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Predictors of uncertainty, stress, anxiety, and depressive symptoms of parents of preterm infants in the neonatal intensive care unit.

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PREDICTORS OF UNCERTAINTY, STRESS, ANXIETY, AND DEPRESSIVE SYMPTOMS OF PARENTS OF PRETERM INFANTS IN THE NEONATAL INTENSIVE CARE UNIT

By

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DEDICATION

To my Guardian Angel, my mother Fatima Ali, Rest in Peace

To my Sunshine, my daughter Hadeel Isa, you will get there

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ABSTRACT

PREDICTORS OF UNCERTAINTY, STRESS, ANXIETY, AND DEPRESSIVE SYMPTOMS OF PARENTS OF PRETERM INFANTS IN THE NEONATAL INTENSIVE CARE UNIT

Maryam Isa Alaradi

July 29, 2014

Admission of a sick neonate to the neonatal intensive care unit (NICU) can be a very stressful experience for the parents. Parents strive to deal with stress, uncertainty, anxiety, and depressive symptoms in this potentially threatening environment. Research on parental uncertainty in the neonatal population is limited. Moreover, very few studies examined predictors of stress, anxiety and depressive symptoms in parents of NICU infants. The purpose of this study was to identify predictors of uncertainty, stress, anxiety, and depressive symptoms in parents of preterm infants in the NICU. A cross-sectional explorative design was used to recruit a convenience sample of 32 pairs of parents of preterm infants from NICUs in three Hospitals in Louisville, Kentucky. Parents completed the Parental Perception of Uncertainty in Illness Scale (PPUS), the Parental Stressor Scale: NICU (PSS: NICU), the State Anxiety Inventory (SAI), and the Center for Epidemiologic Studies-Depression (CES-D) scale. Descriptive statistics and correlational analysis were conducted. Multiple linear regressions were used to identify predictors of uncertainty, stress, anxiety, and depressive symptoms followed by path analysis for the significant predictors. The results showed that NICU parents experienced

moderate to high levels of uncertainty, stress, and state anxiety and low levels of depressive symptoms. Statistically significant differences were found between parents in level of stress and state anxiety, but not in uncertainty or depressive symptoms. Uncertainty had the greatest effect on state anxiety and depressive symptoms.
Keyword: Parents, preterm infants, NICU, uncertainty, stress, state anxiety, depressive symptoms

TABLE OF CONTENTS

PAGE

LIST OF TABLES

TABLE PAGE

LIST OF FIGURES

FIGURE PAGE

CHAPTER I

BACKGROUND AND SIGNIFICANCE AND THEORETICAL FRAMEWORK

Background and Significance

Prematurity is defined as birth that occurs before 37 weeks gestation (Macones, 2005). Worldwide, approximately 15 million infants are born prematurely every year (World Health Organization [WHO], 2012). The rate of preterm birth in the United States in 2010 was estimated to be 11.6% (March of Dimes, 2012a), which is higher than the global preterm birth rate of 11.1% (Blencowe et al., 2012). When the United States percentage of preterm birth is converted to an actual number, estimates of 517,443 infants are born prematurely every year (Blencowe et al., 2012). That is one preterm birth for every eight live births (Centers for Disease Control and Prevention [CDC], 2010). In 2010, with a rate of 13.7%, the preterm birth rate in Kentucky was considered among the highest in the U.S. (Hamilton, Martin, & Ventura, 2011).

The survival rates for infants born at 24 to 26 weeks gestation are 70% and 85%, respectively (EXPRESS Group et al., 2009). These extremely preterm infants are subjected to lengthy hospitalizations and parents may encounter periods of stress, anxiety and depressive symptoms during their infant's stay in the neonatal intensive care unit (NICU) (Grunau, Holsti, & Peters, 2006; Maher, 2011; Obeidat, Bond, & Callister, 2009). These emotions occur when the parents have to deal with the unfamiliar and unknown NICU environment (Cleveland, 2008). Dealing with the unknown may have undesirable effects on the parents including stress, which could be as high as 40% in the

parents of a preterm infant cared for in the NICU (D'Souza, Karkada, Lewis, Mayya, & Guddattu, 2009). Shaw, Ikuta, and Fleisher (2006) found that 28% of parents with a preterm infant developed Acute Stress Disorder (ASD). Similarly, Dudek-Shriber (2004) reported high general stress in parents of a preterm infant.

Several researchers conducted studies to identify NICU sources of parental stress. Researchers reported that the loss of parental role with their infant, the look and behavior of the infant, and staff behavior and communication with the parents were the most common sources of stress to the parents of infants in the NICU (Dudek-Shriber, 2004; Miles & Holditch-Davis, 1997; Reid & Bramwell, 2003; Seideman et al., 1997; Turan, Başbakkal, & Özbek, 2008). Findings from the stress literature were incongruent about whether different infant and parental characteristics were associated with stress levels in the NICU parents (Ichijima, Kirk, & Hornblow, 2011; Mackley, Locke, & Spear, 2010; Reid & Bramwell, 2003; Turan et al., 2008). A small number of investigators evaluated predictors of stress in NICU parents (Dudek-Shriber, 2004; Lee, Lee, Rankin, Alkon, & Weiss, 2005; Meyer et al., 1995; Shields-Poë & Pinelli, 1997). Numerous researchers investigated the topic of parental stress but few investigators explored parental uncertainty and predictors of uncertainty experienced by parents with infants in the NICU (Lam, Spence, & Halliday, 2007; Miles & Holditch-Davis, 1997). A dearth of research on uncertainty in parents of sick children exists in the neonatal population (Mishel, 1983; Santacroce, 2003; Tomlinson, Kirschbaum, Harbaugh, & Anderson, 1996). Furthermore, no research was found that evaluated predictors of uncertainty in NICU parents.

A number of investigators studied anxiety and depressive symptoms in parents of a term or preterm infants admitted in the NICU (Kong et al., 2013; Korja et al., 2008;

Holditch-Davis et al., 2009; Padovani, Carvalho, Duarte, Martínez, & Linhares, 2009). Parental anxiety and depressive symptoms are studied to a lesser extent than parental stress. The main focus of the studies on parental anxiety and depressive symptoms was on mothers of preterm infants, as fathers were not studied as much. Depressive symptoms were reported as high as 63% in mothers of prematurely born infants (Miles, Holditch-Davis, Schwartz, & Scher, 2007). Thirty-two percent of mothers of preterm infants reported having clinical symptoms of anxiety (Padovani et al., 2009). Studies on predictors of anxiety and depressive symptoms in parents of infants in the NICU are limited.

There is a paucity of research on predictors of uncertainty, stress, anxiety, and depressive symptoms. Identifying predictors of parental uncertainty, stress, anxiety, and depressive symptoms may guide neonatal health care professionals in orienting, educating and informing the parents with important information, thus reducing parental uncertainty, stress, anxiety and depressive symptoms levels. Therefore, the purpose of this study was to identify predictors of uncertainty, stress, anxiety, and depressive symptoms in parents of preterm infants in the NICU.

Theoretical Framework

The theoretical framework that guided this study was the parental uncertainty and stress model. This model was developed by merging the theory of uncertainty in illness (Mishel, 1988), the theory of stress, appraisal, and coping (Lazarus & Folkman, 1984), and the parental NICU stress model (Wereszczak, Miles, & Holditch-Davis, 1997). The theory of uncertainty in illness, the parental NICU stress model, and the theory of stress, appraisal, and coping are described in the following sections.

Theory of Uncertainty in Illness

The theory of uncertainty in illness (Mishel, 1988) has three major concepts: (1) antecedents of uncertainty, (2) appraisal, and (3) coping and adaptation. The main antecedents of uncertainty are: stimuli frame, cognitive capacities, and structure providers.

The first antecedent, stimuli frame is the structure or form of stimulation that the parent perceives. These include symptom pattern, symptom familiarity, and event congruency. The second antecedent, cognitive capacity refers to the ability of the person to process information (Mishel, 1988). Parents could encounter an abundant amount of information from healthcare providers in the NICU which may affect their ability to process everything they are told. The ability to process the abundant amount of information depends on the individual and the surrounding situation (Mishel, 1988). The third antecedent, structure providers, consists of resources to assist parents in interpreting the stimuli frame (Mishel, 1988). The structure provider is composed of three variables: (1) credible authority, (2) social support, and (3) education. Credible authority is the amount of trust parents have in healthcare providers (Mishel, 1988). Social support can reduce uncertainty by modifying ambiguity, unpredictability, and the complexity of medical and nursing treatments (Mishel, 1983). Social support helps parents interpret the meaning of events (Mishel, 1988). Lastly, education, that is the amount of education the parent has, may directly or indirectly influence the level of uncertainty. For example, a parent with a college education would demonstrate less uncertainty for a shorter period of time compared to a parent with high school education (Mishel, 1988).

Parents move from antecedents of uncertainty into the appraisal phase. Parents may use one or both of the following appraisal processes: inference, and/or illusion. Inference is used to evaluate uncertainty based on a previous similar experience. When parental beliefs provide parents with a positive outlook, they use illusion. If the parents view the appraisal process positively, then they will appraise uncertainty as an opportunity. But, if the appraisal process is viewed negatively then uncertainty will be appraised as danger (Mishel, 1990).

If a parent appraised uncertainty as danger, coping strategies will be directed toward reducing the uncertainty. This is done by using either (1) mobilizing strategies, which include direct action, vigilance, and information seeking; or (2) affect-control including methods of faith, disengagement, and cognitive support (Mishel, 1988). If a parent appraised uncertainty as an opportunity, then hope will be dominant. The parent will use buffering methods such as avoidance, selective ignoring, and reordering priorities to support the uncertainty. With buffering, the parent will block any stimuli that might alter the maintenance of the uncertainty. Thus, uncertainty will continue to be viewed as an opportunity (Mishel, 1988). Adaptation occurs when the coping strategies were effective in reducing or maintaining the uncertainty (Mishel, 1988).

Propositions. The propositions define the theoretical relationship and the directions of the relationships of the theory's concepts (Fawcett, 2009). The three antecedents: stimuli frame, cognitive capacities, and structure providers precede the occurrence of uncertainty. The components of the stimuli frame: symptom pattern, event familiarity, and event congruency provide information to the parents and they then form a cognitive schema (Mishel, 1988). The cognitive capacity and structure providers might

influence the stimuli frame in a positive or a negative way, both of which could affect the cognitive schema indirectly by providing information to the parents or directly when the parents rely on the health care providers to assume the responsibility for providing logics to the events (Mishel, 1988). Uncertainty results when a sufficient cognitive schema cannot be formed to interpret the meaning of illness-related events (Mishel, 1988).

Uncertainty is not desired or dreaded until it is appraised. The appraisal occurs through inference and/or illusion (Mishel, 1988). When uncertainty generates illusion it will be appraised as an opportunity. In this case, uncertainty provides the parents with the hope that there will be a better outcome. Inference occurs when the parent's level of mastery and skill cause him to view uncertainty as danger or as an opportunity (Mishel, 1988). The way the parent appraises uncertainty will result in mobilizing strategies to cope with the situation. Eventually, adaptation occurs if the strategies used to cope with uncertainty were effective (Mishel, 1988) (Figure 1).

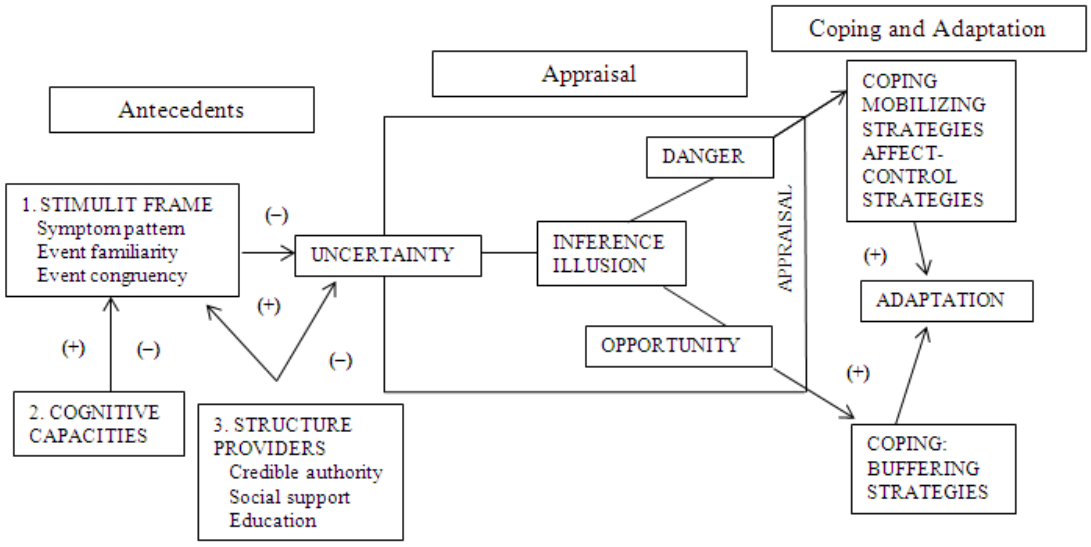

Figure 1. Model of Perceived Uncertainty in Illness.

Note. Reproduced with permission from "Uncertainty in Illness" by M. H. Mishel, 1988, *IMAGE: Journal of Nursing Scholarship, 20*, p.226. Copyright 2007 by John Wiley and Sons.

Parental NICU Stress Model

The parental NICU stress model (Wereszczak et al., 1997) was adapted from the Miles and Carter (1983) model for assessing parental stress in the pediatric intensive care unit (PICU), tailored to assess stress in NICU parents. Several factors emerged from maternal interviews, which contributed to the development of the maternal stress response. These factors are: (1) environmental stressors, (2) situational stressors, (3) personal stressors, and (4) resources (Wereszczak et al., 1997). Environmental stressors comprise the first factor, which include the infant's appearance, behavior, and pain response, alteration in parental role, staff behaviors, communication and caregiving, and sights and sounds of the NICU. Situational stressors comprise the second factor, which include uncertainty, perception of illness severity, and postnatal effect of prenatal

stressors. Personal stressors encompass the third factor, which include family support; resources received from the healthcare providers in the NICU, and stress management strategies that mothers use to assist them through their infant's hospitalization. All of these factors/stressors combine to produce a stress response in NICU parents (Wereszczak et al., 1997).

The Theory of Stress, Appraisal and Coping

According to Lazarus and Folkman (1984), psychological stress is viewed as the result of a relationship between the person and the environment. This relationship takes into account the characteristics of the person and the nature of the environmental event. The judgment of the person-environmental relationship as stressful is centered on two processes: (1) cognitive appraisal and (2) coping.

Cognitive appraisal. Cognitive appraisal is an evaluative process in which the relationship between the person and the environment is considered stressful and is based on its significance to the well-being of the person. Cognitive appraisal takes three forms: primary, secondary, and reappraisal. There are three kinds of primary appraisal: (1) irrelevant, (2) benign-positive, and (3) stressful (Lazarus & Folkman, 1984). The person's encounter with the environment is considered irrelevant when it has no implication for a person's well-being. When the outcome of the encounter with the environment enhances the person's well-being, then the appraisal is considered benign or positive. The third kind of primary appraisal is stressful appraisal, which can take three forms: harm/loss, threat, and challenge. Harm/loss refers to the damage or loss that has already occurred such as illness, loss of a loved one, or loss of a commitment. Threat occurs when harm or loss are anticipated but have not actually happened. Threat is

characterized by negative emotions such as anxiety, fear, and anger. Challenge focuses on gain and is characterized by pleasurable emotions such as excitement and eagerness (Lazarus & Folkman, 1984).

In secondary appraisal, the person evaluates what might and can be done taking into account coping options and the effectiveness of the applied coping strategies. The degree of stress and the quality of the emotional reaction are the result of the interaction between the primary and the secondary appraisal. The third type of appraisal is reappraisal. Reappraisal occurs as a result of changes in appraisal based on new information from the environment and from the person's reaction to the event or situation (Lazarus & Folkman, 1984).

Factors influencing appraisal. Two interdependent factors may affect cognitive appraisal: person factors, and situation factors. Commitments and beliefs are the most important person factors that may affect cognitive appraisal. Commitments refer to what is important to the person. They determine what is at stake in stressful situations. Commitments underlie the choices a person makes to procure desired goals or sustain valued ideals. Commitments direct people toward or away from events that can threaten, challenge or harm them.

Beliefs are cognitive patterns formed by the person or shared by the culture. Beliefs determine the facts in the environment, and shape the understanding of its meaning. Beliefs determine how a person evaluates what is transpiring or is imminent. Two major categories emerged when discussing beliefs that pertain to appraisal: beliefs about personal control, and existential beliefs. The feeling of mastery and confidence provide the person with a sense of control. Appraising an outcome as controllable may

assist in reducing stress. Existential beliefs enable people to engender meanings and maintain hope in difficult situations. The extents to which harm/loss, threat, or challenges are experienced are determined by the interdependence of both the person factors and situation factors (Lazarus & Folkman, 1984).

In situation factors, three formal properties for the person-environmental encounter could create the potential for threat, harm, or challenge. They are: novelty, predictability, and event uncertainty. In novelty, stressful situations are appraised as threat, harm or challenge based on related previous experience or on general knowledge. Predictability refers to signals or warnings that something harmful or painful is imminent. Environmental situations that are unpredictable could increase stress levels. The third property is event uncertainty, which is extremely stressful and has an immobilizing effect on coping processes and could cause mental confusion. Beside formal factors, appraisal could be influenced by temporal situational factors such as imminence, duration, and temporal uncertainty. Imminence refers to how much time is anticipated before the occurrence of an event. The appraisal of a stressful event becomes more intense when the event is more imminent. This occurs only when sufficient cues exist to signal harm, danger, or opportunity for gain or mastery. While imminence denotes the time before the occurrence of an event, duration refers to the length of time that a stressful event persists. Temporal uncertainty arises when the person does not know when an event is going to occur. Contrary to imminence, a person with temporal uncertainty will have lower levels of arousal as a result of an avoidant-like mode of coping (Lazarus & Folkman, 1984).

The appraisal of whether an event is stressful or not depends on the information the person perceives from the formal properties of the event (novelty, predictability, and

event uncertainty), and from the temporal factors (imminence, duration, and temporal uncertainty). Lazarus and Folkman (1984) argue that lack of situational clarity (ambiguity) is not always a predictor for uncertainty. Sometimes, uncertainty could arise from conflict between commitments and goals in spite of the availability of clear information. Other times, even when ambiguity is present about an event, the person may be confident about knowing what to do. Accordingly, ambiguity may intensify or reduce the threat that results from a stressful event. To be able to manage demands arising from stressful events, the person will use coping strategies (Lazarus & Folkman, 1984).

Coping. Coping is defined as a process in which a person continuously changes his cognition and behavior in an effort to manage internal or external demands that are beyond his resources (Lazarus & Folkman, 1984). There are two major groups of coping: problem focused coping in which the person manages or alters the problem with environmental stress, or emotion-focus coping in which regulating the emotional responses to the problem is dominant. Coping is determined by the availability of resources such as health, energy, existential beliefs, beliefs about control and commitments, and by constraints that alleviate the use of resources such as personal and/or environmental constraints. The importance of appraisal and coping lies in their effect on adaptational outcomes. Functioning in work and social living, morale or life satisfaction, and somatic health are the three basic adaptational outcomes (Lazarus & Folkman, 1984).

Limitations of the Theoretical Frameworks

The theory of uncertainty in illness and the associated model were tested extensively in adult patients and in parents of sick children. Few studies have been done

on uncertainty in parents of NICU infants. Some of the studies done on NICU parents as well as on other populations showed an association between uncertainty and stress (Carpentier, Mullins, Chaney, & Wagner, 2006; Ichijima et al., 2011; Lee, Yoo, & Yoo, 2007). On the contrary, Mishel (1984) found no relationship between uncertainty and stress in NICU parents. Mishel addressed stress as an outcome to uncertainty in the initial model of uncertainty (Mishel, 1981). Stress as a concept was not included in the theory of uncertainty in illness.

The theory of stress, appraisal, and coping covers components of stress as well as some aspects of uncertainty. Lazarus and Folkman (1984) clearly linked stress to uncertainty during the appraisal phase of stress. In addition, the authors briefly noted anxiety as a negative emotion that characterizes the appraisal of stress as a threat. However, depressive symptoms were not part of the theory of stress, appraisal, and coping.

In the parental NICU stress model, uncertainty was an element of the situational factor and was identified as one of the predictors for parental stress although it was not depicted in the figure. Moreover, elements that can predict uncertainty were not included. Steedman (2007) is the only researcher identified who used the parental NICU stress model. Although the parental NICU stress model was not tested, it fit the purposes of this study: to determine the predictors of uncertainty, stress, anxiety, and depressive symptoms in parents of preterm infants in the NICU.

The NICU Parental Uncertainty and Stress Model

The predictors of uncertainty, stress, anxiety, and depressive symptoms in parents of preterm infants in the NICU were examined. The NICU Parental Uncertainty and

Stress model (NICU-PUSM) (Figure 2) was adapted from the uncertainty and stress theories and parental NICU stress model previously described. Several concepts from the theory of uncertainty in illness were included in the NICU-PUSM. For example, the antecedent of cognitive capacity depends on the ability of the parent to process information, the clarity and the availability of the information provided to the parents by the healthcare providers (Mishel, 1988). This also applies to the antecedent credible authority.

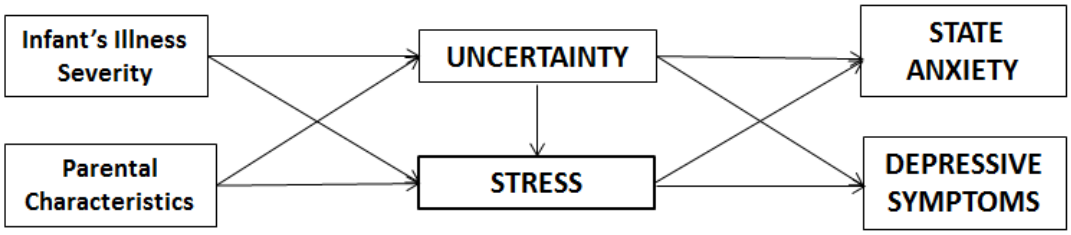

Figure 2. The NICU Parental Uncertainty and Stress Model.

Components of the parental NICU stress model (Wereszczak et al., 1997) included in the NICU-PUSM were: environmental factors such as infant's appearance and behavior, alteration in parental role, and the sights and sounds of the environment; and the situational factors such as uncertainty and infant's illness severity. Similarly, Lazarus and Folkman (1984) in their theory of stress, appraisal, and coping focused on the role of the encounter between the person and the environment on the appraisal of stress. The appraisal of a situation as stressful depends on its predictability, novelty, event uncertainty, and ambiguity (Lazarus & Folkman, 1984). In addition, lack of control could influence the person's appraisal of stress. This factor is embedded in the alteration of parental role, as parents are not able to control what is happening to their infant (Miles, Funk, & Kasper, 1991; Wereszczak et al., 1997). These factors are predictors of stress as

can be seen in the discussion of the NICU-PUSM. Although the uncertainty in illness theory and the theory of stress, appraisal, and coping includes the coping and adaptation concepts, the NICU-PUSM focuses solely on uncertainty, stress, anxiety, and depressive symptoms and their predictors.

The NICU-PUSM is comprised of six main components: infant's illness severity, parental characteristics, uncertainty, stress, state anxiety, and depressive symptoms. Critical concepts and theoretical relationships in this model are described as they relate to the purpose of this study.

Concepts and variables. The parental characteristics variables include demographic data of the parents such as sex, age, marital status, education level, employment status, and having a prior experience with the NICU. Parental characteristics were measured by a questionnaire developed by the investigator.

The infant's illness severity refers to the severity of the disease based on infant's demographic, physiological, and clinical data. The infant's illness severity variables include birth weight in grams, gestational age in weeks, the presence or absence of congenital malformations, maximum base excess, minimum and maximum fraction of inspired oxygen (FiO_2) in the first 12 hours of life. The infant's illness severity was measured by the Clinical Risk Index for Babies (CRIB).

Uncertainty refers to the inability of the parents to determine the meaning of illness-related events. Uncertainty is a cognitive state created when a person cannot adequately structure an event because of inadequate cues from the illness-related events (Mishel, 1988). Substantial uncertainty levels were reported by parents of sick children and infants (Ichijima et al., 2011; Ju et al., 2011; Madeo, O'Brien, Bernhardt, &

Biesecker, 2012; Mu, 2005). Uncertainty was measured by the Parental Perception of Uncertainty Scale (PPUS), which is comprised of four subscales (a) ambiguity, (b) lack of clarity, (c) lack of information, and (d) unpredictability.

Parental stress, is a complex and a dynamic process that links to the infant's behavior, parental demands, and resources, physiological reactions to parental demands, other family members, and healthcare providers. This complex process involves psychological reactions caused by the attempts of parents to adapt to their needs (Deater-Deckard, 2004). Several investigators reported that parents of preterm infants in the NICU experienced significant levels of stress (Bouet, Claudio, Ramírez, & Gracia-Fragoso, 2012; Dudek-Shriber, 2004; Meyer et al., 1995; Reid & Bramwell, 2003; Turan et al., 2008). Stress was measured by the Parental Stressor Scale: NICU (PSS: NICU), which encompasses three subscales (a) baby looks and behaves, (b) sights and sounds of the NICU environment, and (c) parental role.

Anxiety is an emotion characterized by feelings of tension, worried thoughts and physiologic changes including increased blood pressure, sweating, trembling, dizziness or a rapid heartbeat (American Psychological Association [APA], 2013). Two types of anxiety exist: (a) trait anxiety or the heritable personality profile, and (b) state anxiety or situational anxiety (Zelkowitz & Papageorgiou, 2012). A number of investigators found that parents of preterm infants hospitalized in the NICU experienced varying levels of anxiety (Busse, Stromgren, Thorngate, Thomas, 2013; Davis, Edwards, Mohay, & Wollin, 2003; Doering, Moser, & Dracup, 2000; Padovani, Linhares, Carvalho, Duarte, & Martinez, 2004). The state anxiety was measured by the short form of the State Anxiety Inventory (SAI).

Depression is characterized by symptoms of sadness, loss of interest, feeling of guilt, loss of appetite, disturbed sleep, feeling of tiredness and poor concentration (World Health Organization, Regional Office for Europ, 2013). The percent of depressive symptoms was 31% to 75% in parents of preterm infants in the NICU (Davis, Edwards, Mohay, & Wollin, 2004; Howland, Pickler, McCain, Glaser, & Lewis, 2011; Kong et al., 2013; Mackley et al., 2010; Miles et al., 2007). Depressive symptoms were measured by the Center of Epidemiologic Studies-Depression scale (CES-D).

Theoretical relationships. The NICU-PUSM proposes that infant's illness severity and parental characteristics directly predicts parental uncertainty and stress, and indirectly predicts parental anxiety and depressive symptoms. Uncertainty and stress are related to each other. Uncertainty and stress predict state anxiety and depressive symptoms.

Purpose of the Study

The purpose of this study was to explore predictors of uncertainty, stress, anxiety, and depressive symptoms of parents of preterm infants in the NICU. The specific aims and their associated hypotheses were:

Aim I

To identify predictors of stress and uncertainty in parents of preterm infants in the NICU.

Aim II

To identify predictors of anxiety and depressive symptoms in parents of preterm infants in the NICU.

Aim III

To determine if mothers and fathers of a preterm infant differ in their levels of uncertainty.

Hypothesis I for Aim III

Maternal levels of uncertainty in illness will be significantly greater than paternal levels of uncertainty in illness.

Aim IV

To determine if mothers and fathers of a preterm infant differ in their levels of stress.

Hypothesis II for Aim IV

Maternal stress levels will be significantly greater than paternal stress levels.

CHAPTER II

REVIEW OF THE LITERATURE

The recent advances in medical technologies in the fields of perinatology and neonatology led to a dramatic increase in the survival rates of preterm infants (Simons et al., 2003). More than 500,000 infants in the United States are born preterm every year; that is one in every eight live births (CDC, 2010). Prematurity, which is defined as birth that occurs before 37 weeks gestation (Macones, 2005), has increased to 12.8% of all births in 2006 according to the National Vital Statistics report (Martin et al. 2009). The preterm birth rate increased by 20% between 1990 and 2006 (Martin et al., 2009), but has dropped to 11.9% in 2010 (Hamilton et al., 2011). The preterm birth rate in Kentucky was considered among the highest in the United States with a preterm birth rate of 13.7 in 2010 (Hamilton et al., 2011).

The survival rates for infants born at 24 to 26 weeks gestation are 70% and 85% respectively (EXPRESS Group et al., 2009). As a result, these preterm infants are subjected to lengthy hospitalizations (Grunau et al., 2006). This can be a very stressful experience for the parents. Uncertainty in illness is often associated with parental stress (Hilton, 1994; Lee et al., 2005; Matricardi, Agostino, Fedeli, & Montirosso, 2013; Mishel, 1984; Santacroce, 2003). Lee et al. (2007) reported a significant relationship between uncertainty and stress in mothers of children with congenital heart disease ($r = 0.463$, $p < 0.01$). Although there is literature about stress, anxiety, and depressive symptoms in parents of preterm infants, there is a paucity of literature on uncertainty and

the predictors of stress, uncertainty, anxiety, and depressive symptoms in parents of preterm infants.

Researchers reported that parents with an infant admitted to the NICU experienced feelings of anxiety, depression, stress, and distress (Davis et al., 2003; Doering et al., 2000; Dudek-Shriber, 2004; Ukpong, 2011). Anxiety, depression, and distress are concepts studied concurrently with stress. Mothers of preterm infants (N = 57) during NICU hospitalization reported high levels of psychological distress (36.8%), depressive symptoms (19.3%), and anxiety (12.3%) related to their infant's low birth weight and low gestational age (Ukpong, 2011).

The terms stress, distress, anxiety, and depression were not clearly defined. Moreover, the term "stress" and "distress" were used interchangeably (Emmanuel & St John, 2010). While distress is defined as the negative emotional state that arises from the perception of stress (Hoffman & Hatch, 1996), stress is defined as a situation that is appraised by an individual as important and in which the demands of the situation exceed the person's coping resources (Folkman, 2010). Aldwin (2007) defined stress as the transaction between the environment and the person that might affect the quality of the experience and that results in psychological or physiological distress. Both definitions imply that stress precedes distress as asserted by Cox (1978) who identified that stress resulted in fatigue and distress. However, stress is not always negative; it has positive aspects as well. Positive stress outcome occurs when a person appraises stress as a challenge rather than a threat (Folkman & Moskowitz, 2000).

Stress, anxiety, and depressive symptoms are feelings experienced by parents during their infant's hospitalization in the NICU. Anxiety and depression were found to

have a strong relationship with parental stress (Amankwaa, Pickler, & Boonmee, 2007; Ballantyne, Benzies, & Trute, 2013; Holditch-Davis, et al., 2009; Kong et al., 2013). Literature about uncertainty, stress, anxiety, and depressive symptoms were reviewed.

Uncertainty in Illness

Uncertainty is a major component of illness (Neville, 2003). Uncertainty was studied in adult patients with acute and chronic illnesses (Bailey Jr. et al., 2010; Lee, 2006; Mast, 1995; Padilla, Mishel, & Grant, 1992). Severity of illness, specificity of diagnosis, social support, and healthcare providers were associated with uncertainty in illness (Mishel, 1997a). Uncertainty can last for long periods of time in patients with chronic diseases (Bailey Jr. & Stewart, 2010), in which coping and adaptive responses of the sick adult are influenced (Mast, 1995).

Research on uncertainty in the pediatric population has focused on the families and parents of children suffering from various disorders (Ju et al., 2011; Madeo et al., 2012; Mu, 2005; Santacroce, 2003; Stewart & Mishel, 2000). Mu (2005) found that fathers of children with epilepsy ($N = 210$) reported moderate levels of uncertainty ($M = 85.6$, $SD = 16.41$) on the PPUS scale. Similar findings were reported by Ju et al. (2011) who found that mothers of children with febrile convulsions ($N = 102$) experienced moderate levels of uncertainty on the PPUS scale ($M = 2.29$, $SD = .34$). Parental uncertainty is associated with lack of control in parents of children with undiagnosed medical conditions as uncertainty was found to be inversely associated with perceived parental control ($\beta = -4.044$, $p \leq 0.001$). Less control perceived by the parents could lead to ineffective coping and poor adaptation (Madeo et al., 2012).

The main cause of uncertainty among parents of a hospitalized infant is attributed to inadequate or lack of information regarding their infant's condition and difficulties in obtaining the information from the healthcare providers in the NICU (Ichijima et al., 2011). Severity of illness in the children and the amount of family cohesion were found to be strongly correlated with maternal uncertainty ($r = 0.36$, $p < 0.01$; $r = 0.39$, $p < 0.01$, respectively) (Tomlinson et al., 1996). Illness severity was significantly correlated with uncertainty in parents of children with undiagnosed medical conditions ($r = 0.18$, $p < 0.01$). Parental age was inversely correlated with the total PPUS scale in parents of children with rare chromosome conditions ($N = 363$) ($r = -0.13$, $p < 0.05$). Unpredictability, which is the inability to predict a child's outcome, was perceived as causing a high level of uncertainty among parents (Miles, Funk, and Kasper, 1992). Moreover, other aspects of uncertainty, such as lack of information, and lack of clarity were found to decrease over time, while, unpredictability remained constant (Miles et al., 1992).

