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Parental Uncertainty in Illness of an Infant and Perinatal Post-traumatic Stress Disorder in the NICU

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PARENTAL UNCERTAINTY IN ILLNESS OF AN INFANT
AND
PERINATAL POST-TRAUMATIC STRESS DISORDER IN THE NICU

by

Kathryn J. Malin

A Dissertation Submitted in
Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy
in Nursing
at
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May 2020

ABSTRACT

PARENTAL UNCERTAINTY IN ILLNESS OF AN INFANT AND PERINATAL POST-TRAUMATIC STRESS DISORDER IN THE NICU by

Kathryn J. Main

University of Wisconsin-Milwaukee, 2020
Under the Supervision of Teresa S. Johnson, PhD, RN

Varying and conflicting risk factors for perinatal post-traumatic stress disorder (PPTSD) have been reported in the literature in parents after having an infant in the neonatal intensive care unit (NICU). Furthermore, relationships between feelings of parental uncertainty in illness of an infant in the NICU and PPTSD in parents have not been established. The purpose of this study was to (a) investigate the factor structure underlying parental perception of uncertainty scale (PPUS) in a sample of parents in the NICU; (b) describe how parental uncertainty in illness changes throughout the NICU course and after discharge; (c) evaluate if infant illness severity correlates with higher scores of perceptions of uncertainty in illness at three points in time; (d) assess if parental and/or infant clinical characteristics correlate with screening positive for PPTSD three months after NICU discharge; and (e) explore if more parents who experience high levels of uncertainty about their infant's illness screen positive for PPTSD.

The Uncertainty in Illness Theory guided this research. A sample of 176 parent-infant dyads participated in this prospective, longitudinal, correlational study. The confirmatory factor analysis of the PPUS demonstrated that the four-factor structure and a shorter, two factor model, fits in the sample. Parental uncertainty in illness decreased over time for most parents, though less decrease was associated with social determinants of health and gestational age of infant. Screening positive for PPTSD was associated with both parental and infant characteristics. In the

final regression, history of mental health illness ($p = 0.015$; 95% CI 0.05-0.45), elevated postpartum depression screening scores ($p = 0.003$; 95% CI 0.096-0.436), and uncertainty after discharge ($p = 0.05$; 95% CI 0.00-0.13), were associated with screening positive for PPTSD. Healthcare providers in the NICU need to assess parental mental health and assist in development of healthy coping strategies.

DEDICATION

I first dedicate this dissertation to my family. To my husband, Rob, thank you for being my best friend and biggest support throughout the last four years. To my children, Louis, Aidenn, Mae, and Darcy, thank you for always reminding me of what matters the most. Having you in my life has helped to not take myself too seriously and to continue to work for the health and wellbeing of all families.

To my parents, Shelly and Tom, thank you for giving me the gift of a happy and healthy childhood. Your unconditional love and belief that I can do anything has lifted me through countless low points and pushed me to do things that are hard and scary.

To my mother-in-law, Elise, thank you for buying me a desk when I started my PhD program. Many people questioned why I would start a PhD program with four small children and a career. Instead, you asked me how you could help. Your love and time has been instrumental in getting this finished.

Finally, thank you to all of the families who participated in this study. Thank you for your trust. Your willingness to share your experiences in the NICU is a gift to healthcare workers and families alike.

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To my committee members, Drs Jennifer Doering, Kaboni Gondwe, and Susan Rose, thank you for your guidance and support during this journey. You have been the "dream team".

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Chapter I: Introduction

Chapter Introduction

The purpose of this chapter is to provide the introduction and basis for the dissertation. Many varying and occasionally conflicting risk factors for perinatal post-traumatic stress disorder (PPTSD) in parents after having an infant in the neonatal intensive care unit (NICU) have been described in the literature. These inconsistencies make it difficult for nurses to identify and develop interventions for parents at highest risk for future development of PPTSD. Furthermore, the relationships between feelings of parental uncertainty in illness of an infant and PPTSD in parents in the NICU have not been established.

Significance

Posttraumatic stress disorder (PTSD) is characterized by disturbances that fall into one or more distinct clusters: re-experiencing, avoidance, negative cognitions and mood, and arousal. These disturbances are a direct result of exposure to actual or threatened death, serious injury or sexual violation. The duration of the disturbances must be more than one month (American Psychological Association [APA], 2013). PPTSD is defined as PTSD that occurs anytime between pregnancy up to one year following childbirth (McKenzie-McHarg et al., 2015). Parents of sick or premature infants in the NICU are at risk for developing PPTSD secondary to the often unexpected, traumatic nature of the birth of a child and/or the events that occur during the NICU hospitalization (Lefkowitz, Baxt, & Evans, 2010).

The effects of PPTSD on parental and infant development have been described in the literature (Davidson, Jones, & Bienvenu, 2012; Hoirisch-Clapauch, Brenner, & Nardi, 2015). Specifically, mothers who suffer from symptoms of PPTSD are more likely to display controlling patterns of interaction with their infants (Forcada-Guex, Borghini, Pierrehumbert,

Ansermet, & Muller-Nix, 2011). The altered maternal-infant interaction, secondary to PPTSD, was found to be significant at six and 12 months after birth (Petit et al., 2016). Mothers with symptoms of PPTSD are also more likely to report that their infants are less easily soothed and more apt to be distressed (Shaw et al., 2013). Additionally, infants of parents suffering from PPTSD are at risk for lower developmental social skills at six months corrected gestational age (Forcada-Guex et al., 2011).

Prevalence

An estimated 13 percent of women experience a perinatal mental health disorder around the time of pregnancy and birth. These women suffer from symptoms of depression, stress, anxiety, and trauma (World Health Organization [WHO], 2013). PPTSD is reported to affect up to 9 percent of women in the United States and until recently it has often been missed as an important mental health concern (Vignato, Georges, Bush, & Connelly, 2017). For parents with an infant in the NICU the incidence of PPTSD is increased, with a reported 23%-33% of these parents screening positive for PPTSD between the time of birth and 18 months (Hynan, Mounts, & Vanderbilt, 2013). These statistics are even more urgent in light of the fact that there is an increasing number of parents at risk for experiencing the detrimental effects of lasting traumatic stress secondary to having a sick or premature infant in the NICU. In 2012, 77.9 per 1000 infants born alive in the United States were admitted to the NICU. This is an increase from 64 per 1000 live births in 2009 (Harrison & Goodman, 2015).

It has been theorized that uncertainty is an antecedent to traumatic stress (Santacrose, 2003). Parental uncertainty in illness of an infant is a paradoxical, cognitive, and emotion experience (Malin & Johnson, 2019). Research has shown that parents of ill children manage their feelings of uncertainty illness using information management. Information management is

typically done through either 1) an intensive pursuit of information or 2) careful evasion of encounters that increase awareness of negative feelings. These two forms of information management are similar to two of the symptom clusters of PTSD: hyperarousal and avoidance (Santacroce, 2003).

Purpose

The purpose of this study is to investigate the factor structure underlying the parental perception of uncertainty scale (PPUS) in a sample of parents in the NICU. The purpose is also to examine the relationships between parental uncertainty in illness of an infant in the NICU and PPTSD in parents of sick or premature infants three months after discharge from the NICU.

Research Questions

- 1. What is the factor structure of the PPUS in parents with a sick or premature infant in the NICU?*
- 2. How does parental uncertainty in illness change throughout the NICU course and after NICU discharge?*
- 3. Do parental and/or infant clinical characteristics correlate with higher scores of parental perceptions of uncertainty in illness?*
- 4. Do parental and/or infant clinical characteristics correlate with higher levels of screening positive for PPTSD three months after infant discharge from the NICU?*
- 5. Do parents who experience high levels of uncertainty about their infant's illness screen positive for PPTSD more frequently after discharge from the NICU?*

Theoretical Framework

The Uncertainty in Illness Theory (UIT) guides this dissertation. The UIT is a middle range nursing theory created by Dr. Merle Mishel in 1988. Dr. Mishel defines uncertainty in

illness as, "...the inability to determine the meaning of illness-related events. It is a cognitive state created when the individual cannot adequately structure or categorize an illness event because of insufficient cure" (Mishel, 1988, p.225). As a middle range nursing theory, the UIT falls between the abstract philosophical level and the concrete empirical level of abstraction on Smith and Leibr's (2013) ladder of abstraction. The philosophical underpinnings that ground middle range theories are often empirical in nature but also provide space for the lived experience. Contemporary empiricism accounts for the need and ability to empirically approach theory development while also placing emphasis on developing concepts that are clear and linked to corresponding pieces of reality (Giuliano, 2003).

The UIT holds the assumption that uncertainty in illness occurs during the diagnostic phase of illness that has a downward trajectory (Mishel, 1988). Uncertainty is not fundamentally a positive or a negative state. Once the possible implications of uncertainty are understood an evaluation of the meaning can be made. Three themes lay the framework for the UIT. The antecedents of uncertainty, appraisal of uncertainty and coping with uncertainty.

Movement through these three themes are further defined by Mishel. The theme of antecedents of uncertainty is operationalized as the stimuli frame, cognitive capacity and structure providers. The stimuli frame describes the stimuli a person perceives during an illness related event. Cognitive capacity depicts the ability of an individual to process information. The structure providers are the resources an individual can utilize to interpret the stimuli frame (Mishel, 1988). The theme of appraisal of uncertainty is defined as "the process of placing a value on the uncertain event or situation" (Mishel, 2014, p. 57). Appraisal of uncertainty is done through inference and illusion and it is from this process that one places a value on uncertainty. The two trajectories from the appraisal theme are either danger or opportunity (Mishel, 1988). Finally, once the appraisal of uncertainty is completed there is movement into the third theme of the UIT, coping with uncertainty. The major definitions central to the coping theme of the UIT include

coping with danger, coping with opportunity, and adaptation. According to Mishel, the appraisal of uncertainty which occurs when the predictive accuracy of the inferences is unknown leads to the stage of coping with danger. When coping with danger, efforts to reduce the uncertainty are made and manage the emotions that are generated (Mishel, 1988). When the appraisal of uncertainty leads to the possibility of a positive outcome there is coping with opportunity. Finally, when there is effective coping with uncertainty as either a danger or opportunity there is movement into adaptation. Adaptation is defined as, “a biopsychosocial behavior occurring within persons’ individually defined range of usual behavior” (Mishel, 1988, p. 231).

Rationale for Use of the Uncertainty in Illness Theory as a Theoretical Framework

At the time of admission to the NICU parents of a sick or premature infant are at high risk for developing feelings of uncertainty. According to the UIT, the antecedents of uncertainty (stimuli frame, cognitive capacities and structure providers) will begin to influence how parents perceive and understand the diagnosis and potential outcomes for their sick or premature infant. Unfamiliarity with the NICU, new diagnoses, new environments, and loss of expected pregnancy outcome are all components of the stimuli frame for parents in the NICU. How parents cognitively make sense of the new reality of having a sick or premature infant and what kind of resources are available to the parents also influence the antecedents of uncertainty. Once parents appraise their experience of uncertainty as either a danger or an opportunity they will then move to coping with uncertainty. Mishel (1988) asserts that uncertainty for these parents will be reduced when stimuli are more recognizable and are congruent with what is expected. On the other hand, when information is not consistent with parents’ ability to process stimuli there will be an increase in uncertainty.

This study proposes that if NICU parents negatively experience uncertainty in illness of their infant they will not be able to create meaning or place value in the experience. As a result,

they will not enter the coping stage of the UIT. Instead, parents will have an altered appraisal of the events that lead to uncertainty. Thus, resulting in continued threatening memories of their infant's hospitalization/illness. These continued threatening memories are manifested through symptoms of PTSD that endure for at least one month after the event.

Methods

This study is both a confirmatory factor analysis and a non-experimental prospective longitudinal correlational study. Specifically, this is a study of parent-infant dyads hospitalized in the a 70-bed, level 4 NICU in a large urban area of Southeast Wisconsin. A confirmatory factor analysis of the PPUS in a sample of parents in the NICU is important to help determine which scientific interest explain the constructs of parental perceptions of uncertainty. Correlational-cause probing research design allows or a description of the relationships between parental perception of uncertainty in illness of an infant in the NICU and PPTSD which has not been described in the literature.

Placement of Manuscripts in the Dissertation

This dissertation will be completed using the non-traditional approach in which at least three manuscripts of publishable quality are included. These proposed manuscripts include:

1. Malin, K.J., & Johnson, T.S. (2019). A concept analysis of parental uncertainty in illness of an infant. *The American Journal of Maternal Child Nursing*, 44 (4), 206-211. doi: 10.1097/NMC.0000000000000535

This manuscript will be placed in chapter two of the proposal and dissertation.

2. A systematic review of PPTSD in parents of infants in the neonatal NICU.

This manuscript will be submitted to *American Journal of Perinatology*

This manuscript will be placed in chapter two of the proposal and dissertation.

3. Confirmatory factor analysis of the parental perception of illness scale among parents of sick or premature infants in the NICU. This manuscript will be submitted to *Journal of Nursing Measurement*.

This manuscript will be placed in chapter four of the dissertation.

4. The relationships between parental uncertainty in illness of an infant and perinatal post-traumatic stress disorder in the NICU. This manuscript will be submitted to *Western Journal of Nursing Research*.

This manuscript will be placed in chapter four of the dissertation.

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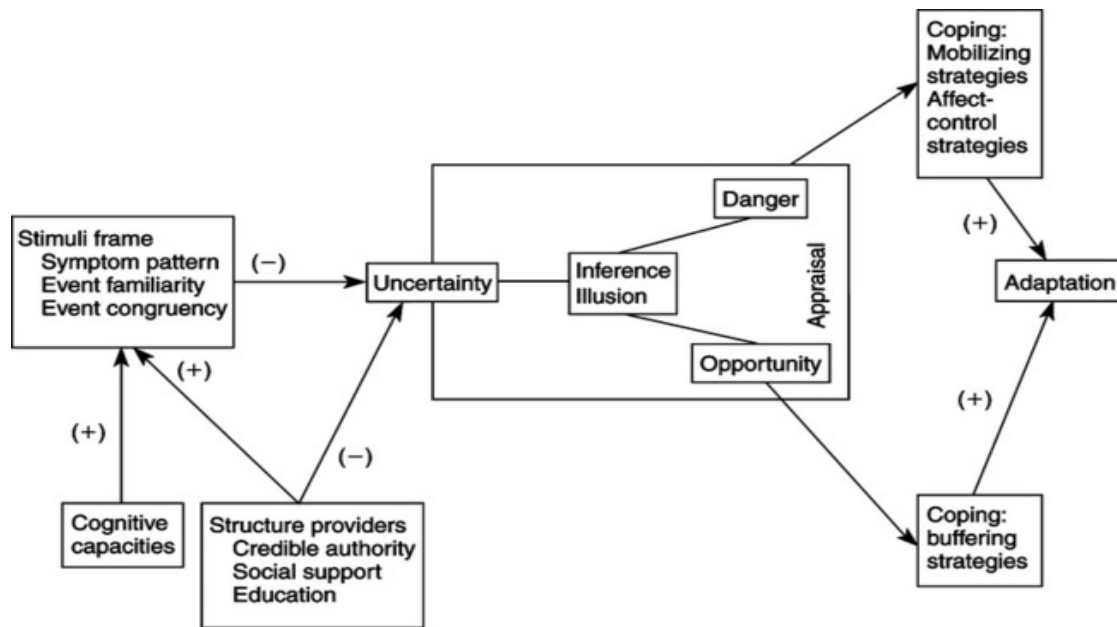
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10.1111/jocn.13800

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Figure 1.1: The Uncertainty in Illness Theory



Mischel, M. (1988). Uncertainty in illness. *The Journal of Nursing Scholarship*, 20(4), 225-232.

Chapter II: Concept Analysis and Literature Review

Chapter Introduction

This chapter will present a concept analysis of Parental Uncertainty in Illness of an Infant and systematic literature review of perinatal posttraumatic stress disorder (PPTSD) in parents of infants in the NICU. The concept analysis provides a definition of parental uncertainty in illness of an infant using the Roger's Evolutionary Method of Concept Analysis. This inductive method provides a holistic framework to create a timely definition of a concept. The systematic literature review provides an examination of recent literature pertaining to PPTSD in parents who have had infants in the NICU. This serves to identify the gaps in the literature and rationale for variables chosen in the methodology of the study.

Manuscript #1: A Concept Analysis of Parental Uncertainty in Illness of an Infant



A CONCEPT ANALYSIS OF Parental Uncertainty in Illness of an Infant

Abstract

Background: The concept of uncertainty in illness has been well described and applied to many different areas of nursing and other disciplines. Specifically, parental uncertainty in illness of an infant is a meaningful concept that has specific attributes and implications. A current concept analysis that considers the changing healthcare setting, historical conceptual inconsistencies, and a lack of information concerning parents of infants is needed.

Purpose: To identify essential antecedents, attributes, and consequences of parental uncertainty in illness using Rodgers' Evolutionary Concept Analysis method.

Methods: A literature search was conducted using PubMed, CINAHL, and PsycInfo. The following keywords were used in combination using the Boolean terms "AND" and "OR": parental uncertainty; infants; parental uncertainty in illness; preterm infants; parent; uncertainty. Inclusion criteria: articles published between 2000 and 2017 and published in English. The search included 38 articles published from 2000 to 2017 with a specific focus on parental uncertainty in illness.

Findings: Parental uncertainty in illness of an infant is a paradoxical, cognitive, and emotional experience in which there is an inability to create meaning and may cause disruption in parental role development.

Implications for Practice: Nursing care of parents with ill infants and children must include sensitivity to parents' experiences of uncertainty in illness. Nurses are uniquely positioned to normalize parental uncertainty and facilitate healthy coping.

Key words: Concept analysis; Infant; Neonatal intensive care; Parents; Uncertainty.

Kathryn Jeanne Malin, MSN, RN, NNP-BC, and Teresa S. Johnson, PhD, RN

The environment in which parents of sick or premature infants are being asked to make healthcare decisions is different than it was 20 years ago, which may contribute to more uncertainty.



The concept of uncertainty in illness has been well described and applied to many areas of nursing and other disciplines. Uncertainty is central to the illness experience and it is from this uncertainty that all activities related to healthcare are motivated (Han, Klein, & Arora, 2011). Florence Nightingale wrote about uncertainty in "Notes on Nursing" in 1895 saying, "Apprehension, uncertainty, waiting, exception, fear of surprise, do a patient more harm than any exertion" (Nightingale, 1992, p. 22).

Parents' descriptions of having an infant in the neonatal intensive care unit (NICU) vary. Some described their experiences as stressful, depressing, disappointing, and with a loss of control (Obeidat, Bond, & Callister, 2009). Others reported feelings of gratitude, optimism and hope, even in the face of death or disability for their child (Arnolds, Xu, Hughes, McCoy, & Meadow, 2018). Few researchers have focused specifically on the parental experience of uncertainty in illness of an infant. Therefore, nurses often turn to the literature on uncertainty in illness of pediatric patients to find the nuanced differences between uncertainty in the pediatric and infant populations.

Nurses use the practice of concept analyses to help examine and describe the fundamental components that are central to their discipline. Concept analyses offer meaningful definitions that help describe relationships and application to nursing practice (Rodgers & Knaf, 2000). Helping clinicians and researchers to fully describe parental uncertainty of illness in infants allows nurses to conduct a comprehensive assessment of parental needs and then develop interventions to help parents cope with the uncertainty of having a sick or premature infant.

Background

Changes and advancements in technology and practice standards have increased survival rates of extremely premature infants over the last 20 years. Thus, the environment in which parents of sick or premature infants are being asked to make healthcare decisions is different than it was 20 years ago, which may contribute to more uncertainty. Parents have described experiencing uncertainty

during the entire duration of having an ill child and when survival is uncertain. This uncertainty permeates through attaining diagnoses, adjusting to complex treatments, achieving confidence as a parent, and optimizing quality of life for all family members (Alvesson, Lindelow, Khantaphat, & Laflamme, 2013; Carpentier, Mullins, Chaney, & Wagner, 2006).

Methods

The concept of parental uncertainty is dynamic and cyclic in nature and thus the tool used to evaluate and define it must also provide for these qualities. Rodger's seven-step evolutionary method is the most appropriate method for concept analysis in this instance as it is a re-examination of a concept that has been defined in the past. Significant components of Rodger's evolutionary method include identification of the following: the concept of interest; surrogate terms; realm for data collection; attributes of the concept; references; antecedents and consequences of the concept; related concepts; and a model case of the concept (Rodgers, 1989). The purpose of this analysis is to reexamine the concept of uncertainty in illness of an infant. Although this is not a new concept, technologies have changed, illness trajectories have been altered, and the age of viability continues to be modified. Nurses need an updated concept analysis of parental uncertainty in illness of an infant to holistically care for infants and families.

Search Strategy

There are several definitions of uncertainty in illness reported in the literature. One example is a multidimensional concept that is a neutral cognitive state and not an emotional outcome (McCormick, 2002). Another is that it is a dynamic state in which there is an inability to assign possibilities for outcomes (Penrod, 2001). Surrogate and related terms identified include: unpredictability, inconsistency, stress, hope, and distress (Arnolds et al., 2018; Chaney et al., 2016; Holm et al., 2008). A literature search was conducted using the following databases: PubMed, CINAHL, and PsycInfo. The following keywords were used in combination using the Boolean terms "AND" and

“OR”: parental uncertainty; infants; parental uncertainty in illness; preterm infants; parent; uncertainty. Inclusion criteria included: articles published between 2000 and 2017 and articles published in English. The years searched was chosen as the last comprehensive review that examined the concept of illness uncertainty in parents was published in 2000 (Stewart & Mishel, 2000). Exclusion criteria included: opinion articles; book chapters and books; and articles in which the concept of interest was something other than uncertainty in illness or parental uncertainty of a child’s illness. Forty-two articles were identified after duplicates were removed; 38 articles were included in the final analysis. See Figure 1 for a flow diagram of the literature search. See Table 1 for a detailed summary of reviewed literature (Supplemental Digital Content, <http://links.lww.com/MCN/A52>).

Data Analysis

During the data analysis phase, themes are identified and labels are created through inductive reasoning. Conclusions about themes and labels were broadly generated from the data (Rodgers & Knafel, 2000). This analysis led us to identify *parental uncertainty in illness of an infant* as the concept of interest, and not the broader concept of uncertainty in illness. This concept is described by its antecedents (a preceding event, condition, or cause); attributes (a quality, character, or characteristic ascribed to something) and consequences (something that is produced by a cause or necessarily following a set of conditions). See Figure 2.

Antecedents

Complexity in childhood illness, diagnosis, and management in multifaceted environments appears to be an antecedent to parental uncertainty in illness. The reciprocal influences of family, health-care systems, and environment are often associated with the development of parental uncertainty (Shannon & Lee, 2008). Undiagnosed conditions and prognostic ambiguity are also examples of this complexity contributing to parents developing uncertainty (Chaney et al., 2016; Dodgson et al., 2000; Hayeems

et al., 2017; Kerr & Haas, 2014; Tluczek, Mckechnie, & Lynam, 2010). The antecedent of *lack of meaning* is another theme in the literature (Santacroce, 2003). Parents of preterm infants experience a lack of meaning as a disruption and alteration in parental understanding of reality (Lasiuk, Comeau, & Newburn-Cook, 2013). *Ambiguity* is identified across all disciplines as an antecedent to describe parental uncertainty in illness (Nelson, Kirk, Caress, & Glenn, 2012; Tackett et al., 2016). Parents described this ambiguity as never feeling safe and

as though their child’s life is always at risk despite the passing of time (Tong, Lowe, Sainsbury, & Craig, 2008).

