraumatic stress; **PTSD**-posttraumatic stress disorder; **RCT**-randomized control trial; **SAS**-Zung Self-Rating Anxiety Scale; **SASRQ**-Stanford Acute Stress Reaction Questionnaire; **SCID**- Structured Clinical interview for Diagnostic and Statistical Manual of Mental Disorders, IV; **SDS**-Zung Self-Rating Depression Scale; **SNAP**-Score of Neonatal Acute Physiology; **SRRS**-Social Readjustment Rating Scale; **SSRS**-Social Support Rating Scale; **STAI**-State Trait Anxiety Inventory

Table 2. Table of Evidence depicting the manuscripts systematically reviewed.

Table 3. Intrapersonal Factors Associated with Parental Distress in the NICU.

Theme of Results	Publication
h/o mental illness	Bergstrom, Wallin, Thompson & Flacking, 2012
	Garfield, et. al, 2015
	Hawes, McGowan, O'Donnell, Tucker & Vohr, 2016
	Helle, et. al, 2015
	Vasa, et. al, 2015
birth weight (BW, LBW, VLBW, ELBW)	Al-Akour, Khassawneh, Mohammad Jaradat & Khader, 2014
	Chang, et. al, 2016
	Greene, et. al, 2015
	Helle, et. al, 2015
	Ukpong, 2011
gestational age (GA)	Al-Akour, Khassawneh, Mohammad Jaradat & Khader, 2014
	Chang, et. al, 2016 (not statistically significant)
	Misund, Nerdrum & Diseth, 2014
	Ukpong, 2011
mechanical ventilation (MV)	Al-Akour, Khassawneh, Mohammad Jaradat & Khader, 2014
	Chang, et. al, 2016 (not statistically significant)
	Rogers, Kidokoro, Wallendorf & Inder, 2013

birth trauma	Alkozei, McMahon & Lahav, 2014
	Goutaudier, Lopez, Sejourne, Denis, & Chabrol, 2011
	Greene, et. al, 2015
	Hawes, McGowan, O'Donnell, Tucker & Vohr, 2016
	Jubinville, Newburn-Cook, Hegadoren, Lacaze-Masmonteil, 2012
	Kim et. al, 2015
	Woodward, et. al, 2014
pre-term birth related	Bergstrom, Wallin, Thompson & Flacking, 2012
	Chang, et. al, 2016
	Hawes, McGowan, O'Donnell, Tucker & Vohr, 2016
	Pace, et.al, 2016
	Rogers, Kidokoro, Wallendorf & Inder, 2013
altered parenting role	Alkozei, McMahon & Lahav, 2014
	Busse, Stromgren, Thorngate & Thomas, 2013
	Rogers, Kidokoro, Wallendorf & Inder, 2013
	Woodward, et. al, 2014

Table 4.
Interpersonal Factors Associated with Parental Distress in the NICU.

Theme of Results	Publication
marital status	Alkozei, McMahon & Lahav, 2014
	Rogers, Kidokoro, Wallendorf & Inder, 2913
gender differences	Busse, Stromgren, Thorngate & Thomas, 2013
	Candelori, Trumello, Babore, Keren & Romanelli, 2015
	Helle, et. al, 2015
	Pace, et.al, 2016
family cohesion	Yaman & Altay, 2015

Table 5.
Institutional, Community and Policy Factors associated with Parental Distress in the NICU.

SEM domain	Theme	Publication
Institutional	NICU environment	Al-Akour, Khassawneh, Mohammad Jaradat & Khader, 2014
		Busse, Stromgren, Thorngate & Thomas, 2013
		Goutaudier, Lopez, Sejourne, Denis, & Chabrol, 2011

		Jubinville, Newburn-Cook, Hegadoren, Lacaze-Masmonteil, 2012
		Montirosso, et. al, 2014
		Yaman & Altay, 2015
	NICU staff	Kong, et. al, 2012
		Yaman & Altay, 2015
Community and Public Policy (Level 4 & Level 5)	Screening for parental distress	Cherry, et. al, 2016
		Shaw, et. al, 2014

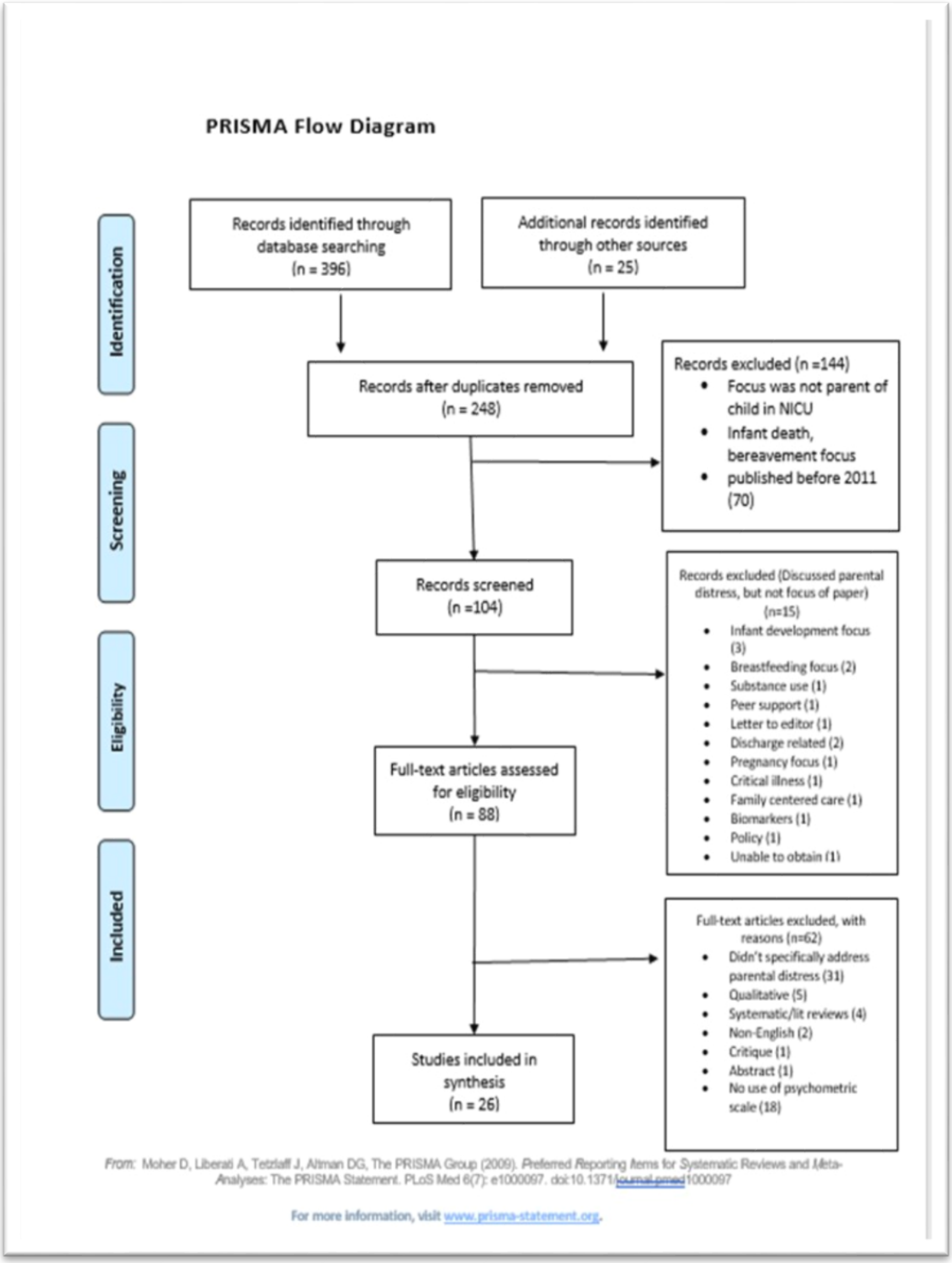
*Mulder et.al., 2014 showed no significant relationship with a NICU admission and parental distress within 2 years

**Distance to NICU, infant length of stay and separation from infant were only themes in one publication each, respectively

Figure 1. Results

Within
SEM

Figure 2.
Flow of
studies



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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The experiences of parents in the neonatal intensive care unit: An integrative review of qualitative studies within the transactional model of stress and coping

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Abstract

Introduction: Having a child hospitalized in the neonatal intensive care unit (NICU) is a deviation from the norms expected for pregnancy and childbirth. A NICU admission may be traumatic for some parents, causing psychological distress, and altered parenting roles. The aim of this integrative review is to examine the experiences and perceptions of a NICU hospitalization from the perspective of both parents to improve practices related to family support and future research.

Methods: A systematic search of 3 databases was conducted and included studies were evaluated by the Critical Skills Appraisal Programme (CASP) checklist for qualitative studies. The Whittemore and Knafl integrative review methodology (2005) and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) methodology were followed to provide a structure for searching and reporting findings.

Results: There were 248 participants (153 mothers and 95 fathers) from 9 countries and of varying socioeconomic backgrounds in the 16 primary qualitative studies included in this review. The resulting major themes included panic sequence, emotional upheaval, social support, faith, and adjusting.

Conclusion: Interventions directed at managing parents' emotions, supporting their spiritual needs, facilitating parenting skills and infant attachment, and adapting the environment to parents' needs can help to improve the NICU experience.

Keywords: neonatal intensive care unit, parents, experiences, qualitative

THE EXPERIENCES OF PARENTS IN THE NEONATAL INTENSIVE CARE UNIT: AN INTEGRATIVE REVIEW OF QUALITATIVE STUDIES

Introduction

The cause of health inequalities is not always clear[1]. Social and psychological circumstances can cause long-term stress, increase the chances of poor mental health, and even lead to premature death[2]. The hospitalization of one's child in the neonatal intensive care unit, for example, is a stressful experience for parents and it is critical to understand those experiences. NICU admissions occur when a neonate is born prematurely, has complications that require intensive nursing care, or is critically ill. Babies who survive prematurity or neonatal illness often face chronic health problems, and developmental or intellectual delays. Having a child hospitalized in the NICU is an aberration from the norms expected for pregnancy and childbirth[3-5]; parents generally have the hope of a healthy pregnancy and leaving the hospital with their new baby. When this is not the case, a NICU hospitalization may be traumatic for some parents, causing psychological distress, and altered parenting roles.[5-8]

Parents in the NICU are at increased risk for depression, anxiety, acute stress, and/or posttraumatic stress, each of which can be lasting and have negative impacts on the relationship between the parents, the ability to bond with and nurture their child, and child development.[6, 8-13] Mothers in the NICU have been found to have up to a 40% rate of postpartum depression[9-11] compared to 11.5% in the general population.[12] Fathers in the NICU are also at risk for depression, and one study found they had a 33% risk of posttraumatic stress disorder.[7] There are many studies examining and measuring the mental health and psychosocial status of NICU parents using psychometric instruments.[9,13-25] Several studies explore the experiences of mothers or fathers in the NICU individually,[26-32] but there is limited research describing the personal experiences of a NICU hospitalization for the parent dyad, and their specific needs as a couple in the context of their ability to cope with stress. Examination of the differing experiences that parents in a dyad experience may lead to a better understanding of their needs, both shared and individual. It is also necessary to understand the social determinants of parents' mental health and psychosocial well-being during their time spent in the NICU in order to assure their access to appropriate assistance and services.[2]

Stress alone is a social determinant of health; mounting stress from trying to cope with hardships, or availability of resources may have physiologic consequences. There may be disparities in care among NICU parents; access to mental health care is challenging in any situation, and more so for parents in the NICU. Social determinants of health and the socioeconomic status of parents may cause visiting their child to be difficult, and the parents themselves may be treated differently depending on their background or gender identity. The accumulated strain from trying to cope with a demanding circumstance or having inadequate daily resources can have lasting physiologic consequences to parents.[33]

There is no current national standard of care for psychological distress screening of parents who have infants hospitalized in the NICU, or for offering any type of treatment.[34] Access to mental health care may be limited; programs and policies that affect the health care choices available to parents can either constrain or enable parents' mental health,[33] especially among low income populations.[35] This is significant, as parent psychological distress related to a NICU hospitalization may lead to decreased bonding and attachment with the infant, negative effects on the parents' relationship, and a negative impact on child development.[8,10,25,36-39] In general, the literature revealed a deficit in examining the relationship between parental distress and a NICU hospitalization in fathers and non-birth mothers.

The aim of this integrative review is to synthesize qualitative evidence examining the experiences and perceptions of a NICU hospitalization from the perspective of both parents in the parental dyad and their coping mechanisms, through the lens of transactional stress and coping. Learning about both parents' experiences in the NICU can inform clinicians and assist in identifying disparities in care that may not be evident to neonatal providers. Ultimately, this can provide a focus for future work in this population, and lead to an increase in care accessibility for parents in the NICU. This review will elucidate the perceptions of parents about the NICU experience and the coping strategies, adaptive or maladaptive, they utilize. Effective coping strategies can strengthen parents' abilities to make healthy choices[33] for themselves and their infant, in the long-term.

Methods

The Whittemore and Knafl methodology (2005) guided this review, beginning with identification of the problem, then flowing through the stages of systematic search of the literature, data evaluation for inclusion or exclusion in the review, data analysis for patterns and common themes, and presentation of the findings in the form of conclusions and tabular depictions.[40] The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) methodology[41] provided a structure for searching and reporting findings. The transactional theory of stress and coping,[42-44] originally published by Lazarus and Folkman in 1984,[45] provides the structure for this integrative review and subsequent organization, analysis, and synthesis of the results. It is a cognitive theory of the person-environment relationship in the context of the stress response[42] (Figure 1).

A search of the literature regarding the experiences of parents in the NICU, as reported in qualitative studies, occurred in the last quarter of 2017. Keywords for parents, NICU, experiences, and various qualitative methods were searched in three databases: CINAHL (n=250), PsychInfo (n=170), and PubMed (n=222). Sixty-five articles were identified for abstract and/or full text review. Studies that focused on only one parent (the mother ***or*** the father) were excluded, leaving 16 studies that met the final inclusion criteria, as depicted in Figure 2, and described in Table 1. The included studies were evaluated by assessing the quality of the methods, recruitment strategy, data collection and analysis, ethical considerations, and findings as per the Critical Skills Appraisal Programme (CASP)[46] checklist for qualitative studies. Data were analyzed within the framework of the Transactional Model of Stress and Coping[47] and analyzed using the Whittemore and Knafl[40] integrative review method of constant comparison during data extraction and coding. Data reduction was accomplished by organizing identified themes from the results of each publication within the Transactional Model of Stress and Coping, and by grouping the emergent themes from the second and third level of coding, as presented in Table 2.

Results

There were 248 participants (153 mothers and 95 fathers) in the 16 primary qualitative studies included in this review (Table 1) that examined the experience of parents who had infants hospitalized in the NICU. Studies used a variety of qualitative methodologies in several differing populations; four studies occurred in the United States,[48-51] three studies occurred in Canada,[50,52-54] three studies occurred in the Middle East/Asia,[55-57] three studies were conducted in Australia,[58-60] and three studies occurred in Europe.[61-63] The ages of parents included in the studies ranged from 19-45 years old and the sample included parents of wide-ranging educational levels, employment status, income, and distance to travel to the NICU. The infants hospitalized in the NICU in this sample had differing gestational ages and birth weights. The qualitative methodologies used varied among the studies; four studies used phenomenology,[55,56,58,59] one study used narrative inquiry,[48] two studies specified use of the interpretive descriptive design,[52,53] two studies designated “exploratory” as the qualitative design,[54,60] and two studies designated “descriptive” as the design.[51,57] The remainder of the studies did not specify the qualitative methodology used, and rather discussed the use of interviews as the qualitative method.[49,50,61-63]

Although all studies explored the experiences of both parents, not all reported the differences or similarities between them. There were commonalities to mothers' and fathers' experiences: the mixed emotions and conflicting feelings of parents in the NICU are similar.[57] Some couples in one study felt as though they were now more attuned to their partner's feelings and their relationship had matured[48] despite the new reality of the NICU and the uncertainty they had. When mothers were too vulnerable to participate in care, fathers took on more responsibility and vice versa.[61] The differences between mothers' and fathers' experiences were apparent immediately after birth; fathers experienced additional stress when having to choose between going with their child to the NICU or staying with the mother of their child after a traumatic birth.[52] Fathers also were found to be more engaged in the infant's care in the initial hours and days after birth, due to the mother's recovery.[62] On the other hand, mothers spoke more about the birth experience, and expressed more concern about their infant's health status.[62] Two studies found that mothers indicated their greatest source of support throughout the experience was her husband or the father of the infant,[49,57] which is the opposite of the results obtained in previous studies that found marriage to be an additional stressor and risk factor for depression.[6,8]

Only one study described use of a theoretical framework to guide the development of interview questions and analysis of emergent themes.[51] The themes that emerged from this data analysis are reported below within the context of the Transactional Stress and Coping Model (Table 2).

Cognitive Appraisal

Primary Appraisal

Primary appraisal focuses on how a person perceives an event, and whether they found it to be irrelevant, benign, or stressful.[47] If an event was stressful, as is the case with a NICU hospitalization, parents then appraised the situation as harmful, a threat, or a challenge. This appraisal happened almost immediately during their emotional experience,[47] and two major themes were identified.

Panic Sequence. Panic sequence is the shock, worry, and anxiety parents perceived immediately after the admission of their child to the NICU. The infants' status and prognosis were identified as factors in two studies, as part of primary appraisal and the perceived susceptibility of risk and worry about harm to a loved one.[52,63] The well-being of the infant impacted parents and manifested in initial reactions of shock,[55] worry,[55] and anxiety.[51,55,56] Shock, worry, and anxiety were identified as symptoms or antecedents of panic. Concern for the infant was an identified subtheme of the major theme of panic sequence, within the process of primary appraisal for NICU parents.

Violated Cognitive Schema. The violated cognitive schema, defined as a diversion from the expected experience of childbirth and becoming a parent, was the primary theme to emerge in four studies.[50,52,53,62] Departure from normal expectations was a subtheme in which the shock of the environment, the technology and accompanying sounds of the NICU, and the appearance of their infant confronted parents. The NICU was an overwhelming foreign environment, and not the location parents expected to begin their parenting journey. Primary appraisal of the NICU environment was described as “culture shock”[53] and a “surreal experience”[52,61] for parents in which “expectations had been shattered.”[52] Many parents experienced premature labor that was described as traumatic, and faced helplessness and horror[51,52] at the situation and how their baby looked. Parental vulnerabilities, such as helplessness and stress[50,55,57] were identified as a second subtheme of the violated cognitive schema. Parents had to face the unexpected,[62] and quickly experienced the resulting emotional reactions to their situation and utilized secondary appraisal.

Secondary Appraisal

Secondary appraisal is the second type of cognitive appraisal process and was dependent on the parents’ available coping skills and perception of control over the situation or outcomes. When parents determined the NICU hospitalization of their infant as a harm or a threat, they began to make judgments about the outcomes based on their initial appraisal. One major theme emerged in the analysis of secondary appraisal factors within the included studies.

Emotional Upheaval. Within the process of secondary appraisal, the major theme to emerge was emotional upheaval.[50,52,55-57,61-63] Emotional assessment was identified as the first subtheme in this process. Because of the NICU hospitalization of their child, parents had to consider how to manage the situation, and how they would cope with the hospitalization. Parents had to assess their existing coping skills, and whether they were able to manage the situation and their emotional reactions effectively. Parents described the NICU experience as a "rollercoaster of emotions"[63] that was chaotic and changed as the prognosis of the infant changed.[57,61-63] Mixed emotions was the second subtheme identified. As parents appraised their situation for the first time after the traumatic birth of their child, they did not know how to feel. The appearance of their infant was sometimes shocking,[52,63] and parents described feelings of guilt, blame, and inadequacy.[52,57] As a result of this complex evaluative process[47] two additional subthemes were identified: negative feelings and positive feelings. Parents described negative feelings of sadness,[51,55] fear,[50,51,57,62] and loss and grief, both anticipated and actual,[56] in addition to somatic complaints.[55,63] Conversely, three studies discussed the subtheme of positive feelings, or happiness and joy at the miracle of the infant's survival;[50,57,62] parents still felt happiness and joy at the birth of their child, and had to reckon with these conflicting emotions. Combined with shattered expectations of what becoming a parent would be like, parents had to reconcile their feelings of guilt and blame[52] and their mixed emotions in order to cope with the hospitalization of their child.

Coping

Coping is the next progression in the model and is defined by Lazarus and Folkman as a constantly changing process to manage specific demands that are perceived as stressful and exceeding the resources of the person.[47] Coping is categorized in the model as emotion-focused or problem-focused.

Emotion-Focused Coping

Emotion-focused coping is directed at regulating emotional responses to problems, and is more likely to be utilized when cognitive appraisal determines little can be done to change the stressful situation.[47] Two major themes were identified in this process: Regulating Emotions, and Social Support.

Regulating Emotions. Beyond the conflicting emotions of shock,[55] worry,[55] anxiety,[51,55,56] stress,[50,55,57] sadness,[51,55] and fear,[50,51,57,62] the balancing or managing of those emotions was a key component of emotion-focused coping strategies that emanated from cognitive appraisal. Balancing emotions is how parents moved along the continuum from feelings of hopelessness to hopefulness[52] and learned to manage their anxiety and fear. Parents used optimism[50,58] as an emotional coping tool. Parents in one study stated they wanted to remain positive although they were aware that their child could die.[50] Similarly, parents tried to avoid thinking about the experience while they were going through the hospitalization and thought of it as "stoic survival,"[58] an escape avoidance strategy. Avoidant coping was an emotion-focused coping strategy identified in another study as "getting away from the NICU"[49] in which parents found time away from the stressors of the NICU environment was necessary to decompress and manage their emotions. Parents' abilities to cope and manage their conflicting emotions also affected how they reappraised their experience in the NICU.[60,64,65]

Social Support. Relationships in the NICU were identified as an aspect of emotion-focused coping. Social supports and relationships in the NICU, especially those with other parents of the infants hospitalized in the NICU, was identified as a theme within five studies in this domain.[49,53,57,63] The ability to share experiences and have empathy for other parents in a similar situation was a strategy parents in the NICU identified as significant, as it allowed them to manage their feelings by talking to others who understood what they were going through.