Uncertainty Predictors

To date, no studies examining predictors of uncertainty in parents of infants in the NICU were found. However, a few studies were done on parents of sick children (Lipinski, Lipinski, Biesecker, & Biesecker, 2006; Madeo et al., 2012; Tomlinson et al., 1996). In these studies, different predictors were explored. Lipinski et al. (2006) tested the association of parental uncertainty and perceived control with the perceived helpfulness of genetic counseling in parents of children with rare chromosomal conditions. They found that perceived seriousness of the child's condition was the only positive predictor of uncertainty. For each unit increase in the perceived seriousness of a

child's condition, uncertainty increased by 1.05 units ($p < 0.02$). Perceived helpfulness of the genetic counselor ($\beta = -1.03$, $SE = 0.32$, $p < 0.002$), perceived personal control ($\beta = -1.04$, $SE = 0.38$, $p < 0.01$) and perceived benefit of diagnosis ($\beta = -.072$, $SE = 0.35$, $p < 0.05$) were all significant negative predictors for uncertainty. Parents' age, educational level, marital status, and child's age were not significant predictors of parental uncertainty (Lipinski et al., 2006). Similarly, disease severity, perceived personal control, and optimism accounted for 23% of the variance in overall uncertainty in parents ($N = 266$) of children with undiagnosed medical conditions. Socio-demographic variables (parental age, country of residence, highest education, and marital status) were not statistically significant predictors of uncertainty (Madeo et al., 2012). Family cohesion, illness severity, and social support explained 22% of the variance in uncertainty with family cohesion explaining the greatest variance in uncertainty ($R^2 = 0.15$, $F = 0.08$, $p < 0.04$) in mothers of hospitalized sick children ($N = 40$). Moreover, infant's illness severity was significantly correlated with maternal uncertainty ($r = 0.36$, $p < 0.01$) (Tomlinson et al., 1996). Illness severity/seriousness of the child's condition was a common predictor for uncertainty in these three studies.

Limitations in the study of parental uncertainty remain. First, research conducted on parental uncertainty is from the 1990s, which is outdated given the rapid advances in the NICU's medical and nursing sciences. However, these studies added to the body of knowledge about parental uncertainty and provided invaluable contributions on this topic. Second, the focus of the above literature was on uncertainty in parents of children with specific diagnoses such as rare chromosomal conditions, undiagnosed medical conditions, and febrile convulsions, which might render them inapplicable to the parents

of preterm infants due to the very different nature of the conditions and situations encountered by NICU parents. Third, a large amount of the variance in uncertainty remained unexplained. Therefore, research is needed to explore predictors of uncertainty in parents of infants in the NICU in order to advance the science in this area.

Uncertainty and Stress

Uncertainty in illness was reported to be associated with stress in sick patients (Lee, 2006; Lee, Gau, Hsu, & Chang, 2009; Wineman, Schwetz, Goodkin, & Ruick, 1996). Lee (2006) found a strong correlation between uncertainty and PTSD in young adult survivors of childhood cancer ($r = 0.40$, $p < 0.05$). The researchers concluded that uncertainty could lead to the development of PTSD symptoms (Lee et al., 2009). Likewise, Mishel (1984) found that a strong correlation existed between uncertainty and hospital stress ($r = 0.35$, $p < 0.001$) (Mishel, 1984).

Researchers explored uncertainty and stress in parents of sick children (Carpentier et al., 2006; Lee et al., 2007). Carpentier et al. (2006) found that illness uncertainty was positively correlated with psychological distress in parents of children with type 1 diabetes mellitus ($r = 0.46$, $p < 0.05$). Lee et al. (2007) reported a significant correlation between stress and uncertainty in mothers of children with congenital heart disease ($r = 0.46$, $p < 0.01$). Parental stress was also found to have a significant relationship with components of uncertainty including ambiguity ($r = 0.455$, $p < 0.01$), lack of clarity ($r = 0.39$, $p < 0.01$), and lack of information ($r = 0.379$, $p < 0.01$), but was not significantly related to unpredictability (Lee et al., 2007).

Uncertainty was found to be associated with stress in parents of NICU infants (Ichijima et al., 2011; Lee et al., 2005). Uncertainty was one of the themes that emerged

from the qualitative interviews that were conducted with parents of preterm infants (N = 121) to examine sources of stress in the NICU (Ichijima et al., 2011). Lee et al. (2005) reported a significant correlation between stress and uncertainty regarding the future impact of an infant's illness in Chinese-American fathers ($r = 0.65$, $p < 0.01$), but not in Chinese-American mothers ($r = 0.33$). Miles et al. (1992) used the PSS: NICU, the PPUS and STAI scales to examine levels of parental stress, uncertainty and anxiety in parents of preterm infants (N = 23 pairs). No significant relationship between maternal stress and uncertainty was detected, which the investigators attributed to the small sample size (Miles et al., 1992).

In summary, uncertainty is reported to have a significant relationship with stress in the adult population and in parents of sick children. Findings from the two studies that examined uncertainty and stress in parents of infants in the NICU yielded inconsistent findings.

Summary of Uncertainty Literature

Uncertainty in illness has been studied in adult patients and in parents of pediatric patients with various illnesses. Parents of sick children were found to experience uncertainties regarding their child's condition. A handful of studies were done on the uncertainty that the parents of NICU infants experience. Of the few studies that were done on uncertainty in NICU parents, inconsistencies were reported regarding the presence of a link between stress and uncertainty (Carpentier et al., 2006; Lee et al., 2007; Miles et al., 1992). No studies were found evaluating predictors of parental uncertainty in the NICU. Further research is warranted to describe parental uncertainty and to determine predictors of uncertainty in NICU parents.

Parental Stress

Becoming a parent is a period of change and instability. It is a period of transition, adaptation, and attainment to a new role (Alden, 2012). Parenthood is a time filled of fun, excitement, joy, and trouble (Hall, 1995). Although parenting is a normal predicted developmental event, becoming a parent to a healthy infant is an overwhelming experience (Nyström & Öhrling, 2004). Becoming a parent to a sick infant is far more stressful than having a normal infant (Deater-Deckard, 2004). Parental stress is defined as a variety of developments leading to negative psychological and physiological reactions secondary to adaptive responses to being a parent (Deater-Deckard, 2004). Demands of parenthood may produce negative feelings toward the self and the child (Deater-Deckard, 2004).

Parents of hospitalized sick children experience substantial levels of stress (Colville & Pierce, 2012; Commodari, 2010; Jee et al., 2012). Parents of hospitalized sick children ($N = 219$) reported significant stress levels ($M = 103$, $p < 0.001$) on a psychological stress measure (PSM) (Commodari, 2010). Parents reported high stress for not being able to care for their children and for feelings of uncertainty and helplessness (Jee et al., 2012). Johnson, Nelson, and Brunnquell (1988) studied parents ($N = 41$) of children in the PICU and found that fathers scored significantly higher than mothers ($M =$ 2.44 vs. 2.06, $p < 0.05$) in the sights and sound subscale on PSS: PICU scale.

Qualitative Stress Studies

A few qualitative and mixed-method designs studies were done on the topic of parental stress. Raeside (1997) using a phenomenological approach compared the perceptions of the NICU environmental stressors between mothers (n = 12) and nurses (n

= 12) using semi-structured interviews. The themes identified were: (1) physiological mode including stress caused by the environment and stress caused by the neonate, (2) self-concept/role function modes including communication and antenatal preparation, and (3) interdependence mode which included maternal-infant bonding. While mothers perceived heat intensity, infant appearance, and alarms to be the most stressful environmental stressors, nurses perceived the monitors attached to the infant and alarms as the most stressful to mothers (Raeside, 1997). Ninety one percent of the mothers perceived the NICU environment to be stressful compared to 100% of nurses (Raeside, 1997). In addition, 83% of the nurses perceived communication with the doctor to be stressful for the mothers of infants weighing less than 1500 grams. Conversely, mothers with infants weighing more than 1500 grams reported that communication with the doctors was not stressful (Raeside, 1997). These findings suggest that neonatal nurses perceived maternal stress differently than the mothers did. However, due to the small sample size and unreported method of trustworthiness of the qualitative data as well as unreported reliability and validity of the instrument, the results of this study are cautiously considered.

Holditch-Davis and Miles (2000) conducted a phenomenological qualitative study on 31 mothers of preterm infants at the sixth month of infant's age. Six themes were identified as major sources of stress: (1) pre-existing and concurrent personal and family factors (i.e. family configuration and financial concerns), (2) prenatal and perinatal experiences, (3) infant illness, treatments, and appearance; (4) concerns about infant's outcome (particularly death), (5) loss of the parental role, and (6) healthcare providers as they may hinder or help mothers in dealing with the NICU stressors (Holditch-Davis &

Miles, 2000). Most of the themes were consistent with an earlier study done by Wereszczak et al. (1997) who explored maternal recall of the NICU. Wereszczak et al. (1997) studied 44 primary caregivers; mothers and grandmothers with custody of preterm children were interviewed. Mothers of three-year-old prematurely born children were asked to recall their experiences in the NICU. Four main themes emerged: (1) environmental stressors including infant's appearance, behavior, and pain, staff behavior, alteration in parental role, communication and caregiving, and sights and sounds of the NICU; (2) situational stressors including uncertainty and perception of severity, and postnatal effect of prenatal stressors; (3) personal stressors including family support, and (4) resources including staff support and stress management strategies (Wereszczak et al., 1997). Quantitatively, 90% of the mothers perceived the infant's appearance and behavior as stressful, 94% reported frustration of parenting their infants in the NICU, and 46% reported being stressed related to staff behavior and inadequate communication (Wereszczak et al., 1997).

While the focus of the above investigators was on the levels and sources of stress in mothers, Holditch-Davis, Bartlett, Blickman, and Miles (2003) focused on the symptoms of posttraumatic stress disorder (PTSD) in mothers of preterm infants. Mothers (N = 30) were interviewed immediately before the infants' discharge from the NICU and again when the infants were six months old. The themes that the researchers identified were: (1) re-experiencing in which mothers (n = 24) described intrusive thoughts of the experience of preterm birth, (2) avoidance where 24 mothers described their attempts to forget the preterm birth experience, and (3) heightened arousal in which 24 mothers

described being continuously aroused, which is exhibited by sleep difficulties, generalized anxiety, and overprotection of the child (Holditch-Davis et al., 2003).

In summary, the mixed-method design qualitative studies were similar in sample size and in the focus on mothers of preterm infants. The findings of the qualitative research on parental stress showed some consensus in the sources of maternal stress in the NICU such as infant appearance, NICU environment, parental role, and prenatal experiences. Findings varied regarding whether or not communication with the healthcare providers causes stress to mothers. Two of the studies were conducted when the infants were six months and three years of age introducing another variable, time, in maternal recall of the NICU experience (Holditch-Davis & Miles, 2000; Wereszczak et al., 1997).

Quantitative Stress Studies

Quantitative research on stress in parents of infants in the NICU is abundant. Most of the research is descriptive; however, four groups of researchers evaluated the effect of an intervention on parental stress levels (Ahn & Kim, 2007; Chourasia, Surianarayanan, Bethou, & Bhat, 2012; Matricardi et al., 2013; Turan et al., 2008). Ahn and Kim (2007) compared stress levels and parental perception between parents of full-term infants (n = 26), and parents of preterm infants (n = 22) using PSS: NICU and the Neonatal Perception Inventory before and after an educational intervention. The 40 to 50 minute educational intervention provided parents with information on sharing emotions, premature infants, the NICU environment, the diagnostic examinations, feeding support, technical support and equipment (Ahn & Kim, 2007). The authors found that educational sessions reduced the scores of PSS: NICU in fathers (pre-intervention $M = 3.23$, $SD = .65$, Post-intervention $M = 2.90$, $SD = .76$, $t = -2.03$, $p = 0.05$) but not in mothers (pre-

intervention $M = 3.43$, $SD = 0.89$, Post-intervention $M = 3.35$, $SD = .81$, $t = - 0.45$, $p = 0.67$) (Ahn & Kim, 2007).

Chourasia et al. (2012) found that counseling sessions reduced stress levels in mothers. The researchers assessed stress levels of NICU mothers ($N = 100$) using the PSS: NICU scale before and after a 30-40 minute counseling session (Chourasia et al., 2012). The researchers found that maternal stress levels reduced significantly after counseling in the sights and sounds subscale ($M =2.55$ vs. $M = 1.48$, $p < 0.001$), looks and behavior of the infant subscale ($M = 4.10$ vs. $M = 2.72$, $p < 0.001$), and in parental role subscale ($M = 4.12$ vs. $M = 2.60$, $p < 0.001$) (Chourasia et al., 2012). Turan et al. (2008) compared stress of parents who received standard NICU care (control) with stress of parents who received a 30-minute educational session (intervention). Stress levels were assessed after the intervention using the PSS: NICU. The authors found that the mothers' scores in the intervention group were significantly lower than the mothers' scores in the control group ($M = 3.14$ vs. $M = 3.37$, $p < 0.001$). No significant differences were found between fathers in both groups ($M = 3.03$ vs. $M = 3.22$, $p = 0.256$) (Turan et al., 2008).

Matricardi et al. (2013) examined the effects of a parental intervention on the reduction of parental stress. Parents of preterm infants were randomly assigned to a control group (n= 21) or to an intervention group (n =21). The parental intervention involved eight sessions with the unit's physical therapist to improve physical contact with the infant and to increase observation abilities of the fathers. The intervention also included instructing parents on massaging their infants with oil (Matricardi et al., 2013). Data collection using the PSS: NICU was carried out after one week of the infant's

hospitalization (Time 1) and at the infant's discharge (Time 2). The parents in the control and intervention groups scored high on the PSS: NICU at Time 1 (M = 3.19, SD = 1.12) and lower at Time 2 (M = 2.81, SD = .92). However, on the subscales in the PSS: NICU, the intervention group scored lower stress related to infant appearance and behavior at Time 2 (M = 2.56, p = 0.014), while the control group's stress increased at Time 2 (M = 4.31, $p < 0.001$). Moreover, mothers reported higher stress in all PSS: NICU subscales compared to fathers. The scores on the parental role alteration subscale reduced significantly in the intervention mothers between Time 1 and Time 2 (M = 3.67, SD = .97 vs. M = 2.98, SD = .97), but not in fathers (Matricardi et al., 2013).

Levels of stress experienced by the parents of NICU infants varied among studies. In a recent study of 156 parents of infants admitted to the NICU, 46% of the sample rated the NICU experience as extremely stressful (Bouet et al., 2012). Meyer et al. (1995) showed that 28 % of 142 mothers of preterm infants reported significant psychological distress. Many factors were found to contribute to the variations in stress levels. Factors like timing of the assessment, characteristics of the parents such as educational level and age, characteristics of the infant, and number of visitations, all contributed to differences in parental stress levels (Dudek-Shriber, 2004; Reid & Bramwell, 2003, Turan et al., 2008).

Regardless of the level of stress parents experience during their preterm infant's hospitalization, the majority of the researchers in this field reached a consensus that having a preterm infant in the NICU is a stressful and emotionally-draining experience for the parents (Carter, Mulder, & Darlow, 2007; Franck, Cox, Allen, & Winter, 2005; Mew, Holditch-Davis, Belyea, Miles, & Fishel, 2003; Seideman et al., 1997; Shaw,

Bernard, DeBlois, Ikuta, & Ginzburg, 2009). Parents may endure a variety of emotions that are associated with stress including fear, lack of control, self-blame, shock, guilt, feelings of hopelessness, and uncertainty (Arockiasamy, Holsti, & Albersheim, 2008; Feldman, Weller, Leckman, Kuint, & Eidelman, 1999; Gavey, 2007; Holditch-Davis et al., 2009; Miles & Holditch-Davis, 1997; Obeidat et al., 2009; Spear, Leef, Epps, & Locke, 2002). Untreated stress could lead to ASD and posttraumatic stress disorder (PTSD) (Shaw et al., 2006; Shaw et al., 2009). These disorders may interfere with parents' ability to cope with the hospitalization of their infant (Spear et al., 2002).

Sources of Stress

Several investigators studying parents of sick infants hospitalized in the NICU identified different sources of parental stress (Dudek-Shriber, 2004; Miles & Holditch-Davis, 1997; Shields-Poë & Pinelli, 1997). Common sources of stress are: when parents observe cessations of breathing in their sick infant, seeing needles and tubes in their infant's bodies, and the limp and weak appearance of their infant (Grosik, Snyder, Cleary, Breckenridge, & Tidwell, 2013; Miles et al., 1991). The NICU physical environment is another source of parental stress. Parents reported being overwhelmed with the sights and sounds of the NICU (Gavey, 2007). The NICU environmental sights and sounds increased parent's stress and parents perceived the environment as harmful to their infant (Turan et al., 2008).

One of the highest identified sources of parental stress is the loss of the expected parental role, which renders parents helpless, disappointed, and frustrated (Dudek-Shriber, 2004; Turan et al., 2008). Miles et al. (1992) found that the greatest amount of stress perceived by parents was the alteration in their parental role ($M = 2.96$, $p < 0.05$).

Similarly, Seideman et al. (1997) reported that the highest mean score in the PSS: NICU scale was alteration in parental role (N = 31, M= 3.29, SD = .90) followed by the infant's appearance and behavior (M = 3.15, SD = .96). This result was supported by Busse et al. (2013) who reported that alteration in parental role ranked highest as a source of stress for the NICU parents (M = 3.25, SD = .99) whereas, the sights and sounds of the NICU were reported the lowest source of stress (M = 2.37, SD = .81). The inability to perform the expected parental role in the unfamiliar NICU environment may delay maternal attachment with the infant (Feldman et al., 1999).

Prenatal and perinatal as well as previous NICU experiences are associated with parental stress (Holditch-Davis & Miles, 2000). Furthermore, frequency of visitation by the mothers to the NICU was inversely related to the levels of maternal stress: as the frequency of the visitations increased, maternal stress levels decreased (Ichijima et al., 2011; Turan et al., 2008). Frequent visitations may increase mother-infant attachment and thus contribute to the reduction of maternal stress levels (Zeskind & Iacino, 1984).

Infant characteristics. Infant characteristics were associated with the level of stress in parents. Mackley et al. (2010) found that infant's severity of illness was not significantly related to the total Parent Stressor Scale: Infant Hospitalization (PSS: IH) and subscales scores ($p \geq 0.20$). The PSS: IH was adapted from the PSS: NICU to measure parental stress perception associated with infant's admission to the hospital (Miles & Brunssen, 2003). On the contrary, Turan et al. (2008) reported that mechanical ventilation of the infants affected the total PSS: NICU scores in mothers of preterm infants (M = 90.91, SD = 7.07, $p < 0.05$). Infants' feeding-related characteristics such as commencement of oral feeding and length of tube feeding were significantly related to

the level of stress in mothers in two of the PSS: NICU subscales: infant's appearance and behavior ($p = 0.01$) and sights and sounds ($p = 0.02$) (Ichijima et al. 2011).

Parent characteristics. Maternal age contributed to maternal stress levels. Mothers who were younger, had recent other stressful events, or had infants with low gestational age reported high stress levels (Meyer et al., 1995; Turan et al., 2008). Reid and Bramwell (2003) reported that maternal age was inversely correlated with maternal stress levels related to the alteration in the parental role ($r = -0.35$, $p < 0.05$) in PSS: NICU scale. This result is inconsistent with the findings reported by Chourasia, Surianarayanan, Bethou, and Bhat (2013), who showed that as maternal age increased, maternal stress level increased. However, Ichijima et al. (2011) did not find any significant relationship between maternal age and maternal stress levels ($t = 1.73$, $p = 0.09$), but did find that paternal age was inversely correlated with stress levels ($t = -2.2$, $p < 0.05$).

Marital status was also significantly correlated with PTSD in mothers of preterm infants ($r = .38$, $p < 0.05$) (Holditch-Davis et al., 2003). Similarly, Carter et al. (2007) found that the total scores of the PSS: NICU were higher for unmarried mothers compared to married mothers ($M = 2.2$ vs. $M = 2.0$, $p < 0.05$), and for mothers with low income compared to fathers with low income ($M = 2.2$ vs. $M = 1.7$, $p < 0.05$). This is inconsistent with the findings of Dudek-Shriber (2004) who reported that married parents had higher stress levels on the PSS: NICU scale than single parents ($M = 4.92$, $SD = .80$ vs. $M = 4.55$, $SD = 1.13$).

Educational level was associated with parental stress. Ichijima et al. (2011) found that mothers with a secondary education reported higher stress levels on the PSS: NICU

subscale infant's appearance and behavior ($p = 0.05$) than mothers with less than a secondary education.

Stress Predictors

While most investigators studying parental stress focused on the sources of stress and the association of infant and parental characteristics with parental stress levels, few focused on infant and parental characteristics as predictors of stress (Woodward et al., 2014; Dudek-Shriber, 2004; Lee et al., 2005; Meyer et al., 1995; Shields-Poë & Pinelli, 1997). Woodward et al. (2014) examined sources and predictors associated with NICU-related stress for mothers of very preterm infants. They found that lower maternal education, higher levels of maternal postnatal depressive symptoms, infant unsettled-irregular behavior, and other previous life stressors accounted for 21.2% of the variance in maternal NICU-related stress. Meyer et al. (1995) explored infant (birth weight, gestational age, and ventilator support) and maternal characteristics (age, socioeconomic status, and parity) that predict maternal stress in mothers ($N = 142$) of preterm infants admitted to the NICU. The authors used the PSS: NICU scale to measure maternal stress. Significant predictors of maternal stress were infant characteristics ($F_{(3,135)} = 6.80$, $p < 0.05$), with infant birth weight, gestational age, race, ventilator support, and length of hospitalization, yet these variables accounted for only 12% of the variance in mothers' NICU specific stress (Meyer et al. 1995). Dudek-Shriber (2004) further examined predictors of stress for each PSS: NICU subscale in 162 parents of infants admitted to the NICU. Parental ethnicity and education explained 11% of the variance in parental stress in the sights and sounds subscale. Length of stay and infant cardiovascular diagnosis explained 7.3% of the variance in parental stress in the baby looks and behaves subscale

whereas parent age and infant cardiovascular diagnosis accounted for 8% of the variance in the parental role subscale. Infant cardiovascular diagnosis and sex of the parents accounted for 7% of the variance in the PSS: NICU score (Dudek-Shriber, 2004). As can be seen from the above literature findings, a small percentage of variables accounted for the rather a small levels of variance in stress reported by parents. Thus, a large percentage of the variance is unexplained.

Eight variables (situational variables: hospital type and time from birth to first visit in NICU; parent variables: trait anxiety, marital status, perceived morbidity, and frequency of visiting; and infant variables: sex and morbidity score) were significantly associated with the PSS: NICU total scores in a study of 212 parents of term and preterm infants (Shields-Poë & Pinelli, 1997). These eight variables explained 23% of the variance in the PSS: NICU score (Shields-Poë & Pinelli, 1997). Similarly, state anxiety, infant illness severity, and less frequent visitation explained 31% of the variance in stress experienced by parents of sick infants ($N = 257$) (Franck et al., 2005). Franck, Cox, Allen, & Winter (2004) found that parental state anxiety alone accounted for 25% of variance in parental stress scores in parents of term and preterm infants in the NICU ($N = 257$). Uncertainty, lack of healthcare providers support, and beliefs in Asian family values accounted for 26% of the variance in stress for mothers and 55% for fathers in a Chinese-American sample ($N = 30$), with uncertainty alone explaining 13% of variance in maternal stress and 42% of variance in paternal stress (Lee et al., 2005). Although the percentages of variances in this study were high, the results must be used cautiously when generalizing the findings to other cultures. Although the percentage of stress variances were higher in these studies (Franck et al., 2005; Lee et al., 2005; Shields-Poë

& Pinelli, 1997) compared to the studies done by Dudek-Shriber (2004) and Meyer et al. (1995), a large proportion of stress variance remains unexplained.

The variables that predict stress explained less than 50% of the variance in stress in the majority of studies with a large proportion of the variance in stress remains unexplained. For this reason, in addition to the variables that were found to predict stress, other variables were included in this study in an attempt to predict a greater percent of the variance in parental stress.

Differences between Mothers' and Fathers' Responses to Stress

A number of investigators studied stress in both parents (Ahn & Kim, 2007; Dudek-Shriber, 2004; Franck et al., 2005; Lee et al. 2005; Matricardi et al., 2013; Seideman et al., 1997; Shaw et al., 2009). However, a substantial number of investigators focused on mothers of infants in NICU (Chourasia et al., 2012, 2013; Jubinville Newburn-Cook, Hegadoren, & Lacaze-Masmonteil, 2012; Holditch-Davis et al., 2009; Lau, Hurst, Smith, & Schanler, 2007; Meyer et al., 1995; Trombini, Surcinelli, Piccioni, Alessandroni, & Faldella, 2008). Few researchers studied fathers of infants in the NICU (Arockiasamy et al., 2008; Garten, Nazary, Metze, & Bührer, 2012; Hollywood & Hollywood, 2011; Mackley et al., 2010; Zamanzadeh, Valizadeh, Rahiminia, & Kochaksaraie, 2013). The researchers who studied fathers focused on the experience and the emotional responses of fathers to an infant in the NICU and did not specify stress. All of these studies of fathers were conducted recently (2008 through 2013), which indicates that fathers were the "forgotten parent[s]" for many years (Mackley et al., 2010).

Although a number of investigators found that mothers of infants in NICU reported higher levels of stress compared to fathers, other investigators reported that

fathers demonstrated elevated levels of stress and symptoms of depression (Carter et al., 2007; Mackley et al., 2010; Matricardi et al., 2013; Miles et al., 1992; Shields-Poë & Pinelli, 1997). Mackley et al. (2010) studied stress and depressive symptoms in 35 fathers of preterm infants in the NICU on the seventh (Time 1), 21st (Time 2), and 35th (Time 3) days of hospitalization. They found that stress levels remained constant over time (M = 3.1 to 3.5, SD = .8 to .9, p = 0.05 for Time 1-3). Miles et al. (1992) found that mothers of preterm infants PSS: NICU scores were 40% higher than fathers within a week of the infant's NICU admission (M = 3.80 vs. M = 2.70, respectively). Parental stress a few months after an infant's discharge from the NICU was higher in fathers compared to mothers, which suggests differences in coping mechanisms between mothers and fathers once infants are home (Melnyk et al., 2006; Shaw et al., 2009). Moreover, findings from a recent study showed that fathers require different interventions to cope with stress associated with preterm delivery compared to mothers (Matricardi et al., 2013).

Bouet et al. (2012) found no difference between mothers and fathers in the levels of stress (N = 156) as reported on the PSS: NICU, an inconsistency with the findings of other investigators. Nevertheless, Bouet et al. (2012) findings are congruent with findings from another study done on 212 parents of infants in the NICU, where no significant differences between mothers and fathers in the total PSS: NICU scores were reported (Shields-Poë & Pinelli, 1997). Despite the finding of no difference between mothers and fathers in the total PSS: NICU scores, mothers rated the subscales interaction with the infants (M = 2.9, $p < 0.001$), and sights and sounds of the NICU (M = 2.5, p = 0.01) as significantly more stressful than the fathers (Shields-Poë & Pinelli, 1997).

In summary, there are inconsistent findings in reported stress between mothers and fathers of infants in the NICU. There are also differences in sources of stress perceived by mothers compared to fathers. Parental stress that may be induced by the behavior of the healthcare providers is discussed next.

Healthcare Providers and Parental Stress

The way parents and NICU healthcare providers interact with each other can be a source of parental stress. Parents feared that nurses would not call them if their infant's condition changed ($M = 3.7$, $SD = 1.24$) (Miles et al., 1991). Parents reported that their stress increased when they perceived that nurses were worried about their infant ($M = 3.8$, $SD = 1.34$) (Miles et al., 1991). Because they were excluded from taking care of their own infants, mothers felt that their infants belonged to the healthcare providers and not to them (Wigert, Johansson, Berg, & Hellström, 2006). Parents may find it difficult to understand the roles of certain individuals in the NICU, which may cause more stress to the parents (Maher, 2011).

NICU parents reported having moderate levels of stress related to their relationships with healthcare providers ($M = 2.52$, $SD = .88$) (Seideman et al., 1997). Parents reported higher levels of stress about having nurses help them in their parental role ($M = 3.99$, $SD = .7$, $p = 0.03$) (Seideman et al., 1997). Conversely, Lee et al. (2005) found no significant correlation between parental role-related stress and the perceived support of the healthcare providers in Chinese-American parents ($N = 30$). NICU environment-related parental stress was inversely related to healthcare providers support ($r = - 0.48$, $p < 0.05$) (Lee et al., 2005).

Holditch-Davis and Miles (2000) showed that 32% of mothers studied described negative experiences with healthcare providers while 26% described the experience as positive. The experiences described were mainly related to emotional support, promotion of the parental role, the behavior of the healthcare providers, and communication (Holditch-Davis & Miles, 2000). Communication style was perceived as having the most negative effect on the mothers (Holditch-Davis & Miles, 2000). Ichijima et al. (2011) reported that communication with the nursing staff was the most important stressor to NICU parents. Ichijima et al. (2011) compared parents (N = 121) from New Zealand and Japan concerning environmental influences on parental stress. The qualitative aspect of the study revealed three themes: uncertainty, NICU context such as NICU physical environment, and communication. Three categories emerged from the communication theme: (1) nurses comments and attitudes, (2) the frequency in which nursing staff change, and (3) inconsistency and conflict in nursing care and advice given to the parents (Ichijima et al., 2011).

In summary, a number of groups of investigators showed that healthcare providers working in the NICU could be a source of stress for the parents. The behavior of healthcare providers, the way they interact and communicate with the parents can reduce or increase parental stress levels.

Summary of the Parental Stress Literature

The research in the area of parental stress has increased dramatically since the 1980s. The main goal of these studies was mostly exploratory. That is exploring the level of stress in parents of infants hospitalized in the NICU, or reporting the sources of stress that parents might encounter. A few researchers conducted intervention studies to

evaluate the effect of specific interventions on the reduction of parental stress. The findings were consistent about the stressfulness of the NICU experience on parents with some variation in stress levels. There were some inconsistencies concerning the effect of interventions on reduction of parental stress. In addition, conflicting findings were found in the association between infant's and parental characteristics and parental stress as well as in the differences of stress levels between mothers and fathers. Few researchers explored predictors of parental stress in the NICU and variables that predicted parental stress were not consistent across these studies.

Although, findings from parental stress studies were consistent in occurrence of stress in mothers and fathers of NICU infants, several conflicting findings were reported. Thus, further research is warranted to explicate the predictors of stress in parents of infants in the NICU.

Anxiety

Anxiety is an emotion characterized by feelings of tension, worried thoughts and physical changes like increased blood pressure, sweating, trembling, dizziness or a rapid heartbeat (APA, 2013). Fathers (20%) and mothers (24%) of hospitalized term infants in a sample of 600 parents reported anxiety (Kong et al., 2013). The percentage of state anxiety indicators was higher in mothers of preterm infants (57%, $N = 36$) (Carvalho, Martinez, & Linhares, 2008; Rogers, Kidokoro, Wallendorf, & Inder, 2013). Padovani et al. (2009) reported the difference in the anxiety levels between mothers of term infants versus mothers of preterm infants. These investigators reported a significant difference in the Spielberger's State and Trait Anxiety Inventory (STAI) scores in mothers of full-term infants (n = 25, 4%) versus in mothers of preterm infants (n = 50, 32%), ($p = 0.006$)

(Padovani et al., 2009). Busse et al. (2013) found that 56% of parents with infants hospitalized in the NICU ($N = 30$) reported having anxiety on the Reported Outcomes Measurement Information System. The experience of anxiety was significantly related to the parental fatigue ($r = 0.43$, $p \leq 0.05$) and sleep disturbance ($r = 0.51$, $p < 0.01$) (Busse et al., 2013). Thirty-five percent of mothers of preterm infants in the NICU ($N = 43$) reported clinical signs of state anxiety on the SAI (Padovani et al., 2004).

A small number of investigators evaluated predictors of anxiety in parents of infants in the NICU (Kong et al., 2013; Shields-Poë & Pinelli, 1997). Maternal stress, trait anxiety, and educational levels explained 50% of the variance in the state anxiety scores ($F_{(7,74)} = 9.61$, $p = 0.001$) (n = 122). In fathers, trait anxiety, stress, and perceived infant morbidity accounted for 43% of the variance in state anxiety scores ($F_{(4,75)} = 13.64$, $p = 0.001$) (n = 90) (Shields-Poë & Pinelli, 1997). Stress level and objective support predicted anxiety level in parents of preterm infants ($N = 600$). For every unit increase in the stress level there was an increment of 0.757-point increase in anxiety levels and for every 0.479-point decrease in the objective support, there was one unit increase in the anxiety level. This indicates that as stress levels increase and objective support decreases, anxiety levels increase.