Attributes

The *paradoxical experience* of parental uncertainty in illness comes from the understanding that uncertainty may be perceived as a threat or an opportunity (Czuchta & McCay, 2001; Madeo, O’Brien, Bernhardt, & Bie-secker, 2012). As an example of a threat, mothers of children with chronic health conditions experienced increased levels of psychological and physical symptoms (Holm et al., 2008). Conversely, parents of children with genetic conditions (Whitmarsh, Davis, Skinner, & Bailey, 2007) and parents of children with childhood multiple sclerosis (Hinton & Kirk, 2017) reported valuing uncertainty in their child’s illness as representing future possibilities and fragile hope. Another attribute of parental uncertainty in illness is the experience as both *emotional and cognitive*. Fear, hopelessness, and feeling overwhelmed are examples of emotional attributes ascribed to parental uncertainty (Benedetti, Garanhani, & Sales, 2014; Bolívar Montes & Montalvo Prieto, 2016; Czuchta & McCay). Cognitive processing is involved with parental psychological adjustment and health behaviors (Page et al., 2012). Multiple authors discussed the *enduring* nature of parental uncertainty as an attribute (Håkstad, Obstfelder, & Øberg, 2016; Lin, Yeh, & Mishel, 2010; Santacroce, 2002; Truitt, Bieseck-

FIGURE 1. Flow Diagram of Article Search and Selection Process

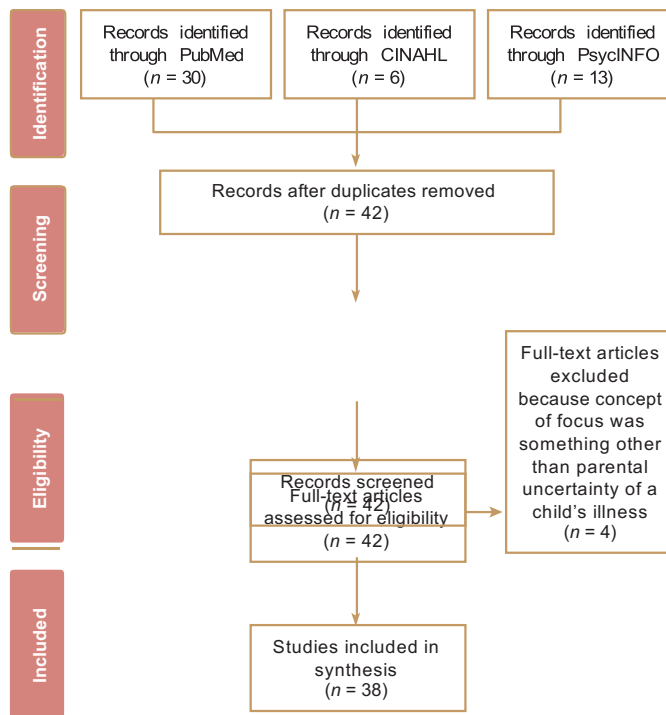
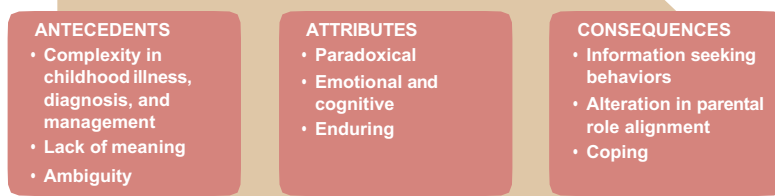


FIGURE 2. Diagram of Antecedents, Attributes, and Consequences



Direction of Further Investigation

An evolutionary concept analysis identifies the direction of further investigation (Rodgers & Knaf, 2000). Research is needed on measurement of psychological and physiological responses to enduring in parental uncertainty to provide for a more comprehensive understanding of the experience of parental uncertainty in illness. More information explaining how parents and patients transition from emotional to cognitive management of uncertain-

er, Capone, Bailey, & Erby, 2012). The enduring quality of uncertainty was described by parents of premature infants for 3, 6, and 12 months corrected gestational age (Håkstad et al.).

Consequences

The need for parents to manage illness-related uncertainty was found across disciplines and often resulted in *information seeking behaviors*. Tluczek et al. (2010) reported that parents who received an equivocal diagnosis for cystic fibrosis on the newborn screen sought to reduce uncertainty through searching for information. Parents seek credible authorities to help reappraise their feelings of uncertainty (Kerr, Harrington, & Scott, 2019). *Alterations in parental role attainment* was uniquely a dominant consequence of uncertainty in illness focused on parents of neonates and infants (Lasiuk et al., 2013; Obas, Leal, Zegray, & Rennick, 2016; Santacroce, 2001). The typical transitions into parenthood were changed across many settings in this population. As an example, parents who experienced illness uncertainty and reliance on nurses to perform parental duties reported decreased parent-infant closeness and decreased attachment (Watson, 2011). *Coping* with uncertainty was also identified as a theme (He, You, Zheng, & Bi, 2016; Stratton, 2004; Zierhut & Bartels, 2012). Examples of coping include positive thinking, delaying worry, managing information, open communication, and hope (Truitt et al., 2012; Zierhut & Bartels).

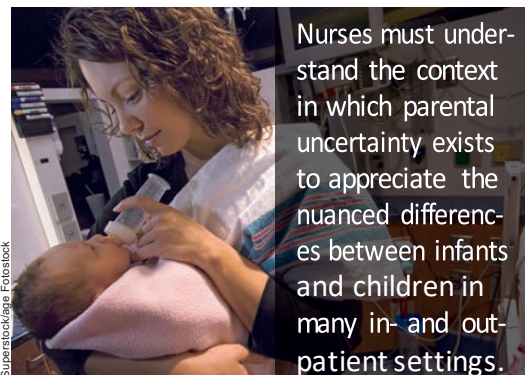
Identification of a Model Case

The rich interviews of parents at home with their infant after discharge from the NICU described by White, Gilstrap, and Hull (2017) provide a model case of parental uncertainty in illness. The following quote from a mother after NICU discharge demonstrates feelings of uncertainty around the transition of becoming a parent (White et al., p. 109): *You are responsible for them. You have to worry... You are staring at them making sure they are breathing. It is so different. You are so used to other people worrying about that stuff for you. You are worried [in the NICU], but they are worried more because that's their job.*

ty would be beneficial to provide a basis for developing associated nursing interventions.

Uncertainty in Illness in Parents of Infants

Twelve of the articles reviewed included a population of parents whose illness uncertainty was concerning their sick or premature infant. Although there is much to be learned about parental uncertainty in illness regardless of the age of the child, one must consider the probability that the uncertainty experienced by parents of sick or premature infants and consequences of their experiences may be uniquely different. For example, in this review researchers found for parents of sick or premature infants, the disruption in both parental role and family role is a consequence of uncertainty in illness (Obas et al., 2016; Santacroce, 2001). This role disruption is distinctively noted in the literature in parents of infants and is not identified as a theme in the greater body of literature. The disruption in parental role development is related to alterations in transitions that normally occur, such as feelings of belonging and parent-infant relationships (Granrud, Ludvigsen, & Andershed, 2014; Watson, 2011). Perhaps the unique experience of parental



Nurses must understand the context in which parental uncertainty exists to appreciate the nuanced differences between infants and children in many in- and out-patient settings.

Suggested Clinical Nursing Implications

- Recognize the parental experience of uncertainty in illness of an infant when working with families in the NICU and offer support as parents cope with the consequences of uncertainty.
- Provide information about the illness to the parents in language they understand, and at the appropriate literacy level; use interpreters as needed.
- Providing a healing environment, involving parents as partners in care of the infant, facilitating education, and offering therapeutic communication all help parents to become comfortable in their role as a parent.
- Assess the parents' family and friend support networks.
- Acknowledge that parental uncertainty in illness is not an explicitly negative experience. Each parental experience is relative and requires unique attention and care planning.
- Use established services, such as palliative care if appropriate, to support parents through feelings of uncertainty about their sick or premature infant. Make sure the parents have referrals as needed when the infant is discharged.

uncertainty in illness of an infant begins at the birth of a premature or sick infant and continues for months to years depending on the trajectory of the infant's health. More research with parents of a sick or premature infant would help nurses care providers further understand the concept.

Clinical Implications

The proposed definition of parental uncertainty in illness in an infant is: *a paradoxical, cognitive and emotional experience of parents with an ill infant, in which there is an inability to create meaning, and may cause disruption in parental role development.* Nurses should work to understand parents' perception of uncertainty. Nurses should provide evidence-based care to normalize parents' experiences of uncertainty and provide the support needed to facilitate coping and optimal parental interactions with their infants. The transition to parenthood is an important developmental step that may be altered as a result of uncertainty. Nurses are well equipped to help facilitate this role development in the face of uncertainty. Nursing interventions such as providing a healing environment, involving parents as partners in care of the infant, facilitating education, and offering therapeutic communication all help parents to become comfortable in their role as a parent. When parents have questions about the illness or status of their infant, information should be provided at the appropriate literacy level and in a language the parents

Parents who suffer psychological harm secondary to a NICU experience have increased risk for long-term emotional problems and altered parent–infant interactions.

understand. Offering established support services, such as palliative care as appropriate, to facilitate parental decision-making and parental role attainment may be beneficial. Referrals for outpatient care if needed should be part of planning for hospital discharge. More research is needed to fully conceptualize how parents experience uncertainty in illness of their infant, and how it impacts the continuum of childhood and family growth and development. ✚

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Supplemental Table 1: Literature Reviewed for Analysis

Citation/Year of Publication/Discipline	Antecedents	Attributes	Consequences	Population Represented	Sociocultural and Temporal Variations
Alvesson et al, 2013 Public Health	Reality of people's everyday life trying to alleviate suffering, unpredictability about cost & diagnosis. Ambiguity about the combination of symptoms.	Misfortunes & people's responses to uncertainty are mediated by values shared with others	Uncertainty is minimized by seeking care from local providers who were known by family, friends or neighbors. Alters health-seeking behaviors	P	Setting of rural communities in the country of Lao PDR, two focus groups (parents) of children < 5, included anthropological entry point of uncertainty in illness
Benedetti et al., 2014 Nursing	Suffering, fear, carelessness of others – multiple different healthcare services, witnessing death of other children	Hopeless, insecure, difficult treatments	Unpleasantness, continue uncertainty	P	Qualitative interviews with 13 parents of eight patients undergoing treatment for cancer in Brazil
Bolivar et al., 2016 Nursing	Infant birth weight less than 1500 gm, illness severity (requirement for ventilator) Not having a partner, & decreased education	Emotional swings, exhausting & overwhelming	Hinders clear assessment of events & limits coping	I, N	Quantitative, correlational cross-sectional study of 117 parents of infants in NICU in Cartagena, Colombia

Carpentier et al., 2006 Psychology	Inability to construct a predictable & logical cognitive schema of illness related events	Inability to cope in cases of prolonged uncertainty	Psychological distress, altered parental adjustment outcomes.	P	Parents of children with type 1 diabetes mellitus. Quantitative evaluation of relationship between illness uncertainty & attributional style to psychological distress
Chaney et al., 2016 Psychology	Diagnostic delay, prognostic ambiguity, regimen complexity, symptom unpredictability	Pivotal to appraisal Ongoing	Increases caregiver demands. Impacts parent distress & child depressive symptoms indirectly through increased perceptions of caregiver demand	P	Quantitative evaluation of caregiver demand & distress as mediators in illness uncertainty in parents of children with juvenile rheumatic disease.
Czuchata & McCay 2001 Nursing	Ambiguous nature of symptoms & unpredictability of illness course, decreased education	Fear, immobilization, burdened, opportunity for hope	Delay in seeking help & then continuous help-seeking	P	Parents of individuals experiencing a first episode of schizophrenia. Evaluation of help-seeking behaviors
Dodgson et al., 2000 Nursing	Chronic and enduring childhood illness	Intermittent and unpredictability of symptoms	Distress and social/familial disruption. Emotional strain (mothers >fathers)	P	Analysis of 223 parental responses to questions about illness uncertainty and family distress. Parents of young children with chronic illness

Fedele et al., 2011 Psychology	Chronic illness Adjustments and appraisal of illness Age of child	Episodic Unpredictable	Parental distress Depression in older children	P	Parents of children of varying ages with juvenile rheumatic disease.
Granrud et al., 2014 Nursing	Multiple transitions Prematurity	Fear, lack of information, being distanced & feeling closeness to baby	Suffering, parental health corresponds with infant health	I, N	Qualitative interviews of 9 sets of parents & 2 mothers. Conducted between 3-8 months after NICU discharge. Description of experience of transfer of premature infant from a university hospital to a community hospital
Hakstad et al., 2016 Physical Therapy	Yearning for normalcy, fear Prematurity Unknown future development	Challenging need for clarity Over an extended period of time	Moving beyond is associated with creating meaning in their situations. Adaptation via normalization Coping Disruption of pursuit of normalcy	I, N	Qualitative interviews of parents of ex-premature infants at 3, 6, & 12 months corrected gestational age. Norway
Hayeems et al. 2017 Medicine	Diagnostic/New Born Screen inconclusiveness	Relief, inability to make sense	Feelings of unsettledness, heightened sense of medical vulnerability	N, I	Mixed-Methods, prospective cohort study of parents in Canada whose child had a persistently inconclusive newborn screen result

He et al., 2016 Nursing	Time since diagnosis, age and education of parents Illness severity	Unpredictability	Growth through uncertainty is mediated by coping.	P	Chinese parents of children with a diagnosis of acute leukemia at two different hospitals in China
Hinton & Kirk 2017 Nursing	Uncommon and complex diagnosis	Living with uncertainty Hope and fragile optimism	Seek information Continuous monitoring	P	Qualitative interviews with parents of children with childhood multiple sclerosis
Holm et al., 2008 Multidisciplinary	Chronic health conditions in child, stressors	A “cascade of distress”	In mothers, more illness related uncertainty associated with increase in subsequent increase in psychological symptoms. Psychological symptoms were associated with subsequent increase in physical symptoms.	P	Impact of uncertainty about a child’s chronic health condition on parents’ mental & physical health
Kerr & Haas 2014 Nursing	Lack of control, lack of adequate information about illness, complexity of care	Normalization uncertainty, information uncertainty, orphan-illness uncertainty, parental proxy	Information seeking behaviors, parents rely on emotional appraisals to manage uncertainty “gut	P	Children with “orphan illness” – not belonging to one medical specialty. Majority of subjects were mothers

		uncertainty, social stigma uncertainty	feeling”, emotional decision making may lead to pursuit in a hasty manner		
Kerr et al., 2017 Communication Science	Inherent uncertainty of pediatric chronic illness	Poor communication and support from providers Lack of credible authority	Reappraisal of uncertainty through communication with credible authorities	P	Interviews with 29 parents at a multidisciplinary clinic for care of children at a vascular anomaly clinic
Lasiuk et al., 2013 Nursing	Distress, preterm birth, disruption in meaning systems, lack of equilibrium, omnipresent threats	Cyclic, “roller coaster” Prolonged	Heightened state of arousal, trauma Altered parental role expectations	I, N	Perspective of parents of preterm infants & healthcare professionals who work with preterm infants & their families
Lin et al., 2010 Nursing	Child’s health status, parent’s perceived, inability to determine meaning, social support, parent’s education	Reappraising Continual uncertainty as a natural rhythm of life	Negative impact on coping strategies while also helping grow through uncertainty. Awareness of the capricious life. Coping through learning from health care professionals. Enduring	P	Parents with children enrolled in a longitudinal cancer study in Taiwan, purpose was to examine the conceptual model depicting coping & growth in parents living with continued uncertainty
Madeo et al., 2012 Medicine	Undiagnosed condition, complex health information,	A barrier & a facilitator of	Parent’s perceived control & optimism	P	Survey of parents with a child or children with an

	indeterminate future outcomes	adaptation to health threat	decrease uncertainty. Feelings of decreased control increase uncertainty		undiagnosed condition for at least two years. Majority of participants were mothers
Miller et al., 2011 Psychology	Perception of external influences, parent characteristics	Moderated by decision making styles	Influences both decision making preferences & coping style. Task focused decision making	P	Surveys of parents who were making decisions for research or treatments of a child
Nelson et al., 2012 Multidisciplinary	Ambiguity about causes and treatment	Lasts over extended periods of time	Emotional tension and attempts to manage through strict adherence to intervention recommendations	P	Qualitative interviews with 35 parents of children with cleft lip and/or palate at different stages of repair/treatment
Obas et al., 2016 Nursing	Transfer of care from intensive care, new environment	Mixed feelings	Rallying, learning new roles	I, N	9 interviews of parents of children with congenital heart disease at the time of transfer from ICU in Canada
Oprescu et al., 2013 Medicine	Illness specific Being the mother of the child	Occurs during or after treatments	Information seeking behaviors	P	Evaluation of uncertainty management theory constructs & the potential contribution of the sense of virtual community. Parents of

					children with a diagnosis of club foot.
Page et al. 2012 Psychology	Unpredictability, complex, ambiguity	Parental & child uncertainty are related to each other, cognitive mechanism	Adjustment in chronic disease processes. Child depressive symptoms (mediated through child uncertainty), insecure parenting	P	Mother-child dyads, chronic illness diagnosis,
Santacroce 2000 Nursing	Diagnostic uncertainty	Ambiguity, unpredictability, lack of information &lack of clarity	Support from healthcare providers to address parental uncertainty is mediated by parental uncertainty about own chronic illness	I,N	HIV positive women during diagnosis phase of perinatally acquired HIV infection
Santacroce 2001 Nursing	Absence of cues or inability to place cues to form a symptom pattern/plan/care	Unpredictability, ambiguity, lack of information, complexity	Loss of confidence in ability to manage child's health &perform parenting role	I, N	Revision of the Parental Perception of Uncertainty Scale (PPUS) for use in measuring parental uncertainty during the diagnosis phase of serious child illness, specifically using mothers who HIV seropositive as a method for validation

Santacroce 2002 Nursing	Extreme vulnerability, distress	Chronic, differences between different races	May be related to the development of symptoms of PTSD	P	15 parents of children with cancer
Santacroce 2003 Nursing	Ambiguity about the illness state, lack of information about the illness, complexity in information, unpredictability	Neutral but can be appraised as dangerous or beneficial	Manage or resolve uncertainty through coping, restricting awareness, emotional distress, reduced quality of life, PTSD symptoms	P	Explication of the link between parental uncertainty & posttraumatic stress
Shannon & Lee 2008 Nursing	Diagnostic uncertainty in infant	Dynamic & decreases with time	Depressive symptoms are associated with more persistent uncertainty even after diagnosis is eventually known	I,N	20 HIV infected pregnant women in the United States who received HIV specialized care & prenatal care.
Stratton 2004 Nursing	Hospitalized child, interactional relationships between parents and caregivers.	Trying to protect. Creating a comfort zone. Dealing with fear.	Coping with uncertainty.	P	Six parents who experienced having a child cared for in a hospitalized setting.
Tackett et al., 2016 Psychology	Ambiguous illness experience	Global psychological distress	Posttraumatic stress symptoms	P	One hundred and five caregivers of children with new diagnosis of cancer

<p> Tluczek et al., 2011 Nursing </p>	<p> Equivocal diagnosis, individual characteristics (cognitive resources, emotional state & gender), time, internet & popular media in addition to structure providers, ambiguity </p>	<p> Cognitive process, Affective response (suffering) View of danger & opportunity as a continuum & not dichotomies </p>	<p> Coping (reducing or managing) Searching for information, mobilizing, monitoring, relabeling </p>	I	<p> Five couples with infants who had an equivocal diagnostic test result for cystic fibrosis on the newborn screen. </p>
<p> Tong et al., 2008 Medicine </p>	<p> Emotional turmoil, unknown prognosis, </p>	<p> Enduring throughout chronic illness </p>	<p> Pursuit of information, fatigue, vigilance, coping </p>	P	<p> Meta-ethnographic approach of reviewing 16 studies that focused on exploring the experiences of parents of children & adolescents with chronic kidney disease </p>
<p> Truitt et al., 2012 Patient Education/Counseling </p>	<p> Prognostic uncertainty related to developmental delay, problem behaviors & other medical issues. </p>	<p> Significantly associated with caregiver adaptation. Despite a diagnosis, continued uncertainty about child's condition </p>	<p> Lower hope & lower adaptation </p>	P	<p> Evaluation of the role of hope in adaptation to uncertainty in 546 caregivers of children with Down Syndrome </p>
<p> Watson 2011 Nursing </p>	<p> Threaded throughout time & associated with parental transitions </p>	<p> Underpins chronic anxiety & associated with parental liminality </p>	<p> A process of discomfort & distress. Influences subjective </p>	N	<p> 20 parents of very preterm infants in the UK & 12 neonatal nurses </p>

	& and infant's health/risk for change in health		confidence & perception of control. A iterative, not linear, process		
White et al., 2017 Communication Science	Parental role shift, communication interactions, caregiving experiences	Unsettling, anxiety, physiologic, ambiguity about role	Managed through reorientation, calibrating appropriate responses, & limiting exposures. Feelings of guilt	N	18 couples of infants who had been discharged from the NICU. Interviews focused on management of uncertainty after NICU discharge
Whitmarsh et al., 2007 Genetic Counseling	Complexity, ambiguity in meaning	Valued, flexibility & resistance to a biomedical perspective	Value is placed on the parental experience not the medical diagnosis	P	Parents & grandparents of children with genetic/chromosomal variants
Zierhut & Bartels 2012 Genetic Counseling	Waiting, frustration, lack of meaning	Psychological distress, anxiety, blame, "happy being ignorant"	Depression, continued fear & grief, coping & normalizing	P	Rare genetic disease, parents

Key: P= Pediatric, I=Infant, N=Neonate

Manuscript #2: A Systematic Review of Perinatal Posttraumatic Stress Disorders in Parents of Infants in the Neonatal Intensive Care Unit

Abstract

Background: Parents of infants in the Neonatal Intensive Care Unit (NICU) are at a unique risk to develop perinatal post-traumatic stress disorder (PPTSD). Supporting parents at most risk for the development of PPTSD is problematic as risk-factors are often ambiguous.

Objective: To provide a systematic literature review of the most recent publications on PPTSD in parents in the NICU in order to identify gaps in the literature and provide guidance for future research and practice.

Methods: A systematic review of the literature was conducted. The databases CINAHL, PubMed, PsychINFO, Web of Science were searched. Articles were limited to those focusing on PPTSD in parents with an infant in the NICU.

Results: Forty-six articles were included in the final analysis. Both infant and parental variables were identified as risk factors for PPTSD. Gaps identified in the literature include research about fathers' and African American women's experiences of PPTSD, the longitudinal trajectory of PPTSD across the perinatal period, and intervention development and implementation.

Conclusion: Health care providers in the NICU have an obligation to provide holistic, family-centered care and should have a broad understanding of PPTSD in the parent population as well as possible preventative and treatment options.

Keywords

NICU, trauma, Perinatal Posttraumatic Stress Disorder, PPTSD, PTSD

Introduction

The perinatal period is often understood to be a time of joyful life transition, though for 13 percent of women this time is overshadowed by perinatal mental health disorders including depression, stress, anxiety, and trauma (World Health Organization [WHO, 2013]). Perinatal posttraumatic stress disorder (PPTSD) affects up to 9 percent of women in the United States, and until recently has often been missed as an important mental health concern (Vignato et al., 2017).

PPTSD is defined as the subjective view of a traumatic event or experience that occurred any time before conception extending to one year after childbirth (McKenzie-McHarg et al., 2015). Symptoms of PPTSD are the same as PTSD and include re-experiencing, avoidance, arousal, and negative cognition. Symptoms must last longer than one month and lead to poor maternal-infant outcomes (American Psychiatric Association [APA, 2013]). When PPTSD is untreated or underdiagnosed, women are more likely to suffer from depression, poor prenatal care, prematurity, risky behaviors, excessive weight gain, lack of breastfeeding, impaired bonding, adverse child cognitive development, and increased healthcare costs (Vignato et al., 2017). Historically, PPTSD has not been recognized as frequently as other perinatal mental health disorders, such as postpartum depression.

Parents of infants in the NICU have an even higher risk to develop symptoms of PPTSD. Researchers report between 23 percent and 33 percent of parents with an infant in the NICU screen positive for PPTSD any time between birth and 18 months (Hynan et al., 2013). This unique risk makes PPTSD for families in the NICU a distinctive problem that deserves careful attention and care. The purpose of this literature review is to synthesize the most current research on PPTSD across the perinatal period with a focus on parents whose infants spend time

in the NICU. Details about differences in study characteristics, PPTSD across the perinatal period, subject risk factors, consequences of PPTSD, and interventions for PPTSD are described.