Problem-Focused Coping

Problem-focused coping is pragmatic and objective and is directed at defining the problem and finding solutions.[47] Although there was little parents could do to change the circumstances of their child's hospitalization, parents employed faith and spirituality through strengthened religious and spiritual beliefs[48], and learned to manage the NICU environment with problem-focused coping strategies.

Faith and Spirituality. Parents perceived a lack of control over their circumstances while living in prolonged uncertainty,[52] but for those with minimal to strong religious beliefs[48] they found faith to be an option for coping with those circumstances that were beyond their control.[48,50,54,57] Spirituality was identified in five studies as a problem-focused coping strategy for NICU parents.[48,50,51,54,57] Parents in the NICU came to a gradual understanding of the level of care their child required, and in some cases, relied on faith to guide their emotional management of the situation.[48,50,51,54,57] Faith was the lens through which some parents viewed their circumstances and was a coping mechanism to help them through the NICU experience and maintain an optimistic outlook for their infant's prognosis, or to rationalize their infant's precarious condition.

Managing the NICU. The most frequently employed problem-focused coping mechanism in this review was the management of the NICU experience by parents. Parenting in the NICU includes the need for information, communication, and positive relationships with NICU staff, as identified in four studies.[49,50,54,56] The subthemes identified in this major theme were communication, learning to parent, and the NICU as an environment.

Communication, or an increased need for contact with NICU staff and information about the health and prognosis of their child, became an imperative for parents.[49,53-57,60,63] It was thematic in more than half the studies included in this review; nine studies cited exchange of information with NICU providers, or the NICU environment, as factors in parents' coping abilities.[49,53-57,60,63] Many parents felt unprepared for a NICU hospitalization and the accompanying prolonged uncertainty.[52,61] Concern for their child's prognosis[63] and fears and uncertainty about decision making[50,53] made information-gathering and evaluating an important coping mechanism.

Learning to parent was accomplished by participating in the in their child's care,[49,56,57,59,63] which allowed parents to feel useful,[59] bond with their child[61] and foster attachment,[60] and to find some normalcy in an otherwise foreign environment and circumstances for parents. Learning to bond with and care for their infant[50,51,53,59,61] in the NICU environment were all factors that impacted the parents' perceptions of control over the situation or their emotions.

The NICU environment had an impact on parent's coping. When parents were met with unit restrictions or prevented from seeing their infant by the NICU staff,[56] or because of their own time and distance constraints,[52] confrontational problem-focused coping was utilized by the parents to reconcile dissatisfaction with their NICU experience. A source of frustration for parents was not being able to see or hold their child; parents felt that even if they couldn't go into their infant's room because a procedure was being done, they should be able to see what is going on through the glass.[56] In cases where that is the practice, parents still felt that communication could be improved between them and the nursing staff- one parent described the nurses using only hand signals to communicate with them through the window, rather than speaking to them.[55] In other instances, parents felt as if they were following the NICU rules, yet staff are still in control of their infant's care and they are not permitted to hold their infant or care for them as they have learned to.[59]

Adaptation

Eight studies had themes that could be examined within the construct of adaptation, defined as resolution to the crisis. In this case, resolution is adjustment to the NICU environment, and acceptance of the circumstances of their child's birth.[64]

Adjusting. The theme of adjusting includes adapting from helplessness to hopefulness, and from dissatisfaction with the NICU experience to satisfaction.[55] It also includes learning to manage grief reactions[56] and uncertainty,[52,61,63] and accepting a new reality.[53,58,62] Parents who were able to adapt successfully discussed a gradual understanding of the NICU, and their role in treatment, their infant's prognosis,[58] finding a way forward,[57] striving for normal,[58] and adjusting to their infant's fragile progress,[60] and ultimately going home.

Discussion

The aim of this integrative review is to synthesize qualitative evidence examining the experiences and perceptions of a NICU hospitalization from the perspective of both parents in the parental dyad, in addition to their chosen coping mechanisms, and to identify barriers to psychosocial care for the parents. An integrative review of qualitative studies provides more profound evidence for advocacy efforts by providing context and data that is difficult to ignore.[66] Four main themes emerged from the extraction and analysis of the data that were codified within the Transactional Model of Stress and Coping. A NICU hospitalization of one's child is the stressor, the antecedent of the processes of the theoretical model, in each study. Most of the studies focus on the first and second processes of the model, cognitive appraisal, and coping, rather than the last process of adaptation.

Coping and adaptation require mental health; interventions must be offered and adapted to the culture and environment where the stressor is occurring- the NICU. It also requires access to mental health care; such factors as insurance issues, stigma, lack of insight into the self-care and mental health of parents in the NICU must be considered. Additional stressors such as the competing demands of other children, employment, spouse/partners/co-parents, housing and the distance of the parent's home from the NICU, and the distinct issue that mental health services are often offered in a different location than where the NICU is physically located may be barriers to mental health for some parents. .[67]

Due to the uncertainty of an infant's prognosis in the NICU, and the roller coaster of emotions parents often describe as they live in a state of heightened emotional arousal, parents can potentially reappraise their circumstances as worse than it was earlier in the NICU hospitalization and exacerbate their emotional distress.[47] As their infant's health status changes during the admission, parents may reappraise their circumstances as worse than they were when the infant was first admitted to the NICU, or even worse than they truly are. Despite this, the coping strategies of parents was the focus of only three studies.[61,68,69] Extensive recommendations have been made by a national consensus panel that outline the care parents should receive in the NICU[22,24], but the question remains, how have those recommendations been translated into practice? Practice guidelines recommend screening mothers for postpartum depression at pediatrician appointments[67], but what of the parents who spend the first weeks and months of their child's life in the NICU who are not going to outpatient pediatrician appointments or of the other parent(s) that cares for the child? In many cases, they are not being screened at all.

Faith is a prominent theme in this review yet discussion of hospital chaplains are only briefly mentioned in one study that asserted chaplains are not always educated to deal with the psychological distresses that blend with faith-based concerns and questions.[48] That study recommended addressing the religious and spiritual needs of families in the NICU. The other unmet needs of parents, including restrictions on visiting and lack of meaningful communication with NICU staff, was identified as a deficit in care provided by the NICU staff, and a dissatisfier for parents.[56] The outcome of a NICU hospitalization, and the way in which parents manage their emotions is not always positive. Psychological trauma due to the violated cognitive schema of parents and the deviation from the norms expected of pregnancy, is not an adaptive response to a NICU hospitalization. Depression, anxiety, and posttraumatic stress can be lasting and have negative impacts on the parents' relationships and their ability to bond with and parent their child, as described in the quantitative literature.[6,7,70] Yet, the results of the sixteen studies in this review paint a more positive picture of adaptation for all the study participants. This is in line with the premise of Lazarus and Folkman that people want to know what is occurring and what it means for them, but also tend to put a positive light on most situations.[47]

Both mothers and fathers have been found to have a decrease in family functioning and scores on standardized scales that indicate depression,[71] yet fathers remain underrepresented, comprising only 38% of study participants in this sample. In a qualitative study focusing solely on fathers it was noted that they had difficulty verbalizing the parenting role beside the mothers of the infant and with healthcare providers, especially within the medical environment[72]. Another qualitative study focusing on fathers quoted a participant stating "…the doctors should talk with the fathers…they [the fathers] are giving support to the mothers but nobody is giving them support…and the fathers are not supposed to cry…"[73p e220] In general, although all the sample studies included mothers and fathers as participants, there was little comparison of the differing experiences of these two groups and the effect of a NICU hospitalization on the parents' relationships and their subsequent ability to parent their child. There were no studies that utilized both individual and dyadic interview methods to collect data, which would have allowed for triangulation of results and the ability to compare parents' experiences within the dyad, nor any studies that only used dyadic interviews.

There were also no studies identified in this systematic search that included non-birth parents and/or same-sex couples in the sample, and only one publication focused on single mothers. The study including single mothers was not included in this review as it did not meet inclusion criteria. However, it is worth noting that there is a clear lack of information about how the NICU hospitalization of one's child affects this vulnerable and increasing population of parents.

All included studies in this review met at least seven out of ten criteria in the CASP qualitative checklist except for one study[51]; the Casteel study (1990) met only 5.5 of the criteria. It is the oldest study included in the review, and it excluded a large portion of the NICU parent population by limiting gestational age to 30-37 weeks and only included parents of infants who were of appropriate size for gestational age. The recruitment strategy wasn't well described and given the exclusion factors, the data wasn't collected in a way that fully answers the research question, and the data analysis description did not describe a sufficiently rigorous process. It is included in this review as it is one of the few studies that compared parents' experiences pre- and post-discharge from the NICU and compared mothers' and fathers' experiences.

Although all included studies were of high quality, only two studies addressed reflexivity.[61,63] In a review of qualitative studies, reflexivity, or discussion of the relationship between the researcher and participants, and the researchers' impetus for conducting the study, merits discussion. The same is true of ethical considerations; only 4 studies[52,55,57,59] addressed ethical issues beyond a statement of approval to conduct research from an Institutional Review Board or similar body. The Provenzi study (2017) was the only one to utilize computer-assisted content analysis to establish themes.

While studies that reported results in a non-English language were excluded, there was transcultural representation in the studies included in this review, spanning four continents and nine countries. The total sample for this review included participants of varying ethnicities, educational backgrounds, and socioeconomic status. Given that there were common themes to emerge in this transcultural representation of study participants, there appears to be transferability of the results. This differs from previous systematic reviews of parents' experience in the NICU which cite limitations of homogeneity in their samples.[74,75] These prior systematic reviews did not utilize a theoretical framework to analyze and organize their results. Themes from previous systematic reviews[74,75] focused on the emotional and psychological impact of the NICU hospitalization for parents and their altered parenting role, and did not result in the emergence of themes related to coping and adaptation, important factors in the health and well-being of NICU parents.

Implications for Practice

Cognitive appraisal, coping, and adaptation are important domains for parents to work through as they experience the NICU hospitalization of their child. This is significant for NICU providers since themes about communication with NICU providers were prominent in this review. The NICU environment can be directly impacted to affect parents' experiences positively during their child's NICU admission by NICU providers. Parents have different experiences in the NICU for any number of reasons, but satisfaction versus dissatisfaction with the entire experience can be dependent on the type, frequency, and tone of communication between parents and the healthcare team, and the restrictions or specific rules of individual NICUs.

Faith can potentially impact all domains of the theoretical model from the initial primary appraisal through learning to cope with the circumstances, and eventually adaptation to the NICU hospitalization. Assessing and addressing parents' spiritual needs can guide clinicians and NICUs in developing and implementing programs to meet the specific needs of NICU parents.

Finally, addressing the psychosocial and emotional needs of parents is an example of both care integration and family-centered care. Addressing the mental health needs of parents while their child is in the NICU and after discharge can improve access to care and reduce mental health disparities. This may help parents to manage their mixed emotions and altered parental role, and can improve outcomes for not only the parents, but the infants as well. Learning techniques to reduce stigma, helping parents gain insight into their own self-care, and learning more about the mental health of parents in the NICU are interventions that can be made by NICU and mental health providers to meet the needs of parents. Barriers, such as the competing demands of daily life with other children, employment, spouse/partners/co-parents, and the burdens caused by the distance of the NICU from their home on top of this very stressful experience creates disparities in the NICU-parent population that may be difficult to address. However, awareness of these issues can help NICU providers develop family-centered treatment plans that adapt to the needs of the specific NICU-family. Offering mental health services in the same location as the NICU can increase access to care for some and may help to mitigate health inequities.

Limitations

This review is limited by the one-person reviewer model, and the subjective nature of developing and coding emergent themes in a qualitative analysis may add additional concern about lack of rigor or unreliability of analysis. Use of methodological frameworks such as Whittemore and Knafl,[40] PRISMA methodology,[41] and the CASP criteria[46] help to assure rigorous research processes in the conduct of the review and reporting of results. This review was also limited to studies that included both parents in the sample; had the studies of mothers' and fathers' individual experiences been included in this review, the emergent themes may have differed.

Future Research

Gaps remain in the literature regarding parents' experiences in the NICU. When the needs of parents of infants hospitalized in the NICU are properly assessed, more appropriate support can be provided to parents during their NICU experience. Strategies to identify, mitigate, and help parents manage psychological distress can be developed, refined, and offered, with a greater understanding of the needs of the parents. Further study is warranted to generate new knowledge about the differing experiences and effects of a NICU hospitalization on each parent of the dyad and their relationship. Research must be inclusive of all types of parents, including fathers, couples who have adopted, and same-sex couples to represent the general population more completely. This will bring a greater understand of the real-life experience of parents in the NICU from multiple and multi-level perspectives to allow for development of family-centered, culturally appropriate, and inclusive care for parent caregivers in the NICU. Feasibility studies to inform the development, refinement, and testing of interventions for parents at risk for psychological distress secondary to a NICU hospitalization of their child, and to assess and address parenting relationship and role conflicts will be required. This can ultimately inform the creation of a family centered care model in partnership with parents. The exclusion of publications that were not written in English leaves information still to be explored in future reviews; sixteen studies were excluded that were written in Portuguese, Spanish, Danish, and Japanese, which may have added additional themes or perceptions of parents' experiences to this review, had they been included.

Conclusion

These integrative review findings provide healthcare providers with a more comprehensive explanation of the experiences of parents in the NICU. The themes of mixed emotions, faith and spirituality, the NICU environment, and parenting affect how parents assess, cope with, and adapt to the circumstances of a NICU hospitalization. Interventions directed at managing parents' emotions, supporting their spiritual needs, facilitating parenting skills and infant attachment, and adapting the environment to parents' needs and becoming family-centered can help to improve the experience of having a child in the NICU for parents.

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APPENDICES

Table 1. Results of Integrative Review

Table 2. Emergent themes within Transactional Model of Stress and Coping

Author/Year	**Title**	**Study Aim**	**Qualitative methodology**	**Sample**	**Key Results and Qualitative Themes Identified**
Abuidhail, J., Al-Motlaq, M., Mrayan, L., and Salameh, T. (2017)	The lived experience of Jordanian parents in a neonatal intensive care unit: A phenomenological study	To describe the lived experience of NICU parents In Jordan, including support systems and care	Phenomenology	n=10, 8 mothers and 2 fathers from 3 NICUs in Jordan interviewed during NICU admission	• Theme 1: Being shocked, worried, and anxious • Theme 2: Influence of NICU admission on parents and family described as stressful, sad • Theme 3: Parents' expectations of the NICU staff • Theme 4: Parental emotions and satisfaction; subtheme of hopeful vs. helpless and satisfaction vs. dissatisfaction
Brelsford, G.M., and Doheny, K.K. (2016)	Religious and spiritual journeys: Brief reflections from mothers and fathers in a neonatal intensive care unit (NICU)	To assess whether the religious world-views of NICU parents were changed after the NICU experience	Narrative Inquiry	n=8, 5 mothers, 3 fathers from different parent dyads. Part of a larger mixed-methods study, interview conducted after NICU discharge in Pennsylvania	• Faith or spirituality as a coping mechanism • Parents more attuned to one another's needs
Casteel, J.K. (1990)	Affects and cognitions of mothers and fathers of preterm infants	To determine the effects and cognitions of mothers and fathers of preterm infants while in a special care nursery and after discharge	Descriptive	n=36, 18 mothers, 18 fathers, parents interviewed as a dyad at 5 days in the NICU and 5 days after discharge in the US	• Affective responses of fear, anxiety, sadness, and helplessness • Cognitive response of protection • Affective responses of amazement, confidence, love, and well-being • Cognitive response of provision • Cognitive response of attachment
Geetanjli, V., Manju, V. K., Paul, M., Manju, and Srinivas, M. (2012)	Loss and grief response and perceived needs of parents with the experience of having their newborn at neonatal care units	To determine the loss and grief response of NICU parents and their perceived needs	Hermeneutic phenomenology, mixed methods	n=16, 8 mothers, 8 fathers in one NICU in India during NICU admission	• Theme 1: Loss, anticipated and actual • Theme 2: Grief reaction, psychological and physical including fear, anxiety, pain, and weakness • Theme 3: Coping emerged as a specific theme subcategorized as helpful and hindering factors. Participating in care is helpful and being unable to care for the infant is hindering • Theme 4: Perceived needs, for information and communication with NICU staff

Hagen, I.H., Iversen, V.C., and Svindseth, M.F. (2016)	Differences and similarities between mothers and fathers of premature children: A qualitative study of parents' coping experiences in a neonatal intensive care unit	To explore and describe the coping experiences of NICU parents	Unspecified, utilized semi-structured interviews	n=16, 8 mothers, 8 fathers in one NICU in Norway interviewed after discharge	• Theme 1: Chaotic emotions including not fulfilling parenting role, contradictory emotions, surrealistic experience, and lack of coping abilities • Theme 2: Approaching the baby and learning to bond
Higgins, I., and Dullow, A. (2003)	Parental perceptions of having a baby in a neonatal intensive care unit	To explore parents' perceptions of the NICU	Phenomenology	n= 6, 5 mothers, 1 father after discharge from the NICU in Australia	• Theme 1: Watchfulness • Theme 2: Needing to be near baby • Theme 3: Feeling useful vs. feeling useless
Lasiuk, G.C., Comeau, T., and Newburn-Cook, C. (2013)	Unexpected: An interpretive description of parental traumas associated with preterm birth	To understand parents' experience of preterm birth	Interpretive descriptive	n=14, 11 mothers and 3 fathers for interviews, and n= 7, 4 mothers and 3 fathers for focus groups after NICU discharge in Canada	• Theme 1: Shattered expectations due to unexpected premature labor, taxing family resources, the surreal experience and choosing between staying with the mother or child for fathers, and feelings of guilt or inadequacy • Theme 2: Helplessness and horror: the trauma of preterm birth including how the baby looks, the NICU environment • Theme 3: Focus on the infant's precarious health, including time spent at the NICU and reorganization of family and work life • Theme 4: Prolonged uncertainty: cycles of crisis and adaptation • Theme 5: Fostering adaptation and the ability to adapt to a new reality, including relationships with NICU staff and social supports
Pepper, D., Rempel, G., Austin, W., Ceci, C., and Hendson, L. (2012)	More than information: A qualitative study of parents' perspectives on neonatal intensive care at the extremes of prematurity	To describe parental perceptions of decision making in the NICU	Interpretive descriptive	n= 7, 5 families, 2 interviews included both parents and 3 with mother alone after discharge in Canada	• Theme 1: Decision making before and in the NICU: moving beyond information includes the first encounter with neonatologist or NP discussing information and statistics • Theme 2: Culture shock in the NICU: Plunging into a strange land includes the strain of the NICU environment and the overwhelming appearance to parents • Theme 3: Relationships in the NICU: Enduring a strange land while feeling powerless and having the NICU staff attend to parents' needs
Provenzi, L., Barello, S., Fumagalli, M., Graffigna, G., Sirgiovanni, I., Savarese, M., and Montirosso, R. (2016)	A comparison of maternal and paternal experiences of becoming parents of a very preterm infant	To compare maternal and paternal experiences of preterm birth and the NICU	Unspecified, used linguistic analysis to compare parents	n= 20, 10 mothers, 10 fathers, interviewed after NICU discharge in Italy	• Theme 1: Facing the unexpected includes managing emotions and fears, and surprising feelings of hope and happiness at the "miracle" of a live birth mixed with feelings of unpreparedness • Theme 2: Learning to parent includes interacting with the NICU staff and managing caregiving in expertise • Theme 3: Finally, back home includes a newfound togetherness as a family and engaging with their infant in daily life

Rowe, J.A., Gardner, G.E., and Gardner, A. (2005)	Parenting a preterm infant: Experiences in a regional neonatal health services programmer	To examine parents' experiences with a regional NICU and community discharge program	Exploratory	n= 19, 11 mothers and 8 fathers, after discharge from the NICU in Australia	• Theme 1: Fragile progress • Theme 2: Parenting by watching what other people do Theme 3: When you could, touch them
Smith, V.C., Steelfisher, G.K., Salhi, C., and Shen, L.Y. (2012)	Coping with the neonatal intensive care unit experience: Parents' strategies and views of staff support	To examine parental reports of the NICU experience, coping strategies, and perceptions of NICU staff support	Unspecified	n=29, 20 mothers and 9 fathers from 24 families, interviews conducted after discharge from a NICU in the US	• Theme 1: Participating in care • Theme 2: Getting away from the NICU including finding support from one's spouse while leaving their infant in the NICU • Theme 3: Gathering Information including asking staff questions and looking for answers online • Theme 4: Involvement of family and friends for practical and emotional support while managing conflicting relationships • Theme 5: Engagement with other NICU parents provides empathy and perspective • Coping strategies that emerged from this study impact the parents' ability to adapt to and handle the stress of the NICU experience
Stacey, S., Osborn, M., and Salkovskis, P. (2015)	Life is a rollercoaster…what helps parents cope with the neonatal intensive care unit (NICU)?	To understand the factors that support parent coping in the NICU	Unspecified	n= 8, 5 mothers and 3 fathers participated in interviews pre- and post-discharge from the NICU in the UK	• Theme 1: Rollercoaster of emotions includes feelings of anxiety, fatigue, joy, and apprehension • Theme 2: Baby's well-being includes the impact of the prognosis and status of the infant • Theme 3: The physical environment in this study was conducive to parenting • Theme 4: Other people includes subthemes of "in the same boat" and the ability to speak with other NICU parents, "talking helps" which includes the value of normal conversation, "feeling involved" in the infant's care and "flexibility" of NICU staff
Wakely, L.T., Rae, K., and Cooper, R (2010)	Stoic survival: The journey of parenting a premature infant in the bush	To examine parents' lived experience of caring for a premature infant during the first year of life while living in a remote rural area	Hermeneutic phenomenology	n=7, 5 mothers, 2 fathers from 5 families, within 1 year of discharge from the NICU in Australia	• Initial shock and confusion followed by a gradual understanding and acceptance as their child made gains • Theme 1: Coping through optimism • Theme 3: Striving for normal • Theme 2: Stoic survival