Anxiety was found to have a significant relationship with stress in a sample of 172 parents of preterm infants (Carter et al., 2007). Similarly, Miles et al. (1991) found a statistically significant relationship between the total score of PSS: NICU and both trait anxiety ($r = 0.21$, $p < 0.05$) and state anxiety ($r = 0.52$, $p < 0.001$) in parents of premature infants. Carter et al. (2007) reported a positive association between total stress and trait anxiety ($F_{(1,165)} = 7.787$, $p = 0.006$) in parents of infants in the NICU. Yet, in some

studies, instruments meant to measure anxiety were used to measure stress. For example, Pinelli (2000) studied stress in 120 parents of NICU infants but used the STAI to measure parental stress. Using an instrument to measure a concept different from what it is intended for poses a threat to the internal validity of the study (Kimberlin & Winterstein, 2008). Total social, subjective, and objective supports, utilization of support, and stress level were all significantly correlated with anxiety levels (r ranged -0.13 to 0.55, $p <$ 0.001) (Kong et al., 2013). Sex of the infant was significantly correlated with state anxiety in 151 Turkish mothers who had infants cared for in the NICU (M = 57.3, SD = 4.41, $p < 0.05$) (Erdem, 2010). Furthermore, maternal academic level (r = -0.33, p = 0.05) and number of children (r = 0.35, p = 0.03) were significantly correlated with state anxiety in 36 mothers of preterm infants. Birth weight (r = -0.53, p = 0.001), gestational age (r = -0.34, p = 0.04), total duration of hospitalization (r = 0.46, p = 0.004), and the CRIB score (r = 0.37, p = 0.03) were significantly correlated with state anxiety (Carvalho et al., 2008).

Depressive Symptoms

Depression is the state in which a person exhibits symptoms of distress, hopelessness, sadness, and lack of energy to conduct activities (Smeltzer, Bare, Hinkle, & Cheever, 2008). The majority of the literature about parental depressive symptoms in the NICU focused on mothers (Davis et al., 2003, 2004; Howland et al., 2011; Miles et al., 2007; Padovani et al., 2009; Rogers et al., 2013). Very few investigators studied depressive symptoms in both parents (Doering et al., 2000; Kong, et al., 2013). Davis et al. (2004) studied 62 mothers of preterm infants during NICU hospitalization and three months after discharge. They found that 40% of the mothers had a significant depressive

symptomology during NICU hospitalization, but this number decreased to 17% three months after discharge. Howland et al. (2011) reported that 75% of mothers of preterm infants ($N = 102$) scored high on the CES-D scale. Results from a recent study done on parents of hospitalized neonates ($N = 600$) using the Self-Rating Depressive Scale (SDS) showed that 31% of fathers and 35% of mothers had depressive symptoms (Kong et al., 2013). Sixty percent of fathers ($N = 35$) scored > 16 in CES-D scale (ranges from 0 to 60) on day seven of their infant's hospitalization. This percentage decreased to 39% and 36% at day 21 and 35 of hospitalization (Mackley et al., 2010).

Depressive symptoms were significantly correlated with stress ($r = 0.59$, $p < 0.05$ and $r = 0.71$, $p < 0.01$) in mothers of preterm infants in two studies ($N = 23$ and $N = 30$, respectively) (Amankwaa et al., 2007; Younger, Kendell, & Pickler, 1997). Logistic regression analysis by Davis et al. (2003) in a sample of 62 mothers of preterm infants revealed that the higher the maternal stress the higher the likelihood of depressive symptoms (95% *CI* [1.040, 1.259], $p < 0.01$). Moreover, the higher the educational levels (95% CI [0.006, 0.556], $p < 0.05$) and the perception of support from nursing staff (95% *CI* [0.883, 1.00], $p < 0.05$) the lower the likelihood of depressive symptoms. Jubinville et al. (2012) studied symptoms of Acute Stress Disorder (ASD) in mothers of preterm infants ($N = 40$) and found a significant relationship between depressive symptoms and ASD ($\chi^2 = 10.23$, $p = 0.001$). Eighty-two percent of the mothers who were classified to have symptoms of ASD were also classified to have symptoms of depression. Similarly, depressive symptoms were found to be significantly associated with anxiety in parents of NICU infants ($N = 469$) ($r = 0.81$, $p < 0.01$) (Doering et al., 2000). The findings from Davis et al. (2003) was supported by Carvalho et al. (2008) in that maternal academic

level was significantly inversely related to maternal depressive symptoms (r = -0.40, p = 0.02). Total duration of hospitalization was significantly correlated with maternal depressive symptoms (r = 0.36, p = 0.03).

Significant differences were found between mothers of preterm infants with CES-D ≥ 16 (n = 19) and mothers of preterm infants with CES-D ≤ 16 (n = 20) in the parental role alteration, infant appearance, and NICU sights and sounds subscales of the PSS: NICU (t = 3.63, p < 0.01), (t = 2.29, p < 0.05), and (t = 2.27, p < 0.05), respectively. The PSS: NICU subscales were significantly correlated with maternal depressive symptoms (r ranged 0.35 to 0.51, p < 0.05) (Mew et al., 2003).

Predictors of depressive symptoms in parents of infants in the NICU are sparsely studied (Ballantyne et al., 2013; Doering et al., 2000; Kong et al., 2013). Single parent status, high stress, poorer family functioning, and less social support accounted for 39% of the variance on the CES-D scores in a subsample of 271 mothers of preterm infants at NICU discharge (Ballantyne et al., 2013). Doering et al. (2000) evaluated parental sex, race, family functioning, perceived control, and social support as predictors of depressive symptoms in 469 parents of infants hospitalized in five level III NICUs. The investigators found that these predictors explained 21.5% of the variance in depressive symptoms ($F_{(6,454)}$ = 22.02, p < 0.001). Kong et al. (2013) found that for every unit increase in the objective support and stress levels there was a decrease of .698 and an increase of 1.068 points on parental depression levels. The findings of the above studies support the premise that stress levels predict parental depressive symptoms.

Gaps in the Literature

Inconsistent results were found from the review of the stress and uncertainty literature. Although, literature is abundant in the area of NICU parental stress and parental uncertainty in the pediatric population, very few studies were conducted about uncertainty in the parents of preterm infants in the NICU. Furthermore, while a few studies were done to determine predictors of parental stress, no studies were found determining predictors of uncertainty in NICU parents. The findings from the parental stress and uncertainty literature revealed that a small percentage of variables explained the variance in stress and uncertainty. Thus, the remaining variances remain unexplained. Therefore, further exploration to discover other variables that might explain the rest of the variances in parental stress and uncertainty is warranted. Moreover, predictors of parental anxiety and depressive symptoms are not well researched. In the light of the above, I examined predictors of parental uncertainty, stress, anxiety, and depressive symptoms in parents of preterm infants in the NICU.

CHAPTER III

METHODS

Study Design

A cross-sectional design was used to examine predictors of stress, uncertainty anxiety, and depressive symptoms in parents of preterm infants admitted to the NICU. Data were collected from the parents during the first two weeks of their preterm infant's NICU hospitalization using a parental demographic questionnaire, the PPUS, the PSS: NICU, the short forms of the SAI, and the CES-D scale. In addition, I completed an infant demographic questionnaire, and the CRIB scale.

The fact that the data in this cross-sectional non-experimental design were collected at one point in time minimized the internal validity threats of maturation and testing. Selection threat occurs when subjects are recruited based on their willingness to participate in a study (LoBiondo-Wood, 2006). Selection threat could also occur because of non-random assignment of subjects to groups (Polit & Beck, 2004). Because, this was a-one-group non-experimental study, non-random selection of the parents increases the risk of selection threat to internal validity. There may be differences in responses of the respondents versus responses from the non-respondents. This threat could be minimized by collecting basic demographic characteristics of those who refused to participate in the study and compare those characteristics with characteristics of the respondents. Attrition is the loss of subjects during the course of data collection (Polit & Beck, 2004). In a cross-sectional design, attrition occurs when participants initially agree to participate but

change their minds prior to or during data collection. The threat of history occurs when an extraneous event takes place simultaneously with the independent variable, which might affect the dependent variable (Polit & Beck, 2004). Although data were collected at one point in time in this cross-sectional design, history can cause a threat to internal validity. For example, stressful events not associated with the birth of a preterm infant might affect parental responses to the stress, uncertainty, anxiety, and depression scales.

External validity refers to the degree to which the study findings are generalizable to other samples, settings, and time (Polit & Beck, 2004). To ensure representativeness of the sample, recruitment took place in three hospitals with the largest NICUs in the city of Louisville, KY. The selection threat may limit the generalizability of the findings as findings may only applicable to those who chose to participate (Cook & Campbell, 1979). Recruiting from three different hospitals may increase the likelihood of improving sample diversity and generalizability.

Settings

Participants were recruited from three hospitals in Louisville, Kentucky. The first study site was the NICU at Kosair Children's Hospital. This hospital is part of Norton Healthcare system, which serves the people of Kentucky and southern Indiana. The NICU at Kosair is considered one of the largest NICUs in the United States with 97 beds for premature infants and infants born with conditions requiring advanced care or surgery (Norton Healthcare, 2011). This NICU has an annual admission rate of 1200 infants. Of the infants admitted to the NICU, approximately 36% have birth weights less than or equal to 2,499 grams (M. Shackelford, personal communication, November, 2011). There

are 33 neonatologists, 25 neonatal nurse practitioners, and 275 nurses working in this NICU (M. Shackelford, email communication, May, 2013).

The second study site was the NICU at the University of Louisville Hospital. This NICU is comprised of an eight-bed Level II unit and a 16-bed Level III unit (Committee on Fetus & Newborn, 2012; Kentucky Health Facts, 2010). This NICU has an annual admission of approximately 300 newborns. There are 15 neonatologists, 16 neonatal nurse practitioners, and 48 nurses working in this NICU (R. Stikes, email communication, May, 2013).

The third study site was the NICU at Norton Suburban Hospital. This NICU serves Kentucky and southern Indiana and is part of Norton Healthcare system. It includes a 30-bed Level II unit, and a 10-bed Level III unit (Committee on Fetus & Newborn, 2012). In 2012, 625 infants were admitted to this NICU with an average of 52 admissions per month, of which 224 (35.8%) had a birth weight of 2,500 grams or less (M. J. Precious, personal communication, March, 2013). This NICU has 14 neonatologists, five neonatal nurse practitioners, and 86 nurses (M. J. Precious, email communication, May, 2013). These three hospitals were selected because they are the largest NICUs in Louisville that have high rates of preterm admissions.

Sample

A non-probability convenience sample of 32 pairs of parents of preterm infants admitted to the NICUs at the three selected hospitals was recruited. A convenience sample is used to recruit the most readily available subjects for study (Haber, 2006). Participant inclusion criteria were: (1) parents of a singleton preterm infant with a post menstrual age equal to or less than 34 weeks and no older than 14 days of life, and who is

admitted to the NICU; (2) parents 18 years old or older, and (3) parents who speak, read, and write in English. Exclusion criteria are: (1) parents of infants who have been in the NICU greater than 14 days, (2) term infants requiring intensive care, (3) parents of infants who require complex surgery, and (4) parents of infants who have complex congenital anomalies.

Parents of term infants were not included in the recruitment criteria for the following reasons. First, the purpose of this study was to explore stress, uncertainty, anxiety, and depression and their predictors in parents of preterm infants. Second, findings from the literature indicated that there were significant differences in parental stress levels between parents of term infants and those of preterm infants (Chourasia et al., 2013; Dudek-Shriber, 2004). Comparing stress, uncertainty, anxiety, and depression levels between parents of term infants and parents of preterm infants was beyond the scope of this study. Similarly, parents of infants with congenital anomalies were not included because parents who have infants with congenital anomalies and parents of infants undergoing surgeries experienced more stress than parents of healthy infants (Al-Akour, Khader, & Hamlan, 2013; Fonseca, Nazaré, & Canavarro, 2012; Joseph, Mackley, Davis, Spear, & Locke, 2007). Therefore, only parents of preterm infants without physical anomalies and complex surgery were included in this study.

Power Analysis

According to Cohen (1988), four factors are needed to perform statistical power analysis: (1) significance level, (2) effect size, (3) desired power, and (4) sample size. G*Power® version 3.1.5 (G*Power, Universität Kiel, Germany) was used to calculate the sample size. A power of 0.80, a medium effect size of 0.15, $\alpha = 0.05$, and 18

predictors were used to calculate the sample size. A sample size of 143 pairs of parents was needed to achieve adequate power. The ability to recruit 143 pairs of parents was not feasible for the time frame for this study, thus 32 pairs of parents were enrolled.

Measures

Five measures and parental and infant demographics questionnaires were used for data collection. Each parent completed the parental demographic questionnaire, the PPUS, the PSS: NICU, the short form of the SAI of the Spielberger STAI, and the short form of the CES-D scale. The investigator collected infant demographic data and the CRIB scores.

The Flesch-Kincaid formula was used to determine readability and grade levels of the parental and infant demographics, the PPUS, the PSS: NICU, the CES-D, and the SAI scales. The Flesch-Kincaid formula determines readability ease and grade levels of written materials based on length of words, length of sentences, and complexity of words. (Freda, 2005). The Flesch-Kincaid reading ease scale ranges from zero to 100. Zero to 40 is very difficult to difficult reading whereas, 80 and above is easy to very easy reading. The Flesch-Kincaid grade level formula measures the readability of a written material based on the minimum educational grade level for a reader to understand it (Stockmeyer, 2009). The Flesch-Kincaid grade level for the parental demographic questionnaire was three and the reading ease was 83, which is considered very easy according to DuBay (2004). The Flesch-Kincaid reading ease for the PPUS was 69. This is a standard reading ease (DuBay, 2004). The Flesch-Kincaid grade level for the PPUS was 6.6. The Flesch-Kincaid reading ease for the PSS: NICU was 77, which indicates a fairly easy reading standard (DuBay, 2004). The Flesch-Kincaid grade level for the PPUS was 7.3. The

STAI scale had a 92 Flesch-Kincaid readability ease and a grade level three. The Flesch-Kincaid readability ease for the CES-D was 90 and the grade level was four.

Demographic Characteristics

Investigator developed data collection forms were used to collect (1) parental characteristics (Appendix A), and (2) infant characteristics (Appendix B). Parental characteristics collected via self-report included: (a) age, (b) sex, (c) race, (d) marital status, (e) level of education, (f) employment, (g) insurance coverage, (h) number of children, (i) prior experience with a premature infant, and (j) antenatal, intra-natal, and postnatal complications. The investigator obtained infant characteristics from the NICU admission registry and medical records. The following variables were collected: (a) gestational age in weeks, (b) infant's age (days of life), (c) sex, (d) birth weight in grams, (e) current weight, (f) mode of delivery, (g) admission diagnosis, (h) mechanical ventilation, (i) umbilical lines, (j) medications, and (k) level of the nursery.

Infant's Illness Severity Scoring

Illness severity scores are widely used in neonatal intensive care units (Dorling, Field, & Manktelow, 2004). These scoring systems quantify infant's morbidity by calculating scores that include infant's demographic, physiological, and clinical data (Dorling et al., 2004). The scores are used to assess the illness severity of infants and predict the outcome to facilitate appropriate medical management (Broughton et al, 2004; Dorling et al., 2004). Several attempts have been made to develop a valid scoring system that takes incorporates the unique physiology and disease conditions of neonates (Maier et al., 2002). Examples of some of the scoring systems are: the Score for Neonatal Acute Physiology (SNAP), SNAP II, Neonatal Mortality Prognosis Index (NMPI), Neonatal

Therapeutic Intervention Scoring System (NTISS), and the CRIB (Gray, Richardson, McCormick, Workman-Daniels, & Goldman, 1992; Richardson, Gray, McCormick, Workman, & Goldman, 1993; The International Neonatal Network, 1993). For this study, the CRIB was chosen to assess the infant's illness severity (The International Neonatal Network, 1993) (Appendix C). The reason for selecting the CRIB over other scoring systems is because the other systems are very lengthy, burdensome, and it is not always possible to find the information required to complete them; whereas the CRIB is accurate, short, and simple enough for routine use (Brito, Matsuo, Gonsalez, de Carvalho, & Ferrari, 2003; Kaaresen, Døhlen, Fundingsrud, & Dahl, 1998; The International Neonatal Network, 1993).

The CRIB was developed in 1993 using a cohort of 812 infants without inevitable lethal congenital anomalies admitted to four United Kingdom teaching hospital NICUs. Initially there were 40 predictor variables with hospital death as the outcome variable. Multiple regression analysis revealed six variables that were independently associated with hospital death. These variables are: birth weight, gestational age, the presence of congenital malformations, maximum base excess in first 12 hours after birth, and maximum and minimum appropriate FiO_2 in the first 12 hours after birth (The International Neonatal Network, 1993). The CRIB was validated in a separate cohort of high-risk preterm infants without inevitably lethal congenital malformations ($N = 488$) admitted to four similar UK hospital NICUs. The CRIB score predicted hospital death with 51% sensitivity and 95% specificity. The hospital mortality was predicted with receiver operating characteristic curve (ROC) of 0.90 ($p = 0.05$) with CRIB and 0.78 ($p = 0.03$) with birth weight alone, which indicates a high cut-off point with great scoring

accuracy (The International Neonatal Network, 1993). Brito et al. (2003) reported CRIB sensitivity of 75.8%, specificity of 86.7%, and a ROC cutoff point of 0.89 in 284 infants. ROC cutoff points were reported as 0.88, 0.87 for the CRIB versus 0.73, 0.75 for gestational age and 0.72, 0.75 for birth weight in samples of 335 and 100 preterm infants, respectively (Kaaresen et al., 1998; Sarquis, Miyaki, & Cat, 2002). These ROC cutoff points indicate that the CRIB is a reliable discriminative scoring system for illness severity in preterm infants (Sarquis et al., 2002).

The CRIB has six variables: (1) birth weight in grams, (2) gestational age in weeks, (3) congenital malformation, (4) a maximum base excess during the first 12 hour of life in mmol/l, (5) minimal appropriate FiO_2 during the first 12 hour of life, (6) and maximum appropriate FiO_2 during the first 12 hour of life (The International Neonatal Network, 1993). Each variable has a predetermined numerical value that varies according to severity. The final scores are classified into four levels: level one (scores 0-5), level two (6-10), level three (11-15), and level four (>15). The higher the CRIB scores, the higher the mortality (Sarquis et al., 2002).

Parental Perception of Uncertainty in Illness Scale

The PPUS (Mishel, 1983) is a 31-item self-report scale designed to measure the cognitive level of uncertainty in illness of parents of sick children (Appendix D). The PPUS was adapted from the Mishel Uncertainty in Illness Scale (Mishel, 1981). The PPUS is composed of four subscales: ambiguity (13 items), lack of clarity (nine items), lack of information (five items), and unpredictability (four items) (Mishel, 1997b). The subscales are not specified in the PPUS scale, but were described in the Uncertainty in Illness Scales manual (Mishel, 1997b). The parents are asked to rate each item on a 5-

point Likert-type ordinal scale ranging from (1) strongly disagree to (5) strongly agree based upon their perception of the present situation. However, some items require reverse scoring. The total score for the PPUS ranges from 31 to 155. The scores are obtained for each subscale and for the total PPUS. A high numerical score indicates high uncertainty (Mishel, 1997b).

The validity of the PPUS was supported through different methods. A group of pediatric nurses who evaluated the items of the PPUS scale supported the PPUS's content validity (Mishel, 1983). Classical factor analysis using Varimax rotation was carried out to investigate factorial construct validity. A four-factor solution emerged: ambiguity, lack of clarity, lack of information, and unpredictability. The subscales ambiguity, lack of clarity, lack of information, and unpredictability were all positively correlated with the total PPUS scale (r = 0.89, 0.80, 0.65, and 0.50, respectively) (Mishel, 1983). Mishel acknowledged that the subscales lack of information and unpredictability had a weak subscale to total correlation coefficient, but the values were within the cutoff criterion alpha of 0.40 and within an acceptable range for a new scale (Mishel, 1983). The results of the factor analysis supported the theoretical framework. Mishel suggested adding more items to the subscales lack of information and unpredictability to raise the coefficient reliability (Mishel, 1983).

The internal consistency reliability of the PPUS was tested by Mishel (1983) who reported a Cronbach's alpha of 0.90 in a sample of 272 parents of hospitalized children. Cronbach's alphas were: ambiguity subscale 0.87, lack of clarity subscale 0.81, lack of information subscale 0.73, and unpredictability subscale 0.72 (Mishel, 1983). Cronbach's alphas of 0.84, 0.86, and 0.88 were reported by other investigators for the PPUS scale in

samples of 30 parents of children with diabetes mellitus, 51 mothers of children with congenital heart disease, 15 parents of children recently diagnosed with cancer, and 40 mothers of children admitted to the PICU (Carpentier et al., 2006; Lee et al., 2007; Santacroce, 2002; Tomlinson et al., 1996). The reported Cronbach's alphas for the total scale were all above 0.80, which demonstrated high internal consistency reliability (Carmines & Zeller, 1979). The subscale unpredictability had a Cronbach's alpha of 0.68 as reported by Tomlinson et al. (1996). Stewart, Mishel, Lynn, and Terhorst (2010) tested a conceptual model of uncertainty in children and adolescents with cancer ($N = 68$ children and their parents) derived from Mishel's uncertainty in illness theory. The researchers reported that the lack of information subscale had a very low reliability with a Cronbach's alpha of 0.37, and the subscale unpredictability was also low with a Cronbach's alpha of 0.65. The subscale ambiguity had a Cronbach's alpha of 0.88. The researchers acknowledged that the sample size ($N = 68$) was small to test their conceptual model of uncertainty (Stewart et al., 2010). In addition, the more items in a scale, the higher the alpha values will be (Waltz, Strickland, & Lenz, 2005). Thus, the low values of the Cronbach's alphas for the subscales lack of information and unpredictability could be attributed to the small number of items in both subscales compared to the subscales ambiguity and lack of clarity (5 & 4 items vs.13 & 9 items respectively).

Parental Stressor Scale: NICU

The PSS: NICU is a 26-item self-report measure of parental stress (Appendix E) (Carter & Miles, 1989; Miles, Funk, & Carlson, 1993). The PSS: NICU scale assesses parental stress on three dimensions: (1) sight and sounds in the NICU (five items), (2) how the baby looks and behaves (14 items), and (3) the parental role (seven items) (Miles

et al., 1993). The PSS: NICU has two possible scoring methods: the stress occurrence level (Metric 1) and the overall stress level (Metric 2). Metric one refers to the amount of stress experienced by the parents about a particular situation in which only parents who have had the experience will rate the related items (Miles et al., 1993). The items that are rated as "not applicable" are treated as missing rendering the following ranges in scores for each of the three dimensions: Sight and Sound (0-25), Baby Looks and Behaves (0-70), Parental Role (0-35), with the total scale score ranging from zero to 130.

Metric 2 measures the overall stress level produced by the NICU environment in which all parents receive scores on items where those who have no stressful experience receive a score of 1 (not at all stressful) (Miles et al., 1993). The possible scores for each of the three dimensions range as follows: Sights and Sounds (1-25), Baby Looks and Behaves (1-70), Parental Role (1-35), with the total scale score ranging from 1 to 130. For both Metric 1 and Metric 2 higher scores indicate higher stress levels.

Content validity of the PSS: NICU scale was reported after revisions were made based upon pilot study findings and expert opinion from experienced NICU nurses, educators, a psychometrician, and a professional editor (Miles et al., 1993). Construct validity of the PSS: NICU was evaluated using principle components analysis with Varimax rotation. Three factors presented with eigenvalues greater than 1.00 were retained explaining 57.5% of the total variance in stress of parents with an infant in the NICU. The factors retained were: infant behavior and appearance, parental role alteration, and sights and sounds (Miles et al., 1993). Subscales were moderately correlated with one another and strongly correlated with the total score of the PSS: NICU (Miles et al., 1993).

Cronbach's alpha for the subscales baby looks and behaves, parental role, and sights and sounds were reported as 0.92, 0.90, and 0.80, respectively (Miles et al., 1993). For the total scale, Cronbach's alpha was 0.94 (Miles et al., 1993). Other investigators reported similar Cronbach's alpha for the subscales ranging from 0.72 to 0.91 (Seideman et al., 1997), and from 0.77 to 0.96 (Franck et al., 2005). Cronbach's alphas for the entire scale were 0.94 and 0.95 indicating a good internal consistency (Franck et al., 2005; Ahn & Kim, 2007).

State Trait Anxiety Inventory

The Spielberger STAI (Appendix F) is 40-item self-administered questionnaire with 20-items measuring state anxiety and 20-items measuring trait anxiety (Spielberger, 1983). The SAI assesses how the respondent feels at the moment whereas the Trait Anxiety Inventory (TAI) scale assesses how a person generally feels (Spielberger, 1983). The STAI is measured using a 4-point Likert-type scale. The total scores of either the SAI or TAI scales range from 20 to 80. The manual of the STAI scales provides clear instructions of scoring methods including a scoring key (Spielberger, 1983).

The reliability of the STAI was evaluated on large samples of working adults (N = 1,838), college students (N = 855), high school students (N = 434), and military recruits (1,964) with a Cronbach's alpha ranging from 0.86 to 0.95 for the SAI and 0.89 to 0.91 for the Trait Anxiety scale. The relationship between age and the STAI scores was evaluated by dividing the working adults into three age groups revealing Cronbach's alpha of 0.90 to 0.94 for the SAI and 0.89 to 0.96 for the TAI. The test-retest correlations for the STAI scale was assessed on high school students (N = 531) and on college student (N = 197) revealing a Cronbach's alphas of 0.65 to 0.75 and 0.73 to 0.86 for high school

students and college students, respectively. The median Cronbach's alpha for the SAI was 0.33 which is relatively low due to the nature of the SAI which measure the situational factors that exists at the time of the testing (Spielberger, 1983).

Contrasted group validity of the STAI scale was supported by comparing the mean scores of neuropsychiatric patients with mean scores of normal subjects. This method revealed that the STAI discriminated between the neuropsychiatric patients and the normal subjects. A good correlation between the State and Trait scale was found (r = 0.65). Construct validity was evaluated through correlations of Trait Anxiety with other Trait anxiety measures (r ranged from 0.52 to 0.80). Correlations of STAI with other personality tests ranged from -0.03 to 0.81. The author attributed the absence of the relationship to the differences in the constructs that some scales measure comparing to the STAI (Spielberger, 1983). The STAI has demonstrated reliability and validity across a variety of patients with different health disorders (Kvaal, Ulstein, Nordhus, & Engedal, 2005; Quek, Razack, Low, Loh, & Chua, 2004; Rojas-Carrasco, 2010). Quek et al. (2004) found a good internal consistency of the STAI (α = 0.86) on a sample of Malaysia patients with or without urinary symptoms (N = 158). STAI Specificity = 0.88 and sensitivity = 0.82 in non-demented geriatric patients (N = 70). (Kvaal et al., 2005). Cronbach's alpha was reported as 0.83 in parents of a hospitalized child in the PICU (N = 210) (Rojas-Carrasco, 2010).

For the purpose of this study, only the SAI was used. In addition, to reduce the testing burden on the parents, a short form of the SAI was used. Marteau and Bekker (1992) reported the results of two studies aiming at developing a short-form of the state measure of the SAI. Study one consisted of selecting items of both anxiety-present and

anxiety-absent items from the full-form SAI. Two-hundred pregnant women completed the full-form of the SAI. The score of each item was correlated with the remaining scores of the scale. Two-, four-, six-, eight-, and ten-item forms of the SAI were created with equal numbers of anxiety-present and anxiety-absent items. The scores were then correlated with scores of the full form of the SAI. The correlations results were: $r = 0.84$, 0.91, 0.95, 0.96, and .096 for the two-, four-, six-, eight-, and ten-item short forms, respectively (Marteau & Bekker, 1992).

The reliability and validity of the four- and six item short forms of the SAI were tested in the second study (Marteau & Bekker, 1992). Four groups of subjects were included: medical students (n = 38), student nurses (n = 45), pregnant women (n = 200), and pregnant women who have received an abnormal result on a routine screening test for fetal abnormality (n = 23). The Cronbach's alpha for the 20-item SAI = 0.91, for the six-item short-form = 0.82, and for the four-item short-form = 0.77. Concurrent validity was determined by comparing the score means of the six-item scale with the 20- and the 14-item scales. The four-item short-form was compared with the 16- and the 20-item scales. The authors found no differences in the mean scores of the full-form and the other short-forms of the State Anxiety, which supported the validity of the short-form. Sensitivity of the six-item scale was tested on the pregnant women who received abnormal test results. The mean scores of the six-item short-form were similar to the mean scores of the full-form of the SAI for these women (Marteau & Bekker, 1992).

The Center for Epidemiologic Studies-Depression Scale

The CES-D is a 20-item self-administered scale. The CES-D was originally developed for the National Institute of Mental Health (NIMH) to study depressive

symptomatology occurring over the past week in the general population (Radloff, 1977). A four-point system is used to rate responses to the CES-D ranging from zero (rarely or none of the time) to three (most or all of the time). These ratings are assigned to the negatively worded items. The scoring is reversed for the positively worded items. The possible range of scores is 0 to 60. The highest scores indicate the presences of symptoms of depression. A score of 16 is used as a standard threshold for possible clinical depression (Radloff, 1977). The CES-D scale was initially validated by the authors on a random household sample of individuals aged 18 and older (N = 1173 and 1673) in Kansas City, and Washington County, respectively (Radloff, 1977).

Reliability of the CES-D was supported by high inter-item and item-scale correlations. The test-retest correlations ranged between 0.45 and 0.70, which are considered within a moderate range of correlation coefficient (Radloff, 1977). The lower correlation values were attributed to the length of the test-retest intervals (from three to 12 months). The CES-D's internal consistency reliability was 0.85 in the general population and 0.90 in one patient sample (Radloff, 1977). The Cronbach's alpha was reported as 0.87 in two studies done on mothers of hospitalized preterm infants (N = 39 and 181) (Mew et al., 2003; Poehlmann, Schwichtenberg, Bolt, & Dilworth-Bart, 2009). Ballantyne et al. (2013) reported a higher Cronbach's alpha of 0.90 in a sample of 291 Canadian mothers of preterm infants.

Validity of the CES-D was supported by moderate correlations between the CES-D and other self-report depression scales such as the Hamilton Depression Rating scale, and the Raskin Depression Rating scale (r = 0.44 to 0.54) (Radloff, 1977). Principle component factor analysis was performed for three sample groups of White individuals

aged 18 and older (N = 2846, 1089, and 1209). Eigenvalues were greater than one and accounted for 48% of the variance in depressive symptoms. Varimax rotation was loaded on four factors: (1) depressed affect (blues, depressed, lonely, cry sad), (2) positive affect (good, hopeful, happy, enjoy), (3) somatic and retarded activity (bothered, appetite, effort, sleep, get going), and (4) interpersonal (unfriendly, dislike). Generalizability of the CES-D was tested on three age groups (under 25, 25-64, and over 64), on males and females, Black and White races, and individuals achieving three levels of education (less than high school, high school, and greater than high school). The results revealed coefficient alphas of 0.80 or above and test-retest correlations were moderate (≥ .40). The CES-D is a reliable and valid instrument to measure depressive symptoms.

A short form of the CES-D (the Rasch-Derived CES-D) was developed for the brevity and reduction of the respondents' burden (Carpenter et al., 1998; Cole, Rabin, Smith, & Kaufman, 2004). Several investigators evaluated short forms of the CES-D scale. The number of items in these studies ranged from four to 16 (Anderson, Malmgren, Carter, & Patrick, 1994; Bohannon, Maljanian, & Goethe, 2003; Carpenter et al., 1998; Cole et al., 2004; Kohout, Berkman, Evans, & Cornoni-Huntley, 1993; Melchior, Huba, Brown, & Reback, 1993). The findings of these studies showed that the short forms of the CES-D were valid and reliable in evaluating depressive symptoms.

Rasch-Derived CES-D short form (Appendix G) was used in this study (Cole et al., 2004). The Rasch-Derived CES-D is a 10-item self-report scale with item scores ranging from zero to three. The total score ranges from zero to 30 with higher scores indicating the presence of depression symptomatology. In the development phase, the investigators obtained raw scores of the CES-D from a dataset with 725 participants from an

undergraduate psychology classes. The Rasch modeling method of item response theory (IRT) was used to independently estimate depression symptomatology of each participant and the depressive severity of each item (Cole et al., 2004). Ten items were found to fit the Rasch model and preserve the original four-factor structure. The coefficient alpha of the Rasch-Derived CES-D scale was 0.82 and item-total correlations were medium to large ranging from 0.39 to 0.59 (Cole et al., 2004).