Methods

Search Strategy

A systematic review of the literature published between 2009 and 2019 was conducted. The databases CINAHL, PubMed, PsychINFO, Web of Science were searched using a combination of the following terms and the Boolean terms AND and OR: perinatal posttraumatic stress, PTSD, neonatal intensive care unit, NICU, and high-risk pregnancy. Titles and abstracts were retrieved and reviewed for relevance to the topic. Full articles were then reviewed for eligibility. Articles were excluded if the focus was on a construct other than posttraumatic stress symptoms or disorder, the environment did not include the NICU, the population of interest was not parents, or if the article was not a research study or literature review [Figure 1].

Data Extraction

Data was extracted and recorded in the tables included: authors, publication year, country of origin, level of evidence/study design, identification of theory or framework, sample characteristics (specifically antepartum, intrapartum, or postpartum), methods of measurement, interventions, and research results. Two authors (KJM & TSJ) screened the data independently to assure the quality of the selected articles.

Results

A total of 633 articles were identified in the systematic review. After duplicates were removed and screening for relevance was completed, a total of 46 articles were included in the final systematic review. The details of these 46 articles are displayed in Table I.

Study Characteristics

The majority of the articles reviewed were non-experimental, observational studies of parents of infants who spent time in NICU (N= 36). Very few studies were intervention studies for parents who suffered from PPTSD (N= 6), one article was a systematic review (Gondwe & Holditch-Davis, 2015), and one article was a meta-analysis of post-traumatic stress symptoms after childbirth (Ayers et al., 2016). Often PPTSD was not examined as a construct in and of itself. Instead, many studies researched perinatal psychological distress and measured many different constructs such as depression, anxiety, coping, worry, and attachment.

Mothers were studied more frequently than fathers; only 12 of the 45 studies included fathers in their samples (Aftyka et al., 2014, Barr, 2011; Barr, 2012; Bevilacqua et al., 2018; Castel et al.; 2016, Cole et al., 2016; Le Gouëz et al., 2016; Mehler et al., 2014; Morisod-Harari et al., 2013; Shaw et al., 2009; Yaman and Altay, 2015). Mothers and fathers both suffered from PPTSD, however mothers reported increased severity of symptoms (Aftyka et al., 2014). Notably, fathers showed more delayed onset of symptoms of PPTSD (Shaw et al., 2009).

To measure PPTSD researcher used a number of different validated tools. The Perinatal Post-Traumatic Stress Disorder Questionnaire (PPQ), both the original scale and the revised scale, were reported most frequently in the literature (Borghini et al., 2014; Castel et al., 2016; Feeley et al., 2011; Gondwe et al., 2017; Greene et al., 2015; Greene et al., 2015; Habersaat et al., 2014; Harris et al., 2018; Hernández-Martínez et al., 2019; Holditch-Davis et al., 2009; Holditch-Davis et al., 2015; Kim et al., 2015; Le Gouëz et al., 2016; MacKinnon et al., 2018; Morisod-Harari et al., 2013; Petit et al., 2016; Santos et al., 2016; Suttora et al., 2014; Toly et al., 2019; Vanderbilt et al., 2009; Zelkowitz et al., 2011; Zerach et al., 2015). Other validated

measurement tools that were frequently reported by researchers included Impact of Event Scale (Aftyka et al., 2014; Bevilacqua et al., 2018; Cole et al., 2016; Goutaudier et al., 2011; Mehler et al., 2014; Misund et al., 2014; Yaman and Altay, 2015), the PTSD Checklist (Barr, 2011; Barr, 2012; Gold et al., 2015; Lotterman et al., 2019), and the Davidson Trauma Scale (Shaw et al., 2009; Shaw et al., 2013, Shaw et al., 2013).

PPTSD affected families of all socioeconomic statuses, regardless of history of trauma (Shaw et al., 2014; Vanderbilt et al., 2009; Yaman and Altay, 2015). However, African American women were found to have a unique risk for undertreatment of PPTSD and chronic distress as compared to women of other races (Gold et al., 2015; Holditch-Davis et al., 2009).

The international impact of PPTSD is evidenced by research that originated from several different countries. The majority of the research studies were conducted in developed countries such as the United States of America, France, Canada, Poland, Italy, Australia, Switzerland, South Korea, Iran, Germany, and Israel [Table 1]. The systematic review of PTSD in mothers of preterm infants was conducted for the purpose of possible application to mothers in developing countries, specifically Malawi (Gondwe and Holditch-Davis, 2015). These findings indicate that PPTSD is cross-cultural and its impact on families residing in both developed and developing countries is of scientific interest.

PPTSD Across the Perinatal Period

Most of the research focused on PPTSD experienced by postpartum families (N= 42). Two articles evaluated PPTSD during the antepartum and the postpartum periods of time (Cole et al., 2016; Morisod-Harari et al., 2013), and there no research studies that focused specifically on PPTSD during the intrapartum period of time in parents with infants in the NICU. However, intrapartum factors, such as instrumental birth and cesarean delivery, were associated with

increased PPTSD in women with infants both in and out of the NICU (Hernández-Martínez et al., 2019; Goutaudier, Lopez, Sejourne, Denis, & Charbol, 2011).

Risks for PPTSD

Numerous studies sought to identify risk factors for development of PPTSD. These risks are categorized as either parental or infant risk factors.

Parental Risk Factors

An interrelatedness between other parental mental health disorders and PPTSD was identified throughout the literature (Greene et al., 2015; Holditch-Davis et al., 2015; Shaw et al., 2014). Specifically, a strong association between depression, both prior to pregnancy and postpartum, and PPTSD was found in numerous studies (Ayers et al., 2016; Cole et al., 2016; Lefkowitz, DS., Baxt, C., & Evans, 2010; Toly et al., 2019). Other important parental risk factors include: higher educational status (Cole et al., 2016; Bernard et al., 2011), complicated pregnancy (Ayers et al., 2016), primigravida status (Kim et al., 2015; Greene et al., 2015), brief antenatal hospitalization (Morisod-Harari et al., 2013), and decreased social support (Gondwe et al., 2017; Toly et al., 2019).

Infant Risk Factors

Associations between infant characteristics and the development of PTSD in their parents varied in the literature. A number of researchers reported that infants who were sicker with more medical complications and required longer hospitalizations had a significant positive relationship with their parents developing PPTSD (Aftyka et al., 2014; Feeley et al., 2011; Hatters Friedman et al., 2013; Suttora et al., 2014; Vinall et al., 2018). Conversely, other researchers reported no relationships between infant illness severity or developmental disabilities and PPTSD among

parents (Aite et al., 2016; Lasiuk et al., 2013; Le Gouëz et al., 2016; Lefkowitz et al., 2010) (Mehler et al., 2014; Shaw et al., 2009; Zerach, Elsayag, Shefer, & Gabis, 2013).

Descriptions of PPTSD in Parents in the NICU

Descriptions and trajectories of PPTSD in parents of infants in the NICU were measured and described. Many researchers reported a decrease in PPTSD symptoms over time (Gondwe and Holditch-Davis, 2015; Greene et al., 2015) Despite this, the quality of how symptoms decreased in this population varied. In one example, Holditch-Davis et al. (2015) described unique patterns of psychological distress. Five distinct groupings of distress were identified (low distress mean, moderate distress mean, high NICU stress mean, high depressive/anxiety mean, and extreme distress mean) and the longitudinal trajectory of symptoms was examined. Mothers in the extreme distress mean group of distress had a decrease in symptoms around 24 – 30 weeks post-term but then experienced an increase in symptoms. This differed from mothers in the other groups who all had a decrease of symptoms in the first 24 -30 weeks post-term and then their trajectories are no longer different from each other. Greene et al. (2015) also found that PPTSD symptoms remained stable over the NICU course despite a decrease in other aspects of psychological distress. Finally, in a qualitative study by Lasiuk, Comeau, and Newburn-Cook (2013) an interpretive description of parental trauma associated with preterm birth was conducted. Parents identified prolonged uncertainty, disruption in meaning systems, and lack of agency as major factors associated with the development of trauma. The authors conclude that parental participation in the NICU through activities such as breast feeding and kangaroo care all help alleviate symptoms of trauma because they address the alteration of parental role that is significant for developing trauma.

Consequences of PPTSD

Profound consequences of PPTSD on the health of families were identified. Mothers suffering from PPTSD were more likely to display controlling dyadic patterns of interactions with their infants (Forcada-Guex et al., 2011). Similarly, mothers with PPTSD were more likely to report lower levels of parenting confidence (Harris et al., 2018), increased difficulty interacting with their infants (Morisod-Harari et al., 2013), and lower perceived quality of life for both themselves and their children (Le Gouëz et al., 2016; Hernández-Martínez et al., 2019). Interestingly, one article reported that mothers suffering from extreme distress actually engaged more in developmental stimulation at 2 and 6 months, respectively, than mothers in lower distress classes. This was hypothesized to be a possible result of maternal compensatory behaviors or increased social support in this group (Santos et al., 2016).

One study, that employed a physiologic framework, found that elevated maternal PPTSD in combination with perinatal stress were associated with flatter diurnal cortisol slopes in premature infants. These findings indicate that the hypothalamic-pituitary-adrenal axis is uniquely altered in this population of infants, leading researchers to hypothesize that early exposure to acute stress may increase infant vulnerability in stressful environments (Habersaat et al., 2014).

Finally, the concept of posttraumatic growth in the population was studied in one research study. Barr (2011) discovered that parents of infants in the NICU found that coping through positive reappraisal predicted increased posttraumatic growth in parents more than existential emotions such as guilt and fear of death.

Interventions

Five of the 46 articles reviewed described and tested interventions for PPTSD in parents with infants in the NICU. Theoretical frameworks for interventions included family system theory (Borghini et al., 2014), attachment theory (Castel et al., 2016), cognitive behavioral therapy (Koochaki et al., 2018; Shaw et al., 2013), and a combination of cognitive behavioral approach with behavioral oriented sensitivity training (Zelkowitz et al., 2011). When the interventions were provided to parents, they all required multiple sessions with parents. All but one (Zelkowitz et al., 2011) intervention study reported improvement in PPTSD symptoms after the intervention was delivered. Decreased PPTSD symptoms were found in parents immediately after the intervention was delivered and, in one study, up to 18 months post intervention (Castel et al., 2016).

Discussion

Forty-six articles were reviewed to describe PPTSD in parents with an infant in the NICU. Overwhelmingly, PPTSD has been found to be a pervasive problem among parents in this population. Despite this, a number of gaps in knowledge are identified. These gaps include conflicting data on risk factors, underrepresentation of specific populations, and a lack of intervention studies.

Numerous infant and parental risk factors for PPTSD makes predicating which families have the highest probability of experiencing PPTSD difficult (Afyka et al., 2014; Feeley et al., 2011; Hatters Friedman et al., 2013; Suttora et al., 2014; Vinall et al., 2018; Greene et al., 2015; Holditch-Davis et al., 2015; Shaw et al., 2014). The lack of research spanning the peripartum period makes it difficult to fully understand the relationships between antepartum, intrapartum,

and postpartum variables, and PPTSD. Without this information, researchers and clinicians are unable to design and administer interventions at the optimal time during the perinatal period.

It is troubling that, despite the agreement that risk for PPTSD appears to cross socioeconomic lines (Shaw et al., 2014; Vanderbilt et al., 2009; Yaman & Altay, 2015), African American mothers are less likely to receive adequate treatment to prevent and treat PPTSD and are at risk for prolonged distress (Gold et al., 2015; Holditch-Davis et al., 2009). Importantly, none of the intervention studies focused on African American mothers specifically, indicating a dearth of research focused on this vulnerable population.

Fathers of infants in the NICU are also underrepresented in the literature. The quality and trajectory of symptoms appears to be different in fathers than mothers (Mehler et al., 2014; Shaw et al., 2009). Whether fathers experience PPTSD in a qualitatively unique manner requires further research that includes unique and innovative measurements and study designs.

Finally, complex variables, such as the NICU setting and numerous risk factors may make it difficult for researchers to develop and implement evidenced-based interventions. However, it appears that any form of intervention is better than none (Borghini et al., 2014; Koochaki et al., 2018; Shaw et al., 2013). Limited intervention studies and no replication studies makes implementation of practice changes difficult for healthcare providers. There appears to be an urgent need for researchers and clinicians to develop, implement, and replicate feasible interventions for this population.

Conclusion

Perinatal post-traumatic stress disorder in parents with infants in the NICU is a well described occurrence with significant morbidity. Despite adequate literature available, healthcare practices still may miss opportunities to screen for and offer support through the use of

interventions for parents at highest risk of PPTSD. While symptoms of depression and PPTSD in NICU parents overlap in many instances, health care team members must remember that they are two discrete disorders that may require different therapies. Parents in the NICU deserve comprehensive care, including identification and support for PPTSD, which will allow opportunities for the healthiest families possible upon the infants' discharge from the NICU. Healthcare providers need to make the inclusion of purposeful interventions for families at-risk for or with PPTSD a high priority in the NICU.

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Figure 2.1: Diagram of Inclusion and Exclusion of Articles Used in Systematic Review

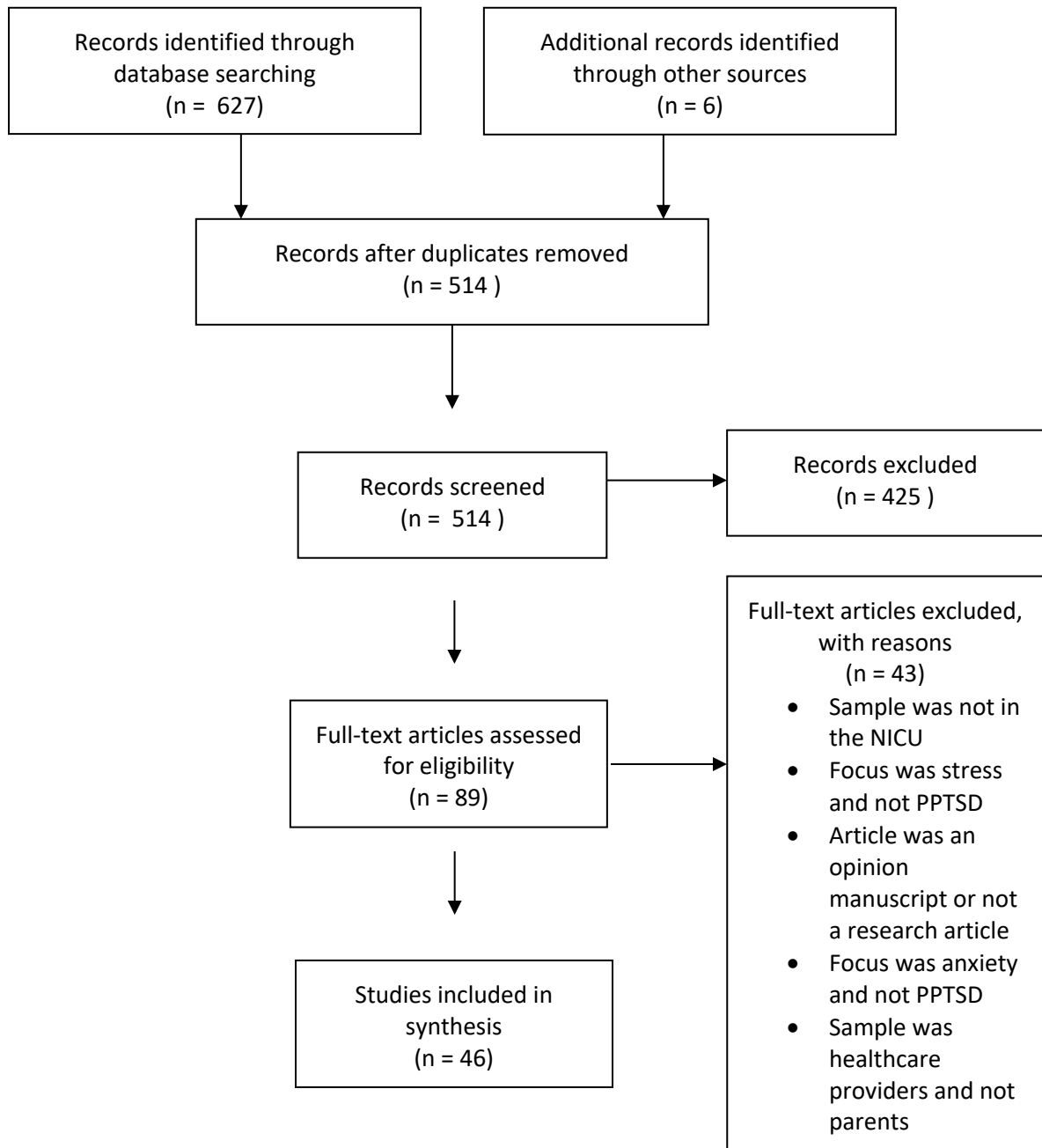


Table 2.2: Data Extraction of Literature

Author/Year/ Country/ Level of Evidence*	Theory/ Framework	Study Sample (antepartum/ intrapartum/postpartum)	Measurements/ Interventions	Study Findings Regarding PPTSD
(Aftyka, Rybojad, Rozalska-Walaszek, Rzońca, & Humeniuk, 2014) Poland Level: III	N/A	39 mothers and 27 fathers of infants aged 1-16 mo in the NICU (postpartum)	<i>Measurements</i> 1. Impact of Event Scale – Revised 2. PSS-10	No difference in PTSD between mothers and fathers. Mothers > Fathers severity of PTSD symptoms (intrusion & arousal). Perceived stress the only significant predictor of PTSD symptoms.
(Aite et al., 2016) Italy Level: III	N/A	120 mothers of infants with congenital anomalies requiring surgery (postpartum)	<i>Measurements</i> 1. Semi-structured interviews adapted from Holditch-Davis et al.,	98.4% of mothers had at least one posttraumatic stress symptom. 88% of mothers had two posttraumatic stress symptoms. The most common symptom was increased arousal. Clinical factors were generally not associated with parental distress
(Ayers, Bond, Bertullies, & Wijma, 2016) Multiple Countries Level: II	Diathesis-stress model of the aetiology of postpartum PTSD	50 studies, from 15 countries that reported primary research that examined factors associated with birth-related PTSD (antepartum, intrapartum, and postpartum)	Meta-analysis	50 studies (60 papers) included, 21,429 participants. Risks for PTSD during pregnancy included depression, fear or childbirth, poor health/complications during pregnancy, hx of PTSD, previous counseling for pregnancy or birth-related factors. Risk for PTSD during birth included subjective birth experience, operative birth, lack of support from staff during birth, and dissociation. Risk for PTSD after birth included depression and poor coping and stress.

<p>(Barr, 2011)</p> <p>Australia</p> <p>Level: III</p>	Posttraumatic Growth	<p>85 mothers and 73 fathers of infants in the NICU born ≥ 34 weeks gestation & ≥ 4 days in the NICU</p> <p>(postpartum)</p>	<p><i>Measurements</i></p> <ol style="list-style-type: none"> 1. Parental Stressor Scale NICU Version 2. Ways of Coping Questionnaire 3. Test of Self-Conscious Affect 4. Collett-Lester Fear of Death Scale 5. Posttraumatic Growth Inventory 	<p>Existential emotions and coping explained 46% & 20% of variance in mothers & fathers respectively in posttraumatic growth.</p> <p>Fear of death and guilt relationships with posttraumatic growth in father were mediated by positive reappraisal.</p> <p>Coping by positive reappraisal was a stronger predictor of posttraumatic growth than existential emotion predisposition.</p>
<p>(Barr, 2012)</p> <p>Australia</p> <p>Level: III</p>	The Actor-Partner Interdependence Model	<p>67 parents of infants in the NICU born ≥ 34 weeks gestation & ≥ 4 days in the NICU</p> <p>(postpartum)</p>	<p><i>Measurements</i></p> <ol style="list-style-type: none"> 1. Parental Stressor Scale: NICU version 2. Posttraumatic Stress Disorder Checklist 3. Depression Anxiety Stress Scale 4. Test of Self-Conscious Affect-3 5. Guilt Inventory 6. Collett-Lester Fear of Death Scale 	<p>Guilt had a significant actor effect with PTSD, anxiety, and depression, and a significant partner effect with anxiety and depression.</p> <p>Guilt explained 15-18% of the variance in these measures of psychological distress.</p> <p>Shame did not predict PTSD or anxiety but there was a significant actor effect with depression.</p>
<p>(Bevilacqua et al., 2018)</p> <p>Italy</p> <p>Level: III</p>	N/A	<p>34 parents of newborns with a congenital anomaly</p> <p>(postpartum)</p>	<p><i>Measurements</i></p> <ol style="list-style-type: none"> 1. Italian Version of the Impact of Event Scale 	<p>52.9% of mothers and 44.1% of fathers reported traumatic stress symptoms above the clinical cutoff at 6 months of age and remained stable at 12 months of age.</p>
<p>(Borghini et al., 2014)</p> <p>Switzerland</p> <p>Level: I</p>	Family system theory	<p>Preterm group: 60 very premature infants (born before 33 weeks) & mothers. This group was randomized into intervention and control groups.</p> <p>Term group: 23 term infants & their mothers</p> <p>(postpartum)</p>	<p><i>Measurements</i></p> <ol style="list-style-type: none"> 1. French Version of the PPQ 1 2. CARE Index (3rd edition) 3. The Perinatal Risk Inventory <p><i>Intervention</i></p> <p>3 phased intervention based on family system theory.</p>	<p>Mothers in both preterm groups > symptoms of PPTSD than mothers of term infants.</p> <p>Mothers with intervention had significant decrease in PTSD symptoms over time.</p>

(Castel et al., 2016) France Level: I	Intervention is based on attachment theory	89 families total: 65 families with preterm infants and 24 families with full-term infants. (postpartum)	<i>Measurements</i> 1. The Parenting Stress Index Sort Form 2. Edinburgh Postnatal Depression Scale 3. PPQ2 4. Neonatal Behavioral Assessment Scale 5. Brunet-Lezine Revised Test <i>Intervention</i> 22 sessions with a focus on triadic attachment.	Parents in the intervention group reported significantly less stress than parents in the control group at 18 months.
(Cole et al., 2016) USA Level: III	N/A	1032 & 788 expectant mothers & fathers respectively of fetuses with confirmed anomaly (Antepartum and postpartum)	<i>Measurements</i> 1. Revised Impact of Event Scale 2. The Center for Epidemiologic Studies Depression Scale 3. Postpartum Depression Screening Scale	19.3% of women and 13.1% of men reported significant PTSD symptoms. 1 Increase risk for PTSD included younger age, minority racial/ethnic status, post-college level educational, and current or prior use of antidepressant medications.
(Feeley et al., 2011) Canada Level: III	N/A	21 mothers of infants in the NICU weighing ≤ 1500 grams (postpartum)	<i>Measurements</i> 1. PPQ1 2. Emotional Availability Scale	23.8% of mothers scored in the clinical range for PTSD Risks for PTSD included lower birth weight, longer length of stay, and increased medical complexity. Mothers who reported more PTSD symptoms were observed to be less sensitive and less effective at structuring interactions with their infants.
(Forcada-Guex, Borghini, Pierrehumbert, Ansermet, & Muller-Nix, 2011) Switzerland Level: II	Framework of unresolved attachment and trauma related symptoms	47 mother/infant dyads in and after NICU discharge. 25 mother/term infant dyads as control subjects. (postpartum)	<i>Measurements</i> 1. PPQ1 2. The Working Model of the Child Interview (WMCI) 3. Video tape of 10 min of parent/infant play and coded using the "Care Index" 4. The Perinatal Risk Inventory	Mothers of preterm infants and with PTSD more likely to follow a "controlling" dyadic pattern of interaction and have a more distorted representation. Mothers of term infants more likely to follow a "cooperative" dyadic pattern of interaction with their infants and demonstrate a balanced representation of the infant
(Gold, Leon, Boggs, & Sen, 2015) USA Level: III	Based on multiple differing perspectives in understanding grief, which overlap but are distinct. Examples include: self-help, making meaning of the loss, and normative resilience	609 bereaved and live-birth mothers. Average gestational age of infant of bereaved mothers = 29 weeks. (postpartum)	<i>Measurements</i> 1. Patient Health Questionnaire-8 2. PTSD Checklist 3. Risk Assessment Monitoring System	Bereaved women: 7-fold higher odds of a positive screen for PTSD after controlling for demographic and personal risk variables. 36% of women with PTSD reported current psychiatric treatment.