Wiebe, A. and Young, B. (2011)	Parent perspectives from a neonatal intensive care unit: A missing piece of the culturally congruent care puzzle	To identify constructs of a patient culturally congruent care puzzle	Exploratory	n=21, 13 two-parent interviews, 7 mother-only interviews, and 1 father-only interview in Canada prior to discharge form the NICU	• Theme 1: Provider-client relationship: caring and trust, specifically parents felt more trust in providers they deemed cared about their infant, especially immigrant parents, while aboriginal parents felt distrust with providers • Theme 2: Communication: respectful and appropriate includes use of medical terminology by providers, nonverbal communication and socioeconomic class • Theme 3: Social and spiritual supports: culturally responsive and accessible • Theme 4: Organizational environment: welcoming and flexible to avoid obstacles for parents and the ability to build trusting relationships with staff • Trust in NICU staff and culturally competent care impact the parent's ability to adapt to the NICU environment
Wraight, C.L., McCoy, J., and Meadow, W. (2015)	Beyond stress: Describing the experiences of families during neonatal intensive care	To determine if parents of critically ill premature infants think the NICU is worthwhile	Unspecified	n= 10, 8 mothers and 2 fathers interviewed during the NICU admission in the US	• Theme 1: Guarded optimism due to the uncertainty of the infant's prognosis • Theme 2: Fear and uncertainty includes parent's fears about the consequences of the decisions they have made • Theme 3: Coping with fear and the use of faith • Theme 4: Stress of the entire situation • Theme 5: Do everything vs. best interest and making life or death decisions • Theme 6: The reality of the NICU as foreign and overwhelming
Yen, Y., Hong-Gu, H., Soke Yee, L., Holroyd, E., Shorey, S., and Koh, S.S. (2017)	Perceptions of parents with preterm infants hospitalized in Singaporean neonatal intensive care unit	Explore the experiences of NICU parent in Singapore	Descriptive	n= 8, 6 mothers and 2 fathers in a Singapore NICU, 1 week prior to discharge	• Theme 1: Negative emotions vs. positive emotions that were subcategorized as "unexpected and shocking," "sadness and a sense of loss," "questioning and blaming," "fear and stress", and "excitement and anticipation"' about impending discharge as well as "concerns about taking over responsibilities" • Theme 2: Finding ways forward is subcategorized into "focusing on the positive and coming to terms with the preterm birth," "turning to spiritual faith," and "interacting and bonding with the infant," and "preparing for baby's discharge" • Theme 3: Nature of the support received from various sources is subcategorized into "informational and emotional support from providers," "emotional support from spouse," "instrumental and emotional support from community," and "emotional support from other parents of preterm infants" • Theme 4: Need for informational and professional support which is subcategorized into "information regarding parenting preterm infants and resources," and "responding to queries in time and having updated knowledge"

Table 1. Results of Integrative Review

Table 2. Emergent themes

Model Domain	**Themes from original studies- first level coding**	**Emergent Theme- second level coding**	**Major Theme- third level coding**
Primary Appraisal	anxiety[55,59] fear[54,55] worry[59]	concern for infant	**Panic Sequence**
	confusion[62] culture shock[57] facing the unexpected[66] horror[56] shattered expectations[56] shock[59,62] surreal experience[56]	departure from normal expectations	**Violated Cognitive Schema**
	helplessness[55,56] stress[54,59]	parental vulnerabilities	
Secondary Appraisal	satisfaction and dissatisfaction[59] coping skills[53,65] satisfaction and parental emotions[59]	emotional assessment	**Emotional Upheaval**
	chaotic emotions[65] conflicting feelings[66] rollercoaster of emotions[67] uncertainty[54] negative vs. positive emotions[61] sadness[55,59] hopelessness[59] loss and grief reactions[60] guilt and inadequacy[56]	mixed emotions	

Model Domain	Themes from original studies- first level coding	Emergent Theme- second level coding	Major Theme- third level coding
	affective response of amazement hopefulness[59]	positive feelings	
Emotion-focused Coping	getting away from the NICU[53] coping through optimism[62] stoic survival[62] guarded optimism[54]	regulating emotions	**Regulating Emotions**
	parents more attuned to one another[52] focus on family[56] relationships in the NICU[57] involvement with family and friends[53] other NICU parents[53,67] nature of support[61]	relationships	**Social Support**
Problem-focused Coping	faith and control over outcomes- in God's hands[52] faith and spirituality to cope[52] spirituality[57] social and spiritual supports[58] coping with fear through faith[54]	faith	**Faith**
	need for information[60] decision making information[57] interacting with staff[66] gathering information[53] provider communication relationship[58] communication[58] need for information[61]	communication	**Managing the NICU**
	cognitive response of attachment[55] touching baby[64] cognitive response of protection[55] cognitive response of provision[55] participating in care[53,60] learning to bond[65] needing to be near baby[63] feeling useful vs. useless[63] focus on infant health[56] learning to parent[66] parenting by watching others[64] infant prognosis[67]	learning to parent in the NICU	

Model Domain	**Themes from original studies- first level coding**	**Emergent Theme- second level coding**	**Major Theme- third level coding**
	trust in staff[56,58] watchfulness[63] NICU staff[57] NICU environment[67] organizational environments[58] parents expectations of staff[59]	the NICU environment	
Adaptation	prolonged uncertainty[56] finding a way forward[61] gradual understanding[62] striving for normal[62] new reality[56] fragile progress[64]	adjusting	**Adjusting**

Figure 1. Transactional Model of Stress and Coping
by Lazarus and Folkman (1984)

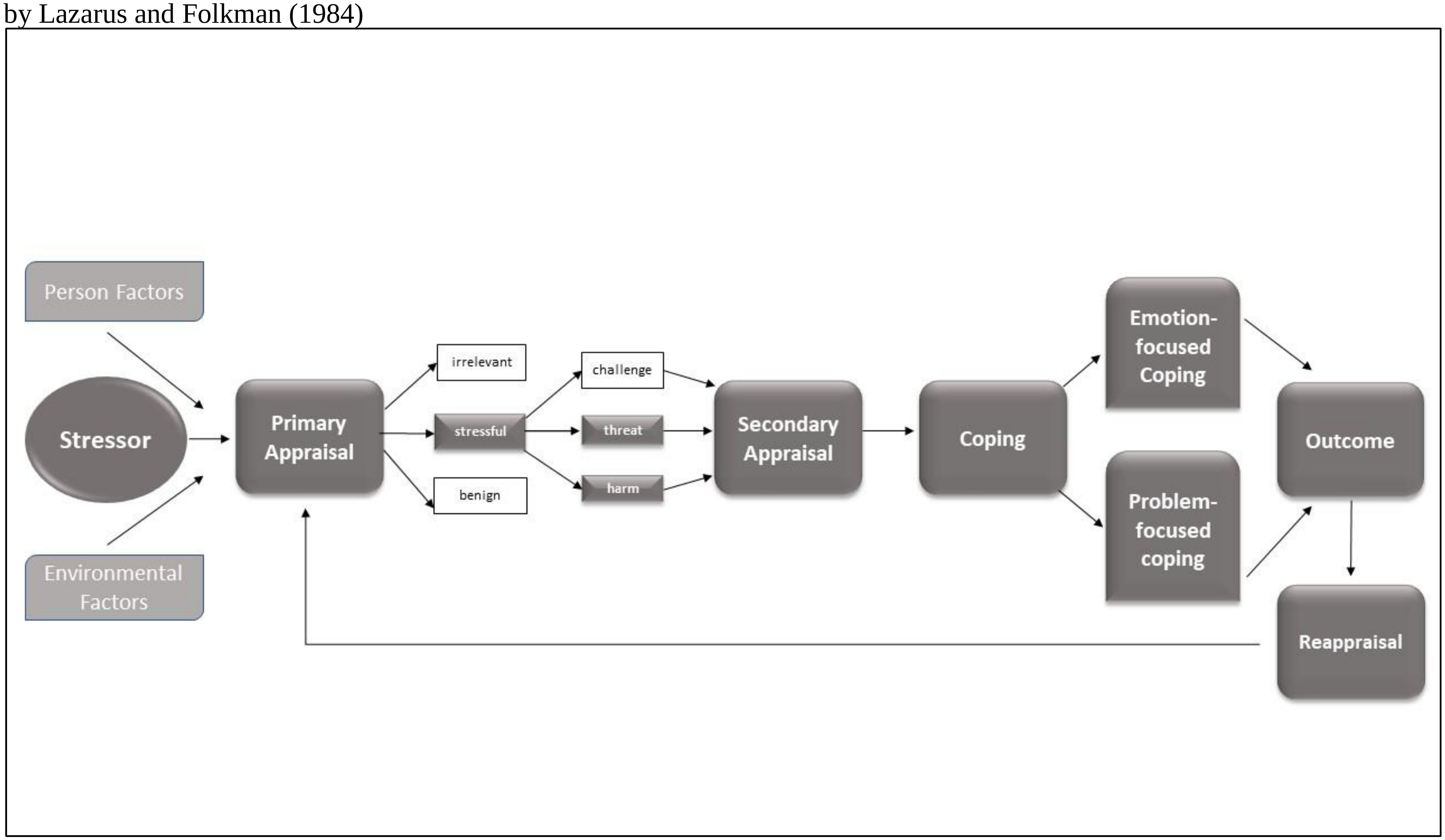
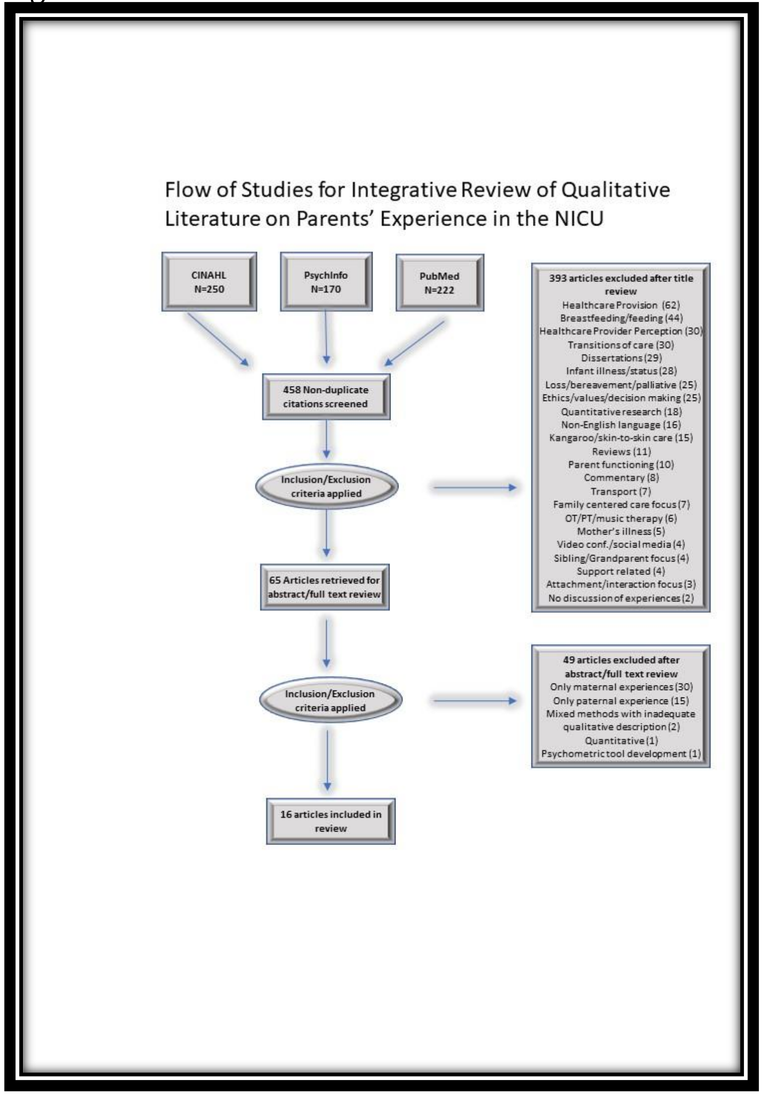


Figure 2. Flow of studies



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The experiences of parent dyads in the neonatal intensive care unit

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Abstract

Background: The hospitalization of an infant in the neonatal intensive care unit (NICU) is a distressing and often unexpected event for parents. Parents have risk for depression, anxiety, and posttraumatic stress, which can adversely impact them and their relationship. The hospitalization and subsequent stress may affect parents' capability to connect with and parent their child.

Purpose: Describe parents' experiences and ability to cope with the NICU; identify experiential and coping differences between mothers and fathers; examine the effect of the NICU hospitalization on the parent dyad relationship.

Methods: A qualitative descriptive design with dyadic interviews examined parents' experiences and coping skills, and subsequent effects on the parental relationship. Data collection continued until saturation was achieved and no new themes emerged. Through content analysis, an accurate description of parents' experiences in the NICU was rendered.

Findings: Nine themes from eight dyad interviews emerged and were categorized within the six domains of the transactional theory of stress and coping. The major themes were: Deeply Distressing, Unexpected and Unprepared, Expecting to Hear and Be Heard, Becoming Parents, Stronger Together, Support is Key, Parents Want Better Communication, and Adjusting to the NICU.

Implications for Practice: Support from professionals and family, and clear and consistent communication from the treatment team helped alleviate parents' anxiety about their infant.

Implications for Research: Research regarding the impact of a NICU hospitalization on the relationship between parent dyad members, specifically longitudinal studies, may lead to a better understanding of the long-term effects of this specific stressor on parents.

Keywords*:* neonatal intensive care unit, NICU,
parents, experience, psychological distress, qualitative

THE EXPERIENCES OF PARENT DYADS IN THE NEONATAL INTENSIVE CARE UNIT

The hospitalization of an infant in the neonatal intensive care unit (NICU) is a distressing event for parents. NICU admissions occur when an infant is premature, suffers from complications that necessitate intensive care, or is acutely ill. Critical illness and an uncertain outcome for infants in the NICU is upsetting to parents,[1] and the resulting heightened risk for future health problems and cognitive consequences is concerning.[2] Most parents expect to have a normal pregnancy and to be discharged from the hospital post-delivery with their infant. When this does not occur as expected, some parents experience psychological disturbances or disrupted bonding and parenting.[3] There may also be damaging consequences to the parents' relationship, such as relationship/marital tension or divorce, an adverse impact on infant development,[4-10] or compensatory parenting.[11] In addition, the NICU hospitalization of their infant makes it problematic for parents to perform usual nurturing actions and functions.[8,12-14] Parents find the hospitalization wearisome because they feel helpless.[15] Among those with premature infants, the idea of becoming a parent is dislocated[16] because of the untimely birth and associated feelings of loss, grief, and anxiety.[14]

Postpartum depression affects up to 70% of mothers in the NICU,[4,16-19] contrasting with 11.5% of mothers in the general population.[20] Fathers are also at risk for psychological disturbances. Studies have shown that up to 37.5% of fathers with infants in the NICU are at risk for depression[18,21] and as many as 33% are at risk for posttraumatic stress disorder.[12] The National Perinatal Association urges screening of parents in the NICU for emotional distress and inclusion of mental health professionals as part of their consensus recommendations for parents in the NICU,[9,22,23] but the rates of national adoption of these recommendations.is unknown. Many studies have examined and measured the mental health and well-being of parents in the NICU[9,16,23-34] and explored the separate experiences of mothers or fathers in the NICU.[18,35-40] Few studies, however, have described the personal experiences of a NICU hospitalization for the parent dyad and examined their specific needs as a dyad in the context of their ability to cope with stress. Moreover, few studies have compared the differing experiences between parents in a dyad, the effect of a NICU hospitalization on their relationship, and their subsequent ability to parent their infant. Thus, a significant gap remains in the literature regarding parents' experiences in the NICU. This study was designed to address that gap.

This study described in this paper examined the parent dyad experience to understand their specific needs as a dyad and individually in the context of coping with the stress of their infant's NICU hospitalization. The specific aims of this study were to: describe the experience of having an infant in the NICU and how parents cope with the experience; identify experiential and coping differences, if any, between mothers and fathers; and examine the effect, if any, that a NICU hospitalization has on the parent dyad relationship.

Methods

Methods and results are reported using the Standards for Reporting Qualitative Research.[41] Qualitative descriptive design was used as described by Sandelowski.[42,43] This study elicited a straightforward description of parents' experiences in the NICU, accurately conveyed the meaning the participants ascribed to their NICU experience, and presented the data without reinterpreting the events, in the words of the parents.[42,44] It was free of an a priori framework, because the goal was to provide new insights and understanding of parental experiences that may resist categorization.[45] However, the transactional theory of stress and coping[46] was applied during the analysis phase as the framework fit the data,[47] as the theory explained the interpretation of complex parental experiences.

The principal investigator (PI) was psychiatric mental health nurse practitioner with more than 20 years' experience as a registered nurse, who had a personal experience with an infant hospitalized in the NICU, thus prompting the research. Reflexive analysis is researcher self-awareness; bracketing[48] was used to set aside the PI's knowledge and assumptions about the phenomenon to attend to participants' accounts with an open mind.

Sample and Setting

Parent dyad participants were recruited from two level III NICUs in the northeastern United States from January-June 2019. Parents were defined as the mother(s) and/or father(s) to the hospitalized infant. Biological parents, parents who used a surrogate, adoptive parents, separated/divorced parents, and parents from same-sex partnerships/gender-minority parents were eligible for this study. Grandparents were excluded from this study, even if they were the primary caregivers of the infant, as were single parents if there was no involvement of the other parent. Inclusion and exclusion criteria are presented in Table 1.

Purposive and snowball sampling strategies were used for this study. Nursing/nurse practitioner staff in the participating NICUs were asked to provide recruitment flyers to parents after the length of stay for their infant reached 2 weeks. Nursing staff introduced the majority of interested participants to the primary investigator, although one dyad did reach out via the phone number on the recruitment flyer. Potential participants were screened for eligibility during the first phone call or meeting.

Institutional Review Board approval was attained for this study prior to data collection. Parents who met the inclusion criteria and gave informed consent were interviewed together as a dyad and then individually. All interviews took place in small, private meeting rooms on the units. Field notes and extensive coding tables were maintained throughout the duration of the study as part of the audit trail, and as a bias reduction method to document reflexivity. Informed consent was obtained from both parents at the first meeting. Parents were consented together as they decided jointly to participate, and in many instances the arrangements were made ahead of time to coincide with their joint visit to the NICU. The study purpose and methods were explained to the participants during the consent process, ensuring they comprehended the risks and benefits of participating in the study, and participants were given the opportunity to ask questions.

Data Collection

After written informed consent was obtained, dyad (joint) interviews were conducted. Participants were offered a $30 Amazon gift card as compensation after the completion of each interview (2 interviews per participant). Interviews took approximately 45-75 minutes. Individual interviews were scheduled after the dyad interview had occurred, generally within the week. Individual interviews took approximately 30-60 minutes. Because there was a risk for attrition between the occurrence of the dyad and individual interviews, individual interviews were scheduled at the end of the dyad interview. Semi-structured dyad interviews occurred first to establish the parents' shared experience of a NICU hospitalization and allowed for observation of the interaction between parents. Initial dyad interview questions were broad to allow parents to tell their story. Parents were asked: Tell me what led to the NICU hospitalization; did you know this was going to happen, or was it unexpected? These questions were followed by: What has your experience in the NICU been like? Additional follow-up questions, as needed, were included. Semi-structured individual interviews followed, which allowed further exploration of the individual parent's experiences that clarified and expanded on data and observations gleaned from dyad interviews, and comparisons and cross-checking of interviews.[49]

All interviews were digitally audio recorded, uploaded to a secure drive, and shared with an approved outside agency for transcription. Demographic information was collected from study participants after the dyad interview was completed. Interview audio files were uploaded to a secure drive and were deleted from the digital recorder as soon as possible. Data was archived on the secure REDCap[50,51] database, accessible only to the primary investigator. For the individual interviews, each member of the dyad was guaranteed confidentiality—their responses were not to be shared with the member of the other dyad to make sure each one felt free to express themselves. Care was taken regarding information from individual interviews that is included and disseminated in this manuscript as well, to maintain the privacy of the individual parents. Information gleaned in individual interviews was not shared with the other parent, parents' names were redacted from interview transcripts, and parents were discussed using pseudonyms in this manuscript.

Data Analysis

Data analysis began after the dyad interview, continued through individual interviews, and remained concurrent to data collection throughout the study until data saturation or informational redundancy was reached, that is, when no new themes emerged from the data.[52-54] Data saturation was reached after 22 interviews. Eight parent dyads generated a total of 22 interviews (8 dyad interviews, 7 mother interviews and 7 father interviews, 1 dyad lost to follow up).