In the validation phase, 410 participants randomly completed either the full form of the CES-D and the Rasch-Derived CES-D scale or the Beck Depression Inventory (BDI) and the Rasch-Derived CES-D scale. The coefficient alpha of the Rasch-Derived CES-D scale was 0.75. The correlation between the Rasch-Derived CES-D and the CES-D and the BDI were 0.73 and 0.74, respectively. The validity of the Rasch-Derived CES-D was supported with a similar fit in the hierarchal model between the short form and the full form (Cole et al., 2004).

Data Collection Procedures

Approvals from the University of Louisville Institutional Review Board (IRB), Norton Healthcare (including Kosair Children's Hospital and Norton Suburban Hospital), and the University of Louisville Hospital were obtained prior to subject recruitment. Parents were recruited over a 17-week period from January 2014 through May 2014.

I contacted the NICU managers at study locations prior to and after IRB approval. An informal meeting with nurses in the NICU at Norton Suburban hospital was conducted. However, meeting with nursing staff at Kosair Children's hospital and University of Louisville hospital was not feasible for the staff. Instead, the nurse managers at the three hospitals sent emails to all the nursing staff to briefly inform them

about the study. Study flyers were posted on the bulletin boards at the NICU, NICU waiting areas, and/or hand washing areas (Appendix H). I or the research assistant visited the NICU at each hospital regularly and whenever a meeting was arranged with a potential parent.

Since the NICU parents do not have a fixed time to visit the NICU and they are usually overwhelmed with the birth of their preterm infants, I adopted four strategies for recruitment. The first strategy involved approaching the parents directly if they were at the infant's bedside. This deemed to be the most successful recruitment strategy. The second strategy was used when the parents were not at the bedside. This encompassed providing the nurse taking care of the infant with the study information sheet and asking her to give it to the parents. The nurse informed the investigator about parents who showed interest in participating in the study. I then set a date and time to meet with the parents. The third strategy was talking to the parents over the phone to briefly discuss the study and then arrange for a meeting if they agreed to participate. The last strategy was the least effective. This strategy included talking to the parents in person about the study and giving the parents the survey packet to take home to complete. This strategy was used when parents said they did not have the time to take the surveys while in the NICU. Eight (57%) of the parents who were given the packets to review at home opted not to participate in the study when I followed-up with them. Data collection took place either in the waiting lounge, at the infant's bedside, or in the maternity unit if the mother was still admitted to the hospital according the parents' convenience. The majority of data collection took place at the infant's bedside.

Data Analysis

Data were analyzed using SPSS® version 22 (IBM, Armonk, NY). Descriptive statistics were used to analyze demographic characteristics of the parents and infants. Multiple linear regressions were used to analyze Aims I and II. The Independent *t*-test and Mann-Whitney U test were employed to analyze Aims III and IV. Correlational analysis was conducted to evaluate relationships among the outcome variables. Path analysis was used to assess the effects of significant predictors on depressive symptoms and state anxiety.

Data Management Procedure

To ensure accurate entry of the data into SPSS, a double data entry was performed by the research assistant. Discrepancies between the two datasets were addressed and corrected by referring to the original surveys. The dataset was then evaluated for errors prior to data analysis. Frequency distributions were run for categorical variables and descriptive statistics for continuous variables. Erroneous values outside the range of possible values for a variable were verified with the original data in the surveys and corrected when identified as erroneous. Three cases were missing one data point each from the PPUS and the CES-D scales, these missing values were replaced with the mean of the respective scale. After the errors were corrected, frequencies and descriptive statistics were run to assess the accuracy of the data entry.

Human Subjects Considerations

Ethical approval and permission to conduct the research at the study sites were obtained from the University of Louisville's Human Subjects Protection Program Office (HSPPO), Norton Healthcare Office of Research Administration (NHORA), the Nursing

and Interdisciplinary Research Committee (NIRC) at University of Louisville Hospital, and the Kentucky One Health Research Center (Appendix I).

A copy of the partial waiver of authorization form was filed with the medical record of every infant screened for the study. I discussed the study with the parents and answered their queries. I also discussed the time needed to complete the questionnaires, which ranged between 15 to 30 minutes. Confidentiality was assured. After obtaining individual parents' signatures in the consent form and the HIPAA complete authorization form, parents completed the PSS: NICU, PPUS, CES-D short-form, and the SAI short-form questionnaires. A copy of the signed consents and HIPAA complete authorization form was then filed in the infant's medical chart and a copy was given to the parents.

To maintain anonymity of the collected data, I assigned a unique number for each pair of parents' survey packet. Each number included two-digit and either a letter D (dad) or M (mom) to differentiate between the surveys completed by dads from those completed by moms. To maintain confidentiality, the data collected from the parents including the surveys, consents, and HIPAA forms were stored in a locked cabinet in the research office in the school of nursing. All the study personnel have maintained CITI, HIPAA, and COI training and certifications as required by the University of Louisville.

CHAPTER IV

RESULTS

Sample Characteristics

Thirty-two pairs of parents completed the surveys. Sixteen pairs of parents were recruited from Norton Suburban Hospital (50.0%), 12 pairs (37.5%) from Kosair Children's Hospital and four pairs (12.5%) from the University of Louisville Hospital. The mean age of the fathers was 30.8 years (*SD* = 5.9) and for mothers was 28.8 (*SD* = 5.5). Infants' day of life mean was eight days (*SD* = 4.0). Infants gestational age ranged from 23 to 34 weeks with a mean of 30.25 weeks gestation (*SD* = 3.13) and birth weight ranged from 580 to 2835 grams with a mean of 1553 grams (*SD* = 621.6). Demographic characteristics of the fathers, mothers, and infants are displayed in Tables 1, 2, and 3. Findings about maternal complications during pregnancy are presented in Table 4.

Table 1

Demographic Characteristics of the Fathers of Preterm Infants in the NICU (n = 32)

Variable	*n* (%)
Ethnicity	
White	24 (75.0)
Black or African American	5 (15.6)
Hispanic or Latino	1 (3.1)
Other	1 (3.1)
Marital Status	
Single	10 (31.3)
Married	19 (59.4)
Cohabitating	3 (9.4)
Educational Level	
Less than High School	2 (6.3)
High School Diploma	10 (31.3)
Some College	16 (50.0)
Bachelor Degree	2 (6.3)
Advanced Degree	2 (6.3)
Employment	
Full-Time	30 (93.8)
Part-Time	2 (6.3)
Income	
≤ $30,000	11 (34.4)
$30,001- $60,000	14 (43.8)
> $60,000	6 (18.8)
Missing	1 (3.1)
Insurance Status	
Private	24 (75.0)
Medicaid	5 (15.6)
No insurance	2 (6.3)
Medicaid and Self-pay	1 (3.1)
Experience with a Preterm Infant	
Yes	6 (18.8)
No	26 (81.3)
Experience with NICU	
Yes	4 (12.5)
No	28 (87.5)
Experience with Child Admission	
Yes	4 (12.5)
No	28 (87.5)

Note. NICU = Neonatal Intensive Care Unit

Table 2

Demographic Characteristics of the Mothers of Preterm Infants in the NICU (n = 32)

Variable	*n (%)*
Ethnicity	
White	24 (75.0)
Black or African American	6 (18.8)
Asian	2 (6.3)
Educational Level	
Less than High School Diploma	1 (3.1)
High School Diploma	7 (21.9)
Some College	16 (50.0)
Bachelor Degree	5 (15.6)
Advanced Degree	3 (9.4)
Employment	
Full-Time	13 (40.6)
Part-Time	7 (21.9)
Unemployed	12 (37.5)
Income	
≤ $30,000	17 (53.1)
$30,001- $60,000	9 (28.1)
> $60,000	2 (6.3)
No income	4 (12.5)
Insurance Status	
Private	18 (56.3)
Medicaid	11 (34.4)
Private and Medicaid	3 (9.4)
Experience with a Preterm Infant	
Yes	7 (21.9)
No	25 (78.1)
Experience with NICU	
Yes	6 (18.7)
No	26 (81.3)
Experience with Child Admission	
Yes	5 (15.6)
No	27 (84.4)

Note. NICU = Neonatal Intensive Care Unit

Table 3

Demographic Characteristics of the Preterm Infants in the NICU (N = 32)

Variable	*n (%)*
Sex	
Male	16 (50.0)
Female	16 (50.0)
Mode of Delivery	
Normal Vaginal	17 (53.1)
Cesarean Section	15 (46.9)
Respiratory Support	
Yes	14 (43.8)
No	18 (56.3)
Type of Respiratory Support	
High Frequency Ventilator	1 (7.1)
Conventional Ventilation	4 (28.5)
NCPAP	5 (35.7)
Nasal Cannula	3 (21.4)
Other	1 (7.1)
Umbilical Line	
Yes	4 (12.5)
No	28 (87.5)
Level of NICU	
Level II	6 (18.7)
Level III	26 (81.3)

Note. NICU = Neonatal Intensive Care Unit; NCPAP = nasal continuous positive airway pressure.

Table 4

Complications during Pregnancy of Mothers of Preterm Infants in the NICU (n =32)

Complication	n (%)
Hypertension	3 (16.6)
Preeclampsia	
& hypertension	4 (22.2)
& abruption placenta	1 (5.5)
& HELLP syndrome	1 (5.5)
Incompetent cervix	2 (11.1)
Diabetes	3 (16.6)
Pulmonary embolism	1 (5.5)
Aspiration pneumonia	1 (5.5)
Subarachnoid hemorrhage and vaginal bleeding	1 (5.5)
Martin Syndrome	1 (5.5)
Total	18 (56.2)

Note. NICU = Neonatal Intensive Care Unit; HELLP syndrome = hemolysis, elevated liver enzymes, low platelet count.

Relationships among Parents' Categorical Demographic Characteristics

Pearson chi-square test for independence was used to examine the relationship of parent (mother/father) and the level of education, income, employment status, number of children, and experience with a preterm infant. Because some frequencies in the crosstabulation were less than five, the assumption for chi-square test was not met (Field, 2009). Therefore, the *Exact* test was used for the frequencies in the crosstabulation that were less than five.

Level of education differed significantly between fathers and mothers χ^2 (1, N = 64) = 0.730, p = 0.007. Mothers reported higher educational levels than fathers in Bachelor degree (15.6% versus 6.3%) and advanced degree (9.4% versus 6.3%). There were significant differences between fathers and mothers in the number of children χ^2 (1, N = 64) = 0.777, $p < 0.001$. Fathers had more children than mothers with mean of 2.06 versus 1.81, respectively. A significant difference was found in the previous experience with a preterm infant χ^2 (1, N = 64) = 0.462, p = 0.012. Approximately 22% of mothers reported having had a previous experience with a preterm infant versus 19% of fathers. No significant differences were found between fathers and mothers in employment status χ^2 (1, N = 64) = 0.226, p = 0.502 and income χ^2 (1, N = 64) = 0.458, p = 0.094.

Reliability Statistics

Analysis was conducted to assess the internal consistency reliabilities for the total PPUS, the PPUS subscales (lack of information, unpredictability, ambiguity, lack of clarity), the total PSS: NICU, the PSS: NICU subscales (sights and sounds, baby looks and behaves, and parental role), the SAI, and the CES-D scale. Cronbach's alphas for all the scales and the subscales were greater than 0.70 which is an acceptable alpha value

(Nunnally & Bernstein, 1994). However, Cronbach's alphas were low for the subscales lack of information and unpredictability for the mothers ($\alpha = 0.36$ and 0.49), the PSS: NICU subscale sights and sounds ($\alpha = 0.66$) for the father, and the CES-D scale for the father ($\alpha = 0.67$) (Table 5).

Table 5

Cronbach's Alpha Coefficients for the PPUS, PSS: NICU, SAI, and CES-D Scales (N = 64)

Scale	# of items	Cronbach's α in this study Fathers	Cronbach's α in this study Mothers	Cronbach's α previously reported
PPUS	31	0.94	0.89	0.90[a]
Lack of Information	5	0.71	0.36	0.73[a]
Lack of Clarity	9	0.83	0.77	0.81[a]
Ambiguity	13	0.92	0.96	0.87[a]
Unpredictability	4	0.77	0.49	0.72[a]
PSS: NICU	26	0.91	0.95	0.89[b]
Sights and Sounds	5	0.66	0.80	0.73[b]
Baby Looks and Behaves	14	0.87	0.88	0.83[b]
Parental Role	7	0.90	0.94	0.83[b]
SAI	6	0.83	0.85	0.82[c]
CES-D	10	0.67	0.82	0.75[d]

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; SAI = State Anxiety Inventory; CES-D = Center for Epidemiologic Studies-Depression scale.
[a]Mishel (1983).
[b]Miles et al. (1993).
[c]Marteau & Bekker (1992).
[d]Cole et al. (2004).

Analysis by Aims and Hypotheses

Prior to conducting the multiple linear regression analysis, categorical variables (marital status, educational level, income, number of children, and employment status) were recoded into dummy variables. For example, the variable marital status had five categories (single, married, divorced, cohabitating, widowed). Since, no parents reported their marital status as divorced or widowed, these categories were excluded. The category *single* was designated to be the reference group. A binary (0, 1) coding was given to the remaining categories (1 for married and 0 for cohabitating). A similar process was applied to the other categorical variables that were entered in the regression model.

The CRIB scale was not entered in the regression model because the results of analysis revealed little variability in the scores rendering no effect if used in the models. Initially, multiple linear regression analysis was conducted with separate models for fathers and mothers. However, neither model was significant. Therefore, data of fathers and mothers were combined in the regression models with sex of the parents entered as one of the predictors. The adjusted R square was used to interpret the results of the regression analyses. Because the sample size was small and 18 predictors were entered in the regression models, the R square tended to over fit the model and overestimate the true values of the population. The Adjusted R square provides a better estimate of the true population value (Pallant, 2013).

Aim I: To identify predictors of stress and uncertainty in parents of preterm infants in the NICU. A multiple linear regression analysis was conducted to predict parental stress as measured by the PSS: NICU from the following predictors: uncertainty as measured by the PPUS scale, parental characteristics (sex, age, race, marital status,

educational level, employment status, income, previous experience with a preterm infant, and number of children), and infant's characteristics (gestational age, birth weight, respiratory support). The data were assessed for outliers using Cook's Distance. The maximum value for Cook's Distance was .162 which is smaller than 1 suggesting that there were no extreme cases. The assumptions for the multiple linear regressions were tested. The normality assumption was assessed using the Shapiro-Wilk test statistic. The Shapiro-Wilk test results showed that the normality assumption was met ($p = 0.095$). The linearity assumption was met as points lay on a straight line as shown in the P-P plot of regression standardized residuals (Figure 3).

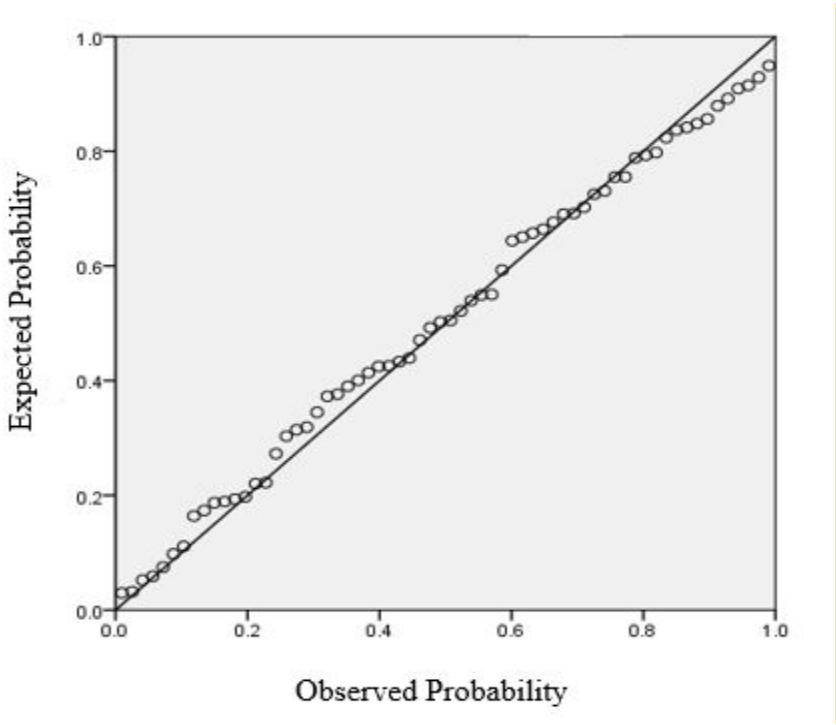

Figure 3. Normal Probability P-P Plot of Regression Standardized Residuals for the PSS: NICU

The Variance Inflation Factor (VIF) and Tolerance were used to assess for multicollinearity in the dataset. The VIF values were less than 10 and the Tolerance

values were greater than .10 indicating that there was no violation in the assumption of multicollinearity. Homoscedasticity was assessed using the plot of standardized residuals by standardized predicted values and showed that the residuals were roughly distributed along the 0 point. This indicates that the assumption of homoscedasticity was met (Figure 4).

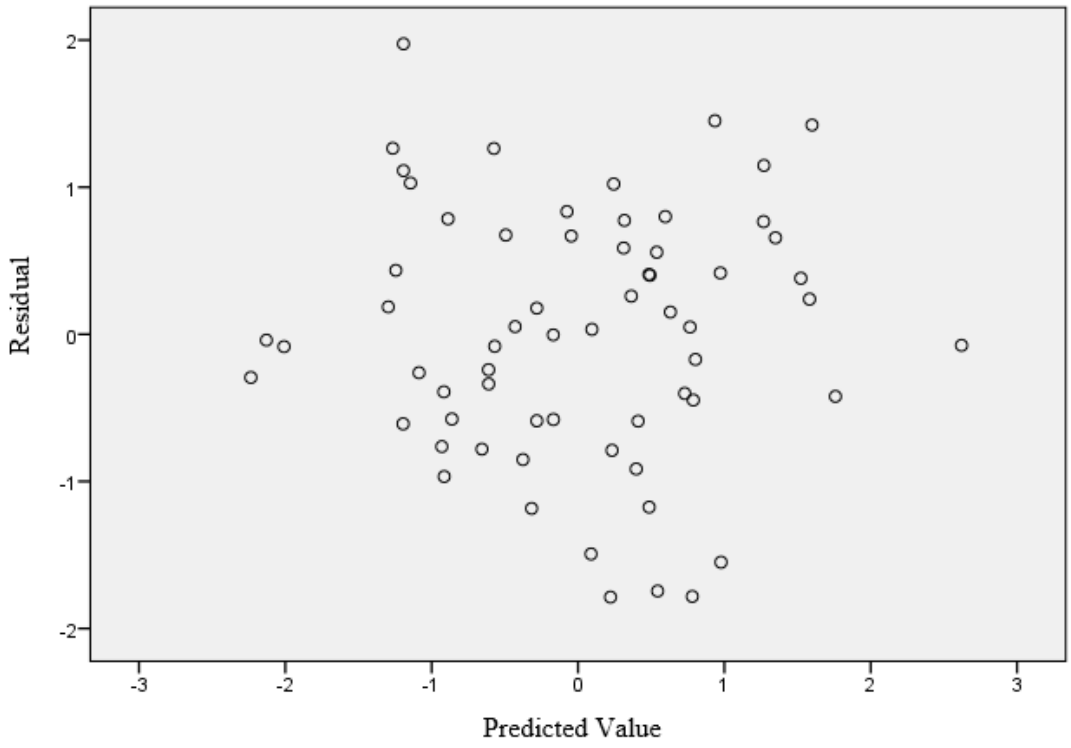

Figure 4. Scatterplot for the Standardized Residuals and Standardized Predicted Values for the PSS: NICU

Initially, all predictors were entered into the model and the model was significant ($F_{(17,46)} = 2.160$, $p = 0.020$). The predictors explained 23.8% of the total variance in parental stress. The coefficient results showed that the PPUS scores and the educational level of the parents with either a high school education or some college education were significant ($p = 0.003$ and 0.012, respectively) (Table 6).

Table 6

Summary of the Multiple Linear Regression for Variables Predicting the PSS: NICU in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
PPUS	.701	.224	**.468***	.444	.238	20.88
Age	-.071	.632	-.017			
Sex	12.369	7.261	.260			
Race	6.019	7.182	.110			
Marital Status						
Married	2.336	7.928	.048			
Cohabitating	-1.890	11.457	-.023			
Educational Level						
HS or Some College	-24.058	9.163	**-.429****			
Bachelor Degree	-12.373	11.569	-.163			
Employment Status						
Full-Time	5.536	10.418	.109			
Part-Time	-4.985	10.429	-.073			
Income						
≤ $30,000	-16.478	8.821	-.333			
>$30,000	-21.907	11.686	-.305			
Number of Children	7.668	6.624	.161			
Previous Experience with a Preterm Infant	-12.006	8.564	-.203			
Gestational Age	1.188	2.274	.154			
Birth Weight	-.009	.010	-.236			
Respiratory Support	1.073	10.359	.022			

Note. PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; PPUS = Parental Perception of Uncertainty Scale; HS = high school.
*$p = 0.003$. **$p = 0.012$.

In the final model, the significant predictors: the PPUS subscales (lack of information, unpredictability, ambiguity, and lack of clarity) and educational level were entered. In addition, because sex of the parents was significantly correlated with the PSS: NICU ($p = 0.002$), it was entered in the model. The model is

$$PSS{:}\,NICU = \beta_0 + \beta_1 LOI + \beta_2 UNPRED + \beta_3 AMBIG + \beta_4 LOC + \beta_5\, Sex + \beta_6\, Educational\ level$$

$$Sex = \begin{cases} 1 & Mothers \\ 0 & Fathers \end{cases}$$

The overall model was significant, $F_{(6, 57)} = 5.187$, $p < 0.001$. The adjusted coefficient of determination showed that 28.5% of the variance in the stress level was explained by the four PPUS subscales, the educational level at high school and some college education, and sex of the parents. The predictors that were significant were the subscale ambiguity ($p = 0.007$) and the sex of the parents ($p = 0.010$). By keeping all other predictors constant, a unit change in ambiguity increased stress level by 1.117. Similarly, by keeping all other predictors constant, the level of stress increased by 13.857 if the sex of the parent was female (Table 7).

Table 7

Summary of the Multiple Linear Regression for the Significant Predictors of the PSS: NICU in Mothers and Fathers of a Preterm Infant in the in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
LOI	-.937	1.291	-.106	.353	.285	20.23
UNPRED	.217	.859	.028			
AMBIG	1.117	.397	**.440***			
LOC	.627	.648	.136			
Sex of the Parents	13.857	5.172	**.292****			
HS or Some College	-9.951	6.195	-.178			

Note. PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; LOI = Lack of Information; UNPRED = Unpredictability; AMBIG = Ambiguity; LOC = Lack of Clarity; HS = high school.
*p = 0.007. **p = 0.010.

Aim I: To identify predictors of stress and uncertainty in parents of preterm infants in the NICU. Multiple linear regression was used to predict level of uncertainty, given the following variables: (1) stress as measured by the PSS: NICU scale, (2) parental characteristics (age, sex, race, marital status, educational level, employment status, income, previous experience with preterm infant, and number of children), and (3) infant's characteristics (gestational age, birth weight, respiratory support). Initially, all predictors were entered into the model.

Multiple linear regression assumptions were evaluated. The normality assumption, assessed using the Shapiro-Wilk test statistic, was met ($p = 0.905$). The linearity assumption was assessed using the normal P-P plot which showed that the assumption was met (Figure 5). The scatterplot for the standardized residual and standardized predicted value showed that the assumption of homoscedasticity was met (Figure 6).

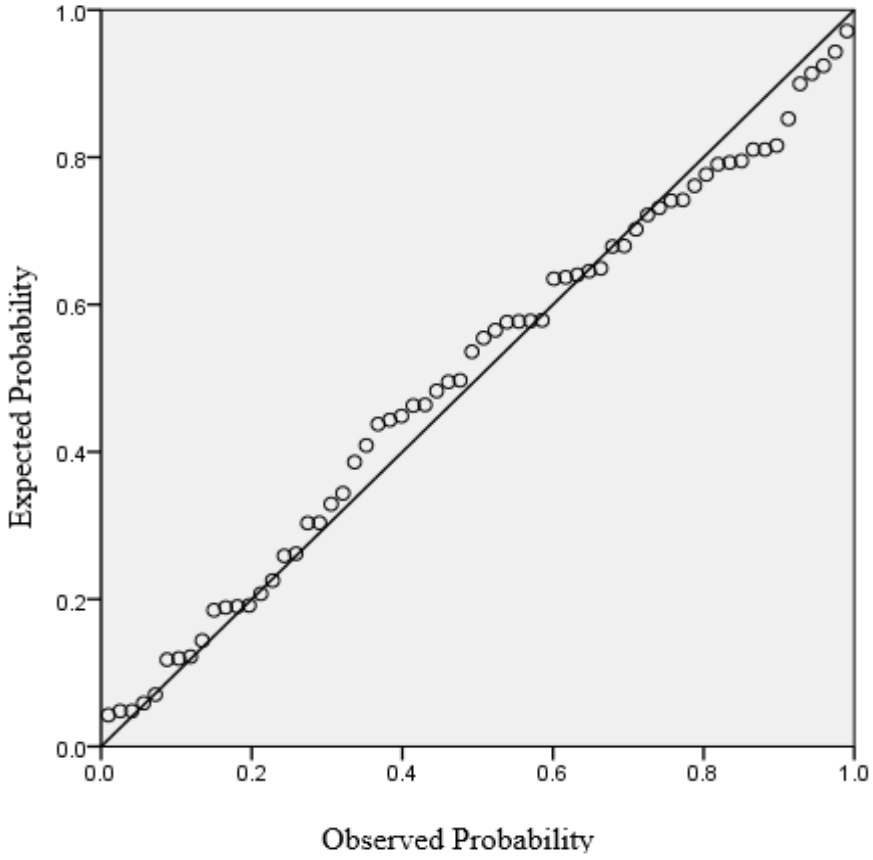

Figure 5. Normal P-P Plot of Regression Standardized Residual for the PPUS

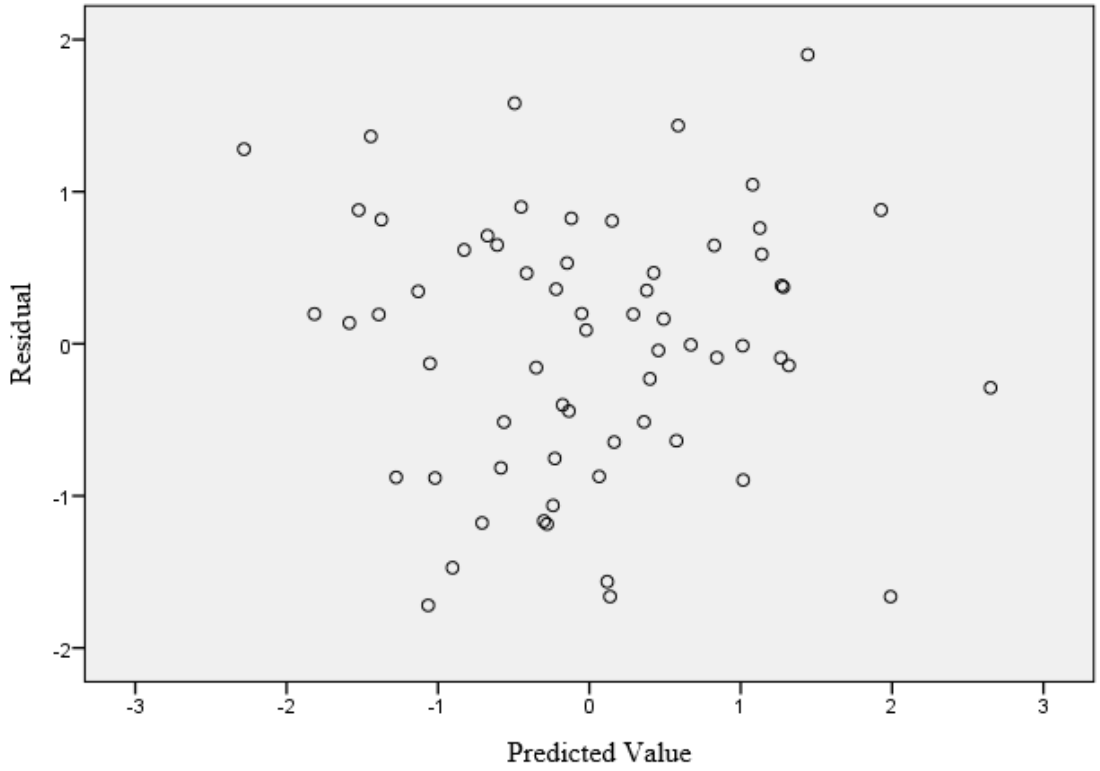

Figure 6. Scatterplot for the Standardized Residual and Standardized Predicted Value for the PPUS

The VIF was used to check for multicollinearity assumption in the dataset. The VIF values were less than five indicating that there was no violation in the assumption of multicollinearity. The maximum Cook's Distance was 0.195, which is less than one indicating that there are no influential outliers. The regression model was significant ($F_{(17,46)} = 3.354$, $p = 0.001$). The PSS: NICU, race, and full-time employment explained 38.8% of the variance in parental uncertainty (Table 8).

Table 8

Summary of the Multiple Linear Regression for Variables Predicting the PPUS in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
PSS: NICU	.250	.080	**.375***	.553	.388	12.84
Age	.345	.374	.126			
Sex	-5.090	4.412	-.161			
Race	-11.268	3.994	**-.308****			
Marital status						
Married	2.062	4.734	.064			
Cohabitating	-2.982	6.837	-.055			
Educational level						
HS or some college	6.666	5.791	.178			
Bachelor	4.395	6.972	.087			
Employment						
Full-Time	-13.138	5.939	**-.389*****			
Part-Time	1.029	6.248	.023			
Income						
≤ $30,000	10.529	5.245	.319			
> $30,000	3.797	7.227	.079			
Number of Children	-1.878	4.008	-.059			
Previous Experience with a Preterm Infant	-8.201	5.086	-.208			
Gestational Age	-.278	1.363	-.054			
Birth Weight	-.001	.006	-.022			
Respiratory Support	8.288	6.071	.260			

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit.
*p = 0.003. **p = 0.007. ***p = 0.032.

Full-time employment, race, and PSS: NICU subscales (sights and sounds, baby looks and behaves, and parental role) were entered in the regression model (Table 9). The model was significant ($F_{(5,58)} = 5.742$, $p < 0.001$). Twenty-seven percent of the variance in the parental uncertainty was explained by the PSS: NICU subscale baby looks and behaves, as it was the only significant predictor for uncertainty.

Table 9

Summary of the Multiple Linear Regression for the Significant Predictors of the PPUS in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
SS	.316	.560	.076	.331	.273	13.60
BLB	.703	.216	**.559***			
PR	-.343	.274	-.201			
Race	-7.730	4.024	-.211			
Employment Full-Time	-6.477	3.747	-.192			

Note. NICU = Neonatal Intensive Care Unit; PPUS = Parental Perception of Uncertainty Scale; SS = Sights and Sound; BLB = Baby Looks and Behaves; PR = Parental Role.
*$p = 0.002$.

Aim II: To identify the significant predictors of anxiety and depressive symptoms in parents of preterm infants in the NICU. Multiple linear regression was used to address this aim. Anxiety as measured by the SAI was the outcome variable and parental characteristics (sex, age, race, marital status, educational levels, employment status, income, previous experience with a preterm infant, and number of children), stress as measured by the PSS: NICU, uncertainty as measured by the PPUS, and infant's characteristics (gestational age, birth weight, respiratory support) were the predictors. Initial analysis showed the VIF values were less than 10 and Tolerance values were larger than .10 indicating that the multicollinearity assumption was met. The linearity assumption was met with the points lying reasonably on the straight line. The maximum Cook's Distance was .143 which is less than one indicating that there were no influential values. Homoscedasticity assumption was violated. For this reason, transformation of the data for the outcome variable anxiety was carried out using the square-root method. Multiple linear regression was run with the transformed data. The scatterplot showed that the residuals of the transformed variable were mostly concentrated in the center indicating that the homoscedasticity assumption was met. The results indicated in Figure 7 showed that the variables in the transformed data were normally distributed.