				Low rates of treatments for African American mothers with significant distress noted
(Gondwe and Holditch-Davis, 2015) USA Level: III	N/A	23 studies from developed countries, focus on PTS symptoms in mothers of premature infants	Systematic Review	Antepartum risks: unexpected timing of birth, perinatal complications, mental health disorders. Mothers > fathers suffer from PTSD Symptoms decrease over time Limited services targeting PTSD in this population
(Gondwe, White-Traut, Brandon, Pan, & Holditch-Davis, 2017) USA Level: III	N/A	239 mothers of preterm infants <1750 (postpartum)	<i>Measurements</i> 1. Sate-Trait Anxiety Inventory 2. PPQ2 3. Parental Stress Scale 4. The Worry Index	No decrease in PTS symptoms over time. Married mothers < PTS symptoms than unmarried mothers. Infant illness severity had contradictory findings regarding psychological distress and interactive dimensions.
(Goutaudier, Lopez, Séjourné, Denis, & Chabrol, 2011) France Level: III	N/A	27 mothers of premature infants in the NICU (postpartum)	<i>Measurements</i> 1. French Version of the Impact of Event Scale-Revised 2. French Version of the Edinburgh Postnatal Depression Scale 3. Qualitative semi-structured interviews	21 mothers scored high enough for possible PTSD. Themes noted in the qualitative interviews included: negative experiences of childbirth. Many were traumatized by needing to have a c-section. Many felt guilty/responsible for having a preterm delivery.
(Greene, Rossman, Patra, Kratovil, Janes, et al., 2015) USA Level: III	N/A	69 mothers of VLBW infants in the NICU (postpartum)	<i>Measurements</i> 1. The Center for Epidemiological Studies Scale 2. The State-Trait Anxiety Inventory 3. PPQ2 4. The Parental Stressor Scale: NICU 5. The Life-Events Checklist	Perinatal PTSD symptoms stable throughout the NICU hospitalization, other aspects of distress decreased over time. Previous psychological history and infant medical variables predicted higher PPTS but no other aspects of distress. Reproductive variables predicted anxiety and PPTS, specifically primipara status

(Greene, Rossman, Patra, Kratovil, Khan, et al., 2015) USA Level: III	N/A	69 mothers of VLBW infants in the NICU (postpartum)	<i>Measurements</i> 1. Maternal Visitation Data 2. The Center for epidemiological Studies 3. The State-Trait Anxiety Inventory 4. PPQ-2 5. The Life Events Checklist	Rates of elevated anxiety and PPTS symptoms significantly declined from 1-month post birth to 4-month CGA. Increased # of traumatic events associated with decreased NICU visitation.
(Habersaat et al., 2014) Switzerland Level: III	Physiologic: the Hypothalamic-pituitary-adrenal (HPA) axis	54 preterm infants (27 girls and 27 boys) and 54 mothers (postpartum)	<i>Measurements</i> 1. Perinatal Risk Inventory 2. The French Version of the PPQ1 3. Infant Saliva samples – measure cortisol levels.	High maternal PTSD symptoms and high perinatal stress were associated with flatter diurnal cortisol slopes.
(Harris, Gibbs, Mangin-Heimos, & Pineda, 2018) USA Level: III	Based on the construct of “occupation” as everyday actions a person needs, wants, or is expected to do.	37 mothers of infants \leq 32 weeks gestation, 47 mothers of term infants \geq 37 weeks gestation (postpartum)	<i>Measurements</i> 1. The Parental Stress Scale 2. Edinburgh Depression Scale 3. The State-Trait Anxiety Inventory 4. PPQ2 5. Engagement in the NICU – maternal self-report on a questionnaire	24% preemie mothers reported elevated PTS symptoms Mothers of preterm infants who had a c-section reported significantly higher psychological distress Higher levels of psychological distress were associated with lower levels of parenting confidence in mothers in both groups
(Hatters Friedman et al., 2013) USA Level: III	N/A	150 mothers of infants in NICU (postpartum)	<i>Measurements</i> 1. Depression, anxiety, PTSD as diagnosed by Psychiatrist and retrieved from chart review	Diagnoses included: 40% depression, 31% anxiety disorders, and 5% PTSD. Mothers of VLBW infants and who had a longer length of stay were most likely to be referred.

<p>(Hernández-Martínez et al., 2019)</p> <p>Spain</p> <p>Level: III</p>	N/A	<p>2290 Spanish women 8.3% of the women's infants were hospitalized after birth</p> <p>(postpartum)</p>	<p><i>Measurements</i></p> <p>1.SF-36 Instrument 2.PPQ2</p>	<p>10.6% of women at risk for PTSD. Protective factors against PTSD included: having a birth plan, using epidural analgesia, skin-to-skin contact.</p> <p>Risk factors for PTSD included instrumental birth and c-section.</p> <p>Women with PTSD presented a mean difference for quality of life of -13.37 points less than those without PTSD</p>
<p>(Holditch-Davis et al., 2009)</p> <p>USA</p> <p>Level III</p>	N/A	<p>177 African American mothers of premature infants < 1500 gm</p> <p>(postpartum)</p>	<p><i>Measurements</i></p> <p>1. The Worry Index 2. The Parental Stressor Scale: NICU 3. The Center for Epidemiologic Studies Depression Scale 4. The State Anxiety Subscale of the State-trait Anxiety Inventory 5. PPQ1</p>	<p>Latent class analysis model showed four class model (56 mothers were "low distress", 49 mothers had "high (NICU related stress", 37 mothers had "high depressive symptoms", and 35 mother had "extreme distress").</p> <p>Mothers with sicker infants, low educational levels and high distress (depression and PTSD) are at high risk for chronic distress.</p>
<p>(Holditch-Davis et al., 2015)</p> <p>USA</p> <p>Level: III</p>	N/A	<p>232 mothers of preterm infants < 1750 gm</p> <p>(postpartum)</p>	<p><i>Measurements</i></p> <p>1. The Center for Epidemiologic Studies Depression Scale 2. The State Sub-Scale of the State Trait Anxiety Inventory 3. The PPQ-1 4. Parental Stress Scale: Prematurely Born Child 5. The Worry Index 6. The Vulnerable Child Scale</p>	<p>Depressive symptoms, state anxiety, post-traumatic stress symptoms, stress due to the infant appearance and behavior, and stress due to parental role alteration significantly interrelated.</p> <p>Five latent classes (low distress, moderate distress, high stress, high depressive and anxiety symptom class and extreme distress) identified based on differing degrees and types of psychological distress.</p> <p>Class membership, as determined at enrollment in the NICU, was related to trajectories of each psychological distress measure one year CGA.</p> <p>Mothers in the extreme distress class & the high depressive and anxiety symptom class, at risk 1 year after d/c. Less positive perceptions of the infants at 1 year after d/c.</p>

(Kim et al., 2015) South Korea Level: III	N/A	183 mothers (130 mothers of infants in the NICU and 53 "control" mothers) (postpartum)	<i>Measurements</i> 1. PPQ2 2. Edinburgh Postnatal Depression Scale 3. State-Trait Anxiety Scale	Significant group X time interactions showed four different patterns (resilient group/no PTSD symptoms, delayed group/developed PTSD after initial screening, and persistent group/consistently exhibited PTSD symptoms, a recovered group/ improved after the initial screening time) First born infant risk for PTSD at 1 year
(Koochaki, Mahmoodi, Esmaelzadeh-Saeieh, Kabir, & Dolatian, 2018) Iran Level: 1	N/A	90 mothers of infant < 37 wks and with Dx of PTSD (postpartum)	<i>Measurements</i> 1. Beck's PTSD Symptom Scale <i>Intervention</i> Eight 40-60 minute sessions held twice a week. Intervention based on cognitive behavioral therapy.	Mean PTSD scores = in both groups at enrollment. Mean PTSD symptoms significantly decreased in the intervention group vs control group immediately after intervention and at 3 weeks.
(Lasiuk et al., 2013) Canada Level: III	N/A	21 parents of premature infants and 5 healthcare providers (postpartum)	<i>Measurements</i> Interviews and focus groups	Preterm birth is a traumatic event leading to psychological distress regardless of infant illness severity.
(Le Gouëz et al., 2016) France Level: III	N/A	38 families of infants born with esophageal atresia (postpartum)	<i>Measurements</i> 1. Child quality of life and global health status 2. French- version of the PPQ and State-trait Anxiety Inventory 3. Neonatal Severity Score – a non-validated score ranging from 1-10 based on risk factors to measure illness severity	59% of parents (69% mothers and 46% fathers) + for PTSD PTSD was not associated with neonatal illness severity nor with severe sequelae at 2 years. Parents with PTSD rated their child's quality of life and global health status significantly lower
(Lefkowitz, Baxt, & Evans, 2010) USA Level III	N/A	86 mothers and 41 fathers of infants in the NICU (postpartum)	<i>Measurements</i> 1. Acute Stress Disorder Scale 2. Parental Perception of Medical Severity 3. PTSD Symptoms Checklist 4. Beck's Postpartum Depression Screening Scale	35% of mothers and 24% of fathers met criteria for ASD at T1. 15% of mothers and 8% of fathers met PTSD diagnostic criteria at T2. PTSD symptoms were associated with concurrent stressors, family hx of anxiety and depression.

(Lotterman, Lorenz, & Bonanno, 2019)	N/A	91 mothers of infants 32 – 36 6/7 wk gestation (postpartum)	<i>Measurements</i> 1. The Center for Epidemiological Studies Depression Scale 2. GAD-7 3. The PTSD Checklist	15.4% of mothers while in the NICU and 15.8% of mothers 6 mo after NICU discharge reported clinically significant PTSD symptoms. Psychopathological symptoms were strongly correlated at enrollment and at 6 mo after discharge
USA Level: III				
(MacKinnon, Houazene, Robins, Feeley, & Zelkowitz, 2018)	The Comprehensive Social Ecological Framework	Postpartum women 1 week after NICU discharge (postpartum)	<i>Measurements</i> 1. PPQ-2 2. PNRQ 3. History of Interpersonal Trauma History 4. Relationship Questionnaire (RQ) – measurement of adult attachment style	Attachment style moderated impact of history of interpersonal trauma on PTSD symptoms. More secure attachment conferred resiliency and more fearful attachment conferred vulnerability in women without hx interpersonal trauma. More preoccupied and more dismissing attachment conferred resiliency among women with a history of interpersonal trauma
Canada Level: III				
(Mehler et al., 2014)	N/A	60 mothers and 56 fathers infants 32 – 37 wk gestation in NICU And a control group of 32 mothers and 29 fathers of full-term infants (postpartum)	<i>Measurements</i> 1. The Nursery Neurobiological Risk Score 2. The Edinburgh Postnatal Depression Scale 3. Impact of Event Scale 4. F-SozU Scale (short version)	Preterm fathers had higher PTSD scores than term fathers (specifically avoidance symptoms) PTSD not associated with infant illness severity PTSD scoring decreased with time for preterm parents but not for full-term parents
Germany Level: III				
(Misund, Nerdrum, & Diseth, 2014)	N/A	29 mothers of infants < 33 wks gestation in NICU (postpartum)	<i>Measurements</i> 1. Impact of Events Scale 2. The General health Questionnaire 3. State Trait Anxiety Inventory	52% prevalence of PTSD symptoms Planned C-section predicted low Impact of Event Scale score.
Norway Level: III				

(Morisod-Harari, Borghini, Hohlfeld, Forcada-Guex, & Muller-Nix, 2013) France Level: III	N/A	51 families of premature infants and a control group of 25 full-term, healthy infants and their families. (ante-partum and postpartum)	<i>Measurements</i> 1. The parental Stressor Scale 2. PPQ1	Mothers hospitalized <8 days reported more PTSD symptoms than mothers hospitalized >8 days. Parents reporting more PTSD symptoms also described more difficulty interacting with their infants in the NICU
(Petit et al., 2016) France Level: III	N/A	100 mother/infant dyads in the NICU (postpartum)	<i>Measurements</i> 1. PPQ2 2. Hospital Anxiety and Depression Scale 3. Edinburgh Postnatal Depression Scale 4. The Social Support Questionnaire 5. Perinatal Risk Inventory 6. Pediatric Infant Parent Exam – evaluates the mother/infant interaction	PPTSD in the mother at 6 months after d/c negatively correlated with quality of the mother-infant interaction at 12 months. Quality of the mother-infant interaction not correlated with infant assessment in NICU. Is correlated with the fine motor skills of the baby at 12 months.
(Santos, Yang, Docherty, White-Traut, & Holditch-Davis, 2016) USA Level: III	N/A	229 mothers of preterm infants weighing \leq 1750 grams (postpartum)	<i>Measurements</i> 1. The Center for epidemiologic Studies Depression Scale 2. The State-trait Anxiety Inventory 3. The PPQ2 4. The Perinatal Stress Scale 5. Mother-Infant Interactions 6. Quality of the Home Environment 7. Interactive Dimensions (positive involvement and developmental stimulation) 8. The Bayley Scales of Infant and Toddler Development	Mothers with extreme distress class engaged in more developmental stimulation at 2 mo and at 6 mo.
(Shaw et al., 2009) USA Level III	N/A	18 parents in the NICU. 5 couples, 2 fathers, and 6 mothers (Postpartum)	<i>Measurements</i> 1. Stanford Acute Stress Reaction Questionnaire 2. Parental stressor Scale: Neonatal Intensive Care Unit 3. Davidson Trauma Scale 4. Beck Depression Inventory	33% of fathers and 9% of mothers met criteria for PTSD at 4 months. ASD symptoms were significantly correlated with both PTSD and depression. Fathers showed more delayed onset of PTSD symptoms than mothers. Infant illness severity did not correlate with PTSD

(Shaw, Bernard, Storfer-Isser, Rhine, & Horwitz, 2013) USA Level: II	N/A	56 mothers of premature infants (postpartum)	<i>Measurements</i> 1. The Stanford Acute Stress Reaction Questionnaire 2. The Davidson Trauma Scale 3. The Brief COPE <i>Intervention</i> Three session incorporating principles of trauma-focused cognitive behavior therapy designed to reduce symptoms of PTSD.	30% of mother screened + for PTSD at one month. Dysfunctional coping was positively associated with an increased risk for PTSD. Maternal education was positively associated with PTSD; each year increase in education was associated with a 17% increase in relative risk for PTSD at one month after NICU discharge.
(Shaw et al., 2013) USA Level: I	N/A	105 mothers of premature infants (postpartum)	<i>Measurements</i> 1. Traumatic Events Questionnaire 2. Davidson Trauma Scale 3. Stanford Acute Stress Reaction Questionnaire 4. Parental Stressor Scale: Neonatal Care Unit 5. Beck Depression Inventory 6. Becks Anxiety Inventory 7. Mini-International Neuropsychiatric Interview 8. Illness Health Severity Index <i>Intervention</i> 6 session intervention that incorporated principles of trauma focused CBT	Mothers in the intervention group reported a > decrease in trauma and depression symptoms compared with the control group. Mothers with higher ratings of baseline NICU stress benefited more from the intervention compared with mothers who had lower ratings.
(Shaw et al., 2014) USA Level: III	N/A	135 mothers of infants 26-34 wks gestation with wt > 1000 gms in the NICU (postpartum)	<i>Measurements</i> 1. Illness Health Severity Index 2. Stanford Acute Stress Reactions Questionnaire 3. Beck Depression Inventory 4. The Beck Anxiety Inventory	77.8% of mothers screened positive on at least one of the three measures No maternal sociodemographic, pregnancy, or infant health severity associations with screening + for PTSD
(Suttora, Spinelli, & Monzani, 2014) Italy Level: III	Transactional model of development	243 mothers: 156 mothers of full-term children and 87 mothers of preterm infants (postpartum)	<i>Measurements</i> 1. Italian version of the PPQ2 2. Parenting Stress Index 3. Multidimensional Scale of Perceived Social Support 4. Family Occupational Index 5. Neonatal Health Risks Index 6. Prematurity Composite (for preterm infants)	Mothers of preterm infants > PTSD symptoms than mothers of term infants. Significant predictors of PPTSD were infant prematurity composite score and maternal social support. PTSD symptoms mediated preterm delivery and subsequent levels of parenting stress

(Toly et al., 2019) USA Level III	Transition Theory	19 mothers of technology dependent infants in the NICU at discharge (postpartum)	<i>Measurements</i> 1. Functional Status II-Revised 2. Technology Dependency Questionnaire 3. Center for Epidemiological Studies-Depression Scale 4. PPQ2 5. Pediatric Inventory for Parents 6. The Resourcefulness Scale	Depressive symptoms in mothers significantly associated with higher PTSD symptoms.
(Vanderbilt, Bushley, Young, & Frank, 2009) USA Level: III	N/A	59 low income mothers of infants' in the NICU and 60 low income mothers of healthy infants (postpartum)	<i>Measurements</i> 1. PPQ1 2. Traumatic events Questionnaire 3. Edinburgh Postpartum Depression Scale 4. Perinatal Risk Inventory	Mothers in NICU > symptoms of acute posttraumatic stress and depression compared mothers of healthy infants, even when controlling for life-time history of trauma and depression.
(Vinall, Noel, Disher, Caddell, & Campbell-Yeo, 2018) Canada Level: III	N/A	36 mother-infant dyads in the NICU (postpartum)	<i>Measurements</i> 1. PTSD Checklist 2. Mother's Memory Interview – qualitative interview at the time of discharge.	Increased invasive procedures associated with > PTSD symptoms. Memories of anxiety re invasive procedures associated with > PTSD symptoms.
(Yaman & Altay, 2015) Turkey Level: III	N/A	66 mothers and 66 fathers of infants in the NICU (for at least 7 days) (postpartum)	<i>Measurements</i> 1. Impact of Events Scale-Revised	The mean score of the impact of events scale-revised for both mothers and fathers were high. Mothers scored significantly higher than father Sociodemographic traits and pregnancy/delivery related factors did not affect PTSD Scores.
(Zelkowitz, Na, Wang, Bardin, & Papageorgiou, 2011) Canada Level: I	N/A	98 mothers of VLBW infants (postpartum)	<i>Measurements</i> 1. State-Trait Anxiety Inventory 2. Parental Stress Scale: NICU 3. Maternal Behavioral Interactions 4. Revised Nursery Neurobiological Score 5. PPQ2 <i>Intervention</i> Cues and Care Intervention administered over multiple weeks, 5 sessions in NICU and one at home	No difference between groups in their levels of stress related to restricted parental role or the infant's appearance. No difference between groups in occurrence of PTSD. Infants in both groups had similar levels of activity, responsiveness, and distress.

(Zerach, Elsayag, Shefer, & Gabis, 2015) Israel Level: III	N/A	78 mothers of ELBW infants born 4-16 years earlier (postpartum)	<i>Measurements</i> 1. State-Trait Anxiety Inventory 2. Parental Stress Scale: NICU 3. Maternal Behavioral Interactions 4. Revised Nursery Neurobiological Score 5. PPQ2 6. Parental Stress Index 7. Life-Events Questionnaire: 8. "Severity of Prematurity Developmental Outcomes": variable created by authors	25.6% of mothers reported PPTSD symptoms > cutoff. No difference between mothers of infants of different developmental outcomes in PPTSD. Increased # of siblings and negative life events associated with PTSD
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*Level of Evidence From [Johns Hopkins nursing evidence-based practice : Models and Guidelines](#)

Dearholt, S., Dang, Deborah, & Sigma Theta Tau International. (2012). *Johns Hopkins Nursing Evidence-based Practice : Models and Guidelines*.

Level I: Experimental study, randomized controlled trial (RCT), Systematic review of RCTs with or without meta-analysis

Level II: Quasi-experimental study, systematic review of combination of RCTs and quasi-experimental studies, or quasi-experimental studies only with or without meta-analysis

Level III: Non-experimental study, systematic review of combination of RCTs, quasi-experimental and non-experimental, or non-experimental only, with or without meta-analysis. Qualitative study or systematic review, with or without meta-analysis

Level IV: Opinion of respected authorities and/or nationally recognized expert committees/census panels based on scientific evidence

Level V: Based on experiential and non-research evidence

Key: Validated Measurement Tools

CARE Index	Used to code the quality of mother/infant interaction
The Bayley Scales of Infant and Toddler Development	Measurement of neurodevelopment
Beck's Depression Inventory	Measurement of postpartum depression
Beck's PTSD Symptom Scale	Measurement of PTSD symptoms in the domains of re-experiencing, avoidance, and arousal
The Brief COPE	Assessment of parental strategies for coping with stressors associated with an infant in the NICU
The Center for Epidemiologic Studies Depression Scale	Measurement of feelings of depression
Collett-Lester Fear of Death Scale	Measurement of personal fear of death (one's own death, fear of one's own dying, fear of the death of others, and fear of the dying of others)
Davidson Trauma Scale	Measurement of posttraumatic stress
Depression Anxiety Stress Scale	Measurement of core symptoms of depression and anxiety
Edinburgh Postnatal Depression Scale	To measure postpartum depression
Emotional Availability Scale	Measurement of mother/infant interactions
F-SozU Scale	Measurement of perceived social support

The Generalized Anxiety Disorder – 7 Item (GAD-7)	Measurement of anxiety symptoms
Guilt Inventory	Measurement of proneness to chronic guilt, namely protracted feelings of guilt/remorse and regret
Hospital Anxiety and Depression Scale	Measurement of recent anxiety and depression
Impact of Event Scale – Revised	Measurement of PTSD
The Life Events Checklist	Quantifies cumulative lifetime exposure to potentially traumatic events
Multidimensional Scale of Perceived Social Support (MSPSS)	Measurement of social support a person experiences from family, friends and significant others
Parenting Stress Index (short form)	Measurement of stress related to the parenting role
The Nursery Neurobiological Risk Score	Measurement to assess preterm infants for abnormal neurologic outcomes
Parental Stressor Scale NICU Version	Measurement of three domains of stress: NICU sights and sounds, infant behavior and appearance, and alteration in parental role
Patient Health Questionnaire - 8	Measurement of symptoms of depression
Perceived Stress Scale (PSS-10 and PSS short version)	Measurement of the current level of stress
Perinatal Posttraumatic Stress Questionnaire (PPQ 1 and PPQ2)	Measurement of Perinatal Posttraumatic Stress Disorder
The Perinatal Risk Inventory	Assessment of infant illness severity/risk
Posttraumatic Growth Inventory	Measurement of five domains of posttraumatic growth
Postnatal Risk Questionnaire (PNRQ)	Measurement of psychosocial risk factors
Posttraumatic Stress Disorder Checklist	Measurement of PTSD
Risk Assessment Monitoring System	Measurement of intimate partner violence during pregnancy
Stanford Acute Stress Reaction Questionnaire	Measurement of acute stress disorder
SF-36 Instrument	Measurement of perceived quality of life
State-Trait Anxiety Inventory	Measurement of anxiety symptoms
Test of Self-Conscious Affect	Measurement of guilt-proneness and shame proneness
The Vulnerable Child Scale	Measurement of parental perception of child's vulnerability to health problems
Ways of Coping Questionnaire	Measurement of cognitive and behavioral coping strategies
The Worry Index	Measurement of mother's worry about the infant's risk for poor health

Chapter III: Methods

Introduction

It has been theorized that uncertainty is an antecedent to traumatic stress (Santacroe, 2003). Parental uncertainty in illness of an infant is a paradoxical, cognitive, and emotional experience (Mishel, 1988; Zelkowitz, Na, Wang, Bardin, & Papageorgiou, 2011). Parents experiencing uncertainty in their infant's illness are often unable to create meaning and may suffer from disrupted parental role development (Page et al., 2012). Research has shown that parents of ill children manage their feelings of uncertainty in illness using information management. Information management is typically done through either 1) an intensive pursuit of information or 2) careful evasion of encounters with that increase awareness of negative feelings. These two forms of information management are similar to two of the symptom clusters of PTSD: hyperarousal and avoidance (Santacroe, 2003)

Problem Statement

Many varying and occasionally conflicting risk factors for PPTSD in parents after having an infant in the NICU have been described in the literature. These inconsistencies make it difficult for nurses to identify and develop interventions for parents at highest risk for future development of PPTSD. Furthermore, the relationships between feelings of parental uncertainty in illness of an infant and PPTSD in parents in the NICU have not been established.

Purpose

The purpose of this study is to examine the relationships between parental uncertainty in illness of an infant in the NICU and PPTSD in parents of sick or premature infants three months after discharge from the NICU.