Demographic data were analyzed for descriptive statistics including frequency, range, and central tendency, using IBM SPSS 24 software.[55] Results from the demographic analyses were used to describe the study sample, and to help interpret the parental qualitative responses. Content analysis was conducted by hand, and qualitative analytic software was not used. This study used conventional content analysis whereby codes were developed from the interview data, and themes derived through inductive reasoning.[56] Interview analyses were conducted by listening to audio recording of interviews, comparing transcripts to recordings for accuracy, and reading and re-reading transcripts. This was followed by line-by-line coding of all transcripts, analyzing transcripts for themes, and then comparing the interviews for common themes that emerged. Dyad interviews were transcribed, and a preliminary reading and analysis of interviews informed and were compared to subsequent individual interviews within the dyad.

A coding table was developed and the qualitative analytic technique of constant comparison[57] was employed, with first level coding occurring simultaneously with data collection. This allowed for data checking and possible adjustments to interview questions or techniques to facilitate follow-up to responses in the dyad interview or to more explicitly answer the research questions. First level coding used the exact words that were spoken by participants. This method allowed the investigator to capture the interview by paraphrasing what the participant said. During level-two coding, first-level codes were re-read to look for repetition of words, ideas, and thoughts from the participants, or themes that were emerging from the individual interviews. The third level of coding was selective coding and occurred across groups and participants, again looking for commonalities and meaning. Data was compared among dyad interviews, and across study participants to form themes of the parents' experiences in the NICU. Selective codes were then categorized into emergent themes, and data was further reduced into themes and associated subthemes within the transactional theory of stress and coping. Through content analysis, an accurate description of parents' experiences in the NICU was rendered.

An experienced qualitative expert reviewed deidentified transcripts with coding and the coding table to ensure accuracy and correct interpretation, and thus added to the rigor of the study. Triangulation, the use of multiple methods of data collection and data analysis, also added to rigor; using observation, dyad interviews, individual interviews, and descriptive statistics allowed for a confluence of data for comparison, thus adding to validity and credibility.[58] Truthfulness (dependability and confirmability) was established as the use of both dyad and individual interviews elucidated similarities between statements parents made in one another's presence and statements parents made when they were alone with the interviewer.[56] Parents were given the opportunity during the individual interviews to clarify or further explain statements they made during the dyad interview; the clarifications and further explanations were compared to the original dyad interview data, which allowed for a more complete representation of the parental dyad experience in the NICU. This manuscript reflects themes that emerged from the dyad interviews representing the joint experience of parents in the NICU.

Results

Participants included eight mothers and eight fathers; one dyad completed the joint interview but did not complete the individual interviews. All were male-female dyads and the majority were married (five out of eight). Participants ranged in age from 27-52 years old, and participants were of varying races, ethnicities, and socioeconomic statuses. Seventy-five percent of dyads had an infant born preterm and 75% of dyads delivered via Cesarean section. The mean length of stay in the NICU at the time of the dyad interview was 62 days; 88% of families had an infant who experienced one or more complications such as the need for respiratory support, necrotizing enterocolitis, gastrointestinal problems, cardiac problems, neurological problems, and/or surgery. Demographic data is presented in Tables 2 and 3.

This is a preliminary study with a lower level of complexity and interpretation, but a high degree of discovery as data is presented from a new dyadic viewpoint.[42,45,59] Data groups are connected in a complete representation of parents' experiences. This interpretation illustrates how distinct data meaningfully come together to describe parents' reflections of the NICU experience.[45] This study explored the experiences of both parents regarding their infant's NICU hospitalization. The differences and similarities of parents' experiences, the subsequent effects of the NICU hospitalization on the parental relationship, and descriptions of parenting styles were specific areas of inquiry. Nine themes emerged from the eight dyad interviews focused on the joint experiences and coping mechanisms of parents. Themes were categorized and analyzed within the six domains of the transactional theory of stress and coping. Major themes to emerge were: Deeply Distressing, Unexpected and Unprepared, Expecting to Hear and Be Heard, Becoming Parents, Stronger Together, Support is Key, Parents Want Better Communication, Parents Do Not Know How Much More They Can Take, and Adjusting to the NICU (Table 4). Themes and subthemes are reported in order of frequency within each domain of the theoretical model (Table 5). The transactional stress and coping model is a cognitive theory of the person-environment relationship in the context of the stress response.[46] Parents have responses to stressful situations, as individual factors influencing appraisal will affect parents' responses to a NICU hospitalization.

Cognitive Appraisal

Cognitive appraisal is an evaluative process whereby one categorizes a situation with regard to how it affects their well-being.[46] Parents appraise their circumstances to determine their available coping skills.

Primary Appraisal

Primary appraisal determines how a person views a situation, and if they found that circumstance irrelevant, benign, or stressful.[46] If a situation was stressful, such as the hospitalization of one's infant in the NICU, parents appraised the situation as harmful, a threat, or a challenge. This appraisal happened almost immediately during their emotional experience,[46] and one major theme was identified.

Theme 1: Deeply Distressing. Deeply distressing reflects the description of a traumatic event. Many of the dyads (five out of eight) felt the NICU hospitalization was a traumatic experience, more so for the dyads who were not aware of the extent of congenital injuries prior to birth or who did not expect a preterm birth. Four subthemes emerged within this theme and an exemplar of each subtheme is provided in Table 6. Parents described the subtheme of traumatic pregnancy, delivery, and birth and the subsequent hospitalization of their infant in the NICU as "terrifying," "horrendous," "scary," "painful," and "critical" during their primary appraisal. The subtheme how could this have happened to us refers to the shock of their circumstances. Unable to accept this outcome was present as a subtheme for three dyads; the birth and hospitalization of their infant was very sudden. The pregnancies did not start out as high risk, and even for those who were aware that there were congenital injuries (e.g., cleft lip, growth restriction, abdominal cyst), a preterm birth was unexpected. For those with full term infants, the extent of congenital injury and ensuing complications (e.g., seizure disorders, cleft palate, heart defects) was unexpected. A stressful environment, the final subtheme in this domain, represents how the same three dyads described their initial experience of the NICU. The NICU environment was a stressor for those parents, and the NICU sights and sounds were anxiety provoking. As one mother (D5M) stated, "It is scary going to visit the NICU, there is always something going on.” For some parents, spending time in the NICU “drove you crazy.” They worried every time they heard an alarm, and “automatically became tense.” In general, the primary appraisal of the birth of their infant and subsequent “whisking away” to the NICU caused anxiety, fear, and stress:

> D5M: "….it was very emergent. So, they put a -- I just remember they put a mask on. I remember they didn't even like -- I remember they Betadine my stomach. They did everything. I was like -- I was awake for everything, and then I said, I was like, 'Hello, please, I'm still awake.' And then finally they -- the guy put a mask on, he said, 'Tilt your chin back,' and that was the last thing I remember."
> D5D: ".... they came out and talked to me.... the baby's doctor came out and she laid it out. You know it's not good. It's not bad.... I didn't know how to react.... I really didn't think he was going to survive when he first came out."

Secondary Appraisal

Secondary appraisal is subsequent to the cognitive appraisal process and was reliant on the parents’ accessible coping abilities and assessment of influence over the circumstances or outcomes.[46] When parents concluded the NICU hospitalization of their infant was a harmful or threatening event, they began to establish views about the outcomes based on their primary appraisal. Two major themes emerged in this domain of the model, Unexpected and Unprepared: An Emotional Rollercoaster, and Expecting to Hear and Be Heard.

Theme 2: Unexpected and Unprepared: An Emotional Rollercoaster. All participants described extreme emotions. There were occasional moments of joy or happiness because of the love they have for their infant, but also fear of the consequences of preterm birth or critical illness. The first subtheme in this theme was unexpected and unprepared. Parents felt unprepared both mentally and physically; they had never considered prematurity or illness a possibility, and they didn’t have a nursery or the required supplies ready to bring an infant home. Many dyads (five) were amid looking for a new home, moving to or renovating a new home, and in two cases, relocating out of state when their infant was delivered unexpectedly. Three of the mothers were admitted to the hospital and were on bed rest for more than a week prior to giving birth. Four additional mothers were admitted briefly with the intent of delaying the delivery; only one mother had induced labor, but that was also unexpected. This was not the experience any dyad expected; for many dyads (five) it was their first child. The expectation was to have an uneventful delivery at full-term and leave the hospital with a healthy infant.

The phrase “ups and downs” or even the word “rollercoaster” was used by dyads to describe the NICU experience. This is the second subtheme, an emotional rollercoaster. The “ups” were experienced when the infant was doing well, feeding, or recovering from a surgery with no signs of infection. The “downs” were experienced when the infant was not progressing as expected: a new diagnosis of infection, a seizure, a test that indicated the need for a surgery. Parents’ emotions were tied closely to the most current state of their infant’s health and prognosis, and in many cases, the status changed quickly and numerous times. As one mother (D8M) stated, “It all depends on how last night ended,” followed by the father’s reply:

> D8D: “I literally don't even want to bring anyone up to speed because it sounds like it is a book at this point because chapter one everyone knew what we were dealing with and we thought we were leaving after chapter one. We are now at chapter 15 and are we at the end of the book, in the middle of the book or somewhere in between? Who knows? And I don't really want to take somebody or even explain to somebody that that's where we're at.”

The final subtheme within the major theme Unexpected and Unprepared is this is different for each of us. For nearly all dyads (seven out of eight) the mother was self-described and referred to by her partner as the more emotional parent. In most of the dyads (seven) the mother described being the parent who cried more, panicked more, and was more easily upset. The fathers portrayed themselves as the stoic parent who had to be strong for the family but was sometimes frustrated by his partner's emotional lability. Two fathers were concerned about their partner crying at the infant's bedside as they did not want negative emotions to affect the infant. This subtheme addressed the second specific aim and identified the experiential and coping differences between mothers and fathers.

Theme 3. Expecting to Hear and Be Heard. In several instances (five), parents felt like they knew something was wrong with their infant and their concerns were not being heard. In other cases, parents felt like they were not being informed of evolving crises with their infant:

> D1D: "Yeah, that is all it took, like you know, just come out and you know, until I raised my voice until I was like, you know, angry. That is when, you know, five people came out telling me we are just trying to get a line, it is difficult. It was like, you could have told us that four hours ago."

Coping

Coping is the next stage in the model and is defined by Lazarus and Folkman as a continually shifting process to handle explicit demands that are comprehended as stressful and beyond the resources of the person.[46] Coping is characterized in the model as emotion-focused or problem-focused.

Emotion-focused coping

Emotion-focused coping is focused on controlling emotional responses to difficulties, and is more likely to be used when cognitive appraisal determines not much can be done to alter the stressful circumstances.[46] Two major themes emerged in the coping domain: Becoming Parents and Stronger Together.

Theme 4. Becoming Parents. Parents often referred to their infants as "fighters." They described their infants as strong and they exuded pride when they spoke about the weight that their infant had gained, or how well the infant had done after surgery. We are parents is the first subtheme within this major theme. Parents learned what their infant did and did not like, and they tried to remain hopeful about their situations:

> D2M: "…. she's doing good, as in good. You could not tell she had surgery…. She is strong, that's what I say all the time- we see that as parents, she's strong. I say you're mommy's strong girl"

Although they remained hopeful, parents were still worried for their infant, the second subtheme within the major theme Becoming Parents. For the most part, parents had confidence in the medical care that their infant was receiving, yet they continued to have a lot of concerns. Some parents did not want to let their emotions negatively impact their infant, so some dyads (three) even set up "no-cry" zones around their infant. There was concern about the future, a perceived vulnerability and need to protect their infant when they do finally go home mixed with the desire for their infant to have a normal childhood. Parents also had feelings of guilt, captured in the next subtheme, we feel like this is our fault. For mothers especially, there was a tremendous sense of guilt and blame, a negative, emotion-focused coping mechanism. Many dyads stated that they "did everything right:" they went to all the prenatal appointments, followed all the rules of pregnancy and recommendations from the obstetrician, yet their infant still required hospitalization in the NICU.

The importance of the staff and the hospital setting was discussed by parents in the final subtheme, the NICU environment is crucial. Participating in their infant's care was an important part of the experience for parents. They were not able to care for their infant at home as they would have if everything had gone as expected, but in most cases, they were able to hold their child, change his/her diaper, bathe and clothe him/her. The rapport parents developed with the staff and with other parents on the unit had either a negative or positive impact depending on the interaction.

Theme 5: Stronger Together. In the second major theme in emotion-focused coping, parents described relying on each other to manage, which satisfied the third specific aim by explaining the effect of the NICU hospitalization on the dyad relationship. All dyads, regardless of romantic or marital status, felt as if this experience brought them closer together and made them stronger.

> D7D: "What I did learn, it definitely showed me from my point of view, looking at mommy when it comes to like how strong we really are as a team, as a dyad with this situation, like it really showed a lot of strength. Because before this, everything was all fun and games, you know the movies, out to eat, laughs and giggles which is the easy stuff. This is our first real test together in our relationship where we really had to like be strong for each other and honestly we did great...we did great."

Problem-focused coping

Problem-focused coping is practical and impartial and is targeted at characterizing the problem and discovering solutions.[46] Although there was not much parents could do to alter the status of their infant's health, parents relied on problem-focused coping strategies such as trying to improve communication with the NICU staff, seeking psychosocial support, and depending on faith and spirituality through strengthened religious and spiritual beliefs. Two major themes emerged in this domain.

Theme 6: Support is Key. Support, in some form or another, was discussed by every dyad. For some, professional support services were requested and/or suggested as a service the NICU could offer to parents. For others, relying on family was an important problem-focused coping strategy, and for many, faith and spirituality helped them through difficult times. Many dyads discussed the need for more on-site services for parents, whether it be in the form of support groups, counselors, or more social work support. This is the first subtheme within the Support is Key major theme: support from family and professionals helps. Dyads found support from family, especially their own parents. Their families brought them food, drove them to the NICU, and watched the other children for those who had them. In addition, they cited the need for more professional support:

> D1D: "…. I wish we had support for parents…. I actually reached out to a social worker- I asked them if they had [services]- she was, you know, very depressive and very stressed out. I could only do so much as her husband…. I am not a professional."

Most dyads (seven out of eight) found some solace in their religion or spirituality, the final subtheme within this major theme, faith helps us. Only one dyad denied organized religion as a coping tool, but the parents in the that dyad also both spoke and prayed to their respective recently deceased grandparents to watch over their infant. For some, it reawakened their faith; for others, they prayed more than they had in the recent past.

Theme 7: Parents Want Better Communication. In the second major theme in this domain, parents discussed how communication could be improved and how it would improve their overall hospitalization experience. Parents felt the need for more information, and for the treatment team to be on the same page as each other. In some cases, miscommunication and lack of information led to dissatisfaction with the NICU.

Conflicting information from providers and NICU staff, who at times described medical conditions in different ways, was sometimes confusing to parents and created stressful situations. The first subtheme within this major theme is we need better communication. Parents felt they could be better informed of procedures being done and medications given to their infants. For some dyads (five) a need arose to escalate their concerns about a situation with their infant in the NICU. Asserting our parenthood was the final subtheme within this major theme**.** Parents questioned the medical care provided to their infant, and they felt the need to be present as often as possible. Seven of the eight dyads were staying at the Ronald McDonald House to facilitate their near constant presence at the NICU. They made it known that they were involved in their infant's care and wanted to be kept informed:

> D1M: "…I will try to get them before they start [rounds] or I just try to make it known that you know, hey this is our baby. We are very involved with his care and you know we just want [you] to keep us informed."

Reappraisal

Reappraisal refers to a changed appraisal based on new information.[46] For parents in the NICU, information about their infant changes daily- in some cases there is good news, and in others the information is now concerning.

Theme 8: Parents Do Not Know How Much More They Can Take. Not every dyad experienced negative reappraisal. The three dyads with the longest length of stay and the most complex cases did, however, and for them, each setback made the experience more stressful. The aftermath of an illness, such as necrotizing enterocolitis, a sometimes-fatal gastrointestinal disease that affects preterm infants, brought further anxiety. When there were setbacks, bad news was devastating, and parents felt like they had to start over:

> D1D: "And I think that is what. Like when you get these, you know bad news that's what like deflates you also. So, like you know, you like, alright it's was time now. He should be healing. He should be doing this. And it's like. When these things happen, it's like, you know, very deterring... devastating, as right now. Because now you got to pick yourself up and start back all over from afresh again."

Adaptation

Adaptation is defined as resolution to the crisis.[46] In this case, resolution is adjustment to the NICU environment and supporting others in similar circumstances.

Theme 9: Adjusting to the NICU. Not all dyads reached adaptation to the NICU. Parent dyads reached the domain of adaptation when they learned to adjust to the NICU. They adjusted to the sights and sounds of the unit, the staff, and their new routine. Two subthemes emerged within this domain: this is our new routine and paying it forward. Parents who adapted to the NICU developed a comfort level with the unit and staff, their visiting routine, and their circumstances, described in the subtheme this is our new routine:

> D2M: "More time, yes. I am very grateful. I have nothing but good things to say about here. Yeah, our experience, I mean, who wouldn't want to go home, but, because of our baby, this place has become home. Until we are ready to go home."

The final subtheme is paying it forward. For some parents (four dyads), helping other parents in the NICU, in similar situations to themselves, was something they felt they were capable of and something they needed to do.

Discussion

This study was designed to elucidate the experiences of parent dyads in the NICU. It highlights how parents appraised and coped with the stressor of their infant's NICU hospitalization, and how they described the effect of that stressor on their relationship. In interviews with eight dyads, parents portrayed their experiences as an emotional rollercoaster that made their relationship stronger and brought them closer together. Parents assessed their circumstances through cognitive appraisal, coped through attempting to manage their emotions (negatively or positively), and took part in the care of their infant as a way of problem-solving.

Findings in the cognitive appraisal domain support the findings of prior research with this population. The trauma and difficulty accepting the circumstances of birth and the consequent "whisking away" of their infant described in the theme of Deeply Distressing in the primary appraisal domain is similar to the themes of panic sequence and violated cognitive schema found in prior work[3] like anxiety, worry, confusion, horror, and helplessness. The secondary appraisal emotional upheaval described in the theme Unexpected and Unprepared: An Emotional Rollercoaster is also congruent with prior qualitative studies[3] in which parents also described the experience like a rollercoaster with chaotic and conflicting emotions, and periods of satisfaction and dissatisfaction with NICU staff. Social support through involvement with family and friends, faith as a mechanism to get through fear and to cope and managing the NICU and the need for information were themes in the coping domains not discovered in prior research.

One key aspect of the hospitalization experience for parents was the differing reactions and emotions undergone by mothers and fathers. This was not an emergent theme discovered in an integrative review of qualitative studies of both parents in the NICU.[3] However, in a literature review of research with parents with children with chronic conditions, Manning (2012) found that mothers and fathers react differently to the experience; mothers have more emotional reactions and fathers take on the role of protector and supporter. This finding is congruent with the parents' experiences as described in the subtheme This Is Different For Each of Us in this study, but Manning concluded that parents are at risk for relationship dissolution[5], which was not a conclusion of this study. In addition, findings from this study emphasize the support members of the dyad give to each other - every dyad contributed experiences to support the theme Stronger Together - feeling closer together and stronger as a unit. Parents felt the NICU hospitalization of their infant "put things in perspective" rather than put a strain on their relationship. They felt more supportive of one another, that they could lean on one another, and that they could talk about anything. There did not appear to be any disagreement about the support parents felt for one another among participants in the interviews, and in cases where one parent cried during the dyad interview, the other parent comforted him/her. This was an unexpected theme to emerge, given Manning's conclusions (2012) and findings from previous studies that suggest parent psychological distress related to a NICU hospitalization may lead to negative effects on the parents' relationship.[3,5,8]

In this study it seems that dyads were not experiencing negative effects on their relationship due to the stress of the hospitalization of their infant. All participants described the positive effects of the hospitalization experience on their relationship, like closeness and increased support. In some ways, it is not unexpected that parents feel closer. It is a stressful, unpredictable time, and each understands what the other is going through. The theme Stronger Together may also have emerged because all parent dyads had infants that were currently hospitalized in the NICU. The range in length of stay varied greatly among families, but no participant had an infant who was close to discharge at the time of the interview. Had participants from the NICU follow-up clinic participated in the study (who may have adjusted to discharge), there may have been different results or themes to emerge regarding the effect of the hospitalization experience on their relationship.

This study confirms the applicability of the transactional theory of stress and coping as a framework for working with this population. It supports the findings of LaMontagne, Johnson and Hepworth (1995) and Lau and Morse (2001) in applying this framework to practice in the NICU.[60,61] The hospitalization of one's infant in the NICU is a stressful experience that is often unexpected. Parents must appraise the situation and their existing ability to manage the situation in order to cope with and adapt to their circumstances. Not all coping strategies are positive, and not all parents adapt to this experience. Parents who had infants with complications, serious critical illnesses, and longer length of stays negatively reappraised their situations. Parents who did not experience serious setbacks did not negatively reappraise their situation. Only five dyads described adaptation to the experience according to the theoretical model. The final theme to emerge in this study was the same theme to emerge in prior studies: Adjusting to the NICU. Some parents had not been in the NICU long enough to adjust, and for others, continuing reappraisal of the situation hindered adaptation.

Limitations

Parents may have had memory or recall bias and may not have remembered specific details or feelings they had during the hospitalization or may have put a more positive light on a situation[46] when looking at it in hindsight.

The dyadic analysis also has benefits and drawbacks. Individual interviews allowed the interviewer to concentrate on the single participant. The respondent may have felt more comfortable speaking about sensitive issues in private. Individual interviews were easier to transcribe than interviews with multiple participants and allowed the individual to tell their story without influence from other participants. The concern with the dyadic interviews was that one person may have censored answers to avoid disclosing feelings or other information to the other. The follow-up individual interviews allowed participants to share experiences they may not have discussed during the dyad interview and were a benefit to this follow-up interview approach.