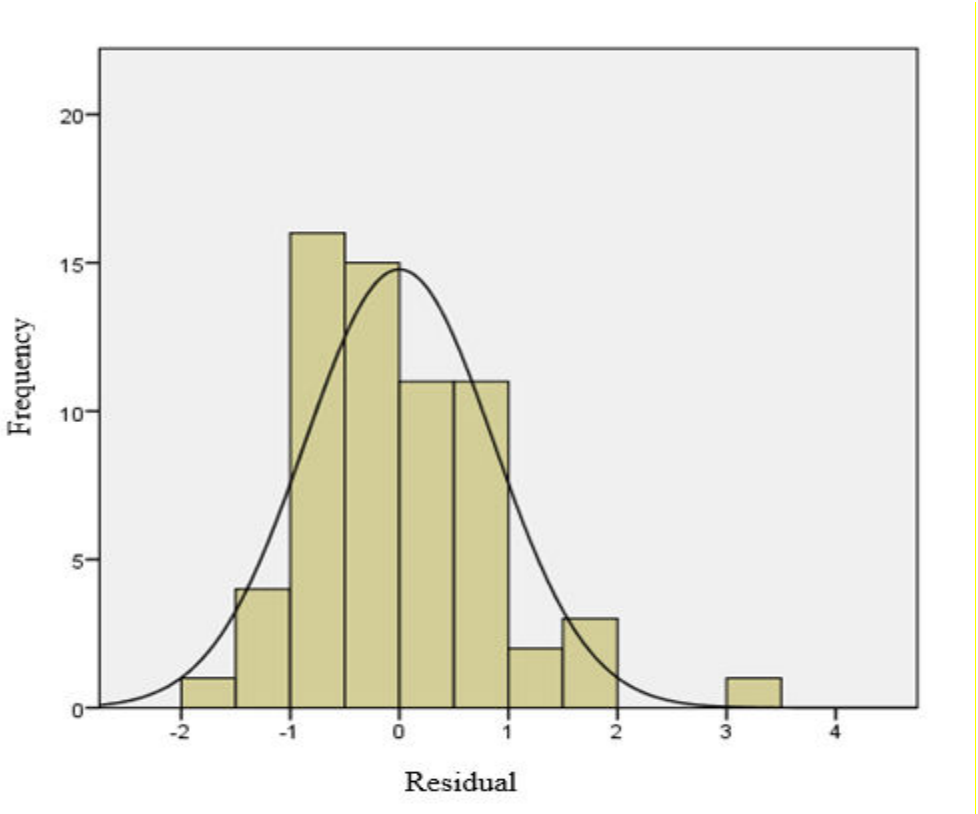

Figure 7. Histogram for the Transformed Data for the SAI

All the predictors were entered in the regression model, which was significant ($F_{(18,45)} = 2.609$, $p = 0.005$). Stress was the only significant predictor in the model ($p =$ .036) and accounted for 31.5% of the total variance in the parental state anxiety levels (Table 10). The PSS: NICU subscales were entered in the final regression model. The model was significant ($F_{(3, 60)} = 4.666$, $p = 0.005$). The subscale baby looks and behaves was the only significant predictor for state anxiety ($p = 0.033$) and accounted for 14.9% of the total variance in parental state anxiety (Table 11).

Table 10

Summary of the Multiple Linear Regression for the Variables Predicting the SAI in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
PPUS	1.693	1.101	.240	.511	.315	93.23
PSS: NICU	1.419	.658	**.301***			
Age	1.548	2.820	.080			
Sex	39.715	33.421	.178			
Race	48.354	32.303	.187			
Marital Status						
Married	-27.626	35.423	-.121			
Cohabitating	-71.956	51.159	-.188			
Educational Level						
HS or Some College	30.444	43.864	.115			
Bachelor Degree	-41.851	52.284	-.117			
Employment Status						
Full-Time	-.639	46.648	-.003			
Part-Time	92.856	46.672	.289			
Number of Children	-21.301	29.999	-.095			
Previous Experience with a Preterm Infant	34.959	39.037	.126			
Income						
≤ $30,000	53.765	40.845	.231			
>$30,000	43.048	54.125	.127			
Gestational Age	-4.398	10.183	-.121			
Birth weight	.026	.045	.145			
Respiratory Support	11.464	46.247	.051			

Note. SAI = State Anxiety Inventory; PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; HS = high school.
*$p = 0.036$.

Table 11

Summary of the Multiple Linear Regression for the Significant Predictors for the SAI in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
SS	-2.382	4.263	-.081	.189	.149	103.93
BLB	3.560	1.634	**.401***			
PR	1.214	2.028	.101			

Note. SAI = State Anxiety Inventory; NICU = Neonatal Intensive Care Unit; SS = Sights and Sounds; BLB = Baby Looks and Behaves; PR = Parental Role.
*$p = 0.033$.

Aim II: To identify the significant predictors of anxiety and depressive symptoms in parents of preterm infants in the NICU. Multiple linear regression was used to analyze this aim. Depressive symptoms as measured by the CES-D was the outcome variable in the model and parental characteristics (sex, age, race, marital status, educational levels, employment status, income, previous experience with a preterm infant, and number of children), stress as measured by the PSS: NICU, uncertainty as measured by the PPUS, and infant's characteristics (gestational age, birth weight, respiratory support) were predictors.

To identify for multicollinearity, the VIF and Tolerance values were checked. All predictors had VIF values less than five and the tolerance values were greater than .10, which indicate that the multicollinearity assumption was met.

To test for linearity, the P-P plot and the scatter plot were examined. The P-P plot of standardized residuals showed that the points lied on a straight diagonal line which suggest that the linearity assumption was met (Figure 8). Similarly, the scatterplot of the standardized residuals showed that the points mostly concentrated in the center suggesting that homoscedasticity assumption was met (Figure 9).

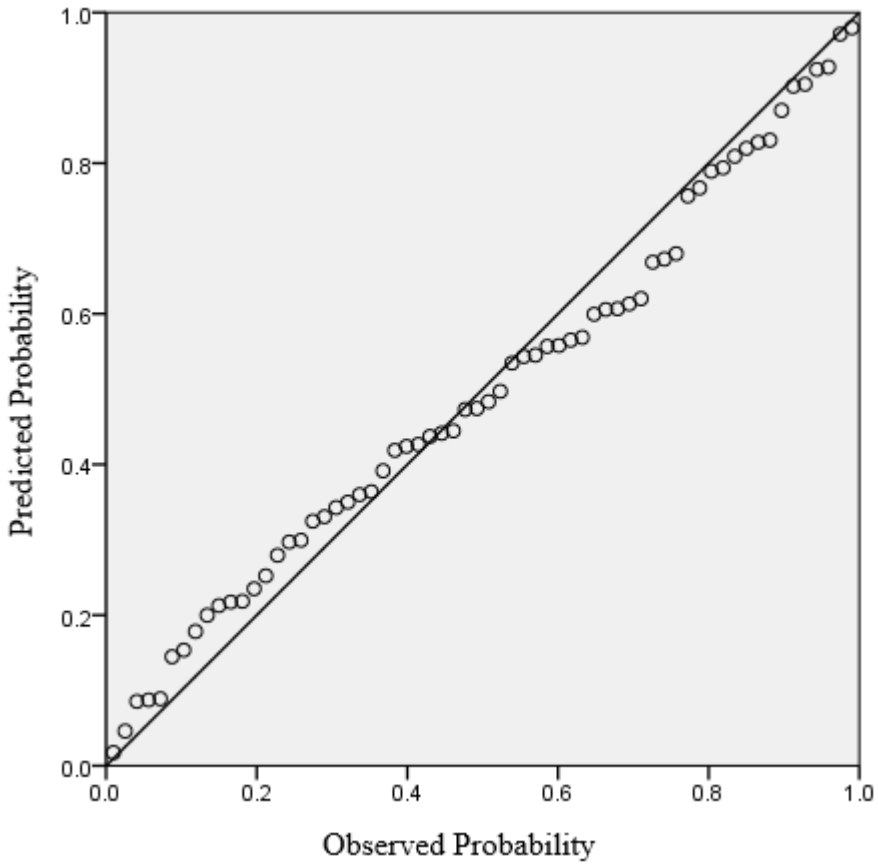

Figure 8. Normal P-P Plot of Regression Standardized Residuals for Depressive Symptoms

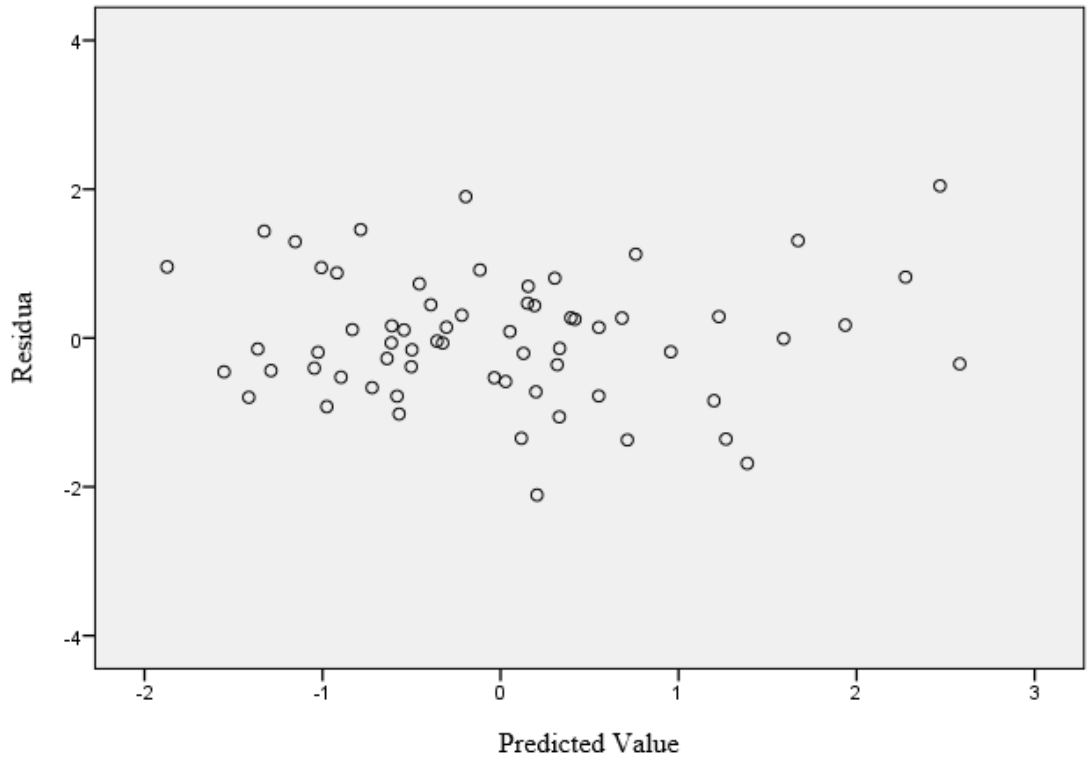

Figure 9. Scatterplot for Standardized Residual and Standardized Predicted Value of Depressive Symptoms

To assess if any case is having a strong influence on the result for the model as a whole, the Cook's Distance was checked. The maximum value for Cook's Distance was .125, which is smaller than one suggesting no influential values (Pallant, 2013). In the initial model, all the predictor variables were entered in the equation. The model was significant ($F_{(18, 45)} = 7.410$, $p < 0.001$). The model explained 64.7% of the total variance in depressive symptoms in both parents. The PPUS, the PSS: NICU, and the cohabitating marital status were the significant predictors in the model (Table 12).

Table 12

Summary of the Multiple Linear Regression for the Variables Predicting the CES-D in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
PPUS	.104	.035	**.335***	.748	.647	2.94
PSS: NICU	.089	.021	**.429****			
Age	.095	.098	.112			
Sex	-.816	1.056	-.083			
Race	-.093	1.020	-.008			
Marital Status						
Married	-1.984	1.119	-.198			
Cohabitating	-3.501	1.616	**-.208*****			
Educational Level						
HS or Some College	2.200	1.385	.190			
Bachelor Degree	2.043	1.651	.130			
Employment Status						
Full-Time	-.310	1.473	-.030			
Part-Time	2.812	1.474	.199			
Number of Children	.447	.947	.045			
Previous Experience with						
a Preterm Infant	.694	1.233	.057			
Income						
≤ $30,000	-.750	1.290	-.073			
>$30,000	-1.391	1.709	-.094			
Gestational Age	-.135	.322	-.085			
Birth weight	.000	.001	.035			
Respiratory Support	1.388	1.461	.140			

Note. CES-D = Center for Epidemiologic Studies-Depression; PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; HS = high school.
*$p = 0.005$. **$p < 0.001$. ***$p = 0.036$

The PPUS subscales, the PSS: NICU subscales, and the cohabitating marital status were entered in the second model, which was significant ($F_{(8, 55)} = 11.481$, $p < 0.001$). The subscales unpredictability and ambiguity were the significant predictors in the model explaining 57.1% of the total variances in the parental depressive symptoms (Table 13).

Table 13

Summary of the Multiple Linear Regression for the Significant Predictors for the CES-D in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
LOC	-.089	.104	-.093	.625	.571	3.245
LOI	-.010	.218	-.005			
AMBIG	.284	.067	**.539***			
UNPRED	.462	.146	**.287****			
SS	.194	.139	.150			
PR	.102	.070	.193			
BLB	.023	.057	.058			
Marital Status:						
Cohabitating	-1.067	1.422	-.063			

Note. NICU = Neonatal Intensive Care Unit; CES-D = Center for Epidemiologic Studies-Depression; LOC = Lack of Clarity; LOI = Lack of Information; AMBIG = Ambiguity; UNPRED = Unpredictability; SS = Sights and Sounds; PR = Parental Role; BLB = Baby Looks and Behaves.
*$p < 0.001$. **$p = 0.002$.

Aim III: To determine if mothers and fathers of a preterm infant differ in the levels of uncertainty. Descriptive statistics were calculated for the total score of PPUS and for the four subscales (ambiguity, lack of clarity, lack of information, and unpredictability). The results of uncertainty level for fathers and mothers are presented in Table 14. Mothers demonstrated a slightly higher level of uncertainty than fathers on the PPUS. The same results were found when comparing the scores of the fathers and the mothers on the PPUS subscales of lack of information, ambiguity, and lack of clarity. However, mothers and fathers did not differ on the subscale of unpredictability.

Descriptive statistics of the individual items revealed that for the subscale lack of information, the item "my child diagnosis is definite and will not change" received the highest mean by the fathers (M = 3.31, SD = 1.22) and mothers (M = 3.46, SD = 1.07). For the subscale unpredictability, the item "I can predict how long my child illness will last" had the highest mean for the fathers (M = 3.43, SD = 1.12) and mothers (M = 3.62, SD = 1.07).

The highest mean in the ambiguity subscale for the fathers was on "I am certain they will not find anything wrong with my child" (M =2.59, SD = 1.13) and the highest mean for the mothers was on the item "it is difficult to determine how long it will be before I can care for my child by myself" (M = 2.65, SD = 1.35). In the subscale lack of information, the item "I don't know when to expect things will be done to my child" had the highest mean for the father (M = 2.28, SD = 1.30), and the item "the purpose of each treatment for my child is clear to me" had the highest mean for the mothers (M = 2.12, SD = 1.28). The item that received the least mean for the fathers was "I am unsure if my child's illness is getting better or worse" (M = 1.46, SD = .71). Mothers reported the

lowest mean scores in the item “I do not know what is wrong with my child” (M = 1.37, SD = .60).

Table 14

Ranges, Means, and Standard Deviations for the PPUS and the PPUS Subscales in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Scale Subscales	Range	*M (SD)*
PPUS	31-155	
Fathers		66.56 (15.41)
Mothers		70.21 (13.21)
LOI	5-25	
Fathers		10.43 (3.04)
Mothers		11.26 (1.88)
UNPRED	4-20	
Fathers		13.26 (3.13)
Mothers		13.39 (2.36)
AMBIG	13-65	
Fathers		26.52 (7.63)
mothers		28.52 (8.71)
LOC	9-45	
Fathers		16.34 (1.11)
Mothers		17.04 (0.95)

Note. NICU = Neonatal Intensive Care Unit; PPUS = Parental Perception of Uncertainty Scale; LOI = Lack of Information; UNPRED = Unpredictability; AMBIG = Ambiguity; LOC = Lack of Clarity.

Hypothesis I for Aim III: Maternal level of uncertainty in illness will be significantly greater than paternal level of uncertainty in illness. Independent t-test for a normally distributed dependent variable and Mann-Whitney U test for the non-normally distributed dependent variable were used. The mean scores for the total PPUS and the means of the subscales were compared with the 5% trimmed mean. There was little difference between the means, indicating that extreme scores if present have no influence on the means. The inspection of the boxplot showed that there were no outliers. The Shapiro-Wilk test was used to assess the normality assumption for the total scores of the PPUS scale and the subscales. The distribution of the total PPUS scales and the subscale unpredictability were normal (p = 0.906 and 0.098, respectively). Moreover, the Q-Q plot followed a normal pattern of distribution since the values fall on the straight line (Figure 10).

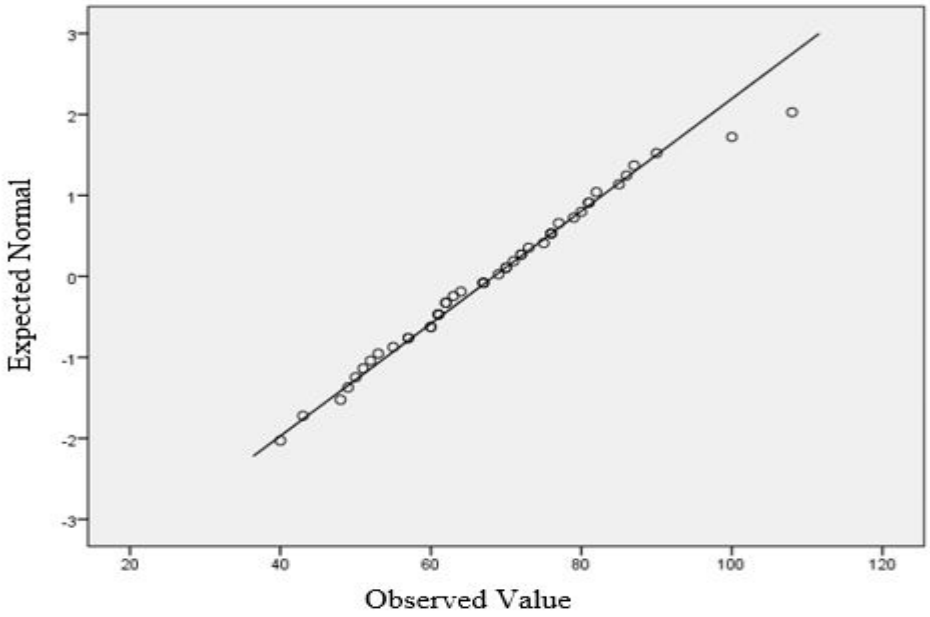

Figure 10. Normal Q-Q Plot for the PPUS Scale

The *p* values in the Shapiro-Wilk test for the lack of information, lack of clarity, and ambiguity subscales were significant ($p = 0.045$, 0.003, and 0.028, respectively), which warranted the use of the Mann-Whitney U test. The Mann-Whitney U test results showed that there were no significant differences between fathers and mothers on the lack of information, lack of clarity, and ambiguity subscales ($p = 0.574$, 0.666, and 0.514, respectively).

Levene's test result showed that the variances were equal for the total PPUS scale and the subscale of unpredictability. Independent *t*-test results showed that the mean scores of the total PPUS scale ($t_{(62)} = -.717$, $p = .476$) and the unpredictability subscale ($t_{(62)} = -.403$, $p = .688$) did not differ. Therefore, the hypothesis was rejected.

Aim IV: To determine if mothers and fathers of a preterm infant differ in the levels of stress. Descriptive statistics were calculated for the total score of PSS: NICU, and for each of the three subscales (sights and sounds, baby looks and behaves, and parental role). The total scores of the PSS: NICU ranges between 0-130. In this study, the stress occurrence score (Metric 1) was used. Metric 1 means that only parents who reported having had the experience receive a score on the item. A score of 0 is given to the parents who report the item as being not applicable (Miles et al., 1993). Mothers reported higher scores in the total PSS: NICU scale compared to fathers. Similar results were found in the mean scores of the PSS: NICU subscales for mothers and fathers: baby looks and behaves and parental role. However, fathers and mothers reported equal mean scores of the subscale sights and sounds (Table 15).

Table 15

Ranges, Means, and Standard Deviations for the PSS: NICU and the PSS: NICU Subscales in Mothers and Fathers of a Preterm Infant in the NICU (N = 64)

Scale Subscales	Range	*M (SD)*
PSS: NICU	0-130	
Fathers		53.46 (19.01)
Mothers		70.09 (25.68)
SS	0-25	
Fathers		9.46 (3.56)
Mothers		9.96 (4.14)
BLB	0-70	
Fathers		26.75 (11.73)
Mothers		32.62 (13.11)
PR	0-35	
Fathers		19.37 (8.52)
Mothers		24.65 (9.51)

Note. PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; SS = Sights and Sounds; BLB = Baby Looks and Behaves; PR = Parental Role.

Investigations of the means of the individual items in the PSS: NICU scale revealed that the sudden noises of monitor alarms was the most stressful aspect for both fathers and mothers in the subscale sights and sounds (M = 2.46, SD = 1.19 vs. M = 2.59, SD = 1.24, respectively). In the subscale baby looks and behaves, both fathers and mothers reported the highest stress in the item "when my baby seemed to be in pain" (M = 2.46 SD = 1.90 vs. M = 3.09, SD = 2.00, respectively). The most stressful aspect in the parental role subscale for fathers and mothers (M = 3.18, SD = 1.40 vs. M = 4.37, SD = .94, respectively) was being separated from the baby. Moreover, mothers reported experiencing higher stress levels in the following items: "not feeding my baby myself" (M = 3.03, SD = 1.69), "not being able to hold my baby when I want" (M = 3.75, SD = 1.62), "feeling helpless and unable to protect my baby from pain and painful procedures" (M = 3.93, SD = 1.50), and "feeling helpless about how to help my baby during this time" (M = 3.71, SD = 1.65). Fathers reported experiencing higher stress level in relation to "feeling helpless and unable to protect my baby from pain" (M = 3.06, SD = 1.75) and "feeling helpless about how to help my baby during this time" (M = 3.12, SD = 1.49). Fathers reported the lowest stress level regarding the wrinkled appearance of the baby (M = 1.06, SD = .66), whereas mothers reported that the large number of people working in the unit caused the low stress level (M = 1.31, SD = .73).

Hypothesis II for Aim IV: Maternal stress level will be significantly greater than paternal stress level. Independent t-test for a normally distributed dependent variable and Mann-Whitney U test for the non-normally distributed dependent variable were used. To assess for outliers in the scores of the PSS: NICU and the subscales, the boxplot was inspected and indicated that there were no extreme values. Furthermore, the

mean values and the 5% trimmed means were similar for the PSS: NICU and the subscales supporting the results of the boxplot. The normality assumption for the means of the total PSS: NICU scale scores indicated that the assumption was met ($p = 0.095$). The Q-Q plot supported the conclusion drawn by the Shapiro-Wilk test as the points did not deviate from the straight line (Figure 11).

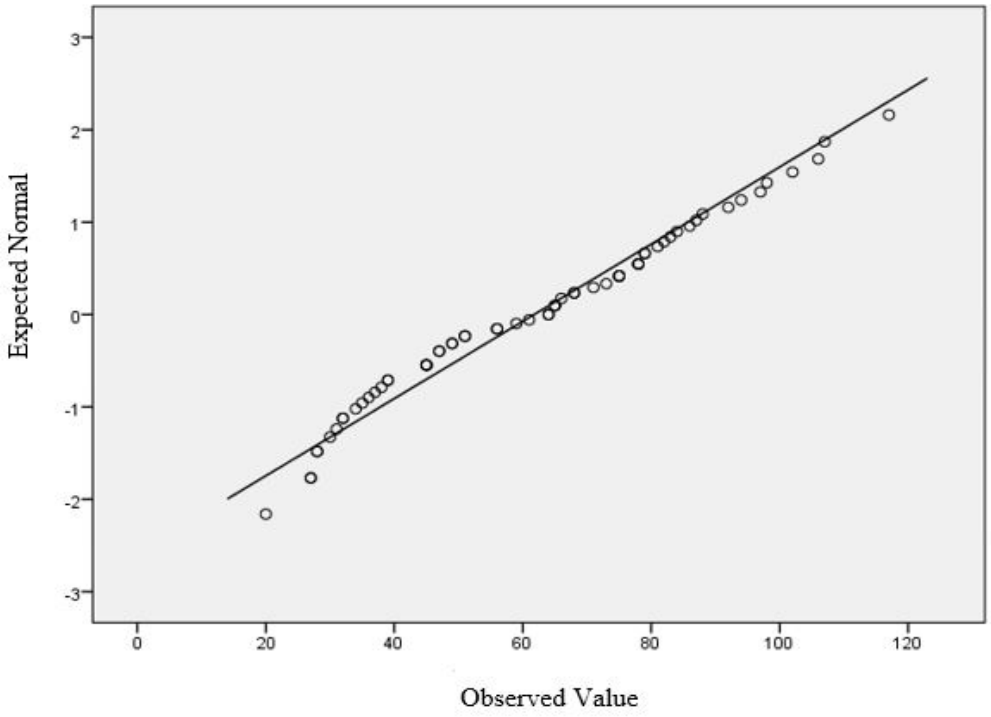

Figure 11. Normal Q-Q Plot for the PSS: NICU Scale

The Levene's test for equality of variances indicated that the variances for the fathers and mothers were equal ($p = 0.066$). The result of the independent *t*-test showed that there was a significant difference in the means between mothers ($M = 70.09$, $SD = 25.68$) and fathers ($M = 53.46$, $SD = 19.01$) on the total PSS: NICU scale ($t_{(62)} = -2.943$, $p = 0.005$).

The normality assumption for all the PSS: NICU subscales using Shapiro-Wilk test was violated with the *p* values less than 0.05. The Q-Q plots indicated that the

subscales did not follow the normal distribution. Therefore, the Mann-Whitney U test statistic was used, which indicated that there were significant differences between the mean ranks of fathers and mothers in the subscale parental role ($p = 0.019$), but not for the sights and sounds subscale ($p = 0.819$) or the baby looks and behaves subscale ($p = 0.061$). The hypothesis that maternal stress level was found to be significantly greater than paternal stress level is accepted.

Descriptive Statistics and Normality Assumption for the State Anxiety Inventory

The short form of the SAI is a 4-point Likert scale (6 items). The scores range between 6 and 24. The total score was readjusted to produce results equivalent to the standard 20-item SAI scale which has a maximum score of 80. The highest scores indicate a higher level of state anxiety. Mothers reported higher mean scores in the SAI scale compared to fathers ($M = 45.20$, $SD = 14.53$ vs. $M = 38.30$, $SD = 12.90$). Being worried was the highest aspect of state anxiety reported by both fathers and mothers ($M = 2.25$, $SD = 1.19$ and $M = 2.53$, $SD = 1.21$, respectively).

The result of the boxplot showed that there were no outliers in the SAI scores. In addition, the original means and the 5% trimmed means were similar indicating that extreme values if present had no influence on the SAI means. The normality assumption for the means in the SAI scale scores using Shapiro-Wilk test showed that the assumption was not met ($p = 0.024$). The Q-Q plot supported the conclusion drawn by the Shapiro-Wilk test statistic. The Mann-Whitney U test showed a significant difference between fathers and mothers in mean ranks of the SAI scale ($p = 0.048$).

Descriptive Statistics and Normality Assumption for the Center for Epidemiologic Studies-Depression Scale

The CES-D is a 4-point Likert scale (10 items). The scores range from 0 to 30, with the highest scores indicating a higher level of depressive symptoms. The total score was readjusted to produce results equivalent to the standard 20-item CES-D scale which has a maximum score of 60. The mean CES-D scores were higher in mothers than fathers (M = 14.18, SD = 11.36 vs. M = 10.92, SD = 8.06). Both fathers (M = 2.05, SD = 1.81) and mothers (M = 1.96, SD = 1.75) reported feeling that everything they did was an effort as the highest scored item.

The boxplot showed that subject number 15 had an extreme value in the CES-D scale (Figure 12). Further investigation was carried out by checking the difference between the original means and the 5% trimmed means. The comparisons between the means showed that they were similar and that the extreme score had no influence on the mean, which warranted no further investigation and the case was retained.

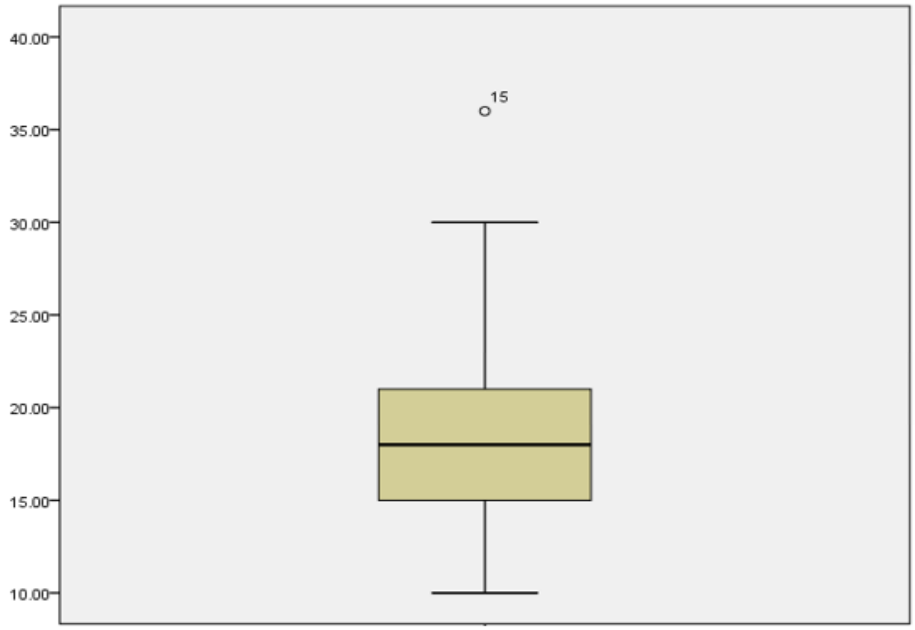

Figure 12. Boxplot of the means of the CES-D Scale

The Shapiro-Wilk test was significant ($p < 0.001$) indicating violation of the normality assumption for the differences in mean scores of the total CES-D scale among fathers and mothers. The values in the Q-Q plot showed deviations from the normality assumption, thus the Mann-Whitney U test was used. The Mann-Whitney U test revealed that there was no significant differences in the mean ranks of CES-D between mothers and fathers ($p = 0.269$).

Correlational Analysis

This section presents the results of the Pearson's product-moment correlation coefficients among the study variables. The strength of the effect size was based on Cohen's conventional definition of small = .10, medium = .30, and large = .50 (Cohen, 1988). The results included: correlations among outcome variables (PPUS, PSS: NICU, SAI, and CES-D) for the fathers and the mothers combined, correlations between the PPUS and the PSS: NICU subscales for fathers and mothers combined, correlations

among outcome variables for fathers, correlations between the PPUS and the PSS: NICU subscales for fathers, correlations among outcome variables for mothers, and correlations between the PPUS and the PSS: NICU subscales for mothers. Finally, correlations between fathers' age, mothers' age, infants' gestational age, birth weight, day of life, and the outcome variables for the fathers and mothers were run. The results of the Pearson's product-moment correlations for the combined results of both fathers and mothers showed that all the outcome variables were significantly correlated with each other (Table 16).

All of the PPUS and the PSS: NICU subscales were significantly correlated with each other except for the subscale unpredictability where no significant correlation with other PPUS and PSS: NICU subscales were found. In addition, there was no significant correlation between the subscale parental role and the subscale lack of information (Table 17). A significant correlation was found between the PPUS and the CES-D scales, the PPUS and the SAI, and the CES-D and the SAI scales for fathers (Table 18). Significant positive correlations were found between the subscales ambiguity and lack of information; lack of clarity and lack of information; lack of clarity and ambiguity; baby looks and behaves and the sights and sounds; and baby looks and behaves and the parental role (Table 19). Contrary to the correlational results for the fathers, the correlations among the outcome variables for mothers were all positive and significant with a medium to a large effect size (Table 20). There were significant positive correlations between the PPUS and the PSS: NICU subscales for mothers. However, similar to the fathers' correlational results, the subscale unpredictability was not correlated with any of the PPUS or the PSS: NICU subscales (Table 21).

Pearson's product-moment correlations among paternal and maternal age, infants' gestational age, birth weight, day of life, and the outcome variables are presented in Table 22. The significant correlation values were medium to large. There were no significant correlations between infants' days of life with any of the other variables. Similarly, no significant correlation was found between the total score of the PSS: NICU for the father and any other variables.

Table 16

Correlations among Outcome Variables for the Fathers and the Mothers of a Preterm Infant in the NICU (N = 64)

	PPUS	PSS: NICU	SAI
PSS: NICU	**.45***		
SAI	**.46***	**.43***	
CES-D	**.66***	**.58***	**.62***

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; SAI = State Anxiety Inventory; CES-D = Center for Epidemiologic Studies-Depression Scale.
*$p < 0.001$.

Table 17

Correlations between the PPUS Subscales and the PSS: NICU Subscales for the Fathers and the Mothers of a Preterm Infant in the NICU (N = 64)

	LOI	UNPRED	AMBIG	LOC	SS	BLB
UNPRED	.10					
AMBIG	**.65****	.18				
LOC	**.55****	.07	**.61****			
SS	**.35****	-.03	**.35****	**.26***		
BLB	**.33****	.20	**.48****	**.34****	**.60****	
PR	.12	-.05	**.35****	**.29***	**.48****	**.72****

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; LOI = Lack of Information; UNPRED = Unpredictability; AMBIG = Ambiguity; LOC = Lack of Clarity; SS = Sights and Sounds; BLB = Baby Looks and Behaves; PR = Parental Role.
*$p < 0.05$. **$p < 0.001$.