Research Questions and Hypotheses

- 1. *What is the factor structure of the parent perception of uncertainty scale in parents with a sick or premature infant in the NICU?*** The hypothesis is that a two-factor structure of the PPUS will be found after confirmatory factor analysis is completed. Specifically, the factors of ambiguity and unpredictability will remain in the final model.
- 2. *How do parental levels of uncertainty in illness change throughout the NICU course and after NICU discharge?*** The hypothesis is that parental levels of uncertainty in illness will decrease over time while the infant is hospitalized in the NICU and after the infant is discharged from the NICU.
- 3. *Do parental and/or infant clinical characteristics correlate with higher scores of parental perceptions of uncertainty in illness?*** The hypothesis is that infants who are sicker and whose parents report a history of mental health illness and/or screen high on the EDPS will correlate with higher scores of parental uncertainty in illness.
- 4. *Do parental and/or infant clinical characteristics correlate with higher levels of screening positive for PPTSD three months after infant discharge from the NICU?*** The hypothesis is that infants who are sicker and whose parents report a history of mental health illness and/or screen high on the EDPS will correlate with increased frequency of screening positive for PPTSD after infant discharge from the NICU.
- 5. *Do parents who experience high levels of uncertainty about their infant's illness screen positive for PPTSD more frequently after discharge from the NICU?*** The hypothesis is that parents with elevated levels of uncertainty at any point during or after the NICU course will screen positive for PPTSD more frequently after hospital discharge.

Research Methods

This study is both a confirmatory factor analysis and a non-experimental prospective longitudinal correlational study. Specifically, this is a study of parent-infant dyads hospitalized in a 70-bed, level 4 NICU in a large urban area in Southeast Wisconsin. A confirmatory factor analysis of the PPUS in a sample of parents in the NICU is important to help determine which constructs explain parental perceptions of uncertainty in this population. Correlational-cause probing research design allows for a description of the relationship between parental perception of uncertainty in the NICU and PPTSD which has not been described in the literature.

Sampling

Sample size was determined through power analysis using data from our previous study on parental perception of illness and perinatal PPTSD.

Inclusion Criteria:

1. Parents of infants who have never been discharged home from the hospital.
2. Parents of infants who are at least two weeks old.
3. Parents are English speaking
4. Parents of infants receiving palliative care unless death is imminent (per providers' discretion)

Protection of Human Subjects

A coordinated Institutional Review Board (IRB) Request form was completed in October 2017. The University of Wisconsin Milwaukee's IRB agreed to a single IRB of record. The Children's Hospital's IRB provided approval for the study in November 2017. This study involves the use of human subjects for the purposes of data collection. There are no planned

samples to be collected that require laboratory analysis, nor any therapies to be administered. As such, this study poses minimal risk to subjects and their families. As with any data collection for research purposes, there is a potential risk of loss of privacy. Confidentiality will be of utmost priority; however, breach of confidentiality is another potential risk.

Confidentiality of the patient data was maintained. Each subject was assigned a unique identifier that will be used to maintain data on each subject. Data was kept locked in compartments and password protected for computer databases. Individuals will not be identified in scientific presentation of findings or in publications. Social support and services were available to anyone who experiences emotional or psychological distress from involvement in this study. Parents who report emotional distress or signs of PPTSD were referred to the staff psychologist in the NICU or the social worker in the neonatal follow-up clinic or special needs clinic. The NICU, follow-up clinic, and special needs clinic regularly follow families of high-risk infants discharged from the NICU and have staff that identifies resources for both complex infants and their families. Nearly all infants that were eligible for enrollment in this study would automatically be referred to NICU follow-up clinic upon NICU discharge as routine practice, as of such provisions are in place to follow up on any issues that might result.

Procedures

Training of all data collectors was completed per IRB requirements (including CITI training and institutional training).

Members of the research team received training for use of the Research Electronic Data Capture (REDCap) program. REDCap will allow the team to build and manage online surveys and databases and will be completed prior to beginning of the study.

Recruitment

Participants were approached during their child's NICU hospitalization by a member of the research team and contacted following discharge to complete the following surveys. Consent was obtained by any member of the research team and copies of written consent are securely stored by the Primary Investigator. An additional copy of the consent was given the parents. If the child admitted to the NICU remained inpatient after two months, families were re-approached prior to NICU discharge to repeat the items marked below. Exact timing of this interview was based on clinician driven assessment of infant's discharge readiness based on chart review and conversation with NICU healthcare team.

Data collection

All data was inputted and recorded electronically into REDCap. If the electronic method is not available, paper copies were available and manually entered by a member of the research team. Parents were asked in the initial survey their preference for contact (phone or email), and their preferred method was used first. If preferred method was by email and a reply was not produced, a follow up contact by phone or in person during a clinic appointment was attempted. Protocol compliance was checked at weekly research meetings involving the research team.

Measurements/Variables

The following measurements were obtained through analysis of the variables associated with the identified measurement: parental characteristics, infant characteristics, parental uncertainty in illness of an infant, and perinatal posttraumatic stress.

1. **Parental characteristic** will be measured at the time of enrollment. Parents will be asked about factors hypothesized to affect PTSD based on previous research. These include:

- a. *Parent Age* (defined in years of life when the infant was born) has been found to impact stress and depression in mothers of preterm infants (Gondwe, White-Traut, Brandon, Pan, & Holditch-Davis, 2017).
- b. *Race* (Black or African American, White, Asian, American Indian or Alaska Native, Native Hawaiian or other Pacific Islander, other) impacts PPTSD secondary to the fact that African American women have been found to have a unique risk for undertreatment of PPTSD and chronic distress (Gold, Leon, Boggs, & Sen, 2015; Holditch-Davis et al., 2009).
- c. *Social Determinants of Health* using data from the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) assessment tool (National Association of Community Health Centers, 2016). The PRAPARE questionnaire is a set of national core measures along with additional measures of community priorities. The questionnaire was created based on research, experiences of social risk, and stakeholder engagement (National Association of Community Health Centers, 2016). Specifically, data regarding *housing security* (what is your housing situation today), *transportation* (has lack of transportation kept you from medical appointments, meetings, work, or from getting things needed for daily living?), and *Education* (have not finished high school, high school graduate, some college or technical school, college or technical school graduate, graduate school) will be included in the data analysis. Social determinants of health have been found to be related to PPTSD in a variety of ways. For example, higher educational status has been found to be a risk factor for PPTSD (Cole et al., 2016; Bernard et al., 2011). Additionally, decreased social support has also been found to be a risk factor for

PPTSD (Gondwe et al., 2017; Toly et al., 2019)

- d. *Family history of mental health disorder* (questions include: Do you have, or have you ever had, an emotional or behavioral health concern like anxiety, depression, bipolar, or post-traumatic stress disorder? Does anyone in your family have an emotional or behavioral health concern like anxiety, depression, bipolar, or post-traumatic stress disorder? If you have had a previous pregnancy or after the birth of a child, have you ever had emotional or behavioral health concerns like depression, anxiety, or post-traumatic stress disorder?) has been found to be associated with PPTSD in parents with an infant in the NICU in previous research (Lefkowitz, Baxt, & Evans, 2010).
 - e. *Postpartum depression* (most recent score on the Edinburgh Postnatal Depression Scale (EPDS), if completed in the electronic health record). Standardized screening for postpartum depression was implemented in the unit during the time of enrollment for this study and scores will be reviewed when available (Cox, Holdenand, & Sagovsky, 1987). Groupings of EPDS scores will be created based on the study site's management of EPDS results (Appendix C). Previous research has demonstrated a strong association between depression and PPTSD (Ayers et al., 2016; Cole et al., 2016; Lefkowitz, DS., Baxt, C., & Evans, 2010; Toly et al., 2019).
2. **Infant characteristics** will be done through reviewing the NICU electronic health care record. The following measurements will be examined based on previous literature on risk for PPTSD and infant illness severity (Malin et al., manuscript submitted for publication).
- a. *NICU length of stay* (measured in number of calendar days from day of admission to day of NICU discharge)

- b. *Days of mechanical ventilation* (the need for mechanical ventilation, not including non-invasive ventilation as measured as either 1) none, 2) 1- 7 days, 3) 8 – 30 days, 3) > 30 days)
- c. *Need for vasopressors* (measured as a dichotomized variable as yes/no)
- d. *Hypoxic Ischemic Encephalopathy (HIE) requiring cooling* (measured based on documentation of a diagnosis of HIE and initiation of total body cooling protocol)
- e. *Palliative care consultation* (measured as a dichotomized variable as yes/no)
- f. *Gestational age* (measured using the documented gestational age at birth in weeks and days).

3. Parental Uncertainty in Illness of an Infant will be measured using the 31-item Parents' Perception of Uncertainty Scale (PPUS). The PPUS will be administered at the time of enrollment, prior to discharge if the infant remains in the hospital for at least 2 months, and three months after discharge from the NICU. Table 3.2.

The PPUS was developed and published in 1983 by Dr. Merle Mishel. The PPUS was created using the previous work Dr. Mishel had done on measuring uncertainty in illness of adult patients (Mishel, 1983). Mishel's work was influenced by Norton's framework that contends when an event generates uncertainty it contains one or more of eight characteristics. These characteristics include vagueness, lack of clarity, ambiguity, unpredictability, probability, multiple meanings, and/or lack of information (Norton, 1975). As a result, the PPUS was created and tested. An exploratory factor analysis in a sample of parents of hospitalized children (N= 237) showed a four factor structure. The four factor solution included the following factors: ambiguity, lack of clarity, lack of information, and unpredictability (Mishel, 1983).

Additionally, testing of the scales ability to distinguish between groups and empirical support

through theoretical prediction was completed (Mishel, 1983). The final scale is the 31-question scale using a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree), which yields scores between 31 and 155. Higher scores indicate greater perceptions of uncertainty. Numerous research studies have since been completed using the PPUS. Validity and reliability of the scale has been reported with Cronbach alphas ranging between 0.86 and 0.87 (Madeo, O'Brien, Bernhardt, & Biesecker, 2012; Santacroce, 2001). Other studies have found anywhere between a one to a four factor model in different populations of parents (He, You, Zheng, & Bi, 2016; Madeo et al., 2012; Molzon et al., 2014; Santacroce, 2001). Translation of the PPUS has been made and Chinese and Arabic versions have been developed and tested (Al-Yateem, Docherty, Altawil, Al-Tamimi, & Ahmad, 2017; He, You, Zheng, & Bi, 2016).

4. **Perinatal Posttraumatic Stress Disorder** will be measured using the Perinatal Post-Traumatic Stress Disorder Questionnaire – the revised edition (PPQ). The PPQ is a validated 14-item questionnaire assessing PPTSD symptoms associated with the birth of an infant. Table 3.3. Scoring is conducted on a five-point Likert scale with 0 = not at all; 1= once or twice; 2 = sometimes, 3= often, but less than one month; 4 = often, for more than one month. Previous literature indicates that scores > 19 warrant clinical treatment (Callahan, Borja, Hynan, 2006). The PPQ will be administered at three months after NICU discharge. Appendix B.

The PPQ was developed and published as a response to the need for reliable methods measurement of post-traumatic symptoms related to childbirth (DeMeir, Hynan, Harris, & Manniello, 1996). The PPQ was then enhanced for ease of clinical utility and the final scale measures symptoms of intrusiveness, avoidance, hyperarousal, and feelings of guilt (Callahan, Borja, & Hynan, 2006). Many research studies and clinical practices have since adapted the PPQ as a reliable tool to screen for perinatal PPTSD (Callahan & Borja, 2008; Gondwe &

Holditch-Davis, 2015; Zhang et al., 2018). The PPQ is consistent with previous Cronbach alpha ranges from 0.85 – 0.90 (Callahan et al., 2006; DeMier, Hynan, Harris, & Manniello, 1996). The convergent and discriminant validity has also been established in previous research (Callahan & Hynan, 2002; Quinnell & Hynan, 1999).

Sample Size

An a priori power analysis was completed. A sample size of at least 127 subjects was determined to be necessary to detect a change of 20% between groups with a p-value set at 0.025.

Data Analysis

This research is a subset of a larger study examining health-related quality of life in parents with an infant in the NICU and after discharge from the NICU. Data analysis was completed using SPSS 26. Data analysis included: a confirmatory factor analysis, bivariate comparisons using Chi-Square and T-Tests, background deletion regression, and repeated measures of ANOVA (Table 3.3). Alpha is set at 0.05. Prior to data analysis, data was cleaned, and descriptive statistics were computed. Missing data was determined to be missing completely at random and imputation was employed.

Summary

Parents with an infant in the NICU have been found to experience both uncertainty in illness and PPTSD. Further research exploring these concepts and potential relationships between them is warranted in this population. This study is the first to prospectively measure both parental uncertainty in illness and PPTSD in a sample of parents during and after discharge from the NICU. The information generated from this study will provide important information about how parents in the NICU experience uncertainty over time, which parents are at risk for

PPTSD after NICU discharge, and if there is a theoretical link between the two concepts. This will provide a sound foundation for development of nursing interventions aimed to reduce the risk for adverse parental mental health outcomes after their infant is discharged from the NICU.

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Table 3.1 Timeline of Study Measurements

	Type	Enrollment	~2 months (if still admitted, pre- discharge)	3 months following discharge from NICU
1) Logistic questionnaire	Interview	x		
2) Perceived Parental Uncertainty Scale	Interview	x	X	x
3) Perinatal PTSD Questionnaire	Interview			x
4) NICU Chart Review	Chart Review			x

Table 3.2: Parental Perception of Uncertainty Scale (PPUS)

PPUS
1) I don't know what is wrong with my child.
2) I have a lot of questions without answers.
3) I am unsure if my child's illness is getting better or worse.
4) It is unclear how bad my child's pain will be.
5) The explanations they give me about my child seem hazy.
6) The purpose of each treatment is clear to me.
7) I do not know when to expect things will be done to my child.
8) My child's symptoms continue to change unpredictably.
9) I understand everything explained to me.
10) The doctors say things to me that could have many meanings.
11) I can predict how long my child's illness will last.
12) My child's treatment is too complex to figure out.
13) It is difficult to know if the treatments or medications my child is getting are helping.
14) With so many different types of staff, it is unclear who is responsible for what.
15) Because of the unpredictability of the illness, I can't plan for the future
16) The course of my child's illness keeps changing. He/She has good and bad days.
17) It is vague to me how I will manage the care of my child after he/she leaves the hospital
18) It is not clear what is going to happen to my child.
19) I usually know if my child will have a good or a bad day.
20) The results of my child's tests are inconsistent.
21) Effectiveness of the treatment is undetermined.
22) It is difficult to determine how long it will be before I can care for my child by myself.
23) I can generally predict the course of my child's illness.
24) Because of the treatment, what my child can do and cannot do keeps changing.
25) I am certain they will not find anything else wrong with my child.
26) They have not given my child a specific diagnosis.
27) My child's physical distress is predictable, I know when it is going to get better or worse.
28) My child's diagnosis is definite and will not change.
29) I can depend on the nurses to be there when I need them.
30) The seriousness of my child's illness has been determined.
31) The doctors and nurses use everyday language so I can understand what they are saying.

Table 3.3: Perinatal Post-Traumatic Stress Questionnaire-Revised Edition (PPQ)

Perinatal Post-Traumatic Stress Disorder Questionnaire II
Did you have bad dreams of giving birth or of your baby's hospital stay?
Did you have upsetting memories of giving birth or of your baby's hospital stay?
Did you have any sudden feelings as though your baby's birth was happening again?
Did you try to avoid thinking about childbirth or your baby's hospital stay?
Did you avoid doing things that might bring up feelings you had about childbirth or your baby's hospital stay (e.g., not watching a TV show about babies)?
Were you unable to remember parts of your baby's hospital stay?
Did you lose interest in doing things you usually do (e.g., did you lose interest in your work or family)?
Did you feel alone and removed from other people (e.g., did you feel like no one understood you)?
Did it become more difficult for you to feel tenderness or love with others?
Did you have unusual difficulty falling asleep or staying asleep?
Were you more irritable or angry with others than usual?
Did you have greater difficulties concentrating than before you gave birth?
Did you feel more jumpy (e.g., did you feel more sensitive to noise, or more easily startled)?
Did you feel more guilt about the childbirth than you felt you should have felt?

Table 3.4: Data Management Plan and Analysis

Research Hypotheses	Unit of Analysis	Variable	Measurement tool	Level of Measurement	Statistical Test
A two-factor structure of the PPUS will be found after factor analysis. Specifically, the factors of ambiguity and unpredictability will remain in the final model.	Factors of PPUS	4 factors include: 1.Ambiguity 2.Lack of Clarity 3. Lack of information 4. Unpredictability	Confirmatory Factor Analysis (CFA)	Nominal	CFA
Objective measures of infant illness severity will correlate with higher scores of parental perceptions of uncertainty in illness.	Infants and Parents	IV: Objective measures of infant illness severity DV: parental perceptions of uncertainty in illness	Chart Review: NICU length of stay, days of mechanical ventilation, need for pressors, HIE requiring cooling, palliative care consultation, gestational age PPUS: Score between 31 and 155	Nominal (need for pressors, HIE requiring cooling, palliative care consultation, sepsis) Continuous (length of NICU stay, days of mechanical ventilation, birth weight, gestational age) Ordinal	Bivariate comparisons using Chi- Square and T-Tests and backward deletion regression

<p>Infants who are sicker and parents with self-reported history of mental health illness will correlate with increased frequency of screening positive for PPTSD.</p>	<p>Infants and parents</p>	<p>IV: Objective measures of infant illness severity and parental history of mental health illness and EDPS score when available</p> <p>DV: perinatal PTSD</p>	<p>Chart Review: self-reported history of mental health illness, first-pregnancy, NICU length of stay, days of mechanical ventilation, need for pressors, HIE requiring cooling, palliative care consultation, gestational age, EDPS score</p> <p>PPQ: <19 screen negative for perinatal PTSD ≥ 19 screen positive for perinatal PTSD</p>	<p>Nominal (need for pressors, HIE requiring cooling, palliative care consultation, sepsis)</p> <p>Ordinal (EDPS score)</p> <p>Continuous (length of NICU stay, days of mechanical ventilation, birth weight, gestational age)</p> <p>Nominal (this will be transformed into a nominal variable from an ordinal variable: screen positive or does not screen positive)</p>	<p>Bivariate comparisons using Chi- Square and T- Tests and backward deletion regression.</p>
<p>Parents with elevated levels of uncertainty throughout the infant's NICU course will be screen positive</p>	<p>Parents</p>	<p>IV: parental perceptions of uncertainty in illness</p>	<p>PPUS: Scores between 31 - 155</p>	<p>Ordinal</p>	<p>Bivariate comparisons using Chi- Square.</p>

for PTSD more frequently after their infant's discharge from the NICU.		DV: perinatal PTSD	PPQ: <19 screen negative for perinatal PTSD ≥ 19 screen positive for perinatal PTSD	Nominal (this will be transformed into a nominal variable from an ordinal variable: screen positive or does not screen positive)	
Parental levels of uncertainty in illness will decrease overtime while in the NICU and three months after discharge.	Parents	IV: time DV: parental perceptions of uncertainty in illness	Points in time during the study (time of enrollment, prior to discharge, and 3 months after discharge) PPUS: Scores between 31 - 155	Continuous Ordinal	Repeated measures ANOVA

Chapter IV: Results

Chapter Introduction

The results of the confirmatory factor analysis and the non-experimental, prospective, longitudinal, and correlational study are presented in this chapter. The first result manuscript provides the factor structure of the PPUS in a sample of parents with an infant in the NICU. The second result manuscript describes parental uncertainty during and after infant NICU hospitalization. The second manuscript also examines the relationships between infant and parental characteristics and parental uncertainty in illness of an infant with screening positive for PPTSD three months after infant discharge from the NICU.

Manuscript 3: Factor Structure of The Parental Perception of Uncertainty Scale in Parents of Infants in the Neonatal Intensive Care Unit

Abstract

Background and Purpose: Parents of infants in the neonatal intensive care unit (NICU) often experience feelings of uncertainty. These feelings have been found to impact parental transitions into parenthood and may impact the future health of the family. The Parental Perception of Uncertainty Scale (PPUS) has been used in the past to measure parental uncertainty in samples of parents with sick children. The purpose of this study is to validate the PPUS factor structure in a sample of parents with an infant in the NICU through confirmatory factor analysis (CFA).

Methods: A sample of parents with an infant in the NICU was enrolled as part of a larger study. Parents completed the PPUS at three different points in time. A total of 267 parents' responses were included, yielding 465 completed instruments. STATA was used to complete the CFA and test the proposed factor structure.

Results: The original four-factor PPUS demonstrated adequate, though not ideal, fit in the sample of parents with an infant in the NICU. A shorter, two-factor model exhibited similar findings.

Conclusions: The PPUS provides an adequate measurement of the uncertainty experienced by parents with an infant in the NICU. More robust measurements of uncertainty that account for the unique NICU experience and advancements in communication and care are needed.

Keywords: Confirmatory Factor Analysis, Parental Perception of Uncertainty Scale, NICU

Introduction

Parents with sick or premature infants in the neonatal intensive care unit (NICU) experience a multitude of emotions. Parents who spent time with their infant in the NICU often describe the experience as stressful, traumatic, and underpinned by prolonged uncertainty that disrupts parental role development (Janvier et al., 2016; Franck, McNulty, & Alderdice, 2017; Lasiuk, Comeau, & Newburn-Cook, 2013). Parental uncertainty in illness regarding their infant's health has been found to be a complex cognitive and emotional experience that may potentially impact the future health of the family (Malin & Johnson, 2019). Developing and testing interventions is needed to support parents facing uncertainty in their infant's illness. Prior to researchers and clinicians developing interventions, there must be sound measurements of the construct of uncertainty. The Parental Perception of Uncertainty Scale (PPUS) is one of the most widely used scales to measure uncertainty in parents (Wright, Afari, & Zautra, 2009). The psychometric properties of the PPUS, to our knowledge, have not been examined in a sample of parents with infants in the NICU. The purpose of this study is to validate the PPUS factor structure in a sample of parents with an infant in the NICU through confirmatory factor analysis (CFA).

Background and Conceptual Framework

The PPUS is a 31-item instrument developed and published by Dr. Merle Mischel (Mishel, 1983). The original scale was developed and tested in a heterogenous sample of parents with a child receiving inpatient hospital care. The initial exploratory factor analysis resulted in a four-factor solution (ambiguity, lack of clarity, lack of information, and unpredictability) (Mishel, 1983). Since its development, the PPUS has been utilized by researchers to test and measure parental uncertainty. Reliability and validity of the scale has

been reported with Cronbach alphas varying from 0.86 to 0.87 (Madeo, O'Brien, Bernhardt, & Biesecker, 2012; Santacrose, 2001). Other researchers have reported anywhere from a one to a four factor structure in different populations of parents with children ranging in ages and diagnoses (He, You, Zheng, & Bi, 2016; Madeo et al., 2012; Molzon et al., 2014; Santacrose, 2001). Translations and testing of the PPUS have been conducted in Arabic and Chinese languages (Al-Yateem, Docherty, Altawil, Al-Tamimi, & Ahmad, 2017; He et al., 2016).

The conceptual framework guiding this investigation is The Uncertainty in Illness Theory (UIT) (Mishel, 1988). The UIT was built on the assumption that uncertainty in illness occurs during the diagnostic phase of illness and that uncertainty typically has a downward trajectory (Mishel, 1988). Uncertainty is not fundamentally a positive or a negative state. Once the possible implications of uncertainty are understood an evaluation of the meaning among parents can be made. The themes of antecedents, appraisal and coping scaffold the theory and provide the foundation for how individuals move through the experience of uncertainty (Mishel, 1988).

Methods

Sample

Sample size for this CFA was determined using Cochran's Sample Size Formula (Cochran, 1977). A sample of at least 300 surveys was determined to be necessary assuming a confidence level of 95% and accounting for the 5-point Likert scale and continuous data of the PPUS.

Recruitment

This CFA is a part of a prospective study to examine relationships between parental uncertainty in illness of an infant and perinatal post-traumatic stress disorder in a sample of

parents with an infant in the NICU. This study took place in a large midwestern, Children's Hospital with a 70-bed, level four NICU over a 10 month period.