Further research regarding the impact of a NICU hospitalization on the relationship between parent dyad members, specifically longitudinal studies, may lead to a better understanding of the long-term effects of this specific stressor on parents: will they continue to feel stronger together after discharge? There were no same sex dyads, or dyads who used a surrogate or who adopted in this sample; there simply were no parents with an infant in the two study sites meeting those characteristics. It would be prudent to gain the perspective of gender minority dyads and/or dyads who adopted or used a surrogate and had an infant in the NICU to guide appropriate care. It is a goal of Healthy People 2020[62] to promote LGBT mental health and well-being, and staff in the NICU note anecdotal increases in gender minority parents who may have different needs, experiences, and coping skills. The need for more support was noted by several dyads. Interventional and implementation studies may address how best to meet the needs of this population by guiding interventions to support the parent dyad relationship to maximize their perceived strengths.

Implications for Practice

This study attempted to address gaps in the literature by examining the experiences of parents as a dyad, and not only as individuals. Findings contribute new knowledge about the differing experiences and effects of a NICU hospitalization on each parent of the dyad, and the perceived positive effects of the NICU hospitalization on the dyad relationship.

Results from this study can inform the design of future studies and the development, refinement, and testing of supportive interventions for parents at risk for psychological distress secondary to a NICU hospitalization of their infant. Results from this study also have the potential to guide supportive interventions for the parent dyad relationship, to maximize the perceived strengths of the dyad, and ultimately could inform the creation of a family-centered care model in partnership with parents. Parents want a cohesive message from the treatment team, need to bond with their infant, and need support. Parents had specific suggestions about the types of support they would like to see on the unit:

- **On-site mental health support**. Parents stated that they would use these types of services if they were there on the unit. The addition of counselors, social workers, psychologists or nurses to the NICU team to proactively assess parents and offer individual services may improve the NICU experience.

- **Support groups**. Although parents were apprehensive about sharing their feelings, they do find value in hearing about other parents' experiences and would like to be able to do so in a more formalized way. Rather than via conversations in hallways, parents would like private group sessions with other parents.
- **Private space**. In addition to professional and support services, parents suggested a more private space for parents on the unit. They would like to be able to talk to each other in more private settings than at their infants' bedsides. They would also like to be able to have socialization time with one another on the unit.

Improving support and communication is a need across the healthcare environment. In the case of this study, parents were able to specifically articulate the types of support they need, just as they were able to articulate the type and content of communication they expected from the NICU treatment team. Parents want family meetings, a cohesive message from team members, and to be notified of changes to the treatment plan in real time. Many dyads noted faith as a problem-solving coping mechanism. Supporting parents' faith and creating greater access to chaplaincy services may improve the experience for those parents who use faith as a means of coping.

Conclusion

Stress, appraisal, and coping provides a lens to better understand how parent dyads experience the NICU. The hospitalization of their infant in the NICU, regardless of the circumstances, is stressful and shocking. Parents find themselves unprepared and on an emotional rollercoaster. Parents have little influence over their circumstances and need information from staff in order to appraise their situation and determine how to cope. Mothers and fathers need to be given the opportunity to bond with their infant and may need help to get past their feelings of guilt and blame. They have become parents in extraordinary circumstances, yet contrary to expectations, parents feel as if this experience has brought them closer together rather causing relationship strain. Although mothers and fathers appraise the situation differently, they share coping strategies and become the main support for one another. Support in general, from professionals and from family or friends, and clear and consistent (whenever possible) communication from the treatment team can help to alleviate some of the anxiety parents feel about their infant. The NICU environment should have private areas accessible to parents that embody a supportive environment. Parents who can successfully cope with the circumstances of the infant's birth and hospitalization adjust to the NICU environment and develop temporary routines to accommodate their circumstances, and in some cases, they even reach out to support others in similar circumstances or help other parents through a deeply distressing time.

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Appendices

Table 1. Inclusion and exclusion criteria

Inclusion	**Exclusion**
Aged 18 years or older	Parent currently pregnant
Able to read and speak English	Infant with terminal illness
Parent dyads of infants currently hospitalized in the NICU or hospitalized in the NICU within the past 12 months	Parent with psychiatric problem (i.e., active psychosis) that would make participation difficult, in the professional opinion of the investigator
Infant hospitalization lasted 2 weeks or more	Death of infant

Table 2. Parent Characteristics

Parents	Male (n= 8)	Female (n=8)	Total (N=16)
	Total/Percent of Males	Total/Percent of Females	Total/Percent of total
Age in years			
25-30	1/12.5%	2/25%	3/19%
30-35	6/75%	5/62.5%	11/69%
35-40	0	1/12.5%	1/6%
>40	1/12.5%	0	1/6%
Race/Ethnicity			
Black/African American	2/25%	1/12.5%	3/19%
Asian	2/25%	2/25%	4/25%
White/non-Hispanic	2/25%	3/37.5%	5/31%
Hispanic/Latino/non-White	2/25%	2/25%	4/25%
Individual Annual Income in USD			
≤19,999	2/25%	2/25%	4/25%
20,000-40,999	2/25%	2/25%	4/25%
41,000-64,999	0	0	0
65,000-99,999	1/12.5%	2/25%	3/19%
≥100,000	3/37.5%	2/25%	5/31%
Use Public Assistance			
Yes	2/25%	1/12.5%	3/19%
No	6/75%	7/87.5%	13/81%
First Child			
Yes	7/87.5%	5/62.5%	12/75%
No	1/12.5%	3/37.5%	4/25%
Relationship status			
Married and co-parenting	5/62.5%	5/62.5%	10/62.5%
In relationship and co-parenting	2/25%	2/25%	4/25%
Separated and co-parenting	1/12.5%	1/12.5%	2/12.5%

Table 3. Infant and delivery characteristics

Family	Delivery method	Premature	Infant sex	Gestational age at birth in weeks	Birth weight in grams	Infant LOS at time of dyad interview in days	Have there been complications
1	V	Y	M	28	737	113	Y
2	C	N	F	36	2268	42	Y
3	V	N	F	37	2920	55	Y
4	C	Y	M	31	624	150	Y
5	C	Y	M	26	652	31	Y
6	C	Y	F	27	709	27	Y
7	C	Y	M	31	1531	15	N
8	C	Y	M	31	1729	60	Y
Total	75% C-section delivery	75% premature births	63% Male infants	Mean GA= 31	Mean birth weight= 1398	Mean LOS= 62	88% experienced complications

V= vaginal, C= Cesarean-section, Y= yes, N= no, M= male, F= female, GA= gestational age, LOS= length of stay

Table 4. Thematic Results Within Transactional Model of Stress and Coping

Stress Coping Domain	Emergent Themes	Subtheme	Theme
Primary Appraisal	This was unexpected and traumatic, and everything happened so fast How could this have happened to us? This is hard to accept- it feels like a bad dream The NICU is a stressful environment for us	1a. Traumatic pregnancy, delivery, and birth 1b. How could this have happened to us 1c. This is hard to accept- it feels like a bad dream 1d. A Stressful Environment	1. Deeply Distressing
Secondary Appraisal	This is an emotional rollercoaster with many ups and downs We weren't prepared for this; this isn't how it was supposed to be This is hard for us- it is a stressful time We take it as it comes We are different- mom is more emotional and dad must be strong Dad is worried but must remain strong for his wife and child	2a. Unexpected and Unprepared 2b. An Emotional Rollercoaster 2c. This is Different for Each of Us	2. Unexpected and Unprepared: An Emotional Rollercoaster
	We need the NICU staff to listen to us and respect us as parents	3. We Expect to Hear and Be Heard	3. Expecting to Hear and Be Heard
Emotion Focused Coping	We are becoming parents Perceived child vulnerability I need to bond with my baby This could have been worse We want our baby to have a normal childhood Guilt and self-blame We put our own needs and feelings aside right now We have become close to other parents here in the NICU	4a. We Are Parents 4b. We Are Worried for Our Infant 4c. We Feel Like This is Our Fault 4d. The NICU Environment is Crucial	4. Becoming Parents

	The staff are amazing and a very important part of the NICU experience		
	This has brought us closer together and has made our relationship stronger We have grown stronger through this experience Sometimes mom must be the strong one We are in constant communication	5. We Are Stronger and Closer Than Ever	5. Stronger Together
Problem Focused Coping	Psychosocial support Faith and prayer help me cope	6a. Support from Family and Professionals Helps 6b. Faith Helps Us	6. Support is Key
	Treatment team communication could be improved Questioning medical care provided We want you to know we are his/her parents and we are involved in his care	7a. We Need Better Communication 7b. Asserting Our Parenthood	7. Parents Want Better Communication
Reappraisal/Primary Appraisal	Bad news is devastating, and we feel like we must start over Fear of another pregnancy	8. We Do Not Know If We Can Keep Doing This	8. Parents Do Not Know How Much More They Can Take
Adaptation	This is our new routine Paying it forward	9a. This Is Our New Routine 9b. Paying It Forward	9. Adjusting to the NICU

Table 5. Frequency of Theme Emergence Among Dyads

Domain	Theme	Dyad 1	Dyad 2	Dyad 3	Dyad 4	Dyad 5	Dyad 6	Dyad 7	Dyad 8
Primary Appraisal	**1. Deeply Distressing**	√		√	√	√		√	
	1a. Traumatic Pregnancy, Birth, and Delivery	√		√	√	√		√	
	1b. How could this have happened to us	√				√		√	
	1c. This is hard to accept- it feels like a bad dream	√				√		√	
	1d. A Stressful Environment	√		√		√		√	
Secondary Appraisal	**2. Unexpected and Unprepared: An Emotional Rollercoaster**	√	√	√	√	√	√	√	√
	2a. Unexpected and unprepared	√	√	√	√	√	√	√	√
	2b. An Emotional Rollercoaster	√	√	√	√	√	√	√	√
	2c. This is Different for Each of Us	√	√	√	√	√	√	√	√
	3. Expecting to Hear and Be Heard	√	√	√	√		√		√
Emotion-focused Coping	**4. Becoming Parents**	√	√	√	√	√	√	√	√
	4a. We Are Parents	√	√	√	√	√	√	√	√
	4b. We Are Worried for Our Infants	√	√	√	√	√		√	√
	4c. We Feel Like This is Our Fault	√	√	√		√		√	√
	4d. The NICU Environment is Crucial	√		√	√	√		√	√
	5. Stronger Together	√	√	√	√	√	√	√	√
Problem-focused Coping	**6. Support is Key**	√	√	√	√	√	√	√	√
	6a. Support from Family and Professionals Helps	√		√	√	√		√	√
	6b. Faith Helps Us	√	√	√	√		√	√	√
	7. Parents Want Better Communication	√		√	√	√	√		√
	7a. We Need Better Communication	√				√	√		√
	7b. Asserting Our Parenthood	√		√	√	√			√

Reappraisal	**8. Parents Do Not Know How Much More They Can Take**	√			√				√
Adaptation	**9. Adjusting to the NICU**		√	√	√	√		√	
	9a. This is our New Routine		√	√	√	√		√	
	9b. Paying it Forward	√	√		√			√	

Table 6. Subtheme Exemplars

Domain/Theme/Subtheme	**Exemplar**
Primary Appraisal: Theme 1: Deeply Distressing	
Subtheme 1a: Traumatic Pregnancy, Delivery, and Birth	D7M: "When my water broke so I was like, I feel fine. I don't know if it was the shock. Everything [was] fine. I don't feel anything. I am fine and I got on the stretcher and they are like look we have to tell you if you go into labor we have to take you to one hospital and not the other...that's where I think more of my scare and panic started coming in because why am [I] at the hospital, what's going on and they explained to me I was going to have an emergency C-section. I was so against C-sections and I want to have him vaginally. I want to experience everything, and they were like miss, he is already coming out. I was out and when I woke up from the anesthesia and everything, I was freezing cold and I'm like where's my baby, where's my baby and they finally brought him to me, and they told me how small he was. The hardest part for me and I think dad too was when they had to take him away and bring him here from another hospital..."
Subtheme 1b: How could this have happened to us	D2M: "I did question myself, what happened, where did this go wrong? Cause I did everything I was supposed to do."
Subtheme 1c: This is hard to accept-it feels like a bad dream	D1M: "It was hard to accept in the beginning. Like we thought that we were going to lose him basically."
Subtheme 1d: A Stressful Environment	D5D: "Sometimes, it gets a little overwhelming in that room. The different doctors and alarms, it's just --" D5M: "Yeah. They always have the lights. Sometimes the lights are so bright, like the other day, he's like, 'I have to leave here, because…' And then I was taking all this blood pressure medication. My blood pressure started to drop, I felt like I was going to pass out."

Secondary Appraisal: Theme 2: Unexpected and Unprepared: An Emotional Rollercoaster	
Subtheme 2a: Unexpected and Unprepared	D1M: "No. I mean I feel like we have been robbed from our like experience that, normal having a baby experience or like, we did not get to experience that the full happiness of it. I mean of course, we were happy that we have our son and, you know, he is getting to a healthy place hopefully, but like having a baby like the weekend I got admitted.... "
Subtheme 2b: An Emotional Rollercoaster	D8M: "Some days better than others, some hours better than others and I think it is like frustrating to be here, but also like he never really looks sick except for when he was like visibly sick and then I think when he initially got sick, we knew something was off, but like all the other pieces when he still fighting a really intense infection, he kind of looked okay." D8D: "It is hard, but nobody wants to be here. Everyone wants to be able to take their daughter or son home and be in the comfort of your own home. We understand some things don't work out that way and like everyone up here has been great, but nobody wants to be here."
Subtheme 2c: This is Different for Each of Us	D5D: "I mean I do get frustrated sometimes when she gets to the emotional part, but that's just me like – 'Don't be around him when you're like that. He needs positivity, not crying, you know. He's not dead.' D5M: "But if you really understand where it's coming from, like it's not -- it's not bad, but sometimes I just want to be like, 'Shut up and let me cry,' like at the same time, I understand because he deals with things like -- and like he said getting angry."
Secondary Appraisal: Theme 3: Expecting to Hear and Be Heard	
Emotion-focused coping: Theme 4: Becoming Parents	
Subtheme 4a: We are Parents	D1D: "If we see something we do not like- we will ask them nicely…" D1M: "…you know to adjust [his] CPAP. Too close to his eyes, or you know, we are known to be very vocal…" D1D: "So we are very protective…. we just want him home healthy and stronger."
Subtheme 4b: We Are Worried for Our Infant	D4M: "Just him not being able to have like a regular child life...that's what I worry about or him asking later on asking questions like how come I have never had a first birthday party, that gets to me."
Subtheme 4c: We Feel Like This Is Our Fault	D1M: "It's very disappointing because like we did everything possible, not to like ruin anything in the pregnancy and like this happens to you, kind of like okay and like why."

Subtheme 4d: The NICU Environment is Crucial	D2M: "...it's an amazing experience... me as a parent, I learned so much from the nurses. Sometimes I help them. It's such a way like when they are doing vitals, I know what's her blood pressure, first I used to ask, 'nurse is that good', now I don't have to ask because I know."
Emotion- focused coping: Theme 5: Stronger Together	
Problem-focused coping: Theme 6: Support is Key	
Subtheme 6a: Support from Family and Professionals Helps	D7D: " It is helping us. We are strong together, but when you have extra support you can't ever be mad at that. So, it definitely helped us a long way. Definitely...because it could have been more stressful if it was just me or her..."
Subtheme 6b: Faith Helps Us	D3D: "So sometimes I lose my patience and sometimes I have patience. But I don't lose my faith. And this is like my only thing, and I'm putting my life on it you know. But I'm coping well, pretty good because of my faith and I pray for her every day. I mean I pray for her like "...God, thank you for another day."
Problem-focused coping: Theme 7: Parents Want Better Communication	
Subtheme 7a: We Need Better Communication	D6M: "I was a little upset because I called them. They were supposed to call me...I was surprised no one called me...little bit after you left, we had to put the tube back in... oh man, no one called me, and I felt really bad."
Subtheme 7b: Asserting our Parenthood	D1D: "It was like, you know, I was not having it that day because I just wanted to know what was going on with our child, you know, that is it. So, that is the day, you know, I wish I did not have to, you know, get angry but it was just frustrating. So, a little more information would be helpful to parents because we are already dealing with stress -- "
Reappraisal: Theme 8: Parents do not Know How Much More They Can Take	
Adaptation: Theme 9: Adjusting to the NICU	
Subtheme 9a: This is Our New Routine	D4M: "I was by myself, but I wasn't by myself. Because we have been here for so long. Like all these nurses became our family…"
Subtheme 9b: Paying it Forward	D4M: "Yeah I always tell if someone should ever need someone to talk to...I have had someone else from a different hospital whose wife was going through the same exact thing and he asked me if I can talk to him, to just explain how things worked...so it's nice. I was just friends with him on Instagram and I guess he saw a picture that I posted of our son and we always posted like preemie strong and stuff like that...so that's how the conversation started."

CONCLUSION

This dissertation consists of three manuscripts: 1. A scoping review of parents' mental health in the NICU within the context of the Social Ecological Model (SEM) (1), 2. An integrative review of qualitative studies on parents' experiences in the NICU through the lens of the transactional model of stress and coping (2), and 3. A qualitative descriptive study of the experiences of parent dyads in the NICU, with the transactional model of stress and coping as a framework for analysis. Together, these manuscripts provide a foundation for future studies to examine the long-term effect of a NICU hospitalization on the parent dyad relationship, and their respective parenting styles.

1. SUMMARY OF MANUSCRIPTS

The initial study was a scoping review of the literature to examine factors contributing to parents' mental health during their infant's NICU hospitalization. This review included 26 studies that quantified parents' mental health using a variety of psychometric tools. The research methodology followed the Arksey and O'Malley framework (3) for scoping reviews, and the PRISMA methodology (4) for systematic reviews of the literature. Data was analyzed within the domains of the SEM (5) to determine multilevel factors contributing to parents' mental health. Intrapersonal characteristics, such as a history of mental illness, birth trauma, or infant characteristics including size and weight, affected the mental health of parents of infants hospitalized in the NICU. Interpersonal characteristics, such as the parent dyad relationship, also affected parents' mental health. Institutional characteristics, such as the experience in the NICU, were sometimes found to be stressor among parents. Finally, community level characteristics, such as screening protocols and availability of support groups, were noted as variables interrelated to parents' mental health when they experience the hospitalization of their infant in the NICU. The SEM is an overlapping model depicted as a nested model in this dissertation. The themes to emerge from the synthesis of quantitative studies of parents' mental health in the NICU within the SEM portrayed the interconnectedness of individual traits, relationships, the healthcare institution and social infrastructure resulting in unique experiences for parents in the NICU. A primary gap identified during the review was a lack of gender minority parents included in study samples. Recommendations emanating from this review were: further research on the incidence, experience, and symptoms of fathers and non-birth parents of infants hospitalized in the NICU, as well as interventions for those parents, and further research to identify and measure the outcome of screening and interventions to lessen the incidence and severity of parent psychological distress symptoms.

Subsequently, an integrative review of qualitative studies was conducted to synthesize findings from qualitative studies on the experiences and perceptions of a NICU hospitalization and coping mechanisms from the perspective of both parents in the dyad, through the lens of transactional model of stress and coping (6). Sixteen studies met final inclusion criteria; one criterion was inclusion of both parents in the study. The requirement that studies include both parents in the sample was intended to address the gap identified in the scoping review and include fathers' experiences in the synthesis of studies. The review followed the Whittemore and Knafl (7) methodology and evaluated the quality of included studies with the Critical Skills Appraisal Programme (CASP) checklist for qualitative studies (8). The major themes identified were: panic sequence, violated cognitive schema, emotional upheaval, regulating emotions, social support, faith, managing the NICU, and adjusting. The joint experience of the parent dyad was underrepresented in the review results because most studies focused on the parents as individuals, even when they participated in an interview together. The results of the integrative review, with the results of the scoping review, provided the foundation for the qualitative descriptive study of the experience of parent dyads in the NICU.

The qualitative descriptive study is presented in the third manuscript in this dissertation compendium. As with the integrative review, the transactional model of stress and coping was applied to describe the experiences of parent dyads with an infant in the NICU. Coping differences were identified between mothers and fathers; mothers had a more personal and emotional reaction to the hospitalization experience. Many mothers described crying more frequently and looking to their partner for support, while fathers adopted the role of the "strong" partner and remained stoic, feeling the need to be supportive of their partners and taking it day by day. Both mothers and fathers used emotion- and problem-focused coping methods; within the domain of emotion-focused coping, the theme *Stronger*

Together was most notable as a unique finding. Prior studies suggested the NICU hospitalization of an infant to be a risk for relationship dissolution, and an additional stressor; however, parents resoundingly endorsed feeling as if their relationships were stronger and they felt closer. Not all parents adjust to the hospitalization experience; the uncertainty associated with neonatal illness and prematurity leads some parents to reappraise their circumstances as worsening over time. Parents who do adjust become comfortable with the NICU environment and staff and their new routine, and some offer support to other parents to help them through difficult and uncertain times in the NICU.

2. LIMITATIONS OF DISSERTATION RESEARCH/LESSONS LEARNED

Parents may have had memory or recall bias and may not have remembered specific details or feelings they had during the hospitalization or may have put a more positive light on a situation when looking at it in hindsight (defensive reappraisal) (6). The sample size was smaller than anticipated as the goal was 30 interviews or data saturation. Just 22 interviews were completed (1 dyad was lost to attrition), yet information redundancy, or data saturation, was achieved. Recruitment proved difficult as parents were not always available, and many parent dyads at the 2 study sites either did not meet inclusion criteria during the recruitment time period or were not interested in research participation. The NICU admission is a stressful time for parents, and those who declined participation stated they did not want to spend the time they could be visiting their infant on an interview.