Table 18

Correlations among Outcome Variables for the Fathers of a Preterm Infant in the NICU (n = 32)

	PPUS	PSS: NICU	SAI
PSS: NICU	.17		
SAI	**.44***	.18	
CES-D	**.70****	**.37***	**.47****

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; SAI = State Anxiety Inventory; CES-D = Center for Epidemiologic Studies-Depression Scale.
*$p < 0.05$. **$p < 0.001$.

Table 19

Correlations between the PPUS Subscales and the PSS: NICU Subscales for the Fathers of a Preterm Infant in the NICU (n = 32)

	LOI	UNPRED	AMBIG	LOC	SS	BLB
UNPRED	.31					
AMBIG	**.72****	.29				
LOC	**.64***	.18	**.72****			
SS	.24	-.09	.08	.18		
BLB	.17	.21	.19	.22	**.44***	
PR	-.10	-.22	.07	.18	.32	**.57****

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; LOI = Lack of Information; UNPRED = Unpredictability; AMBIG = Ambiguity; LOC = Lack of Clarity; SS = Sights and Sounds; BLB = Baby Looks and Behaves; PR = Parental Role.
*$p < 0.05$. **$p < 0.001$.

Table 20

Correlations among Outcome Variables for the Mothers of a Preterm Infant in the NICU (n = 32)

	PPUS	PSS: NICU	SAI
PSS: NICU	**.72***		
SAI	**.51***	**.46***	
CES-D	**.66***	**.68***	**.65***

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; SAI = State Anxiety Inventory; CES-D = Center for Epidemiologic Studies-Depression Scale.
*$p < 0.001$.

Table 21

Correlations between the PPUS Subscales and the PSS: NICU Subscales for the Mothers of a Preterm Infant in the NICU (n = 32)

	LOI	UNPRED	AMBIG	LOC	SS	BLB
UNPRED	-.23					
AMBIG	**.59****	.05				
LOC	**.43***	-.09	**.52****			
SS	**.48****	.02	**.56****	**.36***		
BLB	**.50****	.18	**.69****	**.49****	**.73****	
PR	.34	.09	**.55****	**.44****	**.61****	**.81****

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit; LOI = Lack of Information; UNPRED = Unpredictability; AMBIG = Ambiguity; LOC = Lack of Clarity; SS = Sights and Sounds; BLB = Baby Looks and Behaves; PR = Parental Role.
*$p < 0.05$. **$p < 0.001$.

Table 22

Correlation Matrix for Paternal and Maternal Age, Gestational Age, Birth Weight, Day of Life, PPUS Fathers, PPUS Mothers, PSS: NICU Fathers, PSS: NICU Mothers, SAI Fathers, SAI Mothers, CES-D Fathers, CES-D Mothers (N = 64)

	Age_F	Age_M	GA	BW	DOL	PPUS_F	PPUS_M	PSS_F	PSS_M	SAI_F	SAI_M	CESD_F
Age_M	**.82****											
GA	.14	.17										
BW	.14	.17	**.88****									
DOL	.31	.35	.03	-.01								
PPUS_F	.13	.22	**-.49****	**-.47****	-.05							
PPUS_M	.02	.09	-.29	-.31	-.29	**.47****						
PSS_F	.22	.28	.03	-.04	.08	.17	.08					
PSS_M	-.14	-.09	-.31	-.27	-.30	**.40***	**.72****	.25				
SAI_F	.27	.20	-.29	-.26	.05	**.44***	.25	.18	.19			
SAI_M	-.19	-.21	**-.40***	**-.37***	-.32	**.43***	**.51****	-.30	**.46****	**.48****		
CESD_F	.05	-.06	**-.61****	**-.57****	-.13	**.70****	**.46****	.04	**.40***	**.35***	**.35***	
CESD_M	-.07	-.04	**-.46****	**-.40***	-.26	**.55****	**.66****	.04	**.68****	**.37***	**.65****	**.64****

Note. GA = gestational age; BW = birth weight; DOL = day of life of the Infant; PPUS_F = Parental Perception of Uncertainty Scale for fathers; PPUS_M = PPUS for mothers; PSS_F = Parental Stressor Scale: Neonatal Intensive Care Unit for fathers; PSS_M = PSS: NICU for mothers; SAI_F = State Anxiety Inventory for fathers; SAI_M = SAI for mothers; CESD_F = Center for Epidemiologic Studies-Depression Scale for fathers; CESD_M = CES-D for mothers.
*$p < 0.05$. **$p \leq 0.001$.

Path Analysis

A path analysis approach was used to test the hypothesized causal paths between variables using the significant predictors (sex, race, employment status, educational level, and marital status) from the multiple linear regression analysis. To determine differences in the means in the outcome variables uncertainty, stress, state anxiety, and depressive symptoms, independent *t*-tests were carried out for each of the significant predictors. Results from the independent *t*-tests indicated that mothers scored much higher on the PSS: NICU scale ($M = 70.09$, $SD = 25.68$, $N = 32$) than fathers ($M = 53.46$, $SD = 19.01$, $N = 32$), $t_{(62)} = -2.943$, $p = 0.005$. No further significant difference were found. Sex of the parents was the only covariate that was entered in the regression model for the path analysis.

According to Kellar and Kelvin (2013), there are four statistical assumptions unique to path analysis. First, when two independent variables are correlated with each other and have no relationship depicted in the diagram, their relationship cannot be analyzed. Correlation coefficients are used to indicate the magnitude of the relationship. For this study, the variable sex was the only independent variable that was not influenced by any other variable (exogenous variable). Second, the flow of causation in the model is unidirectional (recursive model). Third, the variables are measured on an interval scale. Finally, all the variables in the model are measured without error. The normality, linearity, homoscedasticity, and multicollinearity assumptions of the conducted multiple linear regressions were met. All the scales used in the regression analysis (PPUS, PSS: NICU, CES-D, and SAI) had good internal consistency reliabilities, which is useful in reducing measurement error.

Regression Analysis for Path Coefficients

The path analyses were conducted using the five steps discussed in Kellar and Kelvin (2013).

Step 1: Draw the Model. The path models were based on the NICU-PUSM theoretical model used as the theoretical framework for this study (Figure 2). However, two reduced models were drawn after using the results of the multiple linear regression analysis to identify which variables from the NICU-PUSM were significantly related to the dependent variables. Two path analysis models were used. The first model examined the direct and indirect effects of sex of the parents on uncertainty and stress; and the direct and indirect effects of uncertainty, stress, and sex on state anxiety. The second model tested the direct and indirect effects of uncertainty, stress, and sex on depressive symptoms.

Based on the correlation matrix and the assumption of one-way flow of causation, directions were assigned to the relationships between the variables. In the first hypothesized model, stress is directly related to state anxiety and uncertainty ($P_{a,s}$) and ($P_{u,s}$). The exogenous variable sex is directly related to state anxiety ($P_{a,x}$). Uncertainty is directly related to state anxiety ($P_{a,u}$). A similar path model was drawn for the dependent variable depressive symptoms. Sex is directly related to stress ($P_{s,x}$) and to depressive symptoms ($P_{d,x}$). Uncertainty is directly related to stress ($P_{s,u}$) and to depressive symptoms ($P_{d,u}$). Stress and uncertainty are directly related to depressive symptoms ($P_{d,s}$) and ($P_{d,u}$).

Step 2: identify the Regression Analyses Needed to Calculate and Test the Path Coefficients. In both path models, there are three endogenous variables:

uncertainty, stress, and state anxiety or depressive symptoms. For the first path model, three regression analyses were needed: (1) state anxiety (a) regressed on uncertainty (u), stress (s), and sex (x), (2) uncertainty (u) was regressed on sex (x), and (3) stress was regressed on uncertainty (u), and sex (x). The second path model had the same regressions except that the state anxiety variable was replaced with the depressive symptoms (d).

Step 3: Calculate the Path Coefficients. The beta weights or the standardized coefficients for the models were used. Sex of the parents was a significant predictor for stress, but not for uncertainty, state anxiety, or depressive symptoms. Sex explained 0.8% of the variance in uncertainty. The results of the regression analyses are depicted in Tables 23-25.

Table 23

Regression Results Used to Create Path Model for the State Anxiety for the Fathers and the Mothers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
PPUS	2.466	.857	**.350***	.300	.265	96.54
PSS: NICU	36.446	25.852	.163			
Sex	1.026	.608	.218			

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit.
*p = 0.006.

Table 24

Regression Results Used to Create Path Model for the Depressive Symptoms for the Fathers and the Mothers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
PPUS	.154	.031	**.496***	.538	.515	3.450
PSS: NICU	.075	.022	**.362***			
Sex	2.085	1.138	-.007			

Note. PPUS = Parental Perception of Uncertainty Scale; PSS: NICU = Parental Stressor Scale: Neonatal Intensive Care Unit.
*$p \leq 0.001$.

Table 25

Regression Results Used to Create Path Model for Stress for the Fathers and the Mothers of a Preterm Infant in the NICU (N = 64)

Variables	B	SE B	β	R^2	Adj. R^2	*SEE*
PPUS	.635	.161	**.424****	.301	.278	20.34
Sex	14.799	5.106	**.312***			

Note. NICU = Neonatal Intensive Care Unit; PPUS = Parental Perception of Uncertainty Scale.
*$p = 0.005$. **$p < 0.001$.

Step 4: Assess Need to Modify or Re-Specify the Path Model. In this step, determinations about significant and nonsignificant paths were made. Because the sample size used for the analysis was small and underpowered, nonsignificant paths in the models were retained. Path models are depicted in Figure 13 and Figure 14.

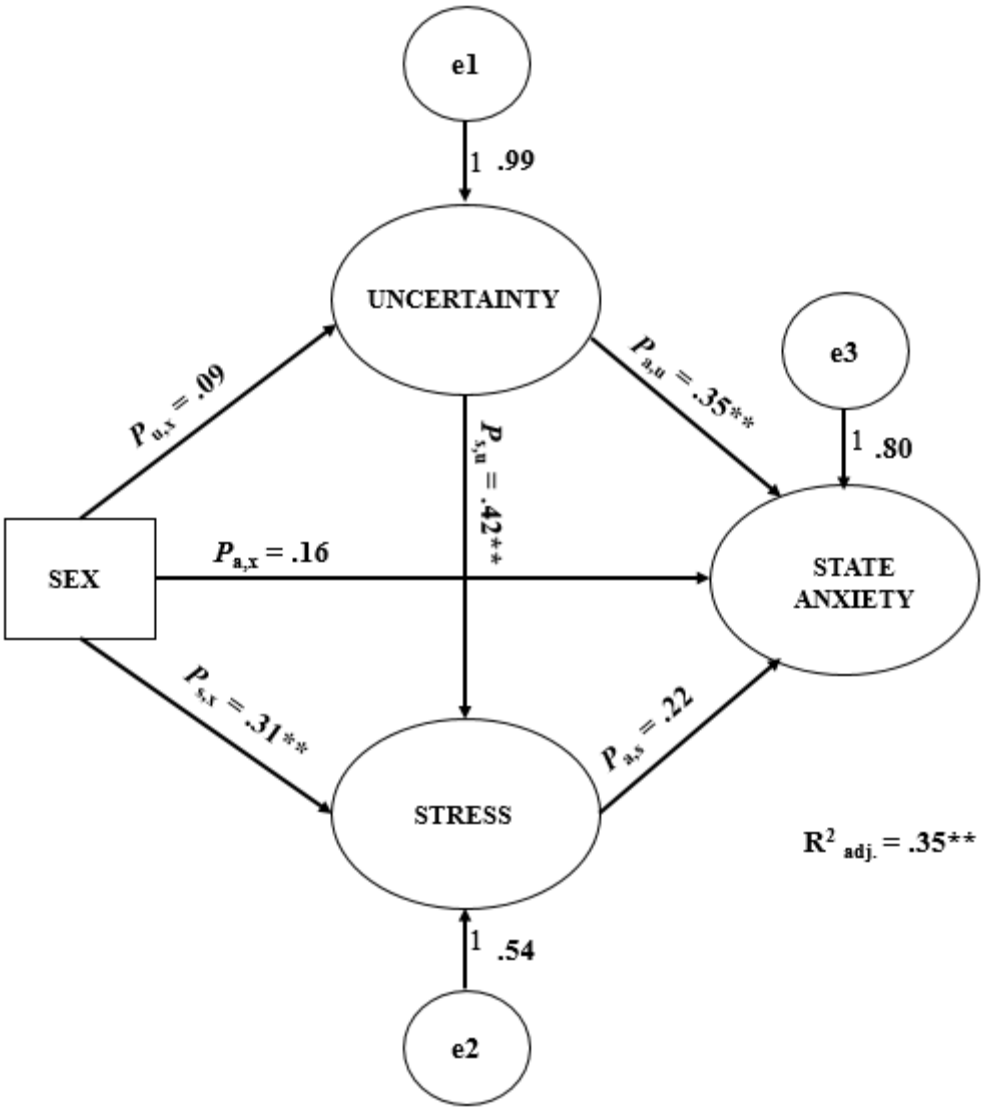

Figure 13. Standardized coefficients for Path Model 1 (**Path coefficient is significant at $p < 0.001$)

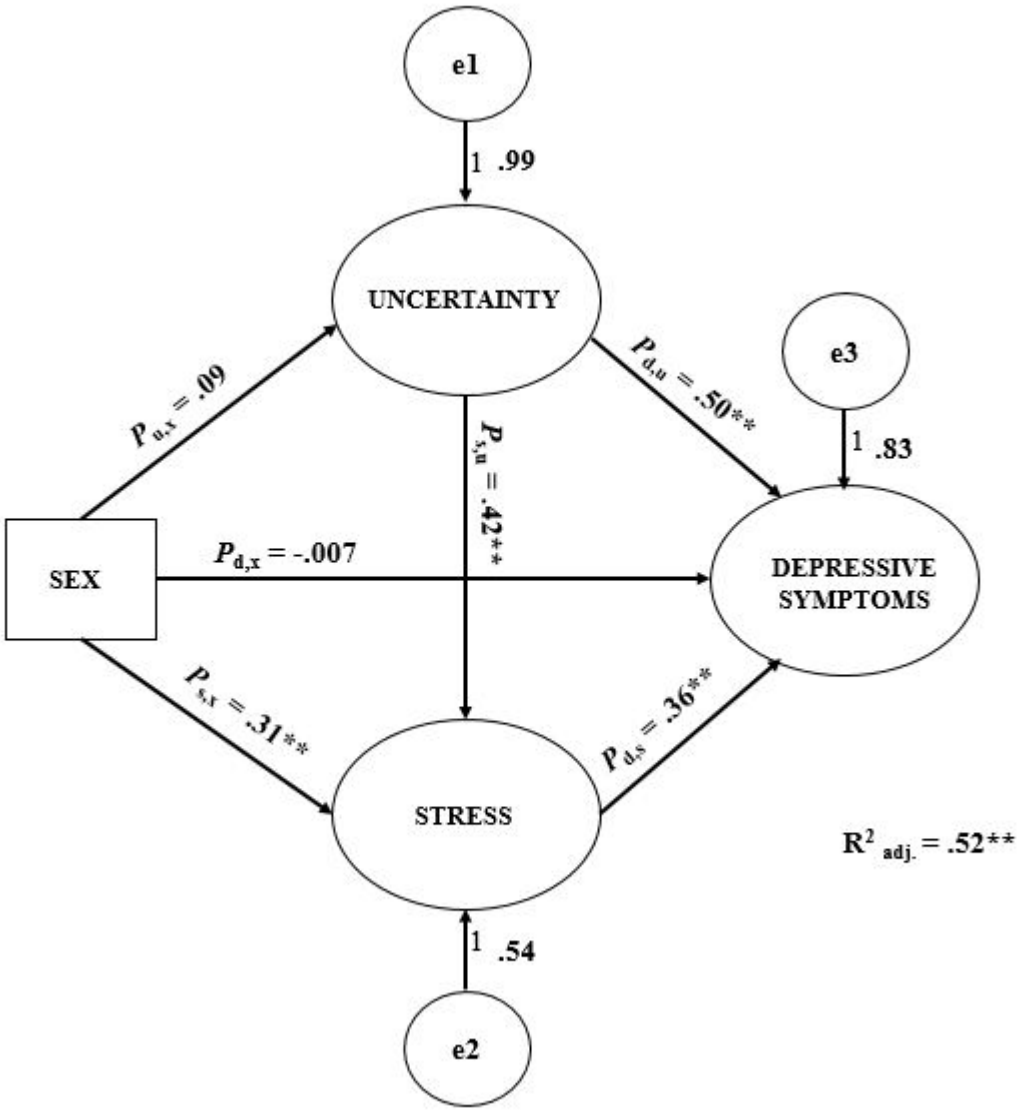

Figure 14. Standardized coefficients for Path Model 2 (**Path coefficient is significant at $p < 0.001$)

Step 5: Determine the Direct, Indirect, and Total Effects of the Independent Variables. To determine the direct, indirect, and total effects of the independent variables, Table 26 and 27 were constructed using the values from the correlation results. The calculation was performed manually based on the Wright's formula used in Kellar and Kelvin (2013). Uncertainty had the greatest effect (.46) on state anxiety followed by stress (.43), and sex (.27). Uncertainty had the greatest effect (.67) on depressive symptoms followed by stress (.58) and sex (.17). In addition, all of the sums of the total effect and non-causal components matched the values of the respective correlation coefficients.

Table 26

Direct Effects, Indirect Effects, and Noncausal Components Associated with each Independent Variable for the Variable State Anxiety for the Fathers and the Mothers of a Preterm Infant in the NICU (N = 64)

Variables	Direct + Indirect	Total Effect	Total Effect + Noncausal
Sex (r = .27)	.16 + .03	.19	.27
Uncertainty (r = .46)	.35 + .09	.44	.46
Stress (r = .43)	.29 + 0	.29	.43

Note. NICU = Neonatal Intensive Care Unit.

Table 27

Direct Effects, Indirect Effects, and Noncausal Components Associated with each Independent Variable for the Variable Depressive Symptoms for the Fathers and the Mothers of a Preterm Infant in the NICU (N = 64)

Variables	Direct + Indirect	Total Effect	Total Effect + Noncausal
Sex (r = .17)	.007 + .04	.05	.17
Uncertainty (r = .66)	.49 + .17	.66	.67
Stress (r = .58)	.36 + 0	.36	.58

Note. NICU = Neonatal Intensive Care Unit.

Review of Responses to an Open-Ended Question on the PSS: NICU Scale

Twenty-one parents responded to the question "feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit" at the end of the PSS: NICU scale. The parental responses were reported as quotations. Responses were reviewed and categorized by the PSS: NICU subscales (sights and sounds of the NICU environment, baby looks and behaves, and parental role). In addition, some parents reported that a stressor was sometimes the healthcare provider. However, some parents reported that the healthcare providers offered reassurance and support. Therefore, healthcare provider was added to the PSS: NICU subscale categories. Twenty-one (32.8%) parents responded to the question (15 mothers and six fathers). Among these parents, 11 (52.3%) showed stress in more than one area. Fifteen (71.4%) parents reported stress concerning parental roles; eight parents (38.0%) reported experiencing stress related to the sights and sounds of the NICU environment. Five (23.8%) parents reported having stress concerning the way the baby looked or behaved and eight (38.0%) parents reported having stress related to the healthcare providers. The parents' quotations and category of stress are listed in Table 28.

Table 28

Parental Responses to the question "feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit"

ID	Quotation	Parental Role Alteration	NICU Environment	Baby Looks and Behaves	Healthcare Providers
1d	Incubator box, seeing it (GA 34, BW 2835 g, Female).		X		
1m	The fact that she was early to begin with, I felt very unprepared for things like seeing the tubes/IV's etc. It was/is very stressful (GA 34, BW 2835 g, Female).	X		X	
2m	The baby next to ours passed away, and the thought that it could be us was very upsetting (GA 30, BW 1162 g, Male).	X	X		
3d	The first week was very stressful because we didn't know what to expect. It is kind of life controlled cases. Once you get used to the environment and understand what all is going on and being done it becomes easier (GA 27, BW 800 g, Female).	X		X	X
3m	The pressures the nurses are under they look worn out from…. Hoping the nurses will not be impatient with my baby because they are tired. Wondering what side effect my baby may have b/c of lack of oxygen—stopping breathing, etc. (GA 27, BW 800 g, Female).			X	X

(continued)

Table 28

Parental Responses to the question "feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit"

ID	Quotation	Parental Role Alteration	NICU Environment	Baby Looks and Behaves	Healthcare Providers
4m	Overall just being separated for the time she is in the hospital. Also, the worry about her health and not knowing when she could come home. Hearing about other babies that were sicker than she was (GA 32, BW 1559 g, Female).	X	X		
9m	One of the most stressful things about being in this situation is being away from my 3 years old son (GA 34, BW 2340 g, Female).	X			
10m	I find it somewhat stressful not being able to get hold of "our" nurse when we call to check on our baby in the NICU (GA 28, BW 1470 g, Female)	X			X
15m	When being taught how to touch the baby. I was very upset because I was over stimulating him and so when I tried to do firm touch my hands were too cold and caused vitals to jump and made me feel like he hated me or that I wasn't good enough (GA 24, BW 800 g, Male).	X			

(continued)

Table 28

Parental Responses to the question "feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit"

ID	Quotation	Parental Role Alteration	NICU Environment	Baby Looks and Behaves	Healthcare Providers
16d	When –my daughter- was born early I got stress because I didn't see her I have to wait I was just not there with her like I was with my other 3. But thank Jesus that she made it safe and healthy I am glad for that (GA 33, BW 2400 g, Female).	X			
18m	Inconsistencies with nursing staff. Different treatments with different nurses, some not explaining what my child is having done (GA 34, BW 2115g, Male).				X
19m	Only stressful at first when the medicine I was on after birth (magnesium) prevented me from seeing her for 12 hours (GA 33, BW 2098 g, Female).	X			
19d	I feel that a viewing window for the children's family to see the child would be extremely helpful. As opposed to just two visitors at a time in area. Also if the window were present for viewing, the stress of possible infection would be lessened (GA 33, BW 2098 g, Female).		X		

(continued)

Table 28

Parental Responses to the question "feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit"

ID	Quotation	Parental Role Alteration	NICU Environment	Baby Looks and Behaves	Healthcare Providers
21m	Having a nurse talk about personal issues. Her schedule seemed to me as a parent, that she was not worried about my child. It was very uncomfortable and stressful (GA 26, BW 794 g, Female).				X
22m	Overall the unit is great and they take great care of my baby and are very welcoming to me as a parent. I think just overall its stressful for one I'm young and two you never know if your baby is going to have a good day or a bad one (GA 23, BW 676 g, Female).	X	X	X	X
24d	Trying to juggle work, family, wife, and visiting my daughter. Having to constantly call daily for the Ronald McDonald House. Times of stress, I forgot to call and have to move, causing more stress (GA 25, BW 580 g, Female).	X			
24m	I find it very stressful when a nurse doesn't seem to respond to the "beeping" monitors fast enough. When our daughter desaturates, I feel beyond stressed, completely helpless and useless. Not being able to hold her for now 13 days is very stressful. I feel guilty that my body wasn't about to hold her full term (GA 25, BW 580 g, Female).	X			X

(continued)

Table 28

Parental Responses to the question "feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit"

ID	Quotation	Parental Role Alteration	NICU Environment	Baby Looks and Behaves	Healthcare Providers
27m	Other than the IV's and me not being able to take the pain for him (GA 29, BW 1800 g, Male).	X	X		
30d	Often had wondered if my baby is able to sleep well in the NICU, with many babies crying out loud and with all alarms/alert sounds from machinery being set for even small variations of vital stats. Had often seen nurses just switching off/lowering volume as some of the alerts are not really important (GA 34, BW 2360 g, Female).		X	X	X
30m	Not able to feed her and not able to take care of her (GA 34, BW 2360 g, Female).	X			
32m	The monitors that my baby was hooked up to that went off made me start to stress and make me very nervous. Not being able to pick my baby up when she was crying. Not being able to change her little outfits when I want to (GA 32, BW 1300 g, Female).	X	X		

Note. m = mom; d = dad; GA = gestational age; BW = birth weight; g = gram; male, female = Infant's Sex.

Summary of the Responses to an Open-Ended Question on the PSS: NICU Scale

Nearly half of the parents who responded to the question (11 out of 21) experienced multiple levels of stress. These parents seemed to find it difficult to find any patterns and rhythms in the busy and stressful NICU. In addition, these parents clearly put words to unpredictability of the situation with the preterm birth such as wondering the side effect the infant might have because of lack of oxygen. Moreover, these parents specifically reported their observations of the healthcare providers particularly nurses in the NICU. Parents reported experiencing stress related to nurses being too tired that they might be "impatient" with the infant, inconsistencies between nurses in the care of their infants, or having nurses who talked about their personal lives. Stress encountered because of alteration in parental role accounted for the largest portion of parental responses. Parents felt unprepared for the preterm birth. They expressed concerns for being separated from their infants at the hospital and not being able to adequately take care of their children at home.

CHAPTER V

DISCUSSION

The purpose of this study was to examine predictors of uncertainty, stress, anxiety, and depressive symptoms in parents of preterm infants in the NICU. The NICU parental uncertainty and stress model was developed to guide this study based upon the theory of uncertainty in illness (Mishel, 1988), parental NICU stress model (Wereszczak et al., 1997), and the theory of stress, appraisal and coping (Lazarus & Folkman, 1984). A cross-sectional design was used to collect data from 32 pairs of parents of preterm infants in the NICU using a convenience sampling method. Parents completed four standardized questionnaires and one investigator-developed questionnaire. I completed the infant demographic questionnaire and the CRIB scale.

Data analysis was done using SPSS® version 22 (IBM, Armonk, NY). Descriptive, frequency statistics, multiple linear regressions, independent *t*-test, Mann-Whitney U test statistics, and correlational analysis were conducted. Finally, path analysis was performed to examine the effect of significant predictors on depressive symptoms and state anxiety.

Instruments

Four Likert-type scales were used in this study to measure uncertainty, stress, state anxiety, and depressive symptoms: the PPUS, the PSS: NICU, the short form of the SAI, and the short form of the CES-D. All scales were easy to read and understand. However, some parents complained about the length of the PPUS scale. Some parents

thought that the items in the PPUS scale were redundant. This could be due to the fact that the PPUS scale, unlike the PSS: NICU scale, is not divided into subscales as the subscales items are scattered throughout the scale.

Psychometric testing of the internal consistency reliability of the study instruments was done separately for the fathers and mothers. The internal consistency of the PPUS scale and the subscales lack of clarity and ambiguity were greater than 0.70 which is congruent with the reliability reported by Mishel (1983). However, in this study, Cronbach's alphas for the subscales lack of information and unpredictability for the mothers were low. Similar low Cronbach's alphas for both scales were reported by Stewart et al. (2010). The PSS: NICU scale and subscales had strong Cronbach's alphas except for the subscale sights and sounds for the fathers had an alpha of 0.66 which is slightly lower than the acceptable value of 0.70. In a recent study a low Cronbach's alpha for the subscale sights and sounds was reported ($\alpha = 0.56$) for mothers using scoring Metric 2 (Ichijima et al., 2011). Again, this subscale is composed of only five items which might explain the low Cronbach's alpha, as reliability can be adversely affected by having only a few items in a scale (Waltz et al., 2005).

The SAI demonstrated a good internal consistency for both parents supporting the Cronbach's alpha in the Maeteau and Bekker (1992) study. The CES-D scale had a slightly lower Cronbach's alpha for the fathers ($\alpha = 0.67$), but was good for the mothers. The small number of items in the subscales lack of information, unpredictability, and sights and sounds and the small sample size could have attributed to the low Cronbach's alphas. Nevertheless, these reasons do not explain the differences between the Cronbach's alphas of the subscales for fathers and mothers.

Sample Characteristics

The final sample size was 64 parents with 32 fathers and 32 mothers. The percentage of births to unmarried mothers was 40.6%, which is similar to the national percentage for 2012 (40.7%) (CDC, 2013). A higher percentage of married parents was reported in other studies; however, the parents in these two studies were Chinese-American and Caucasian (Lee et al., 2005; Shields-Poë & Pinelli, 1997). The difference in the culture and the age of the article may be related to the observed difference in the marital status percentage rate. Two-thirds (75%) of parents were White which is similar to the Jefferson county percentage of 73.9% (US Census Bureau, 2013). A slightly lower percentage of parents were Black or African American (17.1%) in this sample compared to the Jefferson County percentage (21.3%). State anxiety and depressive symptoms were reported to differ between mothers of different races as Caucasian mothers reported higher state anxiety and depressive symptoms compared to African American and Hispanic mothers (Lau et al., 2007). Approximately 50% of parents had some college level education which is higher than the City of Louisville's 22%. Educational level less than high school (4.6%), high school (26.5%), bachelor degree (10.9%), and advanced level education (7.8%) were lower in my study sample compared to Louisville statistics (13%, 33%, 15%, and 10%, respectively) (Live in Lou, 2012). Mothers reported having higher educational levels than fathers. This is in alignment with the results reported by other investigators (Carter et al., 2005; Grosik et al., 2014; Lee et al., 2005).

The mean number of children for both parents was 1.9, which is similar to the national average (CDC, 2013). However, fathers had more children than mothers. This may be because fathers can have many women liaisons, whereas mothers are limited with

age, resources, and the time lost to pregnancy. Six fathers (18.8%) and seven mothers (21.9%) reported having a previous experience with preterm birth. This percentage is higher than the one reported by Shields-Poë and Pinelli (1997) (fathers = 14%, mothers = 16%). This could be attributed to the advancement in fertility sciences and the resultant increase in the number of preterm births since the 1997.

Nearly 47% of infants were born via Cesarean section, which is higher than the national percentage of 32.8% (CDC, 2013). This could be attributed to the high percentage of antenatal complications of the mothers participating in this study (56.2%) necessitating the surgical delivery of the preterm infant which is congruent with the findings of Reid and Bramwell (2003).

Eighty percent of preterm infants born before 27 weeks gestation develop respiratory distress syndrome (RDS) which is treated with some type of respiratory support (Institute of Medicine, 2007). Parents of preterm infants requiring respiratory support reported higher levels of stress (Turan et al., 2008, Foster, Bidewell, Buckmaster, Lee, & Henderson-Smart, 2007). Nineteen infants (59.3%) were diagnosed with RDS. Fourteen (43.7%) infants were on some type of respiratory support. Similar percentages of respiratory support were reported in recent studies (Bouet et al., 2012; Zamanzadeh et al., 2013). A higher percentage (86%) of infants requiring respiratory support was reported by Franck et al. (2005) in the United Kingdom. This may be due to the medical teams in NICUs in other countries using more conservative respiratory management strategies than the NICUs in the U.S.

These data were collected between day one to day 14 of the infants' lives. A wide range of timing of data collection is found in the literature ranging from as early as 12

hours of life to more than 30 days of life (Ahn & Kim, 2007; Arockiasamy et al., 2008; Grosik et al., 2013; Jubinville et al., 2012; Miles et al., 1992; Reid & Bramwell, 2003; Zamanzadeh et al., 2013). Other studies failed to describe the timing of data collection. Timing of data collection is an essential factor in eliciting parental responses as different stressors might occur at different points in time.

Stress

Consistent with previous literature on parental stress, my results showed that parents of preterm infants reported moderate to high level of stress (Dudek-Shriber, 2004; Lau et al., 2007; Mackley et al., 2010; Miles et al., 1992; Miles et al., 1991; Reid & Bramwell, 2003; Woodward et al., 2014). My findings showed that the least amount of stress reported by the parent was related to the sights and sounds subscale. Parents reported the greatest level of stress related to parental role subscale, followed by the stress related to infant's looks and behaves subscale, which coincided with others' research findings (Dudek-Shriber, 2004; Foster et al., 2007; Matricardi et al., 2013; Seideman et al. 1997; Woodward et al., 2014). However, other researchers found that both fathers and mothers scored higher in the infant appearance and behavior aspect of parental stress (Mackley et al., 2010; Meyer et al., 1995; Lee et al., 2005). It is worth noting that Lee and colleagues (2005) used a translated version of the PSS: IH scale on American-Chinese parents in NICU, PICU and cardiac ICU settings. The PSS: IH scale was adapted from the PSS: NICU but is used to assess parents perception of stress associated with their infants hospitalization in the NICU or in other pediatric units (Miles & Brunssen, 2003).