Inclusion/Exclusion Criteria

Parents were eligible to participate in the study if their infant was in the NICU for at least 14 days. Exclusion criteria included non-English speaking parents, parents who would not have custody of their infant at the time of discharge, parents of infants who were previously discharged or who transferred to or from the cardiac intensive care unit. Parents of infants who were transferred from an outside hospital were considered for inclusion if no other exclusion criteria were met. Parents of infants receiving palliative care were considered for inclusion if death was not deemed imminent by the attending provider.

Procedures

The Institutional Review Boards (IRB) of two institutions determined the (IRB) where the study was conducted would be the single IRB of record. After IRB approval was obtained, parent participants were approached by a research assistant (JL) once eligibility was confirmed by the research team. The purpose of the study was explained to potential participants. Participants were informed of their right to refuse enrollment or to leave the study once enrolled, without compromising the quality of care for infant. As this was a prospective study, parents were asked to complete the PPUS at the time of enrollment, prior to the infant's discharge from the NICU, and three months after the infant was discharged from the NICU.

Measurements

The PPUS is a 31-item scale that measures parental uncertainty in illness of a sick child. To complete this scale, parents respond to questions regarding feelings of uncertainty and rank them on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree). Many of the

questions require reverse scoring. Once reverse scoring is completed, a total score is calculated and varies from 31 to 155. Higher scores indicate greater perceptions of parental uncertainty (Mishel, 1983).

Data Analysis

Responses to the PPUS were recorded using a secure database on a tablet (Harris et al., 2009). Confirmatory factor analysis of the data was completed using STATA version 15.1. CFA is a unique form of structural equation modeling used to determine construct validation in psychological assessment tools (Kyriazos, 2018). This procedure provides data regarding the questions comprising the scale and the construct of interest. Once completed, other possible models can be examined based on goodness-of-fit indices and theoretical structures. The root mean square error of approximation (RMSEA) is a strong measure of goodness of fit. RMSEA scores between 0.05 – 0.06 indicate a good fit, while scores >0.1 indicate a poor fit (Browne & Cudeck, 1993). Missing data was evaluated by the authors. Reporting of the missing data and management plan for missing data is reported in the results section.

Model I was the original four factor, 31-item PPUS. The parameters used for appraisal included the chi-square, RMSEA, Comparison Fit Index (CFI), and the Tucker-Lewis Index.

Model II was an exploratory factor analysis of a two-factor PPUS using the domains of ambiguity and unpredictability. Principal component analysis was used as the results were intended to focus on the sample used in this study. Chronbach's alphas were completed for the two-factor model. Parallel analysis was performed and items that double loaded with an eigenvalue-greater than 0.3 were removed. Additionally, items that loaded less than 0.4 were removed. The parameters used for appraisal included the chi-square, RMSEA, Comparison Fit Index (CFI), and the Tucker-Lewis Index.

Results

Two hundred and sixty-seven parents participated in the study, yielding a total of 465 completed PPUS surveys from different points in time during the study. Two percent of the surveys were missing responses to one of the 31 questions. Missing responses were evaluated and determined to be missing completely at random. These values were replaced using imputation of the average response score for the missing questions, at that specific point in time. The average total PPUS was 70 (SD =16.5). Total scores were not normally distributed, with skewness of 0.2167 and kurtosis of 0.0078. The majority of the respondents were the mother of the infant (97%). The reasons for infant admission varied. Fifty-seven percent of the infants were admitted secondary to prematurity (birth prior to <37 1/7 weeks gestation). Twenty-two percent of the infants had a congenital anomaly, and 13% were deemed “medically complex” by a neonatologist.

The CFA of the original four-factor PPUS yielded a chi-square = 0.000, RMSEA = 0.069 (CI: 0.065-0.073), CFI = 0.834, and Tucker-Lewis Index = 0.819. Thus, indicating an acceptable but less than ideal fit. Further theoretical examination of the questions was completed and a two-factor model (ambiguity and unpredictability) was tested based on previous analysis of the PPUS. Using a principal component analysis and varimax with Kaiser rotation, a 20-item model was created. Eleven items had loading values <0.4, which were then dropped. The resulting 20-item model accounted for 42.7% of the variance. Fourteen questions loaded onto the ambiguity factor and six questions loaded onto the unpredictability factor. In Table 1 the final loading structure for a two-factor model is displayed. Cronbach’s alphas of 0.82 (ambiguity) and 0.682 (unpredictability) were found for the two-factor model. CFA of the two-factor PPUS yielded a

chi-square =0.000 and a RMSEA = 0.07 (CI: 0.064-0.077), indicating similar results as the original four-factor model.

Discussion

The current study examined the factor structure of the PPUS in a sample of parents with a sick or premature infant. The original 31-question PPUS demonstrated an adequate, though not ideal, factor structure in our sample of parents. Similar findings were found with the shorter, 20-item scale and two-factor structure that we tested. The original 31-question PPUS demonstrated the better fit of the two models. These results are compatible with previous work examining the factor structure of the PPUS in different samples of parents with children who are sick. The original PPUS was developed and tested using parents of children hospitalized in numerous different areas of the hospital (Mishel, 1983). Since that time, researchers have noted that the experience of parental uncertainty in illness may differ depending on the time of measurement in relation to time of diagnosis (Santacroce, 2001) and nature of the child's illness (Madeo et al., 2012; Molzon et al., 2014; He et al., 2016). This has led to the development of other tools to measure uncertainty (Ueki, Komai, & Ohashi, 2017). Our findings indicate that the PPUS does an adequate job at measuring parental uncertainty in illness of an infant while both in the NICU and after discharge from the NICU. The shorter, two-factor structure model provides a similar fit as the four-factor model and maintains theoretical goodness of fit with the conceptual framework of the study. It should be considered that the four-factor model requires more questions than the two-factor model (31 questions vs 20 questions) and does not provide a superior fit in this sample of parents. Efforts to reduce response burden secondary to questionnaire length need to be considered when survey psychometrics properties are preserved despite reducing the number of questions. The PPUS was developed in 1983 and as time has progressed so have the

interventions, technologies, and modes of communication evolved. The reliance on digital communication and real-time viewing options via smart devices has helped to create a culture where parents with infants in the NICU are able to receive real-time updates regarding the health and wellbeing of their children. Modernized healthcare now supports the survival of much younger premature infants in addition to the survival of many children living with chronic health conditions that often require the use of long-term medical technology.

Our study is limited by the fact that parents were sampled from a single institution and the majority of respondents were mothers. Additionally, the infants of the parents in our study experienced a range of different diagnoses requiring care in the NICU. We were not able to ascertain if parents anticipated the need for neonatal hospitalization at the time of birth secondary to the inability to review the maternal EHR. These differences in diagnoses and conditions undoubtedly impacted the parental experience of uncertainty in ways that are not accounted for in this CFA.

Relevance to Nursing Practice, Education, and Research

The results of this study indicate that the PPUS is an adequate, though not ideal, tool to measure parental uncertainty in illness in parents with an infant in the NICU. In light of the reasons for NICU hospitalization there is a need for more precise measurements of uncertainty within this diverse group of parents. Furthermore, information regarding how uncertainty in parents with sick or premature infants' changes over time throughout the infants' NICU hospitalization and after discharge would be beneficial. NICU nurses are required to assess and provide support for parents who often experience periods of significant stress and uncertainty. Further investigation by researchers into how this uncertainty is experienced and how it changes in parents with sick or premature infants over time would provide necessary information to assist

researchers, nurses, and other healthcare providers to develop more focused, time-specific, interventions to help parents cope with uncertainty.

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Table 4.1: Final Item Loading for Two-Factor Model

<i>PPUS Item</i>	<i>Ambiguity</i>	<i>Unpredictability</i>
# 5: <i>The explanations they give me about my child seem hazy.</i>	0.794	
# 20: <i>The results of my child's tests are inconsistent.</i>	0.754	
# 12: <i>My child's treatment is too complex to figure out.</i>	0.735	
# 21: <i>Effectiveness of the treatment is undetermined.</i>	0.711	
# 2: <i>I have a lot of questions without answers.</i>	0.709	
# 13: <i>It is difficult to know if the treatments or medications my child is getting are helping.</i>	0.698	
# 3: <i>I am unsure if my child's illness is getting better or worse.</i>	0.663	
# 14: <i>With so many different types of staff, it is unclear who is responsible for what.</i>	0.64	
# 10: <i>The doctors say things to me that could have many meanings.</i>	0.635	
# 7: <i>I do not know when to expect things will be done to my child.</i>	0.588	
# 31: <i>The doctors and nurses use everyday language so I can understand what they are saying.</i>	0.582	
# 9: <i>I understand everything explained to me.</i>	0.565	
# 26: <i>They have not given my child a specific diagnosis.</i>	0.448	
# 29: <i>I can depend on the nurses to be there when I need them.</i>	0.442	
# 27: <i>My child's physical distress is predictable; I know when it is going to get better or worse.</i>		0.728
# 23: <i>I can generally predict the course of my child's illness.</i>		0.718
# 11: <i>I can predict how long my child's illness will last.</i>		0.615
# 19: <i>I usually know if my child will have a good day or a bad day.</i>		0.584
# 25: <i>I am certain they will not find anything else wrong with my child.</i>		0.577
# 28: <i>My child's diagnosis is definite and will not change.</i>		0.42

Manuscript 4: Parental Uncertainty and Perinatal Posttraumatic Stress Disorder in the Neonatal Intensive Care Unit

Abstract

Background: Perinatal posttraumatic stress disorder (PPTSD) in parents after having an infant in the NICU is a significant problem that can adversely affect long-term parent and infant health development. PPTSD is associated with a number of different parent and infant variables.

Feelings of uncertainty have been theorized to be associated with posttraumatic stress. Parental uncertainty in illness of an infant is a unique phenomenon and its relationship to PPTSD has not been studied in parents in the NICU.

Purpose: To describe parental uncertainty during and after NICU hospitalization and to evaluate the relationships between infant and parental characteristics with uncertainty in illness of an infant. Also, to examine relationships between infant and parental characteristics and parental uncertainty with screening positive for PPTSD.

Methods: A prospective, longitudinal correlational study of parent-infant dyads during and after NICU hospitalization. Repeated measures of parental uncertainty were administered using the Parental Perception of Uncertainty Scale (PPUS). PPTSD was measured three months after discharge using the Perinatal Posttraumatic Stress Disorder Questionnaire (PPQ). Parental and infant characteristics were collected using self-report and review of the electronic health record.

Results: 176 parent-infant dyads were included in the study. Parental uncertainty in illness decreased over time for most parents, though less decrease in uncertainty was associated with social determinants of health and with gestational age of infant at birth. Screening positive for PPTSD was associated with both parental and infant characteristics. In the final regression, history of mental health illness, screening for postpartum depression, and uncertainty after discharge were statistically associated with screening positive for PPTSD.

Introduction

An estimated 13 % of women experience a perinatal mental health disorder around the time of pregnancy and birth. These women most often suffer from symptoms of depression, anxiety, and trauma (World Health Organization [WHO], 2013). Perinatal posttraumatic stress disorder (PPTSD) is reported to affect up to 9% of women in the United States, and until recently has been overlooked as an important and unique mental health concern (Vignato, Georges, Bush, & Connelly, 2017). PPTSD is defined as posttraumatic stress disorder that occurs anytime between pregnancy and up to one year following birth (McKenzie-McHarg et al., 2015). It is characterized by disturbances that fall into four distinct clusters: re-experiencing, avoidance, negative cognitions and mood, and arousal and is a direct result of exposure to actual or threatened death, serious injury, or sexual violation (American Psychiatric Association [APA], 2013). The risk for PPTSD in parents with an infant in the NICU is increased, with 23-33% of parents screening positive for PPTSD between the time of birth of their infant and 18 months of life (Hynan, Mounts, & Vanderbilt, 2013).

Feelings of uncertainty about illness has been theorized to be an antecedent to traumatic stress (Santacroce, 2003). Parental uncertainty in illness of an infant is a paradoxical, cognitive, and emotional experience (Malin & Johnson, 2019). Previous research has demonstrated that parents of ill children often manage feelings of uncertainty in illness using information management. Information management is often accomplished through either 1) an intensive pursuit of information or 2) careful evasion of encounters that increase awareness of negative feelings. These two forms of information management strategies are similar to two of the symptom clusters of PTSD: hyperarousal and avoidance (Santacroce, 2003). The relationships

between parental uncertainty in illness of an infant and PPTSD has not, to our knowledge, been evaluated in a sample of parents with an infant in the NICU.

Purpose

The purpose of this study was to examine the relationships between parental uncertainty in illness and PPTSD. Specifically, the aims of this study were to (a) describe how parental uncertainty in illness changes throughout the NICU course and after NICU discharge, (b) evaluate if objective measures of infant illness severity correlate with higher scores of parental perceptions of uncertainty in illness at different points in time, (c) assess if parental and/or infant clinical characteristics correlate with higher levels of screening positive for PPTSD three months after NICU discharge, and (d) explore if parents who experience high levels of uncertainty about their infant's illness screen positive for PPTSD more frequently after discharge from the NICU.

Perinatal Posttraumatic Stress Disorder

Previous research on PPTSD in parents in the NICU has established numerous different, and at times conflicting, identifiable risk factors. Examples of these risk factors include parental history of mental health disorders (Greene et al., 2015; Holditch-Davis et al., 2015; Shaw et al., 2014) parental perception of illness severity (Malin et al., 2020), and infant characteristics such as longer hospitalizations and more severe medical complications (Hatters Friedman et al., 2013; Suttora, Spinelli, & Monzani, 2014; Vinall, Noel, Disher, Caddell, & Campbell-Yeo, 2018). The consequences of PPTSD for parents and their families after being in the NICU are significant. PPTSD hinders both healthy parental and infant development (Davidson, Jones, & Bienvenu, 2012; Hoirisch-Clapauch, Brenner, & Nardi, 2015). Altered maternal-infant interactions, secondary to PPTSD, have been found to be significant at six and 12 months after birth (Petit et al., 2016). Mothers with symptoms of PPTSD are also more likely to report their infants as less

easy to sooth and are more apt to report distress (Shaw et al., 2013). Infants with parents suffering from PPTSD are at risk for lower developmental social skills at six months corrected gestational age (Forcada-Guex, Borghini, Pierrehumbert, Ansermet, & Muller-Nix, 2011).

Parental Uncertainty in Illness of an Infant

Parental uncertainty in illness of an infant is associated with complex childhood illness and complex management needs which often prevent parents from creating meaning of their experiences in and out of the NICU (Chaney et al., 2016; Santacroce, 2003; Lasiuk, Comeau, & Newburn-Cook, 2013). The uncertainty is often an enduring experience that does not inherently have value and can be perceived as either a negative or a positive experience (Malin & Johnson, 2019). The consequences of parental uncertainty are unique in parents in the NICU. Importantly, uncertainty disrupts the important processes of family and parental role attainment (Obas, Leal, Zegray, & Rennick, 2016; Granrud, Ludvigsen, & Andershed, 2014; Watson, 2011).

Conceptual Model

Our study is guided by The Uncertainty in Illness Theory (Mishel, 1988). We propose that if parents in the NICU negatively experience uncertainty in illness of their infant they will be more challenged to create meaning and difficulty placing value on their experience. Parents will then have an altered appraisal of the events that lead to uncertainty. This altered appraisal may result in continued threatening memories of their infant's hospitalization/illness. These continued threatening memories are manifested through symptoms of PTSD that endure for at least one month or longer after the event (APA, 2013).

Methods

Research Design

This was a prospective, longitudinal correlational study of parent-infant dyads in a 70-bed, level four NICU. It was a part of a larger study examining parental health-related quality of life in parents with an infant in the NICU. Based on previous research (Malin et al., 2020), an a priori power analysis was completed and a sample size of at least 127 subjects was determined necessary to detect a change of 20% between groups with a p-value set at 0.025. For this dissertation study, the initial 176 parent-infant dyads will be included in this analysis.

Inclusion criteria for enrollment included: parents of infants who have never been discharged from the hospital; parents of infants who are at least 14 days old; parents are English speaking; and parents of infants receiving palliative care as long as imminent death was not likely as determined by the attending physician. Exclusion criteria for enrollment included: parents who would not be caring for the infant after discharge and parents of infants who would be transferred to the cardiac intensive care unit during hospital stay. Parents of infants who died after initial enrollment were excluded from further interviews.

Procedures

The institutional review board approved the study. Participants were approached during their infant's NICU hospitalization by a member of the research team (JL). The purpose of the study was explained to the parents and their written and informed consent was obtained. After consent was obtained, parents completed surveys at the time of enrollment, again prior to discharge if the infant remained inpatient after two months, and again three months after discharge from the NICU. Exact timing of the interviews was based on clinical driven assessment of infant discharge readiness based on chart review and conversations with the NICU

healthcare team. All data was input and recorded electronically using REDCap (Harris et al., 2009). Parents were asked at the initial survey for their preference for contact (email or phone) for the three month surveys. Information regarding parental stress, perinatal post-traumatic stress, and local resources were given to all parents in the study. Additionally, all parents received a stipend for participation.

Measures

Parental characteristics: The measurements hypothesized to be associated with PPTSD based on previous research were collected at the time of enrollment or from review of the electronic health record (EHR) (Bernard et al., 2011; Cole et al., 2016; Gold, Leon, Boggs, & Sen, 2015; Gondwe, White-Traut, Brandon, Pan, & Holditch-Davis, 2017; Holditch-Davis et al., 2009; Toly et al., 2019). Specifically, data regarding parental age, parity, race, social determinants of health, history of mental health illness, and current postpartum depression have been found to be associated with increased risk of PPTSD. Mothers of infants in the NICU are screened by bedside nurses for postpartum depression using the Edinburgh Postnatal Depression Scale (EPDS) at two weeks post-partum and those scores are recorded in the EHR. Measurements of history of mental health illness, history of family mental health illness, and questions regarding housing security, transportation, and education were collected through self-report by the person completing the surveys at the time of enrollment.

Infant characteristics: measurements of infant illness severity, based on previous literature examining risk for PPTSD (Malin et al., 2020), were collected from the EHR at the time of discharge. These infant characteristics included NICU length of stay, days of mechanical ventilation, need for vasopressors, hypoxic ischemic encephalopathy (HIE) requiring cooling, palliative care consultation, and gestational age at birth.

Parental uncertainty in illness of an infant was measured using the 31-item Parents' Perception of Uncertainty Scale (PPUS). The PPUS uses a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree), yielding scores between 31 and 155. Higher scores indicated greater perceptions of uncertainty. Reliability and validity of the scale have been reported with Cronbach alphas that varied between 0.86 and 0.87 (Madeo, O'Brien, Bernhardt, & Biesecker, 2012; Santacrose, 2001). The PPUS was completed at the time of enrolment, prior to discharge if the infant was in the NICU ≥ 2 months, and again at three months after discharge from the NICU.

Perinatal posttraumatic stress disorder was measured using the Perinatal Posttraumatic Stress Disorder Questionnaire – revised edition (PPQ) (Callahan, Borja, & Hynan, 2006). The PPQ is a validated, 14-item questionnaire assessing PPTSD symptoms associated with the birth of an infant. Scoring is conducted on a five-point Likert scale. Previous literature indicates that scores > 19 warrant clinical treatment (Callahan, Borja, & Hynan, 2006). Reliability and validity have been reported with Chronbach's alphas varying between 0.85 and 0.90 (Callahan et al., 2006; DeMier, Hynan, & Harris, 1996). The PPQ was completed three months after the infant's discharge from the NICU.

Statistical Analysis

All data analyses were performed using SPSS (26). Data was first examined using descriptive statistics. Missing data points were determined to be missing completely at random by the authors and mean imputation was used to replace missing variables. Means and percentages were calculated to evaluate scores of the PPUS. Repeated measures of ANOVA were used to compare changes in PPUS over time. The PPQ scores were summed, and two groups were created. These groups were: people who screened positive for PPTSD (score ≥ 19)

and people who did not screen positive for PPTSD (score <19). Pearson's correlation tests were performed to measure the association between parent and infant characteristics and PPUS scores at the time of enrollment and at three months after discharge. Pearson's correlation test was also performed to measure the association between parent and infant characteristics and screening results for PPTSD. Backward deletion regression was used to construct the final model.

Results

A total of 176 parents completed the three-month after discharge surveys at the time of analysis and were included in the sample. The majority (97%) of the parents participating in the study were the mothers. Parental demographics are displayed in table two. The majority of the infants enrolled in the study had been admitted to the NICU for reasons of prematurity; 5% were extremely premature; 47% were premature; and 6% were late premature. Twenty-four percent of the infants enrolled had a congenital anomaly, and 11% were deemed medically complex.

Thirty-four percent of the parents enrolled in the study screened positive for PPTSD three months after discharge from the NICU. Table 1 displays the bivariate relationships between infant and parental characteristics and screening positive for PTPSD. The majority of the infant characteristics were not statistically associated with screening positive for PPTSD. In this sample of parents, the only infant characteristics of 1) days of mechanical ventilation and 2) need for vasoactive pressor support were statistically associated with parents screening positive for PPTSD. Despite this fact, there were a number of infant clinical characteristics that were associated with over 40% of parents screening positive for PPTSD, including; gestational age at birth; HIE requiring cooling; length of stay over 91 days; mechanical ventilation for over a month; requiring vasoactive pressor support, and palliative care consultation.

Mean PPUS scores at the time of enrollment and three months after discharge are displayed in table 2. Forty-eight parents completed the PPUS prior to discharge because their infants were in the NICU for at least two months. This data was not included in the analysis secondary to the small sample size of parents prior to discharge. For the majority of parents, mean uncertainty scores decreased over-time. Notably, the decrease in uncertainty experienced was much less in parents of term infants, infants with HIE, or infants receiving palliative care services. Additionally, there were a number of parental characteristics that were associated with a smaller decrease in uncertainty over time. Parents less than 18 years of age or parents who had not finished high school reported more uncertainty after their infants' discharge from the NICU. Other social determinants of health associated with a smaller decrease in uncertainty after discharge included a lack of transportation and housing. Finally, self-reported history of mental health illness and elevated EPDS scores were associated with a statistically significant smaller decrease in uncertainty. Screening positive for PPTSD was not significantly associated with elevated parental PPUS scores at the time of enrollment. Though, screening positive for PPTSD was significantly associated with elevated PPUS scores three months after the infants' discharge, with an average drop of only one point in uncertainty from the time of enrollment to three months after discharge.

In table 3 the backwards deletion regression is displayed. Parental uncertainty at three months after NICU discharge, along with elevated EPDS score and self-report of mental health illness were all significantly associated with screening positive for PPTSD. Variables put into the model during step one were based on both statistical and theoretical significance. Similar results were identified when other methods of modeling strategies were tested.

Discussion

The purpose of our study was to examine parental uncertainty in illness during and after their infants' discharge from the NICU and its relationship with screening positive for PPTSD after discharge from the NICU. We also sought to examine infant and parental characteristics' relationships with parental uncertainty and with screening positive for PPTSD. Ours is the first study, to our knowledge, to use the PPUS to evaluate parental uncertainty in illness in a NICU setting and after the infants' discharge from the NICU. As a result, typical uncertainty levels for parents with infants in the NICU were not known prior to this study. This inhibited our ability to compare our results with other uncertainty scores in parents with infants in the NICU.

In general, parental uncertainty in illness of their infant decreased overtime for the majority of parents in the NICU. Despite this, there are a few important instances when parental uncertainty does not decrease with the passing of time. For parents with term infants in the NICU, parents of infants with HIE who required whole-body cooling, young teenaged parents, parents with less than a high school degree, or parents without dependable transportation or stable housing, uncertainty about their infant's illness appears to be stagnant after discharge from the NICU. This parental uncertainty most likely speaks to the nature of the diagnosis leading to the need for NICU care or the compounding stress associated with social determinants of health. The possibility that both quality of life and social determinants of health are related to how parents manage feelings of uncertainty about their infant's illness has not been explored in previous literature. Parents of term infants who are sick enough to require NICU care and require complex homecare have been found to have lower quality of life after discharge from the NICU (McAndrew et al., 2019). Furthermore, the relationships between health, stress, allostatic load,

and social determinants of health have previously been described (Braveman & Gottlieb, 2014). Our study adds to this by identifying uncertainty as a health factor that contributes to stress.