3. IMPORTANCE OF THEORY TO GUIDE OVERALL FINDINGS

The transactional model of stress and coping guided the integrative review (manuscript 2) and the qualitative descriptive study. These studies confirm the applicability of the transactional theory of stress and coping as a framework for working with this population. It supports the findings of LaMontagne, Johnson and Hepworth (1995) (9) and Lau and Morse (2001) (10) in applying this framework to practice in the NICU. The NICU hospitalization of an infant is a stressor for parents, and how they cope with the appraised stress varies based on the experience they are having. In both manuscript 1 and 2 parents discussed the anxiety the felt during primary appraisal, and the coping assessments they made during secondary appraisal. Parents have individual responses to stressful situations, as individual factors such as the novelty and predictability of their circumstances, the event uncertainty, and intrapersonal characteristics influencing appraisal will affect parents' responses to a NICU hospitalization. Coping is the key process in the model, and in both the integrative review and qualitative descriptive study, results suggest parents of infants hospitalized in the NICU utilize both emotion-focused and problem-focused methods. The outcome for some parents is adaptation, for others, reappraisal or defensive reappraisal of the NICU hospitalization of their infant. When applying this framework to practice, Lamontagne, Johnson, and Hepworth (1995) recommend nurses can become resources for parents to help them reduce their stress, to help them activate coping mechanisms, and to help them participate in the care of the infant. (9) This qualitative descriptive study in this dissertation furthers those recommendations based on findings within the transactional model of coping and stress: clear and consistent communication from NICU staff members assists parents in problem-solving coping and provides them with the information they need to manage the situation. Supporting the parent dyad relationship and leveraging their strengths assists in emotion-focused coping.

4. RESEARCH TRAJECTORY

Continued analysis of this data set is warranted; themes from the individual interviews with mothers will be analyzed within the birth trauma middle theory, and themes from the individual interviews with fathers will be analyzed using a gender analysis framework. The dyad interviews will also be reexamined through the lens of the SEM, as social determinants of health, health literacy, and unconscious bias were all evident in some of the dyad experiences. Further research regarding the impact of a NICU hospitalization on the relationship between parent dyad members, specifically a longitudinal study in which parents are followed to 6 months post-discharge from the NICU, may lead to a better understanding of the long-term effects of this specific stressor on parents. It would be prudent to gain the perspective of gender minority dyads and/or dyads who adopted or used a surrogate and had an infant in the NICU to guide appropriate care. It is a goal of Healthy People 2020 (11) to promote LGBT mental health and well-being, and staff in the NICU note anecdotal increases in gender minority parents who may have different needs, experiences, and coping skills. The need for more support was noted by several dyads who participated in the dissertation study. Exploratory and experimental research on types and efficacy of support for parents in the NICU may inform and address how best to meet the needs of this population by guiding intervention development and testing to support the parent dyad relationship and maximize on their perceived strengths.

5. CONTRIBUTION OF RESEARCH TO CLINICAL CARE

This study addressed gaps in the literature by examining the experiences of parents with infants in the NICU as a dyad, not only as individuals. Findings contributed new knowledge about the differing experiences and effects of a NICU hospitalization on each parent of the dyad, and the perceived positive effects of the NICU hospitalization on the dyad relationship. Results from this study may inform the design of future studies and the development, refinement, and testing of supportive interventions for parents at risk for psychological distress secondary to a NICU hospitalization of their infant. Results from this study also have the potential to guide supportive interventions for the parent dyad relationship, to maximize the perceived strengths of the dyad, and may ultimately inform the creation of a family-centered care model in partnership with parents. Parents want a cohesive message from the treatment team, need to bond with their infant, and need support; a family-centered care model could address these needs.

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APPENDIX A

Northwell Health℠

Institutional Review Board
FWA #00002505
Office of the Human Research Protection Program
125 Community Drive
Manhasset, NY 11030
Phone: 516-465-1910

The study cannot begin enrollment until you receive Northwell Institutional Approval (IA). Institutional Approval is separate from IRB approval, and will be issued in a separate letter. For IA guidance click here, or visit the HRPP website.

To: Kristy Loewenstein-Meyerowitz
75-59 263RD ST
GLEN OAKS, NY 11004

From: Hallie Kassan, MS, CIP
Director, Human Research Protection Program

Date: October 02, 2018

RE:
IRB #: 18-0701
Protocol Title: The experience of parent dyads in the neonatal intensive care unit
Approval Date: October 02, 2018
Expiration Date: October 01, 2019

Dear Kristy Loewenstein-Meyerowitz

The above referenced project meets the criteria outlined in 45 CFR 46.110 and 21 CFR 56.110 for EXPEDITED REVIEW and has been approved. The following category(ies) apply(ies) to the project:

45 CFR 46.110 (6) – Collection of data from voice, video, digital, or image recordings made for research purposes.

45 CFR 46.110 (7) – Research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Expedited Approval of this project includes:

1. Protocol (version 09/24/18)
2. Consent (version 09/24/18)
3. Recruitment Flyer (version 09/24/18)
4. Individual Interview Guide (version 09/24/18)
5. Dyad Interview Guide (version 09/24/18)
6. Demographic Data Collection (version 09/24/18)
7. Joint Demographic Data Collectino (version 09/24/18)
8. The following study personnel are approved to participate in the study and obtain consent: Kristy

Please note: **Please make sure to use the IRB STAMPED consent form when obtaining consent from subjects**.

The Institutional Review Board will be notified of this action. This study has not been approved for the inclusion of pregnant women, children, or prisoners. If you would like to include these populations, please notify the IRB for further instruction.

The IRB approval expiration date is listed above. As a courtesy, approximately 60 to 90 days prior to expiration of this approval, the Office of the IRB will send an e-mail reminding you to apply for continuing review. Failure to receive renewal notification does not relieve you of your responsibility to provide the Progress Report to the IRB in time for the request to be processed and approved prior to your expiration date. It is your responsibility to apply for continuing review and receive continuing approval for the duration of the study. Lapses in approval should be avoided to protect the safety and welfare of enrolled subjects.

Subject recruitment methods for enrollment are appropriate, there is equitable selection of subjects, and there are provisions to protect and maintain the confidentiality of data and research participants.

Investigators are reminded that research must be conducted in accordance with all applicable Department of Health and Human Services regulations 45 CFR 46, Food and Drug Administration regulations 21CFR 50, 21CFR 56, 21 CFR 812, and the Health Insurance Portability and Accountability Act (HIPAA).

All studies are subject to audits by the Office of Research Compliance and/or Institutional Review Board to confirm adherence to institutional, state, and federal regulations governing research.

NOTE: This approval is subject to recall if at any time the conditions and requirements as specified in the IRB Policies and Procedures are not followed (see next page and web site: http://www.northshorelij.com/body.cfm?ID=2804)

NOTE: All IRB Policies and Procedures must be followed, including the following:

1. Using only IRB-approved consent forms, questionnaires, letters, advertisements, etc. in your research.
2. Submitting any modifications made to the study for IRB review prior to the initiation of changes except when necessary, to eliminate apparent, immediate hazards to the subject.
3. Reporting unanticipated problems involving risk to subjects or others.
4. Prior to implementation, any changes made to studies utilizing TAP must have COPP, as well as IRB approval.

IMPORTANT REMINDER: The International Committee of Medical Journal Editors (ICMJE)

requires registration of clinical research studies meeting specific guidelines prior to publication. Please see ICMJE requirements for registration of clinical trials at http://www.icmje.org. Our organization account is in the name of the North Shore-Long Island Jewish Health System. To register your trial: http://prsinfo.clinicaltrials.gov. You must register your trial PRIOR TO ENROLLING SUBJECTS.

Institutional Review Board
FWA #00002505
Office of the Human Research Protection Program
125 Community Drive
Manhasset, NY 11030
Phone: 516-465-1910

To: Kristy Loewenstein-Meyerowitz

75-59 263RD ST

GLEN OAKS, NY 11004

From: Hallie Kassan, MS, CIP

Director, Human Research Protection Program

Date: February 08, 2019

Re: **IRB #:** 18-0701

Protocol Title: The experience of parent dyads in the neonatal intensive care unit

Modification Approval Date: February 08, 2019

Dear Kristy Loewenstein-Meyerowitz:

This is to advise you that the modification received for the above referenced study was reviewed by the Institutional Review Board and the following determination was made:

Expedited Approval for the following:

1. Revised Protocol (version 01/24/19)

2. Revised Consent Form (version 02/08/19). Re-consent of enrolled subjects is not required.
3. Demographic Questionnaire (dated 02/01/19) 4. Acknowledge:

a. Summary of change (not dated)

Please note: If consent forms have been revised with this modification, please make sure to use the newly stamped consent forms going forward.

This modification was reviewed in accordance with 45 CFR 46.110 (b) and 21 CFR 56.110 (b). All conditions of approval previously established by the IRB for this research project continue to apply. The Institutional Review Board will be notified of this action at its meeting on February

26, 2019

All studies are subject to audits by the Office of Research Compliance and/or Institutional Review Board to confirm adherence to institutional, state, and federal regulations governing research.

NOTE: This approval is subject to recall if at any time the conditions and requirements as specified in the IRB Policies and Procedures are not followed.

1. Using only IRB-approved consent forms, questionnaires, letters, advertisements, etc. in your research.
2. Submitting any modifications made to the study for IRB review prior to the initiation of changes except when necessary, to eliminate apparent, immediate hazards to the subject.
3. Reporting unanticipated problems involving risk to subjects or others.
4. Renewing the study at the interval set by the Institutional Review Board. You should submit a progress report to the Institutional Review Board at least two months prior to expiration of the study. Failure to receive notification that it is time to renew does not relieve you of your responsibility to provide the IRB with the Progress Report in time for the request to be processed and approved prior to your expiration date.
5. Prior to implementation, any changes made to studies utilizing TAP must have COPP, as well as IRB approval.

<u>IMPORTANT REMINDER:</u> The International Committee of Medical Journal Editors

(ICMJE) requires registration of clinical research studies meeting specific guidelines prior to publication. Please see ICMJE requirements for registration of clinical trials at http://www.icmje.org. Our organization account is in the name of the North Shore-Long Island Jewish Health System. To register your trial: http://prsinfo.clinicaltrials.gov.

MUSC
MEDICAL UNIVERSITY
of SOUTH CAROLINA

Institutional Review Board for Human Research (IRB)

Office of Research Integrity (ORI)

Medical University of South Carolina

Harborview Office Tower

19 Hagood Ave., Suite 601, MSC857

Charleston, SC 29425-8570

Federal Wide Assurance # 1888

Pro00079842

Title: The experiences of parent dyads in the neonatal intensive care unit

Submitted by: Kristy Lowenstein

Department: Medical University of South Carolina

External IRB: Northwell Health

MUSC IRB received the below research proposal and reviewed it for local requirements. You have completed the local requirements for External IRB review. This confirms that an IRB authorization agreement with the organization identified above has been executed to rely on their IRB for continuing oversight of this study. This agreement specifies the roles and responsibilities of the respective entities.

This reliance is contingent upon the continued approval of the study by the lead IRB. As the investigator, you should immediately report any unanticipated and/or adverse events, or early termination to the lead IRB.

Annual Status Update Due on or before: 10/1/2019

Type: **External IRB Review**

REPORTING REQUIREMENTS TO MUSC:

It is your responsibility to:

1. Inform the MUSC IRB about any actions by the external IRB affecting their approval to conduct the study, including suspension or termination of approval.

2. Submit a modification to the MUSC IRB if/when new personnel are added to the study team or the study is modified in such a way that additional institutional approvals are required. (e.g. radiation safety, conflict of interest)

3. Report to the IRB of Record as well as the MUSC IRB any complaints from a subject or other person regarding the research.

4. Submit a copy of the external continuing review approval letter to the MUSC IRB when the study is renewed.

5. Maintain compliance with all MUSC policies.

IRB Reliance Manager, **IRB-I - Medical University of South Carolina**

Summer Young, MPH, CIP

∗***Electronic Signature****: This document has been electronically signed by the IRB Administrator through*

the HSSC eIRB Submission System authorizing IRB approval for this study as described in this letter.

MUSC Principal Investigator/Study Team Responsibilities when serving as a Relying Site

As the Relying Site Investigator for which MUSC is deferring IRB review to a Reviewing IRB, the Relying Site Investigator has direct responsibilities that include, but are not limited to, the following:

1. Meet MUSC education requirements (e.g. CITI training)

2. Comply with the determinations and requirements of the Reviewing IRB, which includes conducting the research in accordance with the reviewing IRB's policies and procedures, the IRB-approved documents and conditions of approval, and any applicable laws and regulations.

3. Ensure that the Reviewing Site PI has provided approval letter for the MUSC site before initiation of the research activities at MUSC.

4. Maintain appropriate copies of all approvals, and other correspondence documenting the review and approval of the research as required by the regulations.

5. Submit a modification to the MUSC IRB if/when:

   - new personnel are added to the study team
   - the study is modified in such a way that additional institutional approvals are required. (e.g. radiation safety, conflict of interest)
   - Changes are made which affect institutional policy/state law requirements
   - Changes to conflict of interest

6. Report promptly to the Reviewing IRB any proposed changes in the research. No changes should be initiated in the research (including changes in the consent document) without prior Reviewing IRB review and approval, except where necessary to eliminate apparent immediate hazards to the participants.

7. Report to the Reviewing IRB any unanticipated problems involving risks to participants or others; non-compliance or any complaints from a subject or other person regarding the research according to the Reviewing IRB's reporting policy.

8. Report to the Reviewing IRB protocol deviations according to the Reviewing IRB's reporting policy.

9. Report to the Reviewing IRB as well as the MUSC IRB any complaints from a subject or

APPENDIX B

INFORMED CONSENT

Northwell Health

Campus: CCMC, NSUH

Consent for Participation in a Research Study

Title: **The experiences of parent dyads in the neonatal intensive care unit**

Principal Investigator: Kristy Loewenstein, MSN, RN-BC, PMHNP-BC

About this research

You are being asked to participate in a research study.

This consent form will give you information about the study to help you decide whether you want to participate. Please read this form, and ask any questions you have, before agreeing to be in the study.

Important Information

This information gives you an overview of the research. More information about these topics may be found in the pages that follow.

Please review the rest of this document for details about these topics and additional things you should know before making a decision about whether to participate in this research.

Why am I being asked to provide my consent?	This is a research study, which is different than personal medical care. Scientists do research to answer important questions which might help change or improve the way we do things in the future.
Do I have to join this research study?	No. Taking part in this research study is voluntary. You may choose not to take part in the study or may choose to leave the study at any time. Deciding not to participate, or deciding to leave the study later, will not result in any penalty or loss of benefits to which you are entitled.
Why is this research study being done?	The purpose of this research study is to learn about the experiences and coping tools of parents in the NICU. You are being asked to participate in this study because you have or have had a child in the NICU for more than 2 weeks. The differences and similarities of parents' experiences, the effects of the NICU hospitalization on their relationships, and the effect of the hospitalization on parenting styles will be specific areas examined.
What will happen to me during the study?	If you agree to be in this study, you will be interviewed. The interview will include you and your partner/co-parent. During the first interview, you and your partner/co-parent will be asked to describe what led to your child's NICU hospitalization, and what the experience was like for each of you. You will also complete a demographic survey. At the end of the first interview and survey, you will be asked to schedule the second interview. The second interview will be alone, and each parent will schedule a separate interview.
How long will I participate?	If you choose to take part in this study, the study procedures will last for 2 visits over a period of 1 week. Each visit will last 1-1.5 hours each.
Will taking part expose me to risks?	Some of the questions we will ask you are personal. You may feel embarrassed or stressed. You may ask to see the questions before deciding whether or not to take part in this study. Some of these questions may seem very personal or embarrassing. They may upset you. You may skip any question that you do not want to answer. There is a risk a loss of confidentiality of your personal information or your child's personal information because of participation in this study. To maintain your confidentiality, interviews will take place in a private room, so they are not overheard. Your name and your child's name will be changed during transcription of the interview, to further protect your identities. Protected health information about you and your child will be collected or used for this study and will be stored on a secured database to minimize data breaches or disclosure.

Are there any benefits to participation?	There are no known benefits to subjects, although you will be given a chance to talk about your feelings about your experience in the NICU and you may feel as though you are getting support through the interview. It is hoped this information may help us to learn more about the experiences of parents when their child is in the NICU, and how the needs of parents in the NICU are best met.

Introduction

You are being asked to join a research study. The purpose of a research study is to answer specific questions.

This consent form will explain:

- the purpose of the study
- what you will be asked to do
- the potential risks and benefits

It will also explain that you do not have to be in this study to receive medical care. You should ask questions before you decide if you want to participate. You can also ask questions at any time during the study.

Why is this research study being done?

The purpose of this research study is to learn about the experiences and coping tools of parents in the NICU. You are being asked to participate in this study because you have or have had a child in the NICU for more than 2 weeks. The differences and similarities of parents' experiences, the effects of the NICU hospitalization on their relationships, and the effect of the hospitalization on parenting styles will be specific areas examined.

How many people will take part in this study?

About twenty couples (forty individual parents) will take part in this study. This study will use interviews to explore the experiences of both parents regarding your child's NICU hospitalization. We hope to enroll all forty participants at this site.

How long will you be in this study?

If you choose to take part in this study, the study procedures will last for 2 visits over a period of 1 week. Each visit will last 1-1.5 hours each.

What will happen in this research study?

If you agree to be in this study, the following will happen:

1. The researcher will contact you to set up a time a place for the first interview. This interview will include you and your partner/co-parent.

2. The first interview will take about 1-1½ hours. During the first interview, you and your partner/co-parent will be asked to describe what led to your child's NICU hospitalization, and what the experience was like for each of you. During the joint interview, the researcher will ask you specific demographic questions

about the birth of your child. You will be asked how you coped with the NICU hospitalization of your child. You will also be asked how the NICU experience affected your relationship with the other parent, and how it affected the way in which you parent your child.

3. All interviews will be recorded with a smartphone and digital tape recorder.
4. After the first interview is finished, you will be asked to complete a demographic survey on a tablet/laptop, or if you prefer, on paper. The survey will include questions about your age, race, ethnicity, marital or relationship status, prior children or pregnancies, and other similar questions. It will take about 10 minutes to complete.
5. At the end of the first interview and survey, you will be asked to schedule the second interview. The second interview will be alone, and each parent will schedule a separate interview. The second interview should take place within a week of the first interview and will take 45 minutes- one (1) hour.
6. The second interview will ask questions like those asked in the first interview. You will be asked if you thought of anything else to share since the first interview, in addition to the interviewer asking you follow-up questions.

What are the risks of the research study? What could go wrong?

Interviews/Questionnaires

Some of the questions we will ask you are personal. You may feel embarrassed or stressed. You may ask to see the questions before deciding whether or not to take part in this study.

Some of these questions may seem very personal or embarrassing. They may upset you. You may skip any question that you do not want to answer. If the questions make you very upset, we will help you to find a counselor.

There is a risk of a loss of confidentiality of your personal information or your child’s personal information because of participation in this study. To maintain your confidentiality, interviews will take place in a private room, so they are not overheard. Your name and your child’s name will be changed during transcription of the interview, to further protect your identities. Protected health information about you and your child will be collected or used for this study and will be stored on a secured database to minimize data breaches or disclosure.

Information about your study participation will not be in your medical record. This means that neither your research participation nor any of your research results will be included in any Northwell Health medical record. A possible risk is the loss of confidentiality about your medical information. We will do our best to make sure that your personal information is kept private. The chance that this information will be given to someone else is very small.

What are the benefits of this research study?

There are no known benefits to subjects, although you will be given a chance to talk about your feelings about your experience in the NICU and you may feel as though you are getting support through the interview. It is hoped this information may help us to learn more about the experiences of parents when their child is in the NICU, and how the needs of parents in the NICU are best met.

Are there any costs for being in this research study?

You will not have any added costs from being in this study.

Will you receive any payments for participating in this research study?

You will be paid $60 in total, in the form of gift cards, for your time and travel expenses for being in this study. You will receive a $30 gift card for the joint interview (each parent), and you will receive a $30 gift card for the individual interview (each parent). If you do not complete the entire study, you will be paid for the number of visits that you have completed. Payment will be made at the end of the study or when you end your participation.

If the total payment you receive from Northwell Health, during this year, is equal to $600 or more, the payment is required to be reported to the IRS. Although this study does not pay $600, if you participate in other Northwell Health studies, it is possible your payment could end up totaling $600. If this occurs, the payment you receive on this study will be reported to the IRS. In this case, you will be issued a 1099 form and be required to provide your social security number at that time for reporting purposes. You will also be responsible for reporting this income while filing your tax return.

What are your rights as a research participant?

Your participation in this project is voluntary. The quality of your medical care will be the same, whether you join, refuse to join, or decide to leave the study.

If you do not join the study you will not be penalized or lose benefits to which you are entitled. If you join the study you may withdraw at any time without prejudice to your future care at Northwell Health.

Could you be taken off the study before it is over?

It is also possible that your participation in this study may end without your consent. This decision may be made by a researcher, study sponsor or the Institutional Review Board (IRB- the committee that oversees research at this institution).

Reasons for withdrawal may include:

- failure to follow instructions,
- failure to show up for study visits,

- it is not in your best interest to continue on this study, or the study is stopped.

If you withdraw from this study or if you are withdrawn from the study, any data (or samples) already collected will continue to be used. However, no new data will be collected.

What information will be collected and used for this study?

If you agree to be in this study, we will collect health information that identifies you. We will collect the results of questionnaires and interviews. We will only collect information that is needed for the research. This information has been described in this consent form. If you sign this consent form, you are giving us permission to collect, use and share your health information. This permission is called authorization. If you do not want to provide authorization, then you cannot participate in this research study.