Although, each parent completed the surveys in isolation of the other parent, a mutual agreement existed between fathers and mothers on what was the most stressful aspect of each of the PSS: NICU subscales. On the sights and sounds subscale, the sudden noises of monitor alarms was reported as causing the highest stress for both parents. This is may be because monitors are indicators of the infant's physiological responses such as heart rate, respiratory rate, and oxygen saturation. Parents may associate the alarms with the deterioration of their infant's condition and that something is wrong with the infant which causes their stress level to increase. On the baby looks and behaves subscale, parents reported highest stress when they thought that their infant is in pain. On the parental role subscale, both parents reported experiencing high stress related to separation from the infant. Other items such as feeling of helplessness, not being able to hold or feed their infant were also scored high by both parents and supported the findings reported in other studies (Chouasia et al., 2012; Grosik et al., 2013; Hollywood & Hollywood, 2011; Kynø et al., 2013; Miles et al., 1991). Parents feel helpless for several reasons. First, parents feel that they have no control over the situation and their infant. Second, they are not able to hold, feed, or take care of their infants whenever they wish. Their parental role is taken from them and given to the nurses. Parents cannot take pain from their infants and they cannot understand the infant's cues. Parents may feel helpless because they must obtain permission to enter the NICU and see their infant. They cannot control when the lights are dimmed in the NICU or alarms are silenced so that their infant can sleep. All of these reasons could make parents feel helpless and cause alteration in parental role.

Overall, mothers reported higher stress levels than fathers. A statistically significant difference was found between fathers and mothers in the overall stress level and in relation to parental role. The difference in stress levels between fathers and mothers could be due the inexpressive and protective nature of fathers who tend to hide their emotions and who focus on their wives and children's feelings rather on their own. This result is consistent with the findings reported in the literature (Carter et al., 2007; Miles et al., 1991, 1992). Contrary to my findings, Ann and Kim (2007) and Bouet et al. (2012) found no significant differences in the stress levels between mothers and fathers in Korean and Puerto Rican parents. This discrepancy in the results may be due to the difference in the cultures between the studies' samples.

Predictors of Stress. Uncertainty and educational level at high school or some college level were significant explaining 23.8% of the variance in stress level. This result is congruent with one study that was done on Chinese-American parents, which showed that uncertainty explained 13% of variance in maternal stress and 42% of variance in paternal stress (Lee et al., 2005). No known other studies were found to use uncertainty as a predictor for parental stress levels except for one study conducted by Mishel (1984) on hospitalized adults which maybe incomparable to the current study sample.

Parental educational level and ethnicity accounted for 11% of variance in the sights and sounds subscale of the PSS: NICU scale, but not in the total PSS: NICU scale (Dudek-Shriber, 2004). Meyer et al. (1995) found that birth weight, gestational age, ventilator support, and length of stay explained some portions of variance in the maternal stress, which differ from my results. The Meyer study is two decades old and was done on mothers only. Marital status along with other variables that were not included in my

study explained 23% of the variance in parental stress (Shields-Poë & Pinelli, 1997). Again, the study occurred in 1995 and examined parents of preterm and term infants. As demonstrated by the literature, parents of a preterm infant respond in a different manner than parents of a term infant (Ahn & Kim, 2007; Carter et al., 2005).

Even though sex of the parents was not a significant predictor of stress, it was entered in the reduced model along with high school or some college educational level and the PPUS subscales. The reason for entering sex of the parents in the second model was because the analysis of data revealed that stress level differed significantly between fathers and mothers. Ambiguity and sex of the parents accounted for 28.5% of the variance in parental stress level. Ambiguity is the most general characteristic of uncertainty as novelty and complexity of the NICU environment and equipment may generate uncertainty (Mishel, 1983). The healthcare providers in the NICU should employ different strategies when interacting with fathers and mothers. Moreover, healthcare providers should pay more attention to orienting the parents to the monitors and equipment attached to their infants and to explaining procedures or tests done on their infants, thus reducing the amount of ambiguity and eventually reducing stress level. Although the ambiguity and sex of the parents explained 28.5% of the variance in parental stress, a large amount of variance remained unexplained which warrants further investigation.

Uncertainty

The results of the descriptive analysis of the PPUS scale and the subscales indicated that parents reported moderate levels of uncertainty on the overall PPUS scores. The highest level of uncertainty was in the unpredictability subscale for both the fathers

and the mothers (M = 3.31, SD = .78 and M = 3.34, SD = .59, respectively). The lowest level of uncertainty was in the lack of clarity subscale for both the fathers and the mothers (M = 1.81, SD = .12 and M = 1.89, SD = .10, respectively). Miles et al. (1992) reported similar findings related to the highest and lowest subscales mean scores; however, her scores were higher than my findings. These results showed that parents experienced a higher level of uncertainty on the unpredictability subscale and lower uncertainty levels on the lack of clarity subscale. This may be because healthcare providers tend to clarify issues related to the infant's condition adequately which explains the low scores on the lack of clarity subscale. Frequently, healthcare providers cannot completely predict the outcome of the preterm infant's condition which may be reflected on the high scores of parental unpredictability.

Mothers reported slightly higher level of uncertainty compared to fathers. However, no statistically significant relationship was found between fathers and mothers in the levels of uncertainty. This supports the results by Miles et al. (1992) who found no significant difference between fathers and mothers of a preterm infant in the level of uncertainty. Miles' study is the only known study since 1992 to compare uncertainty levels between fathers and mothers of preterm infants in the NICU. My study adds to the body of knowledge in uncertainty research.

Predictors of Uncertainty. Stress, race, and full-time employment seemed to play the most significant roles in determining parental level of uncertainty. However, when the three components of stress (sights and sounds, baby looks and behaves, and parental role), race, and full-time employment entered in the reduced regression model, only infant's appearance and behavior predicted uncertainty. The results indicated that in

order to reduce parental uncertainty, the healthcare providers should focus on explaining procedures, treatments, the tubes and machines attached to the infant, and the way the infant looks or behaves to the parents.

A few researchers studied predictors of uncertainty in parents of sick children with various diagnoses. Stewart et al. (2010) found that age, knowledge, time since diagnoses, stage of illness, and parental uncertainty predicted uncertainty in sick children. Madeo et al. (2012) found that mothers' age and highest education level attained were not significant predictors of uncertainty in mothers of children with undiagnosed medical conditions. Similarly, parental educational level, age, and marital status did not predict parental uncertainty levels in parents of children with chromosomal conditions (Lipinski et al., 2006). These aforementioned studies were done on parents of sick children; they cannot be compared with the current study sample. My study is the only known study to explore predictors of uncertainty in parents of preterm infants in the NICU.

State Anxiety

Similar to other studies, I found that mothers reported higher state anxiety scores than fathers (Pinelli, 2000). Maternal state anxiety means in my sample were similar to the means reported by Carvalho et al. (2008) on Brazilian mothers and Yurdakul et al. (2009) on Turkish mothers, but were higher compared to American mothers (Rogers et al., 2013). When comparing the means of the SAI scores of the fathers and the mothers with the general population of the age group 19 to 39 years, the current sample revealed higher means (mothers $M = 45.20$, $SD = 14.53$ vs. female in general population $M = 36.17$, $SD = 10.96$) and (fathers $M = 38.30$, $SD = 12.90$ vs. male in general population $M = 36.54$, $SD = 10.22$) (Spielberger, 1983). This indicates that parents of preterm infants in

the NICU experience higher state anxiety level than the general population. Higher mean scores of the state anxiety for both parents were reported by other investigators (Miles et al., 1992; Shields-Poë & Pinelli, 1997). However, Carter et al. (2005) found low levels of anxiety in the NICU parents, albeit higher when compared to parents of healthy infants. Carter and colleagues studied parents of both preterm and term infants in the NICU, which might have yielded different results if parents of preterm infants studied alone.

Predictors of the State Anxiety. Of the independent variables, the findings revealed that stress predicted state anxiety. The other independent variables were not significant predictors of state anxiety. For every unit increase in the stress level, there was a predicted increase of 1.419-point in the state anxiety level. This is a higher prediction value than the one found by Kong et al. (2013). Similarly, stress, parental trait anxiety, maternal education, and perceived morbidity contributed to the increase in the state anxiety in fathers and mothers of NICU infants (Shields-Poë & Pinelli, 1997).

Similar to my findings, Rogers et al. (2013) found that maternal characteristics and infant characteristics did not predict parental state anxiety. Unlike my results, sex and race of the parents were significant predictors of parental anxiety (Doering et al., 2000). Sex of the infant and length of hospitalization were significant predictors of maternal state anxiety (Erdem, 2010). Uncertainty predicted anxiety in children and adolescents with cancer and in mothers of children with febrile convulsion (Ju et al., 2011; Stewart et al., 2010). To date, no study has examined uncertainty as a predictor of parental anxiety in the NICU. My findings were consistent with the findings of other investigators in that stress contributed the most to the state anxiety level in the NICU parents.

The regression model showed that uncertainty alone explained 35% of the variance in state anxiety. The results of the path analysis for the state anxiety revealed a number of direct effects, though no indirect effects were found between sex and the uncertainty, stress, and state anxiety. Uncertainty had a positive significant direct influence upon the state anxiety and stress. Stress did not have a significant direct or indirect effect on the state anxiety. As hypothesized and reported in the literature, uncertainty about events, e.g., NICU admission, precedes the stress response and is considered one of the stressors (Hilton, 1994; Ichijima et al., 2011, Lee et al., 2009; Mishel, 1984). Sex had no significant direct or indirect effect on the state anxiety. This was supportive of previous research findings in that uncertainty directly influenced anxiety and stress in hospitalized adults and in school age children and adolescents (Mishel, 1984; Stewart et al., 2010). The results of the above studies should be viewed cautiously taking into account the differences in the samples studied.

Depressive Symptoms

My results showed that the means of the CES-D were lower than the recommended depressive symptoms cutoff score of 16 (Radloff, 1977). The mean CES-D scores of fathers and mothers were higher than the means of the general population at the age of 28 to 40 years (fathers M = 10.92, SD = 8.06 vs. males in the general population M = 8.9, SD = 6.7) and (mothers M = 14.18, SD = 11.36 vs. females in the general population M = 9.6, SD = 7.5) (Henderson et al., 2005). Mothers' mean CES-D scores were slightly higher than fathers; however, no significant differences were found. Inconsistent with my results, other investigators found that mothers of preterm infants reported depressive symptoms means higher than the minimum value of 16 (Ballantyne et

al., 2013, Mew et al., 2003; Miles et al., 2007). However, the CES-D mean scores reported by Mew and colleagues were combined scores for mothers of single infants and those of twin and triplet preterm infants. Depressive symptoms occur in over 25% of mothers of multiple births (Leonard, 1998). Other investigators evaluated maternal depressive symptoms with different measures including the BDI and the Edinburgh Postnatal Depression Scale (EPDS), finding that mothers of preterm infants in the NICU reported higher depressive symptom scores (Korja et al., 2008; Padovani et al., 2009). Of the studies done on parental depressive symptoms, only one study was found that reported fathers' CES-D mean scores, which were elevated (≥ 16) (Mackley et al., 2010).

Both parents reported higher mean scores on "I felt that everything I did was an effort". This is may be because the birth of the preterm infant added to their parental responsibilities which exhausts parents emotionally, physically, and financially making everything they do an extra effort. To date, no known studies of parental depressive symptoms reported the mean scores of the individualized CES-D items; thus, comparison of the results was not possible.

The difference between my study and the other studies is that I included both fathers and mothers as opposed to only mothers. Fathers are usually forgotten when it comes to studying parental emotional experiences of a preterm birth. This may be because the mothers were thought to be more prone to developing postpartum depression and thus the focus was solely on mothers. Although my findings did not show that fathers are at risk of developing depressive symptoms, it added to the body of knowledge about fathers' NICU experiences.

Predictors of Depressive Symptoms. My findings showed that uncertainty, stress, and marital cohabitating status were predictive of depressive symptoms accounting for 64.7% of the total variance in parental depressive symptoms. When the significant predictors: marital cohabitating status, the PPUS subscales, and PSS: NICU subscales were entered in the second regression model, subscales ambiguity and unpredictability were the only significant predictors explained 57.1% of the variance in depressive symptoms. Congruent with my findings, other studies found that stress and marital status predicted depressive symptoms in mothers of preterm infants (Ballantyne et al., 2013; Davis et al., 2003). However, inconsistent with my findings, literature showed that variables such as number of children, maternal education, alteration in parental role, and number of ventilated days were found to be significant predictors of depressive symptoms (Brooten et al., 1988; Davis et al., 2003; Doering et al., 2000; Rogers et al., 2013).

Uncertainty and stress explained 51.5% of the variance in the path model for depressive symptoms. Uncertainty had the largest direct influence on depressive symptoms. Uncertainty had an indirect effect on depressive symptoms mediated by stress. Stress only had a direct effect upon depressive symptoms. Sex had no direct effect on uncertainty and depressive symptoms, but had a direct effect on stress and indirect effect on depressive symptoms mediated by stress. Similar to my results, but taking into consideration the differences between the samples in these studies, uncertainty was reported to directly influence depressive symptoms in school age children and adolescents and in parents of children with epilepsy (Mu, 2005; Stewart et al., 2010).

Inconsistent with my findings, Doering et al. (2000) reported that sex of the parents directly influenced depressive symptoms in NICU parents.

Relationships Between the Study Variables

My findings provided evidence that parental uncertainty was strongly correlated with parental stress. The link between parental uncertainty and stress is consistent with the findings of Mishel (1984) who reported a strong relationship between uncertainty and stress in hospitalized adult patients. Although the results from Mishel's study were consistent with my results, the participants she studied (sick adults) differed from the participants in my study (parents of preterm infants).

Aspects of uncertainty were linked with those of stress suggesting that novelty, complexity of the situation, lack of comprehension, and lack of information are associated with the stress related to the NICU environment, the appearance of the infant, and lack of control associated with alteration in parental role. Similar to Lee et al., (2007), my results showed that unpredictability was not related to either the other components of uncertainty or to the components of stress. This could be due to the amount of trust parents place in the healthcare providers (credible authority) as speculated by Mishel (1988). Parents rely on healthcare providers to provide judgment about the infant's outcome thus reducing the unpredictability aspect of uncertainty.

Parental stress was strongly related to anxiety and depressive symptoms. This finding is consistent with the literature that documented that parents who experienced the birth and admission of a preterm infant to the NICU as stressful also experienced depressive symptoms and anxiety (Amankwaa et al., 2007; Ballantyne et al., 2013; Beck, 2003; Busse et al., 2013; Holditch-Davis et al., 2009; Kong et al., 2013; Mew et al., 2003;

Miles et al., 2007; Younger et al., 1997). However, the above researchers only studied mothers. Thus, research is needed to study anxiety and depressive symptoms in NICU fathers.

My results showed that parental uncertainty was strongly related to anxiety and depressive symptoms. Miles et al. (1992) found that paternal anxiety was related to uncertainty whereas, no relationship was found between maternal anxiety and uncertainty. Given the paucity in uncertainty research on NICU parents, none has been found to study the relationship between parental uncertainty and depressive symptoms thus comparison with other studies was not possible. My findings are important as they added to the body of knowledge on the relationship between parental uncertainty and depressive symptoms.

Individual correlational analysis of uncertainty, stress, anxiety, and depressive symptoms for fathers and mothers revealed that moderate to strong significant relationship exists between maternal stress, uncertainty, state anxiety, and depressive symptoms. Consistent with the findings from Davis et al. (2003), maternal stress increased with the increase in depressive symptoms. However, Davis and colleagues studied Australian mothers three months after the infant was discharged from the hospital and the effect of time may have been significant.

Stress was not related to uncertainty or state anxiety in the fathers. Consequently, no relationship was found between uncertainty subscales and stress subscales. Similar to my results, uncertainty was associated with depressive symptoms in parents of children with epilepsy (Mu, 2005). Paternal uncertainty levels and depressive symptoms increased as infants' gestational age and birth weight decreased. Likewise, as infants' gestational

age and birth weight decreased maternal state anxiety and depressive symptoms increased, which is consistent with previous reports in the literature (Carvalho et al., 2008). However, no relationship was found between infant's gestational age and birth weight and paternal stress, paternal anxiety, maternal stress, and maternal uncertainty. Infants' gestational age, birth weight, length of hospitalization, and maternal stress did not correlate with maternal depressive symptoms (Korja et al., 2008; Mew et al., 2003). Other researchers reported that infant's length of hospitalization had a significant relationship with parental stress (Lefkowitz, Baxt, & Evans, 2010).

Although length of stay, which can be used as proxy for infant age, was found to be positively related to the stress level in British mothers (Reid & Bramwell, 2003), in my study, infants' age (DOL) was not found to be related to any other variables including stress. Paternal uncertainty was not related to paternal stress, but was related to maternal stress, uncertainty, state anxiety, and depressive symptoms. Reid and Bramwell (2003) similarly found that maternal age was not correlated with stress level. This is inconsistent with the results found by Chourasia et al. (2012) who showed that as maternal age increased, stress level increased. Contrary to mothers, fathers' age was positively correlated with stress levels; the younger the father, the higher the stress level; but not to uncertainty (Ichijima et al., 2009; Mu, 2005). My results showed that none of the variables were correlated with fathers' age except for mothers' age.

Responses to an Open-Ended Question on the PSS: NICU Scale

There was a good response (21 mothers and fathers) to the optional question at the end of the PSS: NICU questionnaire. Interestingly, although the number of female infants to male infants is equal, 81% (n = 17) of parents who responded to this question had a

female infant. Does this imply that parents of a female preterm infant experience higher stress level or are more verbally expressive than parents of a male preterm infant? The answer to this question is beyond the scope of this study, but may warrant further investigation. Studies conducted by Lee et al. (2007) and Shields-Poë and Pinelli (1997) found no significant relationship between sex of the infant and parental stress level.

Four themes were extracted from the responses. These themes were matched to the PSS: NICU subscales. The majority of parents expressed more than one theme. The theme of parental role had the highest number of responses (71.4%).

Parental Role Alteration. Alteration in parental role was the most common stressor reported by the parents. This concurred with the quantitative findings that parents reported the highest stress levels on the parental role subscale. Separation from their infants was identified as the most stressful aspect of having an infant in the NICU. Similar findings were reported by Wereszczak et al. (1997) and by Holditch-Davis and Miles (2000) who found that separation from the infant and inability to participate in the care of the infant were troubling for the mothers. Parents reported stress related to being separated from their other children due to their constant presence in the NICU. Parents were frustrated because they felt helpless for not being able to take care of their infants in the NICU and did not have enough time to take care of their children at home. These findings are consistent with a recent study done on internal and external stressors of NICU parents (Grosik et al., 2013). In my findings, although parents expressed experiencing stress when they had other children at home, the number of children was not a significant predictor of stress. Reid and Bramwell (2003) examined the relationship between stress scores and maternal and infant characteristics reporting that stress levels

did not differ between primigravida mothers and mothers with two or more children. Likewise, Mew et al. (2003) did not find a significant relationship between parity and depressive symptoms.

Not being prepared for the birth of the preterm infant and not knowing what to expect were reported as stressful. Like Holditch-Davis and Miles (2000), I found that mothers felt guilty for not being able to maintain the pregnancy to term. One mother stated that her son "hated her" when she tried to touch him. Although fathers in this study did not explicitly express a feeling of guilt, one father stated that he was not there with his daughter like he was with his other three children. In addition, fathers reported thinking of activities that might cause problems for their infants. For example, a father expressed concerns about alarms that interfered with sleep for his infant. These findings are congruent with the results reported by Zamanzadeh et al. (2013) on Iranian fathers of preterm infants.

NICU Environment. Different aspects of the NICU environment such as sights and sounds are found to be source of stress to the NICU parents (Miles et al., 1991, Raeside, 1997). Mothers expressed feeling of stress over having sicker babies next to their infants or when a baby next to their baby died. This concurs with a previous research showing that mothers become stressed when they see other sick and dying infants (Wereszczak et al., 1997). Foster et al. (2007) found contrary results and reported that parents did not perceive the presence of other sick infants in the room as stressful. This contradicting result may be attributed to the level of NICU where the studies took place as Foster and colleagues' study was conducted in non-tertiary special care nursery where less sick infants are admitted.

Not knowing what to expect was reported as stressful for the one of the parents and the longer an infant is in the NICU, the parents get accustomed to the NICU environment with a subsequent decrease in stress. This onetime subjective statement by one of the parents contradicted the findings from a recent study. Matricardi et al. (2013) found that parental stress level related to the sights and sounds in the NICU increased from the time the infant was admitted to the time of discharge from the NICU. Matricardi and colleagues' findings support the results of a study done by Miles et al. (1992) where mothers' stress level associated with sights and sounds of the NICU decreased from admission of the infant to one week later, but fathers stress levels slightly increased between the two times. A longitudinal study eliciting parental stress responses over time is warranted to clarify these contradictory findings.

Baby Looks and Behaves. The appearance and the behavior of the infants are stressful for the parents (Ichijima et al., 2011; Matricardi et al., 2013; Seideman et al., 1997; Turan et al., 2008; Wereszczak et al., 1997). Parents reported having stress related to the tubes and monitors attached to their infants. Parents wondered about the side effects of lack of oxygen and the situation in which the infant stops breathing. These findings concur with a study done by Grosik et al. (2013) who showed that parents reported highest stress scores on the item "seeing my baby stop breathing".

Healthcare Providers. Health care providers may increase or decrease parental stress levels**.** On one hand, parents consider healthcare providers, particularly nurses, as a source of stress (Arockiasamy et al. 2008; Holditch-Davis & Miles, 2000; Ichijima et al., 2011; Raeside, 1997; Seideman et al., 1997). In my study, parents feared that nurses might be inpatient with their infants. Parents expressed concerns about nurses who were

not present when the monitors alarmed, who were inconsistent with nursing care, and were not available when parents called to inquire about their infants. Inconsistency and the use of different communication styles or attitudes by the healthcare providers could lead parents to feelings of losing control of their infant's situation. Loss of control causes feelings of helplessness, which in turn increases stress levels. On the other hand, parents may report that healthcare providers might help reduce parental stress levels. For example, one mother stated that the health care staff were welcoming and took great care of her infant. Thus, health care providers play a pivotal role when dealing with NICU parents' psychological well-being related to their preterm infants.

Although parental responses indicated various aspects of parental stress aspects of uncertainty were extracted from the responses as well. For example, ambiguity may arise as a result of the novelty and complexity of the monitors and devices connected to the infants. Inability to differentiate between one treatment and another could produce uncertainty. Nurses who are busy or look tired, or who are inconsistent in regard to the information provided to the parents or the care given to the infant could generate lack of clarity and lack of information ultimately leading to uncertainty. Parents who are not clear about the role that they can assume in the NICU and what to expect related to their infant's outcome, are more likely to perceive the situation as uncertain.

Implications for Clinical Practice and Future Research

Clinical Practice

Parents of preterm infants in the NICU experienced moderate levels of uncertainty, stress, and anxiety, but lower levels of depressive symptoms. These findings have a number of important implications for nursing practice in the NICU. First, to

identify those parents who are at risk for developing uncertainty, stress, anxiety, and/or depressive symptoms, a proper screening upon the infants' admission and at various intervals during the infant's NICU hospitalization may be beneficial. Screening may be started in the perinatal period with parents who are at risk of having a preterm birth. Second, it is imperative to prepare parents for the potential psychological reaction that may occur in the event of a NICU hospitalization (Bouet et al., 2012). Third, a properly planned orientation to the NICU and staff that is tailored to individual needs and demands of the parents may reduce the stress and uncertainty parents might face during their first encounter with the NICU environment and throughout the infant's hospitalization. A proper orientation about the different machines in the NICU and the meaning of various alarms could reduce the stress and uncertainty that might arise because of lack of knowledge. Healthcare providers should be sensitive to the difference in psychological responses between fathers and mothers and characteristics that may influence their responses including educational level, socioeconomic status, and marital status. March of Dimes has implemented programs for the NICU parents such as "parents' hour" in which neonatal experts provide interactive educational sessions to the parents concerning all aspects of prematurity. NICU managers and nurse educators may collaborate with March of Dimes to conduct such sessions for the NICU parents.

Healthcare providers, particularly nurses play a pivotal role in aggravating or alleviating psychological reactions of the NICU parents. Nurses should consistently remind the parents and themselves that the infant belongs to the parents and that no one will strip them of their parental role. Nurses should encourage and support the parents to touch their infants and to get involved in their infant's care as is medically appropriate.

Parents reported experiencing stress related to inconsistency in nursing care and communication with health care providers. Therefore, thorough and clear communication among the healthcare providers and the parents is essential. Nurses should encourage the fathers to take photographs of their infants to show to the mothers if the mothers' physical condition prevents NICU visitation. Avoid whenever possible placing infants in critical condition with those who are more stable and be prepared to provide counseling to the parents whenever an infant death occurs in the NICU.

Future Research

Future research could proceed in several directions. First, the sample in this study was predominately White and middle class and little is known about other cultures. As a researcher I especially am interested in learning more about parental responses in the Arabic culture and comparing those findings with the findings from American parents. The PPUS and the PPS: NICU need to be translated into the Arabic language; the CES-D and the STAI have already been translated into Arabic. Psychometric research on the translated instruments is needed. Sex of the infant might be an important predictor of uncertainty, stress, anxiety, and depressive symptoms in Arabic parents, as male offspring are favored over female. Illiterate parents or parents who have difficulty speaking the English language are often not included in these types of studies. Including these parents in future studies may increase the generalization of the findings.

Second, my study and most of the other studies were conducted on adult parents of preterm or term infants. There is a dearth in research on parents with multiple births, infants with congenital anomalies, infants with complex surgeries, parents who have been on infertility treatments, or adolescent parents. It is imperative to study teenage parents

because of the high rate of teen pregnancy. In 2013, there were 274,641 teen births with a rate of 27 births per 1,000 girls (The National Campaign, 2014). Teen mothers are more likely to give birth to a preterm infant compared to mothers over 20 years of age (March of Dimes, 2012b). During data collection, a preterm infant delivered to a 14-year-old mother and a 16-year-old father was admitted to the NICU but due to exclusion criteria, I was not able to include them in my study. Studying the effect of visitation times, distance from the hospital, and availability and accessibility of transportation to and from the hospital on parental psychological responses is needed. One mother I interviewed on day one of her infant's admission to the NICU told me that she would not be able to visit her infant because of the lack of transportation.

Educational sessions called "parent hour" were conducted by neonatal experts and sponsored by the March of Dimes for the NICU parents on a weekly basis in Norton Suburban Hospital; one of the data collection sites. An opportunity for research to assess parental responses before and after the sessions exists. Another potential for future research is to compare psychological responses of the parents whose infants are cared for in a private room versus infants cared for in the ward-type NICU, as newer facilities are using private rooms for NICU patients. Finally, there is a need to conduct longitudinal studies with a larger, randomly selected sample from NICUs in different states to elicit parental responses at different points in time and to increase the generalizability of the findings.

Strengths and Limitations

Strengths

The current study exhibits a number of strengths. First, the results of the study addressed some of the gaps found in the literature particularly related to uncertainty in NICU parents and to the predictors of uncertainty, stress, anxiety, and depressive symptoms. Although the sample size was small, the use of three clinical settings may add to the generalizability of the study. The use of reliable and valid instruments which had been used in several previous studies added strength to my study. The inclusion of both fathers and mothers in my study and the comparison between the parents in uncertainty and stress was not commonly seen in previous studies; thus, these findings add to the body of knowledge in the area of stress, uncertainty, anxiety, and depressive symptoms.

Limitations

A number of limitations were identified. First, the use of a cross-sectional design may fail to capture different stress levels that parents of premature infants in the NICU may experience over time. Second, the use of a convenience sample may lead to bias due to underrepresentation or overrepresentation of certain subgroups of the study population, thus affecting generalizability of the findings. Third, the use of Likert–type scales in the self-report PPUS, PSS: NICU, CES-D, and SAI scales may be subject to bias. Moreover, because this study is descriptive in nature, cause and effect relationships between variables cannot be inferred.

The proposed power analysis for this study revealed a sample size of 143 pairs of parents was needed. However, the final sample size was reduced to 32 pairs of parents because of the difficulties in recruiting parents, the stringent inclusion criteria of having

to recruit both parents, and the constraints of time. Another limitation is related to the recruitment of parents within two weeks of their infant's life in the NICU and to the gestational age of the infants which ranged between 23 to 34 weeks gestation. These restrictions may cause variations in the parental responses to the questionnaires, as different responses might have been elicited at different points in time or at different gestational ages. For example, parents' responses might be different if parents completed the surveys immediately after the birth of their infant or if their infant was extremely preterm versus late preterm.

Conclusions

The purposes of this study were to identify predictors of uncertainty, stress, anxiety, and depressive symptoms in parents of preterm infants in the NICU and to explore the differences between fathers and mothers in the levels of stress and uncertainty. All the self-report scales used to test the study concepts had acceptable to strong internal consistency reliability. My findings supported the results reported in the literature in that parents of preterm infants in the NICU experienced moderate to high levels of stress, uncertainty, and anxiety, but low levels of depressive symptoms. Significant differences in the level of stress and state anxiety were found between the fathers and mothers indicating that parents respond differently to stressful situations. No differences were found between fathers and mothers in uncertainty or depressive symptoms. Uncertainty contributed the most to the parental state anxiety and to depressive symptoms followed by stress.

The NICU-PUSM model was partially supported by the results of my study. As hypothesized, a positive direct relationship exists between uncertainty and stress,

uncertainty and the state anxiety, and uncertainty and depressive symptoms. Likewise, stress had a positive direct relationship with depressive symptoms, but had no influence on state anxiety. However, no significant effect was found for any of the parental or infant characteristics on uncertainty, stress, state anxiety, or depressive symptoms. Sex of the parent was the only variable found to directly influence stress and indirectly influence depressive symptoms mediated by stress.

In summary, my results supported some of the literature findings. However, inconsistent findings may be explained, in part, by differences in the timing of data collection, characteristics of the sample, and the scales selection. Because little is known about predictors of uncertainty, anxiety, and depressive symptoms in NICU parents, most of my findings could not be compared with similar literature. Moreover, a large amount of the variance in uncertainty, stress, state anxiety, and depressive symptoms remains unexplained. In addition, because of the underpowered sample, my results should be interpreted with caution. Therefore, further investigation using a larger sample size is warranted.

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Appendix A

Demographic Data: Parental Characteristics

1. What is your age in years?_____Years

Please place a check (√) by the answers that describe you.

2. What is your sex?

    a. Male _____

    b. Female _____

3. How would you describe yourself?

    a. White, non-Hispanic or Latino _____

    b. White, Hispanic or Latino _____

    c. Black or African American _____

    d. Asian _____

    e. Other _____

4. What is your current marital status?

    a. Single _____

    b. Married _____

    c. Divorced _____

    d. Cohabitating _____

    e. Widowed _____

5. What is your level of education?

    a. Less than high school diploma _____

b. High school diploma _____

c. Some college _____

d. Bachelor degree _____

e. Advanced degree (post Bachelor's degree) _____

6. What is your employment status?

a. Employed _____

Full-time _____

Part-time _____

b. Unemployed _____

7. What is your annual individual income?

a. < $10,000 _____

b. $10,000 – $20,000 _____

c. $20,001– $ 30,000 _____

d. $30,001 – $60,000 _____

e. $60,001 – $90,000 _____

f. $90,001 – $120,000 _____

g. $120,001 – $150,000 _____

h. >$150,000 _____

8. What type of medical health coverage do you have?

a. Private _____

b. Medicaid _____

c. No insurance (self-pay)_____

9. How many children do you have? _____Children

10. Have you had another premature infant?

Yes _____

No_____

11. If so, was your baby admitted to neonatal intensive care?

Yes _____

No _____

12. Have any of your children been hospitalized other than NICU admission?

Yes_____

No_____

13. Did you have any medical issues/complications during:

a. This pregnancy:

Yes_____

No_____

b. Labor and delivery:

Yes _____

No _____

c. After delivery

Yes _____

No _____

If yes, please describe_____

_____

Appendix B

Demographic Data: Infant Characteristics

1. Days of life:_____days
2. Gestational Age _____weeks
3. Sex: Male _____Female _____Other _____
4. Birth weight:_____grams
5. Current weight:_____grams
6. Method of Delivery (check all that apply):
    a. Normal vaginal delivery _____
    b. Cesarean section _____
    c. Vacuum delivery _____
    d. Forceps delivery _____
7. Admission Diagnosis:
    a. _____
    b. _____
    c. _____
    d. _____
8. Respiratory support at the time of data collection

    Yes _____

    No _____

9. Type of assisted ventilation:

   a. High Frequency ventilation _____

   b. Conventional ventilation _____

   c. NCPAP _____

   d. NC _____

   e. Other, specify: _____

10. Type of nutrition (select all that apply)

   a. NPO_____

   b. TPN _____

   c. Dextrose 10% _____

   d. Formula _____

   e. Human milk _____

11. Mode of enteral feeding(select all that apply)

   a. Gavage _____

   b. Breast _____

   c. Other, specify: _____

12. Umbilical Lines:

   Yes _____

   No _____

If yes, specify: _____

13. Medications:

   1. _____

   2. _____

3. _____

4. _____

5. _____

14. Level of nursery:

II _____

III _____

IV _____

Appendix C

Clinical Risk Index for Babies (CRIB)

Factor	Score
Birthweight (g)	
>1350	0
851–1350	1
701–850	4
⩽700	7
Gestation (wk)	
>24	0
⩽24	1
Congenital malformations*	
None	0
Not acutely life-threatening	1
Acutely life-threatening	3
Maximum base excess in first 12 h (mmol/L)†	
> −7·0	0
−7·0 to −9·9	1
−10·0 to 14·9	2
⩽−15·0	3
Minimum appropriate FIO_2 in first 12 h	
⩽0·40	0
0·41–0·60	2
0·61–0·90	3
0·91–1·00	4
Maximum appropriate FIO_2 in first 12 h	
<0·40	0
0·41–0·80	1
0·81–0·90	3
0·91–1·00	5

*Excluding inevitably lethal malformations.
†For example, −3·0 mmol/L scores 0, −16·0 mmol/L scores 3.