Our findings about infant and parent characteristics and their relationships with screening positive for PPTSD support the notion that PPTSD is a multifactorial process with many different risk factors (Beck & Woynar, 2017). In our sample, the strongest predictors for screening positive for PPTSD were associated with parental mental health and parental cognition (uncertainty). These findings build on previous studies that note the importance of parental mental health (Greene et al., 2015) and of parental perception of illness in predicting PPTSD (Aftyka, Rybojad, Rozalska-Walaszek, Rzońca, & Humeniuk, 2014; Malin et al., 2020). Objective measures of infant illness severity were not as strongly associated with screening positive for PPTSD as in other samples of parents in the NICU (Feeley et al., 2011). Despite this, there are a few markers of infant illness severity in the NICU that should be utilized by healthcare providers as indicators of risk for PPTSD in parents after their infants' discharge. These markers of infant illness severity include need for prolonged ventilation and vasoactive pressor agents which were statistically significantly associated with parents screening positive for PPTSD. Additionally, clinically significant markers of infant illness severity included gestational age at birth, HIE requiring cooling, length of stay over 91 days, mechanical ventilation for over a month, and palliative care consultation. These findings support the idea that having a very sick or premature infant in the NICU is often traumatic for parents and may be antecedents to prolonged symptoms of trauma. Furthermore, our findings indicate a demand for wholistic mental health support for parents in the NICU. Personal history of mental health illness and elevated postpartum depression scores were both associated with PPTSD in our final regression model. The relationships between postpartum depression and PPTSD have been

previously described (Ayers, Bond, Bertullies, & Wijma, 2016). It is imperative for NICU healthcare providers to ask about parental mental health histories and to screen parents for concurrent mental health disorders, like depression and anxiety, while their infant is in the NICU. The findings from our study underscore the importance of these discussions and screenings, as these are risk factors that impact mental health long after the infant's discharge from the NICU.

Our findings indicate that parents who screen positive for PPTSD after discharge from the NICU have higher levels of uncertainty three months after discharge than parents who do not screen positive for PPTSD. This relationship is not noted early in the NICU stay, suggesting that for some parents, uncertainty persists beyond the time in the NICU and is related to symptoms of PPTSD. These findings have implications on how health care providers help parents manage feelings of uncertainty about their infant's illness while hospitalized in the NICU and after discharge. Healthcare providers in the NICU have a unique opportunity to help parents manage feelings of uncertainty, thus possibly influencing future perinatal mental health. Furthermore, these findings support the need for parental mental health support after the infant's discharge from the NICU.

This study has several limitations. First, it was a single-center study with English speaking only parents which limits the generalizability of our results. Second, assessment of history of mental health illness, both self and family, was taken via self-report which possibility limited the accuracy of the diagnosis. Third, the number of parents eligible for measurement of uncertainty prior to discharge was small, thus prohibiting a robust description of the parental trajectory of uncertainty during infant hospitalization and after discharge.

Despite these limitations, our results indicate that parental uncertainty regarding infant illness, while both in the NICU and after discharge from the NICU, are salient phenomena that are associated with screening positive for PPTSD. The possibility that parents become stuck in feelings of uncertainty which leads to symptoms of PPTSD after the infant's discharge from the hospital provides numerous opportunities for healthcare providers to intervene. Since uncertainty can be assessed as either a threat or an opportunity (Mishel, 1988), healthcare providers have the opportunity to help parents reframe uncertainty and move forward into coping to help ameliorate the symptoms of PPTSD.

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Table 4.2: Bivariate Associations of Infants and Parent Characteristics and PPTSD

Table 1: Parent and infant characteristics associations with PPTSD			
CHARACTERISTICS	TOTAL	SCREENED + FOR PERINATAL PTSD	P VALUE
		N (%)	
<u>INFANT CHARACTERISTICS</u>			
GESTATIONAL AGE AT BIRTH			0.065
22-25 WEEKS	19	8 (42%)	
26-28 WEEKS	17	9 (53%)	
29-36 WEEKS	100	27 (27%)	
≥ 37 WEEKS	39	13 (33%)	
HYPOXIC ISCHEMIC ENCEPHALOPATHY REQUIRING COOLING			
YES	3	2 (67%)	0.243
NO	171	54 (32%)	
NICU LENGTH OF STAY			
<28 DAYS	45	14 (31%)	0.597
29-60 DAYS	71	20 (28%)	
61-90 DAYS	22	8 (36%)	
>91 DAYS	37	15 (41%)	
DAYS ON A MECHANICAL VENTILATOR			
0 DAYS	74	17 (23%)	0.012
1-7 DAYS	50	20 (40%)	
8-30 DAYS	20	4 (20%)	
>30 DAYS	31	16 (52%)	
REQUIRED PRESSORS			
YES	40	38 (95%)	0.033
NO	129	17 (13%)	
PALLIATIVE CARE CONSULTATION			
YES	5	2 (40%)	0.533
NO	168	55 (33%)	
<u>PARENT CHARACTERISTICS</u>			
AGE AT TIME OF DELIVERY			
≤ 18 YEARS	4	1 (25%)	0.248
19-25 YEARS	40	17 (43%)	
26-30 YEARS	48	12 (25%)	
31-35 YEARS	55	21 (38%)	
>36 YEARS	27	5 (19%)	
RACE			
BLACK/AFRICAN AMERICAN	44	17(39%)	0.32
WHITE	113	34 (30%)	

ASAIN	4	4 (100%)	
AMERICAN INDIAN/ALASKA NATIVE	3	0 (0%)	
OTHER	10	2 (20%)	
HOUSING			0.72
“I HAVE HOUSING”	167	54 (32%)	
“I DON’T HAVE HOUSING”	5	2 (40%)	
HAS LACK OF TRANSPORTATION KEPT YOU FROM MEDICAL APT, MEETINGS, WORK, GETTING THINGS YOU NEED			0.049
YES	12	7 (58%)	
NO	163	50 (31%)	
EDUCATION			0.267
HAVE NOT FINISHED HIGH SCHOOL	11	3 (27%)	
HIGH SCHOOL GRADUATE	39	17 (44%)	
SOME COLLEGE OR TECHNICAL SCHOOL	42	13 (31%)	
COLLEGE OR TECHNICAL SCHOOL GRADUATE	63	19 (30%)	
GRADUATE SCHOOL	20	5 (25%)	
EPDS SCORE			0.001
≤ 13	68	19 (28%)	
14 – 18	6	5 (83%)	
≥ 19	6	5 (83%)	
HISTORY OF MENTAL HEALTH ILLNESS			0.002
YES	73	34 (46%)	
NO	96	20 (21%)	
DON’T KNOW	5	2 (40%)	
FAMILY HISTORY OF MENTAL HEALTH ILLNESS			0.007
YES	70	32 (46%)	
NO	94	21 (22%)	
DON’T KNOW	11	4 (36%)	
FIRST PREGNANCY			0.133
YES	98	28 (29%)	
NO	77	29 (38%)	

Table 4.3: Mean PPUS Scores by Infant and Parent Characteristics Using Repeated Measures of ANOVA

Mean PPUS Scores by Infant and Parent Characteristics at Enrollment and Three Months After Discharge						
CHARACTERISTICS	N	MEAN UNCERTAINTY SCORE TIME 1: Mean (SD)	N	MEAN UNCERTAINTY SCORE TIME 3 Mean (SD)	F	P VALUE
<u>INFANT CHARACTERISTICS</u>						
GESTATIONAL AGE AT BIRTH					F = 10.5 (172)	0.001
22-25 WEEKS	19	76 (12.9)	19	68 (13)		
26-28 WEEKS	17	75 (15.4)	17	68 (14.1)		
29-36 WEEKS	100	67 (16.6)	100	63 (15.4)		
≥ 37 WEEKS	40	74 (16.4)	40	72 (18.1)		
HYPOXIC ISCHEMIC ENCEPHALOPATHY REQUIRING COOLING						
YES	3	71 (13.2)	3	79 (11)	F=0.135 (1,173)	0.714
NO	172	70 (13.2)	172	66 (16)		
NICU LENGTH OF STAY						
<28 DAYS	45	65 (14.1)	45	64 (16.2)	F=15.3 (1,172)	<0.001
29-60 DAYS	72	68 (17.5)	72	66 (18)		
61-90 DAYS	22	78 (14)	22	69 (14.5)		
>91 DAYS	37	77 (14.9)	37	68 (12.7)		
DAYS ON A MECHANICAL VENTILATOR						
0 DAYS	75	67 (16.7)	75	64 (16.5)	F =12.6 (1, 172)	<0.001

1-7 DAYS	50	71 (16.1)	50	67 (16.2)		
8-30 DAYS	20	77 (17.6)	20	67 (16.5)		
>30 Days	31	72 (14.5)	31	69 (14.5)		
REQUIRED PRESSORS					F=6.1 (1, 168)	0.014
YES	130	69 (16.8)	130	65 (16.3)		
NO	40	72 (15)	40	68 (15.9)		
PALLIATIVE CARE CONSULTATION					F =0.12 (1, 172)	0.119
YES	5	81 (10.6)	5	73 (14.2)		
NO	169	70 (16.5)	169	66 (16.2)		
<u>PARENT CHARACTERISTICS</u>						
AGE AT DELIVERY					F= 2.0 (1, 170)	0.159
≤ 18 YEARS	4	63 (20.4)		67 (21.6)		
19-25 YEARS	40	73 (14.5)		67 (14.4)		
26-30 YEARS	48	68 (16.1)		65 (15)		
31-35 YEARS	55	71 (17.5)		68 (17.8)		
≥ 36 YEARS	28	69 (16.5)		64 (16.8)		
RACE					F=5.1 (1, 170)	0.025
BLACK/AFRICAN AMERICAN	45	70 (15.4)		66 (14.9)		
WHITE	113	71 (16.3)		66 (16.9)		
ASAIN	4	94 (14.9)		76 (16.9)		
AMERICAN INDIAN/ALASKA NATIVE	3	57 (11.4)		54 (5.8)		
OTHER	10	64 (15)		63 (12.5)		
HOUSING					F= (1, 171)	0.151
“I HAVE HOUSING”	168	70 (16.4)		66 (16)		
“I DON’T HAVE HOUSING”	5	63 (18.9)		56 (18.3)		

HAS LACK OF TRANSPORTATION KEPT YOU FROM MEDICAL APT, MEETINGS, WORK, GETTING THINGS YOU NEED					F= 2.0 (1, 174)	0.155
NO	163	70 (16.3)		66 (16)		
YES	13	69 (19.1)		67 (17.2)		
EDUCATION					F = 7.4 (1, 171)	0.007
HAVE NOT FINISHED HIGH SCHOOL	11	64 (13.7)		65 (14.2)		
HIGH SCHOOL GRADUATE	40	71 (17.5)		66 (15.6)		
SOME COLLEGE OR TECHNICAL SCHOOL	42	71 (15.5)		66 (15.4)		
COLLEGE OR TECHNICAL SCHOOL GRADUATE	63	70 (15.6)		68 (17.1)		
GRADUATE SCHOOL	20	72 (20.4)		63 (16.9)		
EPDS SCORE OF THE MOTHER					F= 2.99 (1, 77)	0.88
≤ 13	68	69 (16)	68	66 (14.5)		
14 – 18	6	69 (14.5)	6	65 (15.9)		
≥ 19	6	80 (13.8)	6	72 (17.6)		
HISTORY OF MENTAL HEALTH ILLNESS					F= 1.16 (1, 172)	0.282
YES	74	71 (17.6)	74	68 (16.3)		
NO	96	70 (15.9)	96	64 (15.9)		
DON'T KNOW	5	70 (4.9)	5	69 (15)		
FAMILY HISTORY OF MENTAL HEALTH ILLNESS					F = 11.6 (1, 173)	0.001

YES	70	72 (16.4)	70	68 (15.7)		
NO	95	68 (15.7)	95	65 (16.2)		
DON'T KNOW	11	76 (19.8)	11	64 (17.4)		
FIRST PREGNANCY					F = 11.1 (1, 174)	0.001
YES	99	70 (16.7)	99	65 (15)		
NO	77	71 (16.2)	77	67 (16.9)		
Screen + for PPTSD					F = 6.5 (1, 173)	0.012
YES	57	72 (16.9)	57	71 (16.3)		
NO	118	69 (16)	118	63 (15.2)		

Table 4.4: Backward Deletion Regression of Parent and Infant Characteristics and the Dependent Variable, Screening Positive for PPTSD

Variable	Step 1		Step 2		Step 3		Step 4	
	Adjusted OR (95% CI)	P-Value	Adjusted OR (95% CI)	P-Value	Adjusted OR (95% CI)	P-Value	Adjusted OR (95% CI)	P-Value
UNCERTAINTY AT ENROLLMENT	-0.11 – 0.004	0.356	-0.011-0.004	0.350				
UNCERTAINTY 3 MONTHS AFTER DISCHARGE	0.00-0.16	0.042	0.00-0.16	0.040	0.00-0.13	0.064	0.00-0.13	0.050
DAYS OF VENTILATION	-0.024-0.159	0.144	-0.022-0.158	0.136	-0.028-0.15	0.175		
EPDS SCORE	0.085-0.439	0.004	0.088-0.433	0.004	0.080-0.422	0.005	0.096-0.436	0.003
HISTORY OF MENTAL HEALTH ILLNESS	0.037-0.440	0.021	0.038-0.437	0.020	0.047-0.44	0.016	0.050-0.449	0.015
FAMILY HISTORY OF MENTAL HEALTH ILLNESS	-0.006-0.007	0.932						

Chapter V: Discussion

Introduction

Parents of infants requiring admission to the neonatal intensive care unit (NICU) after birth often experience a disruption in the typical transition into parenthood. Many parents who spend time in the NICU describe the experience as stressful, traumatic, and fraught with uncertainty. Previous research has identified numerous parent and infant characteristics as risk factors for perinatal post-traumatic stress disorder (PPTSD) in parents who have an infant in the NICU (Ayers, Bond, Bertullies, & Wijma, 2016). Additionally, parental uncertainty in illness of an infant has not previously been studied in a sample of parents in the NICU. This study explored the factor structure of the parental perception of uncertainty scale (PPUS) in a sample of parents in the NICU. It also described the relationships between parental uncertainty in illness of an infant and parental and infant characteristic. These same parental and infant characteristics were then also examined in relationship to screening positive for PPTSD three months after discharge from the NICU. The findings of this study demonstrate that, for most parents in the NICU, feelings of uncertainty regarding the illness of their infant decreased with time. Less decrease in parental uncertainty was associated with social determinants of health and infant gestational age at birth. Screening positive for PPTSD was associated with both parental and infant characteristics. Specifically, parental mental health, including postpartum depression, and high uncertainty after discharge from the NICU, are significant risk factors for PPTSD in parents who have had an infant in the NICU.

Expansion of the Uncertainty in Illness Theory

The Uncertainty in Illness Theory (UIT) guided this study (Mishel, 1988). The results of the study demonstrate that parents with infants in the NICU frequently experience elevated levels of uncertainty in illness during their stay in the NICU. For the majority of parents, these feelings of uncertainty decreased over time, as demonstrated by lower reported levels of uncertainty at three months after discharge than at the time of enrollment in the study. Importantly, though, this decrease in uncertainty was not seen in parents with infants who had hypoxic ischemic encephalopathy requiring cooling, parents of infants who received palliative care consultation, parents who were less than 18 years old, parents who reported housing or transportation insecurity, parents who self-reported a history of mental health illness or screened high for postpartum depression, or parents who screened positive for PPTSD three months after their infant's discharge from the NICU. The findings from this study indicate that these parents may not adequately appraise their experience of uncertainty as either a danger or opportunity and thus, cannot move into the final stage of the UIT, coping with uncertainty. Instead, there is a continued altered appraisal of the events associated with uncertainty. As a result, parents experience continued threatening memories of their infant's hospitalization/illness. One manifestation of these continued threatening memories is symptoms of PPTSD that endure for at least three months after discharge from the NICU. The expansion of the UIT to account for people who are not able appraise the uncertainty associated with their infant's illness is displayed in Figure 5.1.

An expansion of the UIT to account for people who become stagnant during the appraisal of uncertainty would help to explain other possible symptoms and health outcomes for people experiencing uncertainty in illness. This is not the first time that the UIT has required expansion

or modifications secondary to shortcomings of the UIT. Dr. Mishel's Reconceptualized Uncertainty in Illness Theory (RUIT) was developed after the UIT to address limitations of the UIT, including the fact that not all illness uncertainty is linear (appendix B) (Mishel, 1990). The RUIT was developed using chaos theory as the parent theory and an emphasis is placed on disorder, instability, diversity, disequilibrium, and restructuring (Mishel, 1990). While the RUIT does expand the possibility that uncertainty in illness is not linear, it does not provide adequate structure for people who become stuck before making an appraisal of their feelings of uncertainty. The findings from this study indicate a need for additional modifications of the UIT to account for the sizeable number of people who might not be able to make an adequate appraisal of the uncertainty associated with illness. The reason some people are not able to make an adequate appraisal of their uncertainty should be further investigated. The results of this study suggest both parental and infant characteristics are related to.

The Parental Perception of Uncertainty Scale in Parents in the NICU

The Parental Perception of Uncertainty Scale (PPUS) proved to be an acceptable tool to measure parental perceptions of uncertainty in illness of their infant. This was the first study to use the PPUS to measure uncertainty in a sample of parents with a sick or premature infant in the NICU. The confirmatory factor analysis demonstrated that the original four factor structure of the PPUS provided adequate, though not optimal, structure in this sample of parents. The two factor structure that was explored also demonstrated adequate, though not optimal, structure in this sample of parents. The PPUS was developed almost 40 years ago and was originally tested in a sample of parents with children requiring hospitalization for numerous different reasons (Mishel, 1983). The findings from Mishel's study indicate that parental uncertainty in illness of an infant is a significant phenomenon that impacts perinatal mental health. The tools needed to

measure this salient experience of parental uncertainty in illness must be current and precise. Connecting uncertainty to other measurable, and possibly billable, outcomes would legitimize the continued measurement of the experience. This study indicates a statistically significant relationship between the parental uncertainty and PPTSD after infant discharge from the NICU. If the measurement of uncertainty was more specific to the parental experience of having an infant in the NICU while also accounting for the influence of time, clinicians would be able to utilize screening for uncertainty in more meaningful ways. Specifically, measuring unique aspects of uncertainty in this population, such as uncertainty in parental role development and parental perceived changes in uncertainty, while also adding actionable questions about managing uncertainty, would enhance the measurement of uncertainty in illness of an infant.

Strengths and Limitations of the Study

There are a number of strengths and limitations to this study that must be discussed. This study is strengthened by the prospective design utilized. Despite this, the study was a single center study conducted using a sample of English speaking parents. This limits the generalizability of the results of the study to other samples of parents with infants in the NICU. While the sample used in this study was adequate to detect change in PPTSD, larger multisite studies that include parents with more diverse socioeconomic and cultural backgrounds is needed. Furthermore, data measuring PPTSD beyond 3 months after discharge from the NICU is needed in order to make comprehensive conclusions about the trajectories of PPTSD in this population.

Another limitation of this study is the reliance on self-report for parental mental health history. The use of self-report and surveys in research does decrease the risk of researcher bias but also increases the risk for responder bias (Polit & Beck, 2017). Despite this, the use of

reliable and valid measurements, such as the Perinatal Posttraumatic Stress Disorder Questionnaire (PPQ) (Callahan, Borja, Hynan, 2006) and the Edinburgh Postnatal Depression Scale (EPDS) (Cox, Holdenand, & Sagovsky, 1987), helps decrease this limitation.

The breadth of measurements about social determinants of health is limited in this study. Using questions from the Protocol for Responding to and Assessing Parents' Assets, Risks, and Experiences (PRAPARE) (NACHC, 2016) provided an opportunity to measure clinically meaningful and actionable social determinants of health. Despite this fact, there are a number of other social determinants of health and tools, such as adverse childhood experiences (Felitti et al., 1998), that gather important information regarding a person's social determinants of health. Consensus is lacking regarding how to best measure social determinants of health (Elias, Jutte, & Moore, 2019). This study is one of the first studies to examine the impact of social determinants of health and parental uncertainty in illness and PPTSD in a sample of parents with infants in the NICU. Despite the limited nature of these measurements in this study, the results provides strong early data to support future research into these relationships.

Finally, the small number of parental measurements of uncertainty in illness prior to discharge limits the completeness of the description of uncertainty trajectories in this study. Since parents were only asked to measure uncertainty prior to discharge if their infant had been in the NICU for at least two months, the sample size at this point in time was small. A larger sample size at all three points in time is needed to make conclusive statements regarding how uncertainty changes overtime for parents in the NICU.

Practice and Policy Implications

The results of this research study support a mandate for policy changes surrounding perinatal mental health in institutional settings and at state and federal levels. These policy

recommendations directly impact how clinical practice should be improved as well. Despite the outcry for more structural support around maternal mental health, there continues to be a lack of integration into healthcare policies (Hall, et al., 2015; Kendig et al., 2017; Rahman, Patel, Maselko, & Kirkwood, 2008). Below are evidence based practice and policy recommendations to support perinatal mental health for parents with infants who require or previously required NICU hospitalization.

Recommendations for Practice and Policy Changes

All NICU's should have a standardized policy regarding the provisions of psychosocial support of parents with a sick or premature infant requiring hospitalization. These recommendations of care are largely based on the National Perinatal Association's recommendations for psychosocial program standards (Hynan et al., 2015).

- I. Staff: all NICUs require access to the following staff to implement policy regarding psychosocial support for parents. The number of each staff should be increased incrementally based on the number of NICU beds and patient acuity.
 - a. Masters' level social worker (1 per 20 NICU beds)
 - b. Psychiatric nurses (1 per 20 NICU beds)
 - c. NICU psychologist or Psychiatrists (1 per 20 NICU beds)
- II. Education: formal education for NICU nurses and NICU providers regarding significance and importance of perinatal mental health should be done on a yearly basis with informal updates as needed. Education should also focus on how to therapeutically communicate with families. Support for NICU nurses' and providers' own psychosocial needs should also be created and available on-site.

- III. Environment: the NICU environment needs to be welcoming to parents and other family members. Comfortable private and communal spaces should be available in every NICU. Environments should allow for parent-infant contact without restrictions based on healthcare providers' needs.
- IV. Screening/Assessment: timely screening and assessment of parental mental health should be conducted at incremental intervals throughout the NICU hospitalization. Screening should be done by educated NICU nurses and supported by MSWs and psychiatric nurses. If possible, assessment should occur prior to birth in cases of known NICU admission. Post-discharge screening should also be standardized and completed by home visitors or at follow-up appointments that occur between the time of discharge up to one year of life.
- V. Therapy Services and Referral: provisions for therapy services within the NICU setting should be made for parents who screen positive for stress, anxiety, depression, and posttraumatic stress. Services should be given at the baby's bedside to lessen burden on parents at risk. In instances where services are not immediately available, referrals to outside mental health support should be done within 24 hours of screening positive.
- VI. Use of Technology: when access to mental health support is limited for reasons of geography an established relationship with larger health service organizations should be created. Use of telemedicine and on-line parental support groups should be vetted and used when immediate access to care is not possible.
- VII. Post NICU Support: recognition that parents experience emotional distress after NICU discharge is needed. "Post-NICU Family Follow Up Care" services should be established

in NICU developmental follow up clinics in addition to telephone screening of parents identified as high-risk.

- VIII. Financial Incentives: family screening and support should be a billable service to private insurance companies and Medicaid. Quality measurements such as number of completed screenings and appropriate referrals, utilization of emergency room services, assessments of parent/infant stress can all be used to support billable services.
- IX. Research and Data Collection: incentives for further research into parental mental health in the NICU needs to part of standardized psychosocial support programs. This should include standardized data collection regarding screening, results, and support services.
- X. Spirituality: access to and support for individual spiritual practice needs should be supported. Support should come from staff that has received education about the importance and significance of incorporating parental spiritual needs into the care of their infants. Furthermore, access to formal spiritual/chaplain services should be available in all NICUs (Küçük Alemdar, Özdemir, & Tüfekci, 2017).
- XI. Legitimacy: standardized psychosocial support policies in NICUs need to be legitimized through the recognition of importance in the American Academy of Pediatrics' Levels of Neonatal Care (Committee on Fetus and Newborn, 2012). Any NICU with a designation of level III or IV must have on-site access to psychosocial support services. Any NICU with a designation of level I-II must have a policy in place that address need for access to care through other means such as telemedicine and referral systems.