Who else will see your information?

Study records that identify you will be kept private. You will not be identified in study records or publications disclosed outside Northwell Health, except as detailed below.

Investigators will share information collected from this research study with:

- other researchers,
- accrediting agencies,

The following reviewers may access your study and medical records to make sure that this study is being done properly:

- Representatives from Federal and state government oversight agencies, such as the Department of Health and Human Services.
- Representatives from Northwell Health's Human Research Protection Program (a group of people that oversee research at this institution)
- Representatives from Medical University of South Carolina's Human Research Protection Program

We will do our best to protect the privacy of your records, but it is possible that once information is shared with people listed on this form, it may be released to others. If this happens, your information may no longer be protected by the federal law.

In the future, we may publish results of this study in scientific journals and may present it at scientific meetings. If we do, we will not identify you.

How long will your health information be kept?

There is no limit on the length of time we will keep your information for this research because it may be analyzed for many years. We will keep it as long as it is useful, unless you decide you no longer want to take part or we close the study. You are allowing access to this information indefinitely.

Can you change your mind?

If you change your mind about being in the study, you may withdraw at any time. If you want us to stop collecting your health information, you need to send a letter to the researcher at the following address:

Kristy Loewenstein, RN,
NPP Zucker Hillside
Hospital

75-59 263rd St.
Glen Oaks, NY 11004

Your letter needs to say that you have changed your mind and do not want the researcher to collect and share your health information. You may also need to leave the research study if we cannot collect any more health information. We may still use the information we have already collected. We need to know what happens to everyone who starts a research study, not just those people who stay in it.

Information collected from you for this research may be used for future research studies or shared with other researchers for future research. If this happens, information which could identify you will be removed before any information or specimens are shared. Since identifying information will be removed, there will not be an additional consent for future research. By consenting to participate in this study you are agreeing to allow your de-identified data to be used by future researchers without additional consent.

Does the investigator of this study receive money if you take part?

The investigators on this study do not receive money for your participation in this study.

Who can answer your questions about this study?

If you have any questions about the study, you may call Kristy Loewenstein, RN, NPP at (718)
470-8506. If you have questions about side effects or injury caused by research you should call Kristy Loewenstein, RN, NPP at (718) 470-8506. If you need emergency care, dial 911 or go to the nearest Emergency Room. If you have questions about your rights as a research participant, concerns about being in the study, or would like to offer input, you may contact the Office of the Institutional Review Board (the committee that oversees research at this institution) at (516) 465- 1910.

A signed copy of this consent form will be given to you.

[Signature Page Follows]

Summation/Signature

You have read the above description of the research study. You have been told of the risks and benefits involved and all your questions have been answered to your satisfaction. A member of the research team will answer any future questions you may have. You voluntarily agree to join this study and know that you can withdraw from the study at any time without penalty. By signing this form, you have not given up any of your legal rights.

____

Printed Name of Participant

____ ______________

Signature of Participant Date

___________________________ __________________ __________

Witness's Printed Name Witness's Signature Date

(Note: A witness can be a member of the research team, but cannot be the same person signing consent as the investigator)

Investigator's Statement

I have offered an opportunity for further explanation of the risks and discomforts which are or may be associated with this study and to answer any further questions relating to it.

_____________________________ ___________

Investigator's signature **Date**

____

Investigator's printed name

APPENDIX C DATA USE AGREEMENT BETWEEN NORTHWELL HEALTH AND MUSC

This Academic and Research Program Collaboration Agreement (this "Agreement"), dated as of November 7, 2018 (the "Effective Date") is made by and between Northwell Health, Inc. Institute for Nursing ("Institute") and The Medical University of South Carolina ("University"), each a "Party" and together the "Parties".

WHEREAS, Institute is a New York not-for-profit corporation;

WHEREAS, University is an institution of higher learning having an address at 171 Ashley Avenue, Charleston, SC 29425 which, through its College of Nursing, administers University's Doctor of Philosophy in Nursing Science (the "Program");

WHEREAS, Institute and University are parties to an Educational Affiliation Agreement (the "Affiliation Agreement") in which University expressed an interest in and a desire to, among other things, have its students receive clinical education and training at Northwell facilities; and

WHEREAS, consistent with and in furtherance of the Affiliation Agreement, the purpose of this Agreement is to set forth the basic terms and conditions by which University and Institute shall collaborate to support student Kristy Loewenstein in defending her dissertation pursuant to the Program (the "Purpose").

NOW, THEREFORE, in consideration of the mutual promises set forth in this Agreement, the sufficiency of which is hereby acknowledged, the Parties agree as follows:

1. Program Description and Responsibilities

a.University's Obligations

i. The Program. The Program is an accelerated Ph.D. in Nursing Science designed to prepare graduates for a career of externally funded research, scholarly publication and professional leadership. The curriculum includes a dissertation course that provides students who have entered candidacy and passed their dissertation proposal defense to complete the dissertation research requirements. Except with respect to those activities outlined herein that are Institute's obligations, University is and shall remain fully responsible for all aspects of the Program including, but not limited to, all academic control of the phases of the Program *(e.g.,* administration, recordkeeping, planning, curriculum content and instruction, faculty appointments, requirements for matriculation, promotion and graduation, and

program accreditation). University shall maintain ongoing communication with Institute with respect to Institute's participation in the Program as more fully described herein.

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ii. <u>The Program Scholar</u>. For purposes of this Agreement, Kristy Loewenstein shall serve as the "Program Scholar". The Parties agree Ms. Loewenstein will conduct the research for her dissertation at Institute. A summary of Ms. Loewenstein's research along with the dissertation guidelines, academic process, timeline, and deliverables shall be fully described a Statement of Work (SOW) which, upon acceptance by both Parties and execution by the Program Scholar acknowledging both the terms of this Agreement and the applicable Statement of Work, shall be attached hereto as Exhibit A and made a part hereof by reference. For purposes of clarity, any information pertaining to the Program Scholar's research disclosed to University and its employees, agents and/or contractors, including the Dissertation Chair and the dissertation committee members will be de-identified in accordance with the requirements of the Health Insurance Portability and Accountability Act of 1996, Public Law 104-191 ("HIPAA"), specifically 45 C.F.R §164.514.

iii. <u>Maintenance of Records.</u> Institute shall require Program Scholar to maintain accurate and complete laboratory notebooks and/or other written documentation of Program Scholar's research activities pursuant to the guidance provided in ICH Topic E6, Good Clinical Practice: Consolidated Guidance. Upon completion of the term of this Agreement, Institute shall require Program Scholar to submit original copies of any and all such documentation to her Institute Mentor. The Parties agree Program Scholar may retain a copy of her written documentation for use in accordance with the terms of this Agreement.

iv. <u>Dissertation Chair and Committee Members</u>. University shall provide the Program Scholar with a dissertation chair who shall serve as the Program Scholar's advisor (the "Dissertation Chair"). The Dissertation Chair shall serve as Institute's primary point of contact with respect to the Program Scholar and shall be identified in the corresponding Statement of Work.

v. Institute will require Program Scholar to obtain the required training, approvals and authorizations for performance of the research, in accordance with Institute policies and procedures, as well as applicable laws, regulations and standards.

b. Institute's Obligations

i. <u>Generally</u>. For the Term (as defined below), and in accordance with the terms of this Agreement, Institute agrees to cooperate with University with respect to the Program.

ii. <u>Resources</u>. As more fully described in each Statement of Work, Institute shall make those facilities and other resources available to the Program

Scholar as are necessary and to the extent practicable in order to assist the Program Scholar in carrying out her dissertation.

iii. Institute Mentor. Institute shall provide the Program Scholar with a mentor (the "Institute Mentor"). The Institute Mentor shall supervise the Program Scholar with respect to those dissertation activities related to or involving Institute and be available to answer questions and provide guidance and advice to the Program Scholar both generally and with respect to her dissertation.

2. Rules and Restrictions

i. Institute Policies. The Program Scholar shall at all times be subject to and required to comply with applicable Institute policies, rules, regulations and procedures including, but not limited to, Institute's *Policy on Intellectual Property*.

ii. Removal. At Institute's request, University shall immediately suspend and remove from Northwell premises the Program Scholar should the Program Scholar fail to obey Institute's policies, rules, regulations and procedures or whenever, in the judgment of Institute, such removal shall serve the best interests of Northwell and its patients. The Program Scholar who is removed pursuant to this paragraph may be permitted to return when and if the underlying problem or condition is resolved to the mutual satisfaction of University and Institute.

3. Insurance and Indemnification

The insurance and indemnification provisions set forth in the Affiliation Agreement entered into between the Parties on February 20, 2018 shall govern.

4. Confidentiality and Publication

a. Confidentiality.

i. "Confidential Information" means (i) any nonpublic information concerning Program Scholar's research, or other nonpublic information, of Northwell and/or Institute, or (ii) any nonpublic information of any third party that has been confidentially entrusted to Northwell and/or Institute, in either case (i) or (ii) to which Program Scholar may become privy while conducting the research for her dissertation at Institute. Confidential Information may include but shall not be limited to unpublished data, observations, methods and materials and any Protected Health Information (as defined by HIPAA), medical record or other patient or research subject information that may be disclosed to or observed by Program Scholar.

ii. University (i) may use the Confidential Information for its internal purposes only and (ii) shall hold all Confidential Information in confidence and not, directly or indirectly, publish, disseminate or otherwise disclose, deliver or make available to any third party any Confidential Information, except as expressly permitted hereunder. University may disclose Confidential Information to its employees, agents and contractors on a need-to-know basis, but only if those employees, agents, and contractors are bound by obligations of confidentiality at least as restrictive as those set forth herein. University shall be liable to Institute for the performance of its employees, agents, and contractors hereunder.

iii. Confidential Information shall not include any information which:

1. is, or later becomes, generally available to the public through no breach of this Agreement by University;
2. is obtained by University from a third party who had the legal right to disclose such information to University;
3. is already in possession of University prior to disclosure hereunder as shown by prior written records; or
4. is independently discovered or developed by University without use of Confidential Information as show by prior written records.

In the event that University is required by a governmental authority or by order of a court of competent jurisdiction to disclose any Confidential Information, University will give prompt written notice to Institute of any such required disclosure and will reasonably cooperate with Institute, so Institute can seek an appropriate protective order, or exert any exclusions or exemptions that may be available to it.

b. Publication. Subject to the terms of any grant, award or regulation to which Program Scholar may be subject, Program Scholar may publish, or otherwise publicly disclose (collectively, "Publish"; such a Publishing is a "Publication") or submit for Publication an article, manuscript, abstract, report, poster, presentation, or other material (each a "Manuscript") that may include: (i) an analysis of the results of the research; and (ii) a summary of the protocol including any related methodology used to carry out the research, in each case as would be reasonably required for purposes of publication in a peer-reviewed scientific journal. The information encompassed in (i) and (ii) shall be collectively referred to herein as "Permitted Information". Not less than sixty (60) days prior to the earlier of Publication or submission for Publication of any Manuscript, University shall or shall require the Program Scholar to, provide Institute with a copy of the Manuscript. University and Program Scholar shall consider in good faith any comments submitted by Institute regarding the content thereof, and shall delete any Confidential Information identified in writing by Institute. At Institute's request, University shall require Program Scholar to delay Publication or submission for Publication of the Manuscript, as the case may be, for no more than an additional sixty (60) days to allow Institute to file patent applications at Institute's expense.

5. Term and Termination

a. This Agreement and the SOW shall be effective as of the Effective Date and shall continue for eight (8) months unless terminated. This Agreement and the SOW (i) may be terminated by either Party, with immediate effect, due to the other Party's material breach of its obligations hereunder if not cured within a reasonable time after notice not to exceed thirty (30) days; or (ii) may be terminated by either Party without cause upon sixty (60) days' prior written notice to the other Party.

6. General

a. Intellectual Property. The Parties acknowledge and agree that the terms of Nothwell's *Policy on Intellectual Property* and Northwell's *Policy on Technological Licensing and Distribution of Royalty Income* govern the disposition of *Inventions* as that term is defined therein. University agrees and understands that the Program Scholar is obligated to assign and has preemptively assigned to Institute all of the Program Scholar's rights in intellectual property conceived or made by the Program Scholar and arising from the activities of the Program Scholar that has been or is supported in whole or in part by Institute resources. University has no rights by reason of this Agreement in and to any Invention.

b. No Agency or Joint Venture. It is expressly acknowledged by the Parties that each is an "independent contractor" with respect to the other and nothing in this Agreement is intended or shall be construed to create an employer/employee relationship, an agency relationship or a joint venture relationship.

c. Non-Discrimination. Neither Party shall discriminate against any employee, applicant or program participant on the basis of race, color, handicap, national origin, creed, sex, sexual orientation, age, marital status, physical disability, blindness, genetic predisposition, carrier status or any other protected classification under local, state or federal laws.

d. Compliance with Applicable Laws, Rules and Regulations. In connection with performance under this Agreement, each Party shall comply with all federal, state and local laws, rules and regulations applicable to that Party.

e. Use of Name. No Party will, without the prior written consent of the other Party, use the name, trademark, logo, symbol, or other image or mark of the other Party or that other Party's employee, medical staff member, or agent, or any adaption thereof, for advertising, trade, publicity, news or other commercial purposes or in connection with any press release, advertising, promotional literature, or any other publicity matters relating to this Agreement without the prior written approval of the other Party; provided that (1) this Section shall not restrict a Party's ability to use the other Party's name in regulatory filings, prosecuting or defending litigation, and complying with applicable governmental regulations and legal requirements, and (2) the foregoing will not preclude the use of a Party's name for internal use and reports generated in the normal course of business.

f. Miscellany. This Agreement (including the exhibits attached hereto) contains the entire agreement of the Parties concerning the Program Scholar's dissertation and supersedes all prior agreements, understandings, memoranda, and other such communications, whether oral or written, relating to the subject matter of this Agreement. To the extent that any provision of this Agreement conflicts with the terms of the Affiliation Agreement, the terms of the Affiliation Agreement shall control. To the extent any provision of this Agreement shall be held to be invalid, illegal or unenforceable, the validity, legality and enforceability of the remaining provisions shall in no way be affected or impaired thereby. This Agreement shall be binding upon and inure to the benefit of the Parties and their respective successors and assigns. This Agreement shall not be assigned by either Party except with the prior written consent of the other Party. This Agreement shall not be amended or modified except by agreement of the Parties as memorialized in a signed, written amendment. This Agreement may be executed in counterparts and each such counterpart, when taken together, shall constitute a single and binding agreement. The waiver of any breach of any term or condition of this Agreement shall not be deemed to constitute the waiver of any other breach of the same or any other term or condition. Expiration or earlier termination of this Agreement shall not relieve the Parties of obligations, if any, accruing prior to such expiration or termination or with respect to any obligation under this Agreement that by its nature survives expiration regardless of cause. Nothing express or implied in this Agreement is intended or shall be deemed to confer upon any person other than Institute and University, and their respective successors and assigns, any rights, obligations, remedies or liabilities.

g. Governing Law. The Parties agree to remain silent with respect to governing law.

h. Notices. All requests, reports, approvals and notices required or permitted to be given under this Agreement shall be in writing sent to the address set forth herein and, unless specifically provided otherwise in this Agreement, shall be deemed to have been given when sent if personally delivered, faxed (with receipt confirmed) or mailed by registered or certified air mail, return receipt requested, or by overnight mail (with receipt confirmed), postage prepaid, to the party concerned, at its address or addresses as set forth below or as designated from time to time by notice in writing.

If to Institute:

Northwell Health, Inc.
400 Lakeville Road, Suite 170
New Hyde Park, NY 11042
Attn.: SVP & Chief Nurse Executive
with a copy to Legal (claims or notices, only):

Northwell Health, Inc.
Office of Legal Affairs
2000 Marcus Avenue
New Hyde Park, NY 11042
Attn.: General Counsel

If to University:

MUSC College of Nursing
99 Jonathan Lucas Street MSC 160
Charleston, SC 24425
Attn.: Clinical Education Manager

i. <u>Mutual Cooperation</u>. The Parties recognize that in the performance of this Agreement, the greatest benefits will be derived by promoting the interests of both Parties and each Party does, therefore, enter into this Agreement with the intention of cooperating with the other in carrying out the terms and in advancing the Purpose of this Agreement insofar as it may legally do so.

[Remainder of page intentionally blank. Signature page follows.]

IN WITNESS WHEREOF, the Parties have executed this Agreement as of the Effective Date.

Northwell Health, Inc. Institute for Nursing
Name: Maureen White
Signature:
Title: SVP / Chief Nurse Executive
Date: 12/11/2018

The Medical University of South Carolina
Name: Linda S. Weglicki
Signature:
Title: Dean
Date: 11/14/18

OFFICE OF THE
GENERAL COUNSEL
MUSC/MUHA
- APPROVED AS TO FORM -
By:
Date: 11-12-18

Exhibit A

Statement of Work

Program Scholar: Kristy Loewenstein
Dissertation Title: The experience of parent dyads in the neonatal intensive care unit
SOW Effective Date: 11/7/18
Dissertation Chair and Contact Information: Shannon Phillips, PhD, RN; phillipss@musc.edu; 843-792-9379
Institute Mentor and Contact Information: Nicholas Forand, PhD; nforand@northwell.edu; 718-470-8058
Contact Information for Program Scholar: kloewens@northwell.edu; 718-470-8506

1. Dissertation Summary

The purpose of this research study is to learn about the experiences and coping tools of parents in the NICU. This study will use a qualitative descriptive design to explore the experiences of both parents regarding their child's NICU hospitalization. The differences and similarities of parents' experiences, the subsequent effects of the NICU hospitalization on their relationships, and their parenting styles will be specific areas of inquiry. Approximately twenty parent dyads (forty individuals) will be invited to participate in the study. Parents who meet the inclusion criteria and have given informed consent will take part in two interviews. The first interview will be with both parents together, and the second interview will with each parent individually. Each interview will take 45 minutes to 1 ½ hours and will take place within the same week. After the first interview, parents will be asked to complete a demographic survey on a laptop computer, to provide a description of the sample. The survey will take about 10 minutes to complete. Interviews will take place in a private location of the parents' choosing at a time that is most convenient for them. Interviews will be recorded, written down word for word, and examined for similarities and differences between parents. Data analysis will begin after the dyad interview, will continue through individual interviews, and will remain concurrent to data collection throughout the study until data saturation is achieved, and no new themes are emerging. Through content analysis, an accurate description of parents' experiences in the NICU will be rendered.

There is minimal risk involved in participating in this study. Participants may become upset when discussing the NICU hospitalization of their child. Care will be taken during the interview process to minimize any discomfort participants may have. There are few direct benefits to study participants, although they will be given a chance to talk about their feelings about the experience in the NICU and may feel as though they are getting support through the interview. There is a risk of loss of confidentiality, but the researcher will code the interviews and research information to protect participant privacy. It is hoped this information may help us to learn more about the experiences of parents when their child is in the NICU, and how the needs of parents in the NICU are best met.

2. Dissertation Guidelines

Program Scholar will complete her dissertation in accordance with the requirements set forth in University course NRPHD-990. A description of the course is set forth below.

NRPHD-990. Dissertation. The dissertation course provides students, who have entered Candidacy and passed their Dissertation Proposal Defense, the structure to complete the dissertation research requirements. Students will work with their dissertation chair and dissertation committee members to conduct the dissertation study, develop the dissertation compendium, and finally defend the doctoral dissertation, while maintaining the rigor of their proposed research and acting responsibly in the conduct of research. Meetings of the entire committee are required at least once per semester. Students should facilitate communication with their committee through the dissertation chair. While a total of nine (9) credit hours of NRPHD 990 are required, credits above that amount can be added at 3 credits per semester until the dissertation work is completed and the student remains in good academic standing.

3. Academic Process and Timeline

	May 2018	June 2018	July 2018	Aug 2018	Sept 2018	Oct 2018	Nov 2018	Dec 2018	Jan 2019	Feb 2019	March 2019	April 2019
IRB	X	X	X	X	X	X						
Recruitment							X	X	X			
Interviews							X	X	X			
Coding/Analysis								X	X			
Interpretation								X	X	X		
Manuscript Preparation							X	X	X	X	X	
Dissertation Defense												X

4. Deliverables Term Sheet

De-identified data will be shared with MUSC through the course of the Program Scholar's research. Data will include the transcripts of dyad and individual interviews, data obtained through demographic surveys via REDCap, and data collected verbally during subject interviews. (See interview guides and survey templates in attached hereto as Exhibit B).

5. Institute Resources

Northwell Health is the IRB of record for the research. MUSC IRB entered into an IRB authorization Agreement with the Northwell Health IRB. Recruitment for the research will take place at Cohen's Children's Medical Center (CCMC), North Shore University Hospital (NSUH), and the CCMC Neonatal Outpatient Clinic. Interviews with research participants may take place at any of the aforementioned sites, Zucker Hillside Hospital, a division of Long Island Jewish Medical Center (the Program Scholar's home location), or off-site at the request of research participants. The Northwell Health version of REDCap will be utilized to collect and store data, copies of the informed consent, interview recordings, transcripts, survey results and any collateral or miscellaneous data. Any of the aforementioned data will only be accessible to the Program Scholar. The Program Scholar will utilize a Northwell-issued encrypted laptop with Sophos, as per Northwell IT security, to administer REDCap demographic surveys to research participants. Dragon Naturally Speaking software will be installed on said laptop to facilitate transcription of interviews, as recommended by Northwell IT security. Recruitment flyers approved by the IRB will list the Program Scholar's Northwell office address, as well as her Northwell office phone number and her Northwell cellular phone number so potential participants can contact the Program Scholar.