Table 2: **CRIB score**

Appendix D

Parental Perception of Uncertainty Scale

Instructions:

Please read each statement. Take your time and think about what each statement says. Then circle the response that most closely measures how you are feeling about your child TODAY. If you agree with a statement, then you would circle either "Strongly Agree" or "Agree." If you disagree with a statement, then circle either "Strongly Disagree" or "Disagree." If you are undecided about how you feel about your child, then circle "Undecided" for that statement. Please circle your response and respond to every statement.

1. I don't know what is wrong with my child.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

2. I have a lot of questions without answers.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

3. I am unsure if my child's illness is getting better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

4. It is unclear how bad my child's pain will be.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

5. The explanations they give about my child seem hazy to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

6. The purpose of each treatment for my child is clear to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

7. I do not know when to expect things will be done to my child.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

8. My child's symptoms continue to change unpredictably.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

9. I understand everything explained to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

10. The doctors say things to me that could have many meanings.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

11. I can predict how long my child's illness will last.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

12. My child's treatment is too complex to figure out.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

13. It is difficult to know if the treatments or medications my child is getting are helping.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

14. There are so many different types of staff; it's unclear who is responsible for what.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

15. Because of the unpredictability of my child's illness, I cannot plan for the future.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

16. The course of my child's illness keeps changing. He/she has good and bad days.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

17. It's vague to me how I will manage the care of my child after he/she leaves the hospital.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

18. It is not clear what is going to happen to my child.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

19. I usually know if my child is going to have a good or bad day.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

20. The results of my child's tests are inconsistent.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

21. The effectiveness of the treatment is undetermined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

22. It is difficult to determine how long it will be before I can care for my child by myself.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

23. I can generally predict the course of my child's illness.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

24. Because of the treatment, what my child can do and cannot do keeps changing.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

25. I'm certain they will not find anything else wrong with my child.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

26. They have not given my child a specific diagnosis.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

27. My child's physical distress is predictable; I know when it is going to get better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

28. My child's diagnosis is definite and will not change.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

29. I can depend on the nurses to be there when I need them.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

30. The seriousness of my child's illness has been determined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

31. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

Appendix E

Parental Stressor Scale: Neonatal Intensive Care Unit

We are interested in knowing more about the stresses experienced by parents when a premature is sick and hospitalized in a neonatal intensive care unit (NICU). We would like to know about your experience as a parent whose child is presently in the NICU.

This questionnaire lists various experiences other parents have reported as stressful when their baby was in the NICU. We would like you to indicate how stressful each item listed below has been for you. **By stressful, we mean that the experience has caused you to feel anxious, upset, or tense.** On the questionnaire, circle the single number that best expresses how stressful each experience has been for you. The numbers indicate the following levels of stress:

1 = Not at all stressful the experience did not cause you to feel upset, tense, or anxious

2 = A little stressful

3 = Moderately stressful

4 = Very stressful

5 = Extremely stressful

If you have not experienced an item, please circle NA "not applicable"

Now let's take an item for an example: **The bright lights in the NICU**.

If for example you feel that the bright lights in the neonatal intensive care unit were extremely stressful to you, you would circle the number 5 below:

NA 1 2 3 4 **5**

If you feel that the lights were not stressful at all, you would circle the number 1 below:

NA **1** 2 3 4 5

Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in a NICU. We are interested in knowing about your view of how stressful these **SIGHTS AND SOUNDS** are for you. Circle the number that best represents your level of stress. If you did not see or hear the item, circle the NA meaning "Not applicable."

NA = Not applicable
1 = Not at all stressful the experience did not cause you to feel upset, tense, or anxious
2 = A little stressful
3 = Moderately stressful
4 = Very stressful
5 = Extremely stressful

Response choices:

1.	The presence of monitors and equipment	NA	1	2	3	4	5
2.	The constant noises of monitors and equipment	NA	1	2	3	4	5
3.	The sudden noises of monitor alarms	NA	1	2	3	4	5
4.	The other sick babies in the room	NA	1	2	3	4	5
5.	The large number of people working in the unit	NA	1	2	3	4	5

Below is a list of items that might describe the way your **BABY LOOKS AND BEHAVES** while you are visiting in the NICU as well as some of the **TREATMENTS** that you have seen done to the baby. Not all babies have these experiences or look this way, so circle the NA, if you have not experienced or seen the listed item. If the item reflects something that you have experienced, then indicate how much the experience was stressful or upsetting to you by circling the appropriate number.

NA = Not applicable
1 = Not at all stressful the experience did not cause you to feel upset, tense, or anxious
2 = A little stressful
3 = Moderately stressful
4 = Very stressful
5 = Extremely stressful

Response choices:

1.	Tubes and equipment on or near my baby	NA	1	2	3	4	5
2.	Bruises, cuts or incisions on my baby	NA	1	2	3	4	5
3.	The unusual color of my baby (for example looking pale or yellow jaundiced)	NA	1	2	3	4	5
4.	My baby's unusual or abnormal breathing patterns	NA	1	2	3	4	5
5.	The small size of my baby	NA	1	2	3	4	5
6.	The wrinkled appearance of my baby	NA	1	2	3	4	5
7.	Having a machine (respirator) breathe for my baby	NA	1	2	3	4	5
8.	Seeing needles and tubes put in my baby	NA	1	2	3	4	5
9.	My baby being fed by an intravenous line or tube	NA	1	2	3	4	5
10.	When my baby seemed to be in pain	NA	1	2	3	4	5
11.	When my baby looked sad	NA	1	2	3	4	5
12.	The limp and weak appearance of my baby	NA	1	2	3	4	5
13.	Jerky or restless movements of my baby	NA	1	2	3	4	5
14.	My baby not being able to cry like other babies	NA	1	2	3	4	5

The last area we want to ask you about is how you feel about your own **RELATIONSHIP** with the baby and your **PARENTAL ROLE**. If you have experienced the following situations or feelings, indicate how stressful you have been by

them by circling the appropriate number. Again, circle NA if you did not experience the item.

NA = Not applicable
1 = Not at all stressful the experience did not cause you to feel upset, tense, or anxious
2 = A little stressful
3 = Moderately stressful
4 = Very stressful
5 = Extremely stressful

Response choices:

1.	Being separated from my baby	NA	1	2	3	4	5
2.	Not feeding my baby myself	NA	1	2	3	4	5
3.	Not being able to care for my baby myself (for example, diapering, bathing)	NA	1	2	3	4	5
4.	Not being able to hold my baby when I want	NA	1	2	3	4	5
5.	Feeling helpless and unable to protect my baby from pain and painful procedures	NA	1	2	3	4	5
6.	Feeling helpless about how to help my baby during this time	NA	1	2	3	4	5
7.	Not having time alone with my baby	NA	1	2	3	4	5

Thank you for your help!

Feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit.

Appendix F

STAI Form Y-1 Sample Items

SELF-EVALUATION QUESTIONNAIRE STAI Form Y-1

Please provide the following information:

Name_____Date_____S_____

Age_____ Gender (*Circle*) **M F** T_____

DIRECTIONS:

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I am tense	1	2	3	4
4. I feel strained	1	2	3	4
5. I feel at ease	1	2	3	4

Appendix G

Rasch-Derived Center for Epidemiologic Studies Depression Scale

The following questions concerned how you have been feeling recently. For each statement, please indicate how often you have felt this way during the past week. The choices are:

0 = Rarely or none of the time (less than 1 day)
1 = Some or little of the time (1-2 days)

2 = Occasionally or a moderate amount of time (3-4 days)

3 = Most of the time (5-7 days)

1. I was bothered by things that usually do not bother me	0	1	2	3
2. I felt that I could not shake off the blues even with help from my family or friends	0	1	2	3
3. I felt that I was just as good as other people	0	1	2	3
4. I had trouble keeping my mind on what I was doing	0	1	2	3
5. I felt that everything I did was an effort	0	1	2	3
6. I felt hopeful about the future	0	1	2	3
7. I thought my life had been a failure	0	1	2	3
8. I felt fearful	0	1	2	3
9. I felt lonely	0	1	2	3
10. People were unfriendly	0	1	2	3

Appendix H

Recruitment Flyer

UNIVERSITY OF LOUISVILLE
School of Nursing

Volunteers Needed for Research Study

We need participants for a research study
(IRB #12.0267)
"Predictors of Uncertainty, Stress, Anxiety, and Depression of Parents of Preterm Infants in the Neonatal Intensive Care Unit"

Description: I am researching predictors of uncertainty, stress, anxiety and depression in parents of preterm infants admitted in the NICU. Your participation will take about 30 minutes to complete the questionnaires.

You may qualify for this study if you are:

- ⇒ **Parents of a single preterm infant born at or less than 34 weeks gestation and no older than 14 days,**
- ⇒**18 year or older,**
- ⇒**Able to speak, read and write English.**

Parents' participation will add to the body of knowledge in this area that may lead to interventions that may assist parents in coping with having an infant in the NICU

To learn more, contact the Principle Investigator of the study, Maryam Alaradi, at **502-299-0026** or **mialar01@louisville.edu**

Appendix I

Approval Letters

UNIVERSITY OF LOUISVILLE

Human Subjects Protection Program Office
MedCenter One – Suite 200
501 E. Broadway
Louisville, KY 40202-1798
Office: 502.852.5188 Fax: 502.852.2164

DATE: December 23, 2013

TO: Sandra L Smith, Ph.D.

FROM: The University of Louisville Institutional Review Board

IRB NUMBER: 12.0267

STUDY TITLE: Predictors of uncertainty, stress, anxiety, and depression of parents of preterm infants in the neonatal intensive care unit.

REFERENCE #: 329890

IRB STAFF CONTACT: Name: Sherry Block
Phone: 852-2163
Email: slbloc04@louisville.edu

The amendment request has been received by the Human Subjects Protection Program Office and approved by the Chair/Vice Chair of the Institutional Review Board (IRB) on 12/20/2013 through the expedited review procedure according to 45 CFR 46.110(B). The following documents have been reviewed and approved:

Submission Components			
Submission Form			
Form Name		Outcome	
IRB Amendment Form		Approved as Submitted	
Review Response Submission Form		Approved as Submitted	
Study Document			
Title	Version Number	Version Date	Outcome
Research Protocol Dec 12 highlighted	Version 1.0	12/12/2013	
Research protocol Dec 12 clean	Version 1.0	12/12/2013	
Partial Waiver Form Dec 12 highlighted	Version 1.0	12/12/2013	
Partial Waiver Form Dec 12 clean	Version 1.0	12/12/2013	Approved
HIPAA RA Dec 12 highlighted	Version 1.0	12/12/2013	
SBE Informed Consent Dec 12 clean	Version 1.0	12/12/2013	Approved
HIPAA RA Dec 12 clean	Version 1.0	12/12/2013	Approved
SBE Informed Consent Dec 12 highlighted	Version 1.0	12/12/2013	
REVOCATION OF AUTHORIZATION Dec 12 clean	Version 1.0	12/12/2013	Approved

REVOCATION OF AUTHORIZATION Dec 12 highlighted	Version 1.0	12/12/2013	
Informed consent Dec 13	Version 1.0	12/02/2013	
IRB Protocol	Version 1.0	12/02/2013	
Partial Waiver	Version 1.0	11/26/2013	
HIPAA RA	Version 1.0	11/26/2013	
Recruitment Flyer	Version 1.0	11/26/2013	Approved
Inclusion/exclusion criteria	Version 1.0	11/26/2013	
Revocation of Authorization for use and disclosure of health information	Version 1.0	11/26/2013	
The Clinical Risk Index for Babies (CRIB)	Version 1.0	11/24/2013	
The State Anxiety Inventory	Version 1.0	11/24/2013	
Center for Epidemiologic Studies Depression Scale (CES-D)	Version 1.0	11/24/2013	

The modifications include:

1.The study title was changed to "Predictors of uncertainty, stress, anxiety, and depression of parents of preterm infants in the neonatal intensive care unit" based on the recommendation of the dissertation chair and committee to better serve the purpose of the study.
2. The study purpose was expanded to include depression and anxiety as these two variables may be predicted by stress and uncertainty.
3.Inclusion criteria modified:
a.Parents' age changed from 22 year and older to 18 years and older to accommodate the larger sample size and to include adults.
b. Recruitment of infants' day of life was increased from seven days to 14 days. During the pilot study, the investigator found that it was hard to recruit enough participants in the first seven days of life thus the first 14 days of life will be used.
4.A total of three instruments were added to meet the purpose and the aims of the study:
a.The Clinical Risk Index for Babies (CRIB)
b.The State Anxiety Inventory (SAI)short form
c.The Center for Epidemiologic Studies Depression Scale (CES-D)(short form)
5.Study locations: beside Kosiar Children's Hospital, two hospitals were added to accommodate the sample size and to increase generalizability of the study's findings:
a.The University of Louisville Hospital, and
b.Norton Suburban Hospital
6.The sample size increased to 143 pairs to have adequate sampling power.

Please begin using your newly stamped approved documents with any new subjects. The committee will be advised of this action at a regularly scheduled meeting.

If you have any questions, please contact the HSPPO at (502) 852-5188 or hsppofc@louisville.edu.

Thank you for your submission.

Sincerely,

Peter M. Quesada, Ph.D., Chair
Social/Behavioral/Educational Institutional Review Board
PMQ/SLB

University of Louisville Hospital
KentuckyOne Health™

530 South Jackson Street
Louisville, Kentucky 40202

January 8, 2014
Re: Predictors of Uncertainty, Stress, Anxiety, and Depression of Parents of Preterm Infants in the Neonatal Intensive Care Unit

Ms. M. Alaradi
University of Louisville School of Nursing

Dr. S. Smith
Associate Professor, University of Louisville School of Nursing

Dear Ms. Alaradi and Dr. Smith,

On January 8, 2014 the Nursing and Interdisciplinary Research Committee (NIRC) conducted a scientific review of your proposed research study. The committee members determined that there were no threats to internal and external validity of the study, and that the study had the potential to advance scientific knowledge in the field. In addition, the study does not appear to have an adverse fiscal impact on any nursing unit. As a means of follow-up, the NIRC would appreciate an update on you progress the last month of each quarter at their monthly business meeting.

The next step in the approval process is submission in the iRIS system. You may access the iRIS system online at the following web address: http://louisville.edu/research/humansubjects

Once the iRIS submission is complete an electronic copy of your proposal will be received and reviewed by the Human Subjects Protection Program at the University of Louisville. You may contact them at hsppofc@louisville.edu or (502) 852-5188. It will also be reviewed by the Research and Regulatory Affairs Office at Kentucky One Health to determine that the study does not violate any federal regulations. Please contact Stephanie Copeland, in the Research and Regulatory Affairs office for any questions related to that process at stephaniecopeland@kentuckyonehealth.org .

Thank you for advancing the nursing research enterprise at University of Louisville Hospital.

Sincerely,

Reetta Stikes

Reetta Stikes, MSN, RNC-NIC, CLC
Chair, Nursing and Interdisciplinary Research Committee
University of Louisville Hospital
(502) 562-3710
Junest@ulh.org

cc: Stephanie Copeland

KentuckyOne Health™

March 26th, 2014

Sandra Smith

RE: Requested Approval for KentuckyOne Health as a Research Site

University of Louisville IRB# (Please reference this number for correspondence)	**12.0267**
Site	✓ **UNIVERSITY OF LOUISVILLE HOSPITAL (including UofL Hospital/CCB, James Graham Brown Cancer Center/BCC, ULH services in UofL Health Care Outpatient Center/HCOC)** ☐ **JEWISH HOSPITAL & ST. MARY'S HEALTHCARE (including Frazier Rehab Institute, Jewish Hospital, Jewish Hosp Med Ctr East, Jewish Hosp Med Ctr NE, Jewish Hosp Med Ctr South, Jewish Hosp Med Ctr SW, Jewish Hosp Outpatient Ctr, Jewish Hosp Rudd Heart Lung, Jewish Hosp Shelbyville, Our Lady of Peace, Sts Mary & Elizabeth, St Mary Surgery Ctr, Health Resource Ctr, Southern Ind Rehab, Taylor Regional Hosp, VNA Nazareth Home, Jewish Hosp Meade, Jewish Hosp Hand Care)**
T-Account	**N/A**
NCT Number	**N/A**
IDE Number	**N/A**
Project Title:	**Predictors of uncertainty, stress, anxiety, and depression of parents of preterm infants in the neonatal intensive care unit**
Personnel Approved for this Study	**Sandra Smith, Maryam Alaradi**

Sandra Smith,

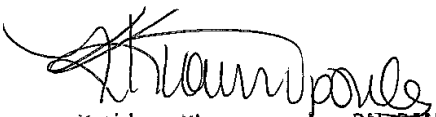
Thank you for submitting your application to conduct research at KentuckyOne Health. The KentuckyOne Health Research Center has completed its review of your submission and it is my pleasure to inform you that Final Institutional Approval has been granted for the project listed above. This study may now be conducted at the KentuckyOne Health sites listed on your IRB application.

Important Investigator Compliance Requirements:

Please note the following requirements and notify the KentuckyOne Health Research Center if you have any questions. Failure to comply with these requirements may result in notification of the IRB. Requested documents should be sent via email to ResearchOffice@kentuckyonehealth.org.

- Research Notification Forms for every subject for every visit.
- Signed Informed Consents
- Human Subjects Protection Training and Conflict of Interest Declaration for all research personnel listed on this study must be updated and provided to the KentuckyOne Health Research Center annually to maintain Institutional approval.
- Any changes to Agreement, Contract or Budgets amendments.
- Any changes in study personnel must be reported to the Research Center.
- Final study closeout/termination information should be sent to the Research Center.
- The Research Center should be provided reports of any outside audits conducted on this project.
- If you have any questions please feel free to email us at researchoffice@kentuckyonehealth.org.

Sincerely,



Kathleen Kioussopoulos, RN, BSN
KentuckyOne Research Center Western Market
KathleenKioussopoulos@catholichealth.net

NORTON® HEALTHCARE
Office of Research Administration (NHORA)

224 E. Broadway
Louisville, KY 40202
(502) 629-3501 Phone
(502) 629-3480 Fax
nhora@nortonhealthcare.org
www.nortonhealthcare.org

January 13, 2014

Sandra Smith, RN, PhD
555 So. Floyd Street
Louisville, KY 40202

NHORA# 12-N0168 / IRB# 12.0267 / Predictors of uncertainty, stress, anxiety, and depression of parents of preterm infants in the neonatal intensive care unit **Amendment**

Dear Smith,

The Norton Healthcare Office of Research Administration (NHORA) is pleased to notify you that your amendment to conduct the above-mentioned research study in the following Norton Healthcare (NHC) facilities has been approved.

- **Kosair Children's Hospital** **Norton Suburban Hospital**

Please note: NHORA approval reflects permission to conduct the study within a Norton Healthcare facility from a regulatory and contractual perspective, and is independent of approval by the sponsor for initiation of the study. The sponsor or site may have additional requirements to address before the study can begin.

The following items must be submitted to the NHORA if your study continues to be conducted in a NHC facility and are applicable to your study:

- **Annual Progress Report/Continuation Review form**
- **Annual Approval letters and current Informed Consent Forms approved by the IRB, if applicable**
- **Amendments and Amendment Approval letters**
- **Revised HIPAA documents such as revised Partial Waivers/Complete Waivers of authorization for each change in personnel**
- **Changes in the Conflict of Interest status**
- **Status change of study, i.e. closed to enrollment, study termination etc.**

To comply with HIPAA regulations:

- **A copy of the Partial Waiver of Authorization must be filed with the medical record of every patient screened for the study, if applicable.**
- **For retrospective chart reviews, a copy of the Complete Waiver of Authorization must be filed with the medical record of every patient whose chart is reviewed for the study.**
- **Studies utilizing the HIPAA "Rule of 50" are exempt from these requirements.**

For studies utilizing an Informed Consent Form, **a signed copy of the Informed Consent Form and Research Authorization must be filed with the medical record of each subject enrolled in your study in a NHC facility.**

If applicable, the Research Patient ID form must be submitted to NHORA Finance daily with reportable activity. Please email the form to NHORAFinance@nortonhealthcare.org. Please contact Julie Gray at (502) 629-3565 for specific instructions regarding the notification of your subject enrollment at NHC.

We look forward to the successful completion of your study. If you have any further questions or need assistance, please contact the NHORA at (502) 629-3501.

Please let us know how we are doing. Follow the link https://www.surveymonkey.com/s/NHORAsatisfaction to complete the NHORA Satisfaction Survey in less than two minutes. Your feedback helps NHORA improve the services we provide and meet the needs of the research community.

Sincerely,

Rhonda A. Hoffman

Rhonda Hoffman
System Director Research

Appendix J

Permissions and Copyrights

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THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

CARRINGTON HALL
CAMPUS BOX 7460
CHAPEL HILL, NC 27599-7460
http://nursing.unc.edu

March 6, 2013

Permission is hereby granted for the use and reproduction of my Perceived Uncertainty in Illness model to Maryam Alaradi, for her dissertation entitled *Relationship Between Uncertainty in Illness and Stress in Parents of Preterm Infants in the NICU* for dissertation and possible publication purposes.

Merle Mishel

RN, PhD, FAAN
Kenan Professor of Nursing

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Jun 13, 2013

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To whom it may concern,

This letter is to grant permission for the above named person to use the following copyright material for his/her thesis or dissertation research.

Instrument: ***State-Trait Anxiety Inventory for Adults***

Authors: ***Charles D. Spielberger, in collaboration with R.L. Gorsuch, G.A. Jacobs, R. Lushene, and P.R. Vagg***

Copyright: ***1968, 1977 by Charles D. Spielberger***

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Sincerely,

Robert Most
Mind Garden, Inc.
www.mindgarden.com

From: Miles, Margaret S [mailto:mmiles@email.unc.edu]
Sent: Monday, August 20, 2012 1:46 PM
To: Alaradi,Maryam Isa
Subject: RE: Request for permission to use PSS: NICU

You have my permission to use the PSS:NICU in your study.

Margaret S. Miles

From: Alaradi,Maryam Isa [mailto:maryam.alaradi@louisville.edu]
Sent: Monday, August 20, 2012 12:34 PM
To: Miles, Margaret S
Subject: Request for permission to use PSS: NICU

Dear Dr. Miles,

My name is Maryam Alaradi, a doctoral nursing student at University of Louisville. I am currently working on a proposal about parental stress in the NICU. I will be using PSS: NICU scale along with other scales. I will be grateful if you advise me on how to obtain a copy of the scale and grant me permission to use it

I look forward to hearing from you

Thank you

Sincerely,

Maryam Alaradi
Doctoral Nursing Student
Graduate Research Assistant
School of Nursing
University of Louisville
600-1193mialar01@louisville.edu
Cell 502 821-2935

CURRICULUM VITAE

MARYAM ALARADI, PhD, NNP-BC, RN

nnp2006@gmail.com

A. Education:

Doctor of Philosophy, August, 2014
University of Louisville, Louisville, Kentucky, USA

Master of Nursing, August, 2006
University of Pennsylvania, Philadelphia, Pennsylvania, USA
Clinical Area: Neonatal Nursing

BSc. Nursing, August, 1998
College of Health Sciences, Manama, Kingdom of Bahrain

Midwifery Diploma, November 1994
College of Health Sciences, Manama, Kingdom of Bahrain

A.D. Nursing, November, 1991
College of Health Sciences, Manama, Kingdom of Bahrain

Practical Nursing Diploma, August, 1989
College of Health Sciences, Manama, Kingdom of Bahrain

B. Academic Appointments

Lecturer, School of Nursing, June-August, 2014

School of Nursing, University of Louisville, Louisville, Kentucky, USA

Graduate Research Assistant, School of Nursing, August, 2010-July 2014

University of Louisville, Louisville, Kentucky, USA

Guest lecturer, School of Nursing, October, November, 2012

Royal College of Surgeons in Ireland-Medical University of Bahrain, Busaiteen, Kingdom of Bahrain

Part-time lecturer, School of Nursing, 2009-2010, Royal College of Surgeons in Ireland - Medical University of Bahrain, Busaiteen, Kingdom of Bahrain

Clinical Instructor, Department of Maternity, 2009-2010

Royal College of Surgeons in Ireland - Medical University of Bahrain, Busaiteen, Kingdom of Bahrain

Clinical Instructor, Department of Maternity, 2006-2010, College of Health Sciences, Manama, Kingdom of Bahrain

C. Other employment:

Nurse Supervisor, NICU, Salmaniya Medical Complex, September-December, 2012
Manama, Kingdom of Bahrain

Nurse Educator, NICU, Salmaniya Medical Complex, 2006-2010
Manama, Kingdom of Bahrain

Nurse Supervisor, NICU, Salmaniya Medical Complex, 2000- 2004
Manama, Kingdom of Bahrain

Acting Nurse Supervisor, L & D, Muharraq Maternity Hospital, 1999-2000
Muharraq, Kingdom of Bahrain

Nurse Midwife, L & D, Muharraq Maternity Hospital, 1994- 1998

Muharraq, Kingdom of Bahrain

Staff Nurse, medical wards, Salmaniya Medical Complex, 1992- 1993
Manama, Kingdom of Bahrain

D. National Board Certification(s) and state RN Licensure(s)

Neonatal Nurse Practitioner Board Certification- National Certification Corporation- Active

S.T.A.B.L.E Provider 2011-2015

BLS for Health Care Provider (CPR-A.E.D) program, American Heart Association, November 2011- Aug 2015

California (RN), 2008- present— Active

Neonatal Nurse Provider (NRP) Regional Instructor, 2005- Present

Bahrain (RN Midwife), 1994- 2006— Inactive

Bahrain (RN), 1992- present — Active

E. Professional Memberships and Activities

Florida Association of Neonatal Nurse Practitioner, 2013- Present

National Association of Neonatal Nurses, 2013-Present

Counsel of Advancement of Nursing Sciences, 2013-Present

Sigma Theta Tau International, the Iota Zeta Chapter, March, 2011-Present

Southern Nursing Research Society (SNRS), January, 2011-Present

Maternity Recruitment Committee, Feb- April, 2010

Neonatal Nursing Council of Nursing Specialization Council for Corporation Council State (NSCCCS) - Head, 2009-2010

NICU Educational Committee - Head, 2006-2010

Academy of Neonatal Nursing, 2006-2009

Maternal/Child Accreditation Team, 2008-2010

Bahrain Nursing Licensure Exams Review Committee, Jan-June 2009

International Nurses Day Symposium and Skills Fair Committee- Chair, March-May, 2009

F. Honors and Awards

Dissertation Completion Award, Summer, 2014, School of Interdisciplinary and Graduate Studies, University of Louisville, Louisville, Kentucky, USA

Graduate Research Assistantship for the years 2010-2014, School of Nursing, University of Louisville, Louisville, Kentucky

Fulbright Scholarship for PhD degree, 2010-2012, AMIDEAST

Ministry of Health Scholarship for Master degree, 2004-2006, University of Pennsylvania, USA

Ministry of Health Scholarship for BSN degree, 1996-1998, College of Health Sciences, Bahrain

Ministry of Health Scholarship for Midwifery diploma, 1993-1994, College of Health Sciences, Bahrain

J. Teaching

a. Undergraduate

2014

Nursing 395 (Summer), lecturer, School of Nursing University of Louisville, Louisville, Kentucky

2010

Nursing 305A (Spring), lecturer, 60 students (2 groups), RCSI-MUB, Bahrain

Nursing 107 (Spring), Guest lecturer, 100 students (4 groups), RCSI-MUB, Bahrain

2009

Nursing 305A (Fall), lecturer, 60 students (2 groups), RCSI-MUB, Bahrain

Nursing 302 (Fall), Guest lecturer, 25 students, RCSI-MUB, Bahrain

H. Abstracts and Presentations

a. Oral Presentations: National/International Meetings

Skin care for premies, Prematurity Awareness Day, Salmaniya Medical Complex, Manama, Bahrain, December 1st, 2012.

Neonatal Resuscitation Provider workshop, Shaikh Khalifa Medical Center, Abu Dhabi, United Arab Emirates, March 7, 2009.

Neonatal Resuscitation Provider and Instructor workshop. National Guard Hospital, Riyadh, Kingdom of Saudi Arabia, June, 2008.

Neonatal Pain Management. 5th Pan Arab Neonatology Conference, Manama, Bahrain. January 15-17, 2008

b. Oral Presentations: Local/Regional Meetings

Alaradi, M. The Lived Experience of Mothers towards their Infants' Pain in the Neonatal Intensive Care Unit. 2014. The 28th Annual SNRS Conference, Saint Antonio, Taxes.

Jackson, B., Lehna, C., **Alaradi, M.,** Ling, J. Enhancing Developmental Care: Dynamics of Parental Behaviors in the Home Environment. 2014. The 28th Annual SNRS Conference, Saint Antonio, Taxes.

Alaradi, M., Smith, S. Relationship between Uncertainty and Stress in Parents of Preterm Infants in the NICU, 2013. The 5th Annual Graduate Research Symposium, Louisville, KY.

Jackson, B., Lehna, C., **Alaradi, M.,** Ling, J. Differences in Children's Home Safety Practices between Families Living in Rural

and Urban Areas. 2013. The 27th Annual SNRS Conference, Little Rock, AR.

Ling, J., **Alaradi, M.,** Jackson, B., & Lehna, C. What Baccalaureate registered nursing students found out from a home safety assignment. 2012. The 26th Annual SNRS Conference. New Orleans, LA, February 22-25, 2012.

Alaradi, M., Mainous, R., Ipsan, C., Myers, J., Adams, G. Impact of Umbilical Artery Catheter Level on Renal and Cerebral Oxygenation in Pre-Term Neonates. Research Louisville, Louisville, KY, October 11, 2011.

Alaradi, M., Mainous, R., Ipsan, C., Myers, J., Adams, G. Impact of umbilical artery catheter level on renal and cerebral oxygenation in pre-term neonates. National Institute of Nursing Research, 25th Anniversary, Washington DC, October 13, 2011.

Neonatal Nursing, Little wonders every day. RCSI Bahrain's first public health awareness conference, Busaiteen, Bahrain. April 15-17, 2010.

I. Grant Funding

a. Research Grants

Sigma Theta Tau International Iota Zeta Chapter Research Fund. March, 2014, $1,000

Ruth Craddock Research Fund. February, 2014, $600

b. Program/Training Grants

A comprehensive Competency-Based Orientation Program. Abbott. February, 2008, $2,085.

J. Publications, Book Chapters, Monographs and Textbooks

a. Publications

Jackson, B., **Alaradi, M.,** Ling, J., & Lehna, C. (2014 ahead of press) Assessment of home safety in children from Kentuckiana. *Pediatric Nursing.*

Alaradi, M. I., & Mainous, R. O. (2012). Guidelines for hypoglycemia screening and intervention in at-risk infants. *Nurse Currents, 6*(1), 1-10.

Featured in:

Brott, S.J. (September/October 2007). ANN members with heart. *News of the Academy of Neonatal Nursing*, *26*(5), 314.

Acknowledged in:

Aljeesh, Y., Alkariri, N., Abusalem, S., Myers, J., & Alaloul, F. (2014). Staff-developed infection prevention program decreases health care: Associated infection rates in pediatric clinical care. *Journal of Nursing Care Quality* (ahead of press).

K. Clinical Practice/Service

2006-2010 Nurse Educator, NICU, Salmaniya Medical Complex, Manama, Bahrain

Provide nursing professional development and education services by supporting neonatal nurses in acquiring the knowledge and skills.

2000- 2004 Nurse Supervisor, NICU, Salmaniya Medical Complex, Manama, Bahrain

Plan and organize activities in NICU. Supervise neonatal nurses. Ensure the availability of items, and equipment necessary to ensure smooth flow of work. Involve in day-to-day problem solving and decision making.

1999-2000 Acting Nurse Supervisor, L & D, Muharraq Maternity Hospital, Muharraq, Bahrain

Take position of unit supervisor in her absence. Plan and organize activities in NICU. Supervise neonatal nurses. Ensure the availability of items, and equipment necessary for a smooth flow of work. Involve in day-to-day problem solving and decision making activities.

1994- 1998 Nurse Midwife, L & D, Muharraq Maternity Hospital, Muharraq, Bahrain

Receive patients in labor, perform physical assessment, observe patients in labor closely, conduct normal vaginal deliveries, assist obstetrician in instrumental and surgical deliveries. Provide immediate postnatal and newborn care.

1992- 1993 Staff Nurse, medical wards, Salmaniya Medical Complex, Manama, Bahrain

Take care of medical patients, administer medications, assist patients perform Activities of daily living, provide health education.