Future Research

This study lays the groundwork for future research. The quantitative design of this study provides strong empirical evidence of parental uncertainty in illness of and infant in the NICU in

addition to evidence of significant risk for PPTSD in parents after infant discharge from the NICU. Adding a qualitative component to this research would strengthen the evidence and give more of a voice to the parents who experience uncertainty and PPTSD. Qualitative methods provide more information about the complexity of variables and can mitigate some of the inability to control for variability (Carr, 1994). Specifically, qualitative interviewing of parents about their uncertainty in illness of an infant would provide space for the possibility that uncertainty may be a concept of hope for some parents. Other measurements of parental reactions to illness of their infant, such as The Reaction to Diagnosis Interview would also provide structure to the description of parental uncertainty in illness of an infant (Marvin & Pianta, 1996).

Longer prospective data regarding symptoms of PPTSD and uncertainty in illness would also be additive to this study. The follow up after infant discharge from the NICU occurred at three months in this study. It would be meaningful to have repeated measures of the PPUS and PPQ points in time beyond 3 months so to better map out trajectories of uncertainty and how they impact PPTSD. Furthermore, prospective data regarding the impact of parental uncertainty in illness and PPTSD on infant health is needed. Previous research has indicated that parental PTSD impacts parental bonding and infant health long after discharge from the hospital (Beck, Gable, Sakala, & Declercq, 2011; Forcada-Guex, Borghini, Pierrehumbert, Answermet, & Muller-Nix, 2011; Parfitt & Ayers, 2009).

Finally, exploration of the interactions between the mental health of infants in the NICU and perinatal mental health is needed to complete the picture on how the family unit's health is impacted by NICU hospitalization (Ashby & Bromber, 2016). Previous research has established that parent/infant attachment in the NICU can be supported with interventions like kangaroo care

and the Neonatal Individualized Developmental Care and Assessment Program (Fabbro & Cain, 2016). Expansion of interventions with a focus on parents with perinatal mental health illness in the NICU and its impact on infant mental health would be valuable.

Conclusion

This study was the first to prospectively explore the relationships between parental uncertainty in illness of an infant and PPTSD. The findings indicate that parental uncertainty in illness of an infant is a prevalent phenomenon in parents with infants in the NICU. Additionally, uncertainty in illness of an infant after discharge from the NICU is associated with screening positive for PPTSD. This study confirms that PPTSD is a complex illness with numerous risk factors. Interventions to decrease risk for PPTSD need to be comprehensive and healthcare providers who interact with parents in the NICU need to have a robust understanding of risks and opportunities for alterations in perinatal mental health. Uncertainty in illness of an infant is a piece of this puzzle. The linkage between uncertainty and PPTSD in this sample suggest there are opportunities to help mitigate PPTSD through management of uncertainty. Furthermore, interventions that focus on managing uncertainty should begin early in the NICU stay when the highest levels of uncertainty are prominent. Comprehensive policy and practice changes need to be implemented to account for the challenges associated with working in the NICU and caring for families long-term. The high risk for altered health of the family unit after discharge from the NICU mandates far-reaching changes in how mental health in the NICU is conceptualized and applied to clinical practice.

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Figure 5.1: Expansion of The Uncertainty in Illness Theory

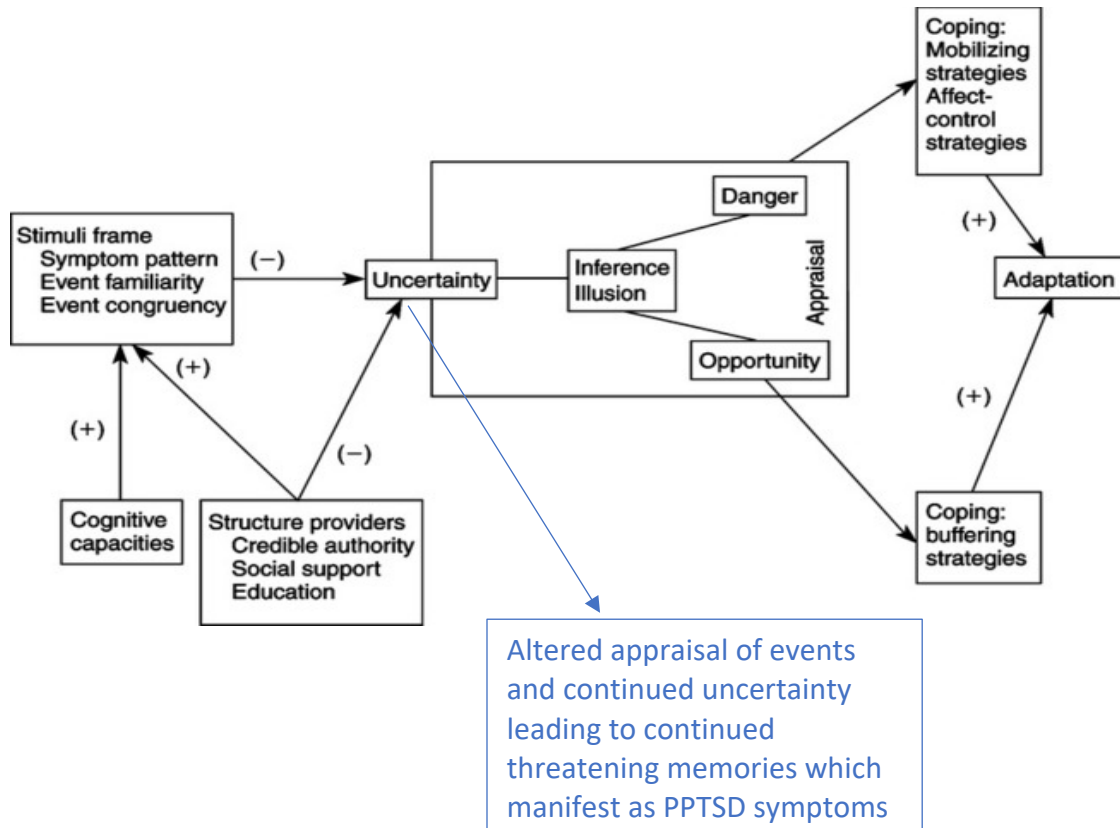
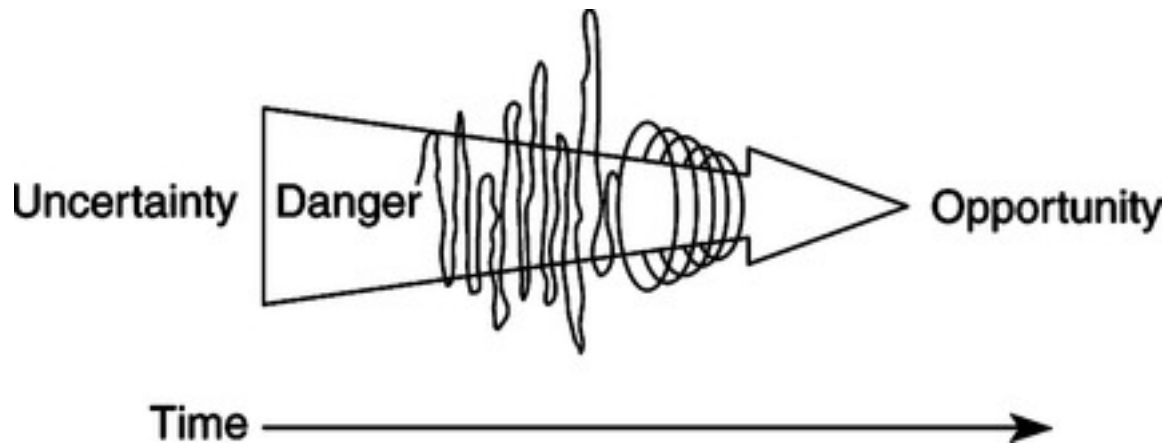


Figure 5.2: The Reconceptualized Uncertainty in Illness Theory



Bailey, D.E. & Stewart, J.L. (2001). Mishel's theory of uncertainty in illness

CURRICULUM VITAE

Kathryn J. Malin RN, MSN, NNP-BC, PhD Candidate

Education

University of Wisconsin- Milwaukee, Milwaukee WI 2016 – Present
Nursing PhD Program
Dissertation Topic: Parental Uncertainty in Illness of an Infant and Perinatal Posttraumatic Stress in the NICU
Major Professor: Dr. Teresa S. Johnson PhD, RN

University of Wisconsin-Milwaukee, Milwaukee WI 2018
Teaching Assistant Professional Development Certificate
Certificate from The University of Wisconsin Milwaukee's Center for Excellence in Teaching and Learning.

University of Wisconsin – Milwaukee, Milwaukee WI 2017 – 2019
Trauma Informed Care Certification

Rush University, Chicago IL 2004-2006
Master of Science in Nursing
Neonatal Advanced Practice Nursing Program, Neonatal Nurse Practitioner

Creighton University, Omaha NE 1997-2001
Bachelor of the Science of Nursing

Academic Appointments

University of Wisconsin Milwaukee: UW Parkside 2018 - 2019
Lead Instructor/Co-Instructor of Nursing 431: Health and Illness Concepts 4
Plan, coordinate, collaborate and co-instruct an interactive senior level nursing class focused on integration of selected nursing concepts. Concepts of focus include family, caregiving, sexuality, and reproduction. Lead instructor for OB and pediatric concepts at UW-Parkside Campus.

University of Wisconsin Milwaukee 2019
Teaching Assistant Nursing 432: Population Health
Plan, coordinate, collaborate and co-instruct an interactive senior level class focused on integration of population health by working collaboratively with the community and other stakeholders to conduct community health assessments and to develop, implement and evaluate population-focused interventions. Concepts of focus include community, culture, care coordination, health policy, levels of prevention, surveillance, and environmental health.

University of Wisconsin Milwaukee 2019
Teaching Assistant/Co-Instructor of Nursing 389: Health Assessment Lab
Plan, coordinate, and execute health assessment lab course for first semester nursing students using hands-on assessment skills and concepts.

Hospital Affiliated Appointments

Children's Hospital of Wisconsin, Milwaukee WI 2010-Present
Neonatal Nurse Practitioner (NNP-BC)

- *Children's Hospital of Wisconsin- NICU*: Neonatal nurse practitioner at a 70 bed, level four NICU. Responsibilities include management and coordination of care for critically ill to convalescence in infants; collaboration with physicians, nurses, and other health care professionals to ensure best outcomes; education of other nurse practitioners and staff nurses; on-going communication with families to allow for family centered care. Technical responsibilities include intubation, PICC line placement, umbilical line placement, lumbar puncture, chest tube placement, CSF reservoir tap, hypothermia management and ventilator management.
- *Froedtert West Bend – Special Care Nursery*: Neonatal nurse practitioner at a small level one NICU and level two OB labor and delivery unit. Responsibilities include attendance at all deliveries, management and coordination of care for infants born at 35 0/7 weeks gestation and above requiring level 1 NICU care, and stabilization and care of critically ill infants until transferred to referring level four NICU.
- *Froedtert Menomonee Falls – Special Care Nursery*: Neonatal nurse practitioner at a level two NICU and level two OB labor and delivery unit. Responsibilities include attendance at all deliveries, management and coordination of care for infants born at 32 0/7 weeks gestation and above requiring level 2 NICU care, and stabilization and care of critically ill infants until transferred to referring level four NICU.

University of Chicago, Chicago IL 2006-2011
Neonatal Nurse Practitioner (NNP-BC)

Neonatal nurse practitioner at a 71 bed, level four NICU. Managing the care of infants ranging from critically ill to convalescence. Collaborating with physicians in management of care, contributing to research in the NICU, educating and participating in on-going continuing education for the staff nurses. Technical responsibilities as a NNP include: intubation, PICC line insertion, umbilical line insertion, lumbar punctures, chest tube insertion, management of infants on ECMO, and transport via ambulance and helicopter.

University of Chicago, Chicago IL 2005-2006
Staff Nurse

Part-time staff nurse at a busy, level four NICU. Managed the continuum of care needed for the critically ill infant throughout their stay. Worked with and supported families through the difficult time of having an ill infant. Educated and empowered families to take an infant with medical needs into the community.

Meriter Hospital, Madison WI 2001-2005
Staff Nurse

Full-time staff nurse at a level three special care nursery. Duties included charge nurse and transport to outlying hospitals.

Publications

Malin, K.J., Johnson, T.S., McAndrew, S., Westerdahl, S., Leuthner, J., & Lagatta, J. (2019) Infant illness severity and perinatal post-traumatic stress disorder after discharge from the neonatal intensive care unit. *Early Human Development*, NOV 140: 104930. doi: 10.1016/j.earlhumdev.2019

Malin, K.J., & Johnson, T.S. (2019). A concept analysis of parental uncertainty in illness of an infant. *The American Journal of Maternal Child Nursing*, 44 (4), 206-211. doi: 10.1097/NMC.0000000000000535.

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Malin, K.J., Johnson, T.S., McAndrew, S., Westerdahl, J., Leuthner, J., & Lagatta, J. (2018). Research abstract: Infant illness severity and development of parent posttraumatic stress disorder after the neonatal intensive care unit. *Advances in Neonatal Care: 18*(3), E11. doi: 10.1097/ANC.0000000000000501.

Malin, K. (2014). President Obama signs PREEMIE reauthorization act. *NANN Central*, 30.1.

Malin, K. (2013). The PREEMIE reauthorization act: Why it matters and what you can do to help. *NANN E-News*: 5, 4.

Malin, K. (2012). State-level advocacy: Universal newborn screening for critical congenital heart defects. *NANN E-News*: 4, 2.

Malin, K. (2011). Donor human milk and reimbursement. *NANN E-News*: 3, 6.

Wang, Y., Hoenig, J., **Malin, K.**, Qamar, S., Petrof, El., Sun, J., Antonopoulos, D., Chang, E., and Claud, E. (2009). 16SrRNA gene-based analysis of fecal microbiota from preterm infants with and without necrotizing enterocolitis. *The International Society for Microbial Ecology Journal*: 1-11.

Presentations

“Caring for the Mother Whose Baby is Born Too Early” – Panel Presentation at the 25th Annual Fulfilling the Promise Conference, March 11th, 2020 in Green Bay, WI.

“Agreement Between NICU Health Care Providers and Parents About Infant Illness Severity: Does Primary Nursing Matter?” –Poster Presentation at the 43rd Annual Research Conference: Midwest Nursing Research Society, March 28th, 2019 in Kansas City, MO.

“Quality Improvement Approach to Reducing Admission Hypothermia” - Poster Presentation at the Vermont Oxford Quality Improvement Congress, 2018 in Chicago IL

“Development of Parental Post-Traumatic Stress Disorder in Parents in the Neonatal Intensive Care Unit” – 20th Annual Southeastern Wisconsin Building Bridges Nursing Research Conference, May 11th, 2018 in Milwaukee WI.

“Infant Illness Severity and the Development of Post-Traumatic Stress in Parents After the Neonatal Intensive Care Unit” – Pediatric Academic Societies 2018 Meeting, May 5 -8, 2018 in Toronto Canada.

“Infant Illness Severity and the Development of Post-Traumatic Stress in the Neonatal Intensive Care Unit” – 13th Annual Research Summit, April 10-12, 2018 in Scottsdale Arizona; The 34th Annual National Association of Neonatal Nurses Conference, October 17-20, 2018, in Anaheim, California.

“Optimizing the NNP Role in a Growing NICU” – Poster Presentation at SWANN: Growing Neonatal Nurse Leaders at the Bedside and Beyond, 2017 in Waukesha Wisconsin. Also, presented at Children’s Hospital Pediatric Conference on November 1st, 2017.

“Advocacy in Action” – Children’s Hospital of Wisconsin Annual Pediatric Nursing Conference, November 5th, 2014 in Brookfield Wisconsin.

“National Drug Shortage Issues” – The National Association of Neonatal Nurses Webinar Series, October 8th, 2014.

Kathryn Malin

“Advocacy – A Strong Nursing Tradition” A Breath of Fresh Air – SWANN’s 1st Annual Conference, February 27th, 2014 in Milwaukee Wisconsin.

“Care of the Hospitalized Neonate: A Case Study” Nursing Grand Rounds – Children’s Hospital of Wisconsin. December 18, 2013 in Milwaukee Wisconsin.

“Advocacy in Action” National Association of Neonatal Nursing – Innovations in Neonatal Care 2013 in Nashville Tennessee. Available on NICUniversity. Co-presenter at plenary session.

“DNP or PhD: Which one is for me?” Poster presentation at Innovations in Neonatal Care, October 2013. Co-Author. Also, presented at Building Bridges to Research Based Nursing Practice: Improving Quality and Safety Through Research, May 9th, 2014 in Milwaukee Wisconsin.

Chest Tube Review and Skills Lab: lecture and review of chest tube indications, management and skills for neonatal nurse practitioner group at Children’s Hospital of Wisconsin. February 13, 2012.

Neonatal APN Journal Club Creator and Facilitator: Review of Intravitreal Bevacizumab for Retinopathy of Prematurity. September 11th, 2012 in Milwaukee Wisconsin.

“Advocacy 101: Finding Your Voice” National Association of Neonatal Nursing – Exploring the Science and Practicing the Art of Neonatal Care 2011 in Orlando Florida. Co-presenter at preconference.

Scholarly Projects

Children’s Hospital of Wisconsin, The Medical College of Wisconsin, and the University of Wisconsin Milwaukee

2018- Present

Co-investigator in the *Parent Experience and Infant Health: Before, During and After the NICU* study. The purposes of the study are assessing how parent health-related quality of life (HRQL), perinatal post-traumatic stress disorder (PPTSD) and infant post-NICU healthcare utilization are affected by parental uncertainty in illness during the NICU stay. Also, to determine how parent-reported measures of social determinants of health correlates with parent HRQL, uncertainty, and perinatal PTSD.

To assess how parent health-related quality of life (HRQL) is affected by infant NICU hospitalization, perinatal post-traumatic stress disorder, and post-NICU discharge healthcare utilization. Also, to determine whether parent and hospital caregiver-reported symptom assessments correlate with each other, parent HRQL and post-discharge healthcare utilization. Funded by the National Center for Advancing Translational Sciences, National Institute of Health [Grant number UL1TR001436] and MCW Presidential Faculty Scholar Award (Dr. Joanne Lagatta).

Children’s Hospital of Wisconsin and The Medical College of Wisconsin

2017- 2018

Co-investigator in the *Health-Related Quality of Life in and After Neonatal Intensive Care: Parent and Health Care Provider Perceptions* study conducted at Children’s Hospital of Wisconsin. The purpose of the study was to prospectively assess how parent health-related quality of life (HRQL), perinatal post-traumatic stress disorder (PPTSD) and infant post-NICU healthcare utilization are associated with perception of infant illness severity.

Children’s Hospital of Wisconsin – EQUIP Program

2017 - 2018

Attend and participated in Excellence in Quality Improvement Principles program. Role as a team member of a group of five representatives from the NICU working on a quality improvement project that addressed infant thermoregulation at the time of admission to the NICU.

Kathryn Malin

University of Chicago NOVA 2 Study

2007-2010

Co-investigator in the gastrointestinal arm of NOVA 2 study at University of Chicago. NOVA 2 was a follow up to the *Inhaled Nitric Oxide in Premature Infants with Respiratory Distress Syndrome* research project that was completed at The University of Chicago and published in *The New England Journal of Medicine* in 2005. The purpose of the gastrointestinal arm of the study was to determine the effects on inhaled nitric oxide on bacterial colonization and growth in premature infants and to study the genetic material of bacteria found in stool to determine the patterns associated with necrotizing enterocolitis.

Children's Hospital of Wisconsin – BPD Workgroup

2014 – 2016

Member of BPD work group charged with examining and improving the care of infants with Bronchopulmonary Dysplasia at Children's Hospital of Wisconsin's NICU. Initiatives included improved parent teaching materials and creation of nutritional recommendations for the post-tracheostomy patient.

Service to the Profession

National Association of Neonatal Nurses

2019 – Present

Co-Chair

Co-lead the task force for development of *The Scope and Standards of Practice: Neonatal Nurses*, 3rd Edition. This document describes the standards for neonatal nursing using the nursing process and encompasses all the significant decision making and actions taken by neonatal registered nurses.

Manuscript Reviewer for *Advances in Neonatal Care*

2019

Invited manuscript reviewer for the journal *Advances in Neonatal Care*

University of Wisconsin Milwaukee

2018-2019

DNP thesis committee for Kirsten Cull, winner of the Graduate Student Recognition Award for Student Project at UWM, 2019

Children's Hospital of Wisconsin

2018 – Present

Evidence Based Practice/Research Council

Attend monthly meetings of the Evidence Based Practice/Research Council. Focus is on supporting the development and continuation of innovative pediatric nursing research and evidence-based practice.

Children's Hospital of Wisconsin

2017- 2019

NNP/DNP Student Support

Support services to large number of new NNP/DNP students at Children's Hospital of Wisconsin. Responsibilities included: development and implementation of formal education sessions, bedside precepting and offering support to bedside preceptors, one-on-one student meetings to support DNP thesis development and implementation, bi-monthly meetings with manager and director of NNPs/NICU.

March of Dime

2015 – 2018

State of Wisconsin – State Advocacy and Government Affairs Committee

Participate in the execution of the annual Advocacy and Government Affairs plan for the chapter, strategic planning, maintaining current knowledge of issues affecting maternal/infant health and relevant advocacy efforts, and participation in meetings with policy makers as appropriate.

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Children's Hospital of Wisconsin

2015 – 2017

*Advanced Practice Nursing Council
Member, co-chair of council*

Plan and attend bi-monthly meetings of APN council members. Oversee professional development opportunities for APNs within Children's Hospital of Wisconsin's Health Systems. Assure the standards are pertinent to APNs meet national and professional standards. Develop and promote a vision of APN practice at Children's Hospital of Wisconsin and contribute to the development of efficient and effective care delivery models to address the needs of patients and families.

Southern Wisconsin Association of Neonatal Nursing

2011-Present

Board Member

Vice President, President Elect, President, Advocacy Chair

Help to create and build a Southern Wisconsin Chapter of NANN. Participate in monthly board meetings, plan and execute educational offerings, created membership materials, and developed philanthropic opportunities. Worked as lead coordinator and creator of the Neonatal APN Journal Club for Southern Wisconsin and the annual conference.

National Association of Neonatal Nursing

2010-2014

Health Policy and Advocacy Committee Member

Co-chair of the State Legislative Liaisons project

Project Manager of 2013 Advocacy Session at National Conference

Advocating and helping to lead the neonatal nursing profession to optimize care for neonates and their families. Participating in committee meetings, following and supporting significant legislation of interest and planning for future projects.

Neonatal Resuscitation Program (NRP) Instructor

2007-2016

Prepare educate, and test other health care workers who seek NRP certification.

Professional Associations

Sigma Theta Tau International

2000-Present

Honor Society of Nursing, 233 Iota Tau

American Nurses Association

2001-Present

-Wisconsin Nurses Association

-Wisconsin APRN Coalition

National Association of Neonatal Nursing

2003-Present

National Association of Neonatal Nurse Practitioners

2007-Present

Southern Wisconsin Association of Neonatal Nursing

2011-Present

Doctoral Nursing Student Association

2016-Present

Midwest Nursing Research Society

2017-Present

Chicago Area Association of Neonatal Nursing

2007-2010

American Academy of Pediatrics

2008-2012

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Honors and Awards

Recipient of the 1st Place 2020 Student Poster Award from Sigma Theta Tau: Eta Nu Chapter

Recipient of the 2019 Student Poster Award from Sigma Theta Tau: Eta Nu Chapter

Recipient of the 2017 March of Dimes Dr. Margaret C. Freda Graduate Nursing Scholarship Award

Recipient of the 2016 – 2017 Provost Scholarship Award from The University of Wisconsin at Milwaukee.

Nominated for 2013 APN Excellence Award at Children’s Hospital of Wisconsin.

Recipient of 2013 “Nurse in Washington Internship Scholarship” from the National Association of Neonatal Nurses.

Nominated for the 2010 NANN Nursing Leadership Award