Exhibit B

Interview Guide and Survey Templates

Individual Interview Guide

Hello, again. Thank you for participating in the follow-up interview. How have you been? This time, I am going to interview you by yourself- it should take about 45-60 minutes. I will ask you a few follow-up questions from the first interview, when I spoke to you and [your partner] together, but the same rules apply. I want you to feel free to discuss your experience in the NICU as you would like to, add anything you may have omitted, or clarify anything you may have thought of since our first interview. I will be recording these sessions, so I may accurately transcribe our interview, but your confidentiality will be maintained. As with the first interview, if there are any questions you do not want to answer, or if you want to stop the interview at any time, just let me know and we can stop, or you can skip the question.

Are there any questions before we begin?

1. Did you think of anything that you may want to add or discuss since the first interview?

2. How do you feel about the experience you are having [had] in the NICU?

3. How was this experience different for you and your partner? How did it affect you differently?

4. How did this experience affect you as a couple?

5. Were you surprised by any of your partner's responses during the last interview? If so, which ones, and why?

6. I asked you this question in the last interview, but perhaps you have had time to consider it further- Is there anything that you feel could make [have made] this experience [the NICU] better for you?

7. How has this experience affected your relationship with your child? Has it changed how you planned to parent?

8. What were your feelings during your child's hospital admission? Follow-up: Did you ever experience any of the following during the NICU hospitalization of your child?

   - depression (feeling blue, sad, down, disinterested),
   - anxiety (nervousness, uneasiness, restlessness, worry),
   - stress (mental or emotional strain), or
   - posttraumatic stress symptoms (persistent mental and emotional stress, sleep disturbances, flashbacks, bad dreams, frightening thoughts, avoiding reminders)

Dyad Interview Guide

Hello, thank you for agreeing be a part of this study about the experiences of parents in the neonatal intensive care unit. As we previously discussed during the initial contact and consent process, my name is Kristy Loewenstein, and I am a psychiatric mental health nurse practitioner, a PhD student in Nursing at the Medical University of South Carolina, College of Nursing, and a fellow NICU parent. This study, that you have agreed to participate in, seeks to provide a greater understanding of the experiences of parents in the NICU, specifically the experiences as a couple, and for each parent individually. This is the first interview, where I will interview you together. I'll ask you a few questions, but I want you to feel free to describe your experience in the NICU as you would like to, in your own words. I want to know what it is [was] like for you to be in that situation, and for you feel [felt] about it. I may ask follow-up questions to one or both of you during the interview. I will be recording these sessions, so I may accurately transcribe our interview, but your confidentiality will be maintained. If you want to stop the interview at any time, or do not wish to answer any questions, just let me know. What questions are there, before we begin?

Thank you. The first question I have is:

1. Tell me what led to the NICU hospitalization. Did you know this was going to happen, or was it unexpected?

2. What has [was] your experience in the NICU been like?

3. How different is [was] this experience than what you expected for the birth of your child?

4. What is [was] it like to go home without your baby?

5. What have you been doing to cope with this experience?

6. What would [have] make this experience better for you?

7. Can you talk about your feelings and coping styles? Follow-up question if there are differences: How do these differences impact you?

8. How has this experience has affected your relationship (with each other)?

9. How has this experience affected your parenting style?

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Demographic data collection tool

Family #__________

Individual demographics for each parent via self-report in REDCap

1. Age
2. Race/Ethnicity
3. Occupation __________
4. Joint Net Income
   - less than 19,999
   - 20,000-40,999
   - 41,000-64,999
   - 65,000-85,999
   - 86,000-100,000
   - 100,000+
5. On public assistance Y/N
6. Sex
7. Gender identity
8. Sexual orientation
9. Marital/Relationship status
10. Length of relationship prior to NICU admission? If separated, when?
11. History of mental illness? (multiselect)
    - Depression
    - Anxiety
    - Posttraumatic stress disorder
    - Bipolar disorder
    - Schizophrenia
    - Personality disorder
12. Did you have a mental health screening while you were in the NICU? Did anyone ask you questions about how you were feeling or coping?
13. Were you offered any support during the NICU admission (support groups/counseling/SW/PhD/chaplain)?

14. Is this your first child? If no, how many other children? Any prior NICU admissions?

If yes, were there any previous pregnancies? If so, how many? Was this a multiple birth? If yes, are both children in the NICU?

Joint Demographic data to be collected verbally during dyad interview and entered in REDCap

Family #_________

1. Gestational age of infant at delivery: (24-40 weeks)

The manner of birth, severity of your infant's illness, or very low birth weight may cause some parents anxiety. I am going to ask you some specifics about the delivery and birth of your child:

2. Gender of infant

3. Birth weight

4. Delivery method: C-section/vaginal

5. If premature delivery: reason (Preterm labor/preeclampsia/intrauterine growth restriction/placenta problem)

6. Distance you live from NICU? Do you drive or take public transportation? How often are you able to visit, and for how long?

7. How long was infant in NICU? (days) How long has it been since you were discharged?

8. Were there complications while in the NICU?

(apnea/CPAP/vent/NEC/GI/optho/NAS)

9. What is the current health status of your child? How is he/she doing?

APPENDIX D
Recruitment Flyer

Neonatal Intensive Care Unit Research Study

Parent Volunteers Needed

Researchers from Medical University of South Carolina and Northwell Health are conducting a study of the experiences of parents in the NICU.

Do you currently have a child in a Northwell Health NICU? Have you had a child in a Northwell Health NICU in the past year? We would like to interview you! We are seeking parents couples of infants currently or recently hospitalized in the NICU at Cohen's Children's Medical Center or North Shore University Hospital to talk about their experiences. If you choose to participate in the study, you will be asked to provide demographic information about you and your child and will take part in 2 interviews- one as a couple (both parents), and the other individually (each parent separately).

Study compensation is available in the form of gift cards. For more information call Kristy Loewenstein, RN, NPP at 516-241-9819 or 718-470-8506 or via email at loewenst@musc.edu or kloewens@northwell.edu

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APPENDIX E

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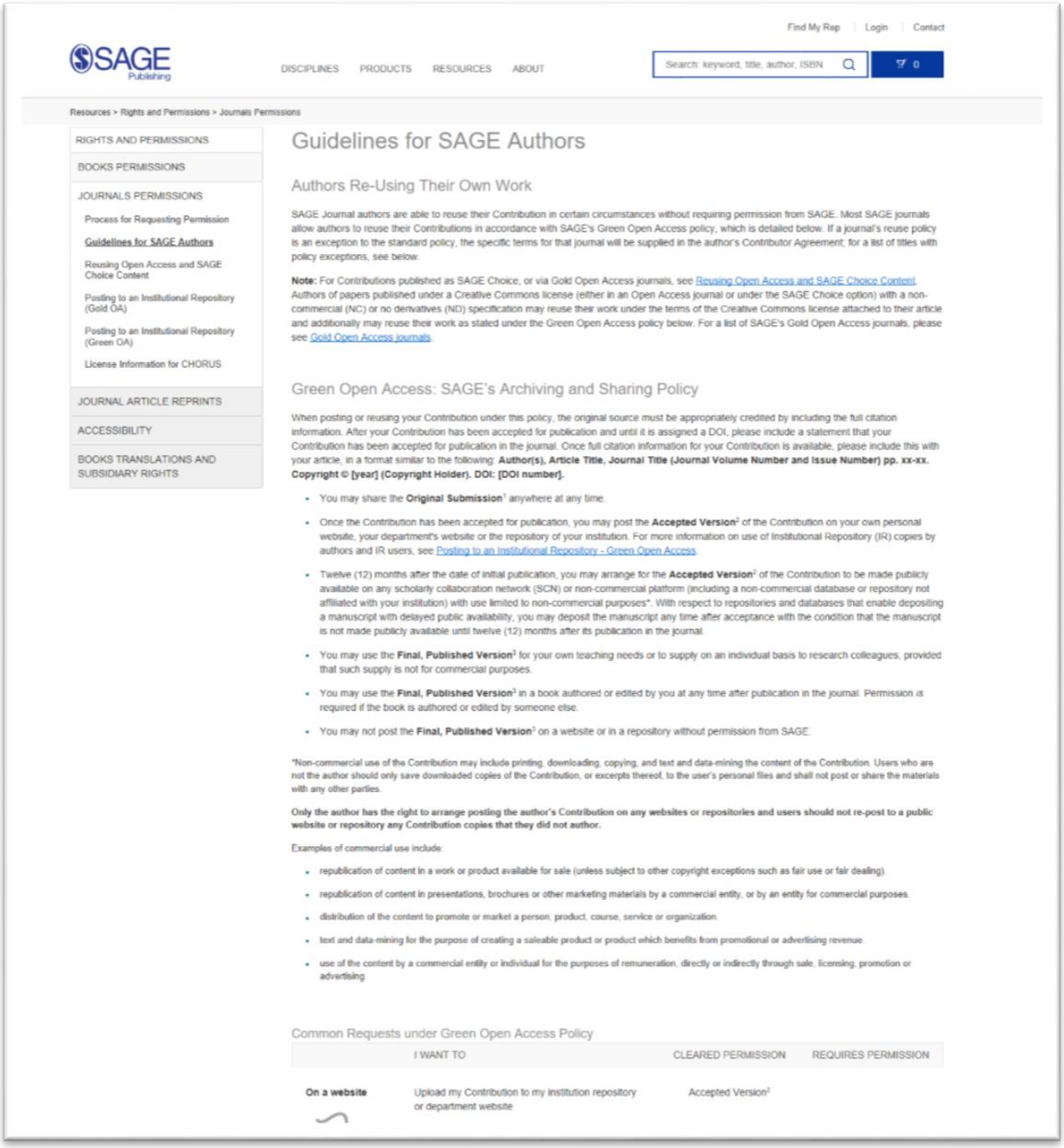

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	I WANT TO	CLEARED PERMISSION	REQUIRES PERMISSION
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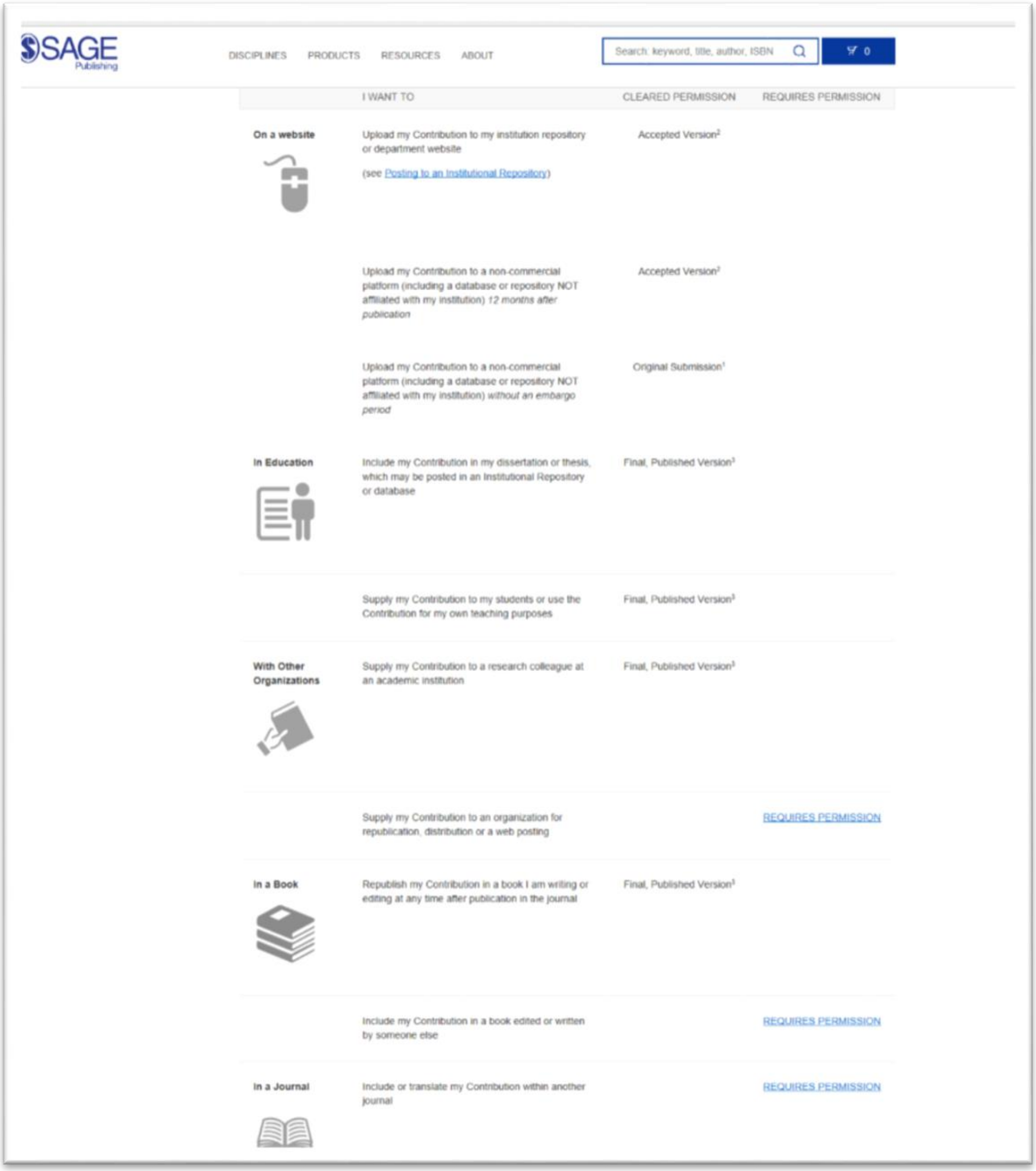

	I WANT TO	CLEARED PERMISSION	REQUIRES PERMISSION
On a website	Upload my Contribution to my institution repository or department website (see Posting to an Institutional Repository)	Accepted Version[2]	
	Upload my Contribution to a non-commercial platform (including a database or repository NOT affiliated with my institution) *12 months after publication*	Accepted Version[2]	
	Upload my Contribution to a non-commercial platform (including a database or repository NOT affiliated with my institution) *without an embargo period*	Original Submission[1]	
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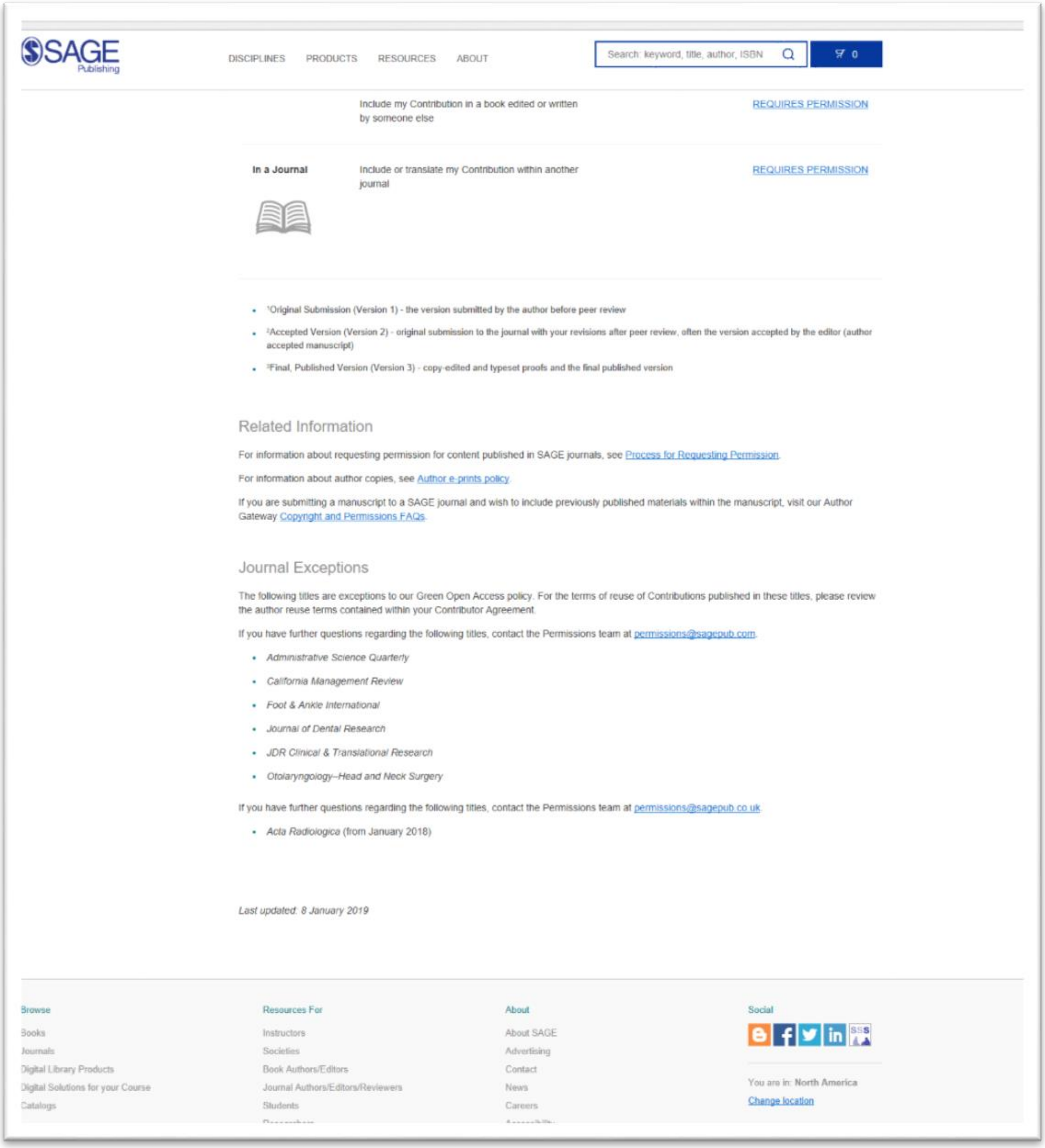

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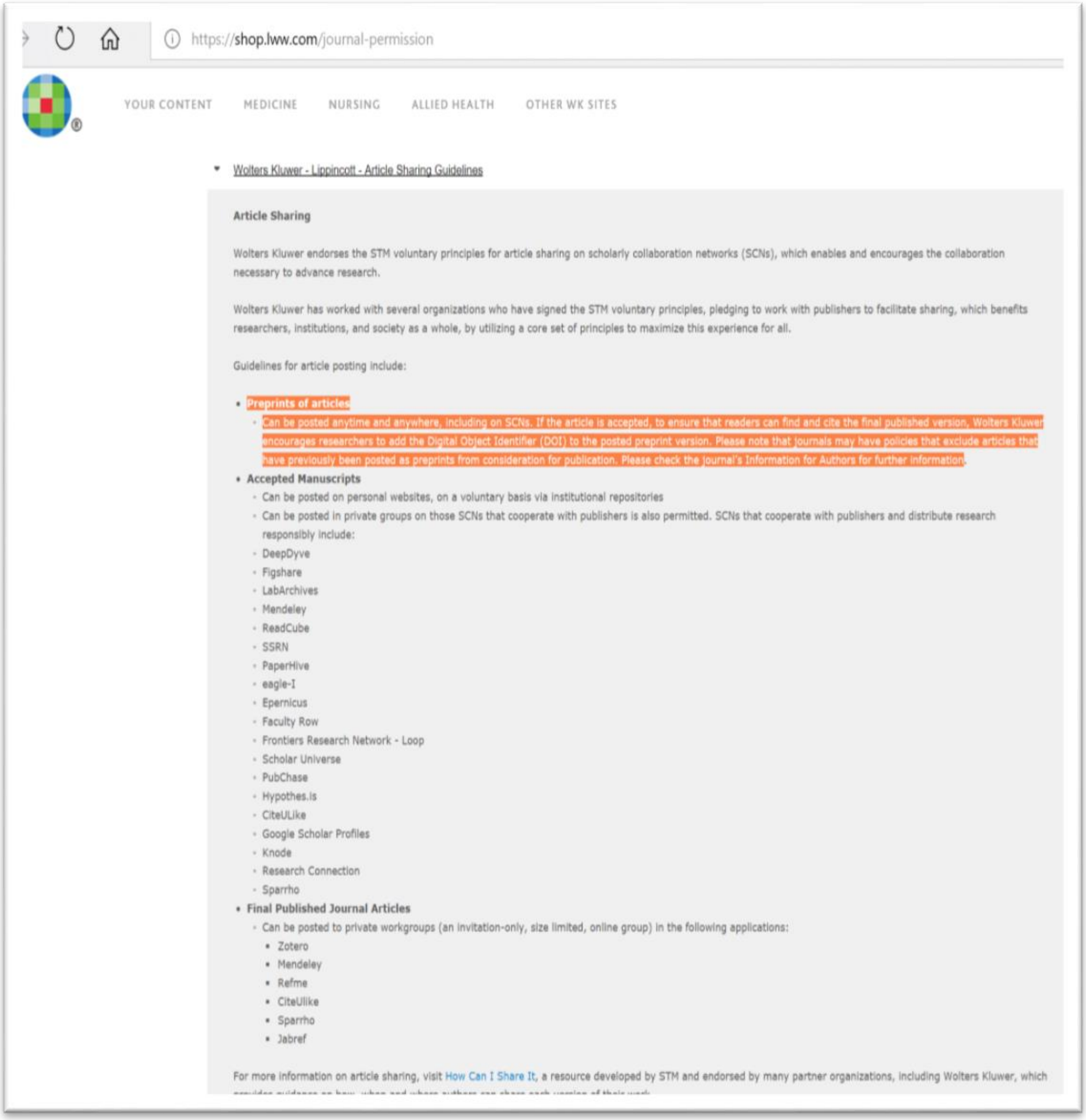

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  - Scholar Universe
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