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Los Angeles

Psychological Well-Being of Mothers with Preterm Infants

A dissertation submitted in partial satisfaction of the
Requirements for the degree Doctor of Philosophy
in Nursing

by

Keejeong Cheon

2012

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ABSTRACT OF THE DISSERTATION

Psychological Well-Being of Mothers with Preterm Infants

By

Keejeong Cheon

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2012

Professor Nancy A. Pike, Chair

This dissertation describes an extensive review of the literature, the conceptual framework, and a study that examined the psychological well-being of mothers who have preterm infants admitted to the neonatal intensive care unit (NICU). The goal was to describe maternal psychological well-being from NICU admission to 2 weeks, and identify factors that influence psychological well-being of these mothers. One hundred mothers were recruited from three level III NICUs in the city of Los Angeles. A repeated-measures design was used to assess maternal psychological well-being at two time points (i.e., NICU admission and at 2 weeks). The dependent variables were anxiety symptoms, depression severity, and general well-being. The independent variables were maternal stress (i.e., NICU-related stress and perceived stress), coping strategies (i.e., problem-focused coping and emotion-focused coping), perceived social support, perceived nursing support, and selected sociodemographic characteristics of the mothers (i.e., age, education, race/ethnicity, employment status, income,

marital status, mother's preferred language, parity, prior NICU experience, pregnancy complications, and lactating status at 2 weeks) and the preterm infants (i.e., gestational age, birth weight, morbidity scores at NICU admission and at 2 weeks, and hospital discharge < 2 weeks).

In this sample of predominantly Hispanic mothers of preterm infants, mild anxiety and depression were noted upon admission to the NICU but normalized at 2 weeks, despite normal general well-being scores at both time points. Maternal stress explained the highest percent of the variance for psychological well-being upon admission (anxiety symptoms 43%, depression severity 22%, and general well-being 2%), with the percent slightly reduced at the second time point. Mothers used more emotion- focused coping strategies at admission and more problem-focused coping strategies at 2 weeks. A decrease in emotion-focused coping strategies explained 4-10% of the variance for the decrease in anxiety symptoms and depression severity. An increase in problem-focused coping strategies explained 3% of the variance for the increase in general well-being over 2 weeks. Perceived social support was significantly related to maternal psychological well-being but only accounted for 3-4% of the variance. Perceived nursing support was not a significant predictor of psychological well-being.

Many maternal and infant characteristics were predictors of psychological well-being. The mother's employment status, pregnancy complications, and education were identified as significant predictors, representing 3-15% of the variance for maternal psychological well-being upon NICU admission. At 2 weeks, employment status, education, income, race/ethnicity, prior NICU experience, breastfeeding at 2 weeks, infant morbidity score, and hospital discharge < 2 weeks were predictors for maternal psychological well-being, accounting for 17-51% of the variance.

These findings warrant assessment of maternal psychological well-being, especially

non-Caucasian mothers, as part of family-centered care in the NICU. Future longitudinal studies are needed to assess psychological well-being at more frequent and longer time points after hospital discharge.

The dissertation of Keejeong Cheon is approved.

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CHAPTER ONE

INTRODUCTION

Preterm birth, defined as born at less than 37 weeks' gestation, is the leading cause of infant morbidity and mortality in the United States (Samra, McGrath, & Wehbe, 2011). Preterm infants are at greater risk of complications, such as respiratory distress syndrome, apnea, intraventricular hemorrhage, feeding intolerance, hyperbilirubinemia, and infectious disease, and require prolonged hospitalization in NICUs (Eichenwald, et al., 2010; Kavsek & Bornstein, 2010; Ramanathan, Sekar, Rasmussen, Bhatia, & Soll, 2012; Resch, et al., 2011). Although general infant mortality has declined, the preterm birth rate in the United States has increased over the past decade from 11.6% in 2000 to 12.7% in 2007 (Centers for Disease Control and Prevention [CDC], 2011).

The birth of a preterm infant is a difficult situation for any mother. When an infant is born with health problems and requires hospitalization in the NICU, parents experience intense emotions and psychological distress (Korja, Latva, & Lehtonen, 2012). However, the impact of preterm infant hospitalization in the NICU on maternal coping and psychological well-being is still poorly understood. Understanding the effects of infant hospitalization on maternal psychological status is particularly important because neonatal nurses provide care to preterm infants and their mothers as a family unit. Without an understanding of this phenomenon, nurses may fail to identify mothers at risk.

Maternal Stress and Coping Related to Preterm Birth

Mothers of preterm infants in the NICU experience various degree of stress and negative emotions (Voegtline & Stifter, 2010). Untreated maternal stress is associated with psychological dysfunction, such as anxiety, depression, acute stress disorder, and post-traumatic stress disorder (Miles, Holditch-Davis, Schwartz, & Scher, 2007; Shaw, et al., 2009;

Vanderbilt, Bushley, Young & Grank, 2009). Moreover, prolonged maternal stress leads to low parenting skills, which may have a negative impact on mother - infant attachment, resulting in the infant's abnormal attachment behavior to the mother in early childhood (Voegtline & Stifter, 2010).

Elevated parental stress is associated with less effective coping strategies, which result in an increased perception of a disruption in parenting roles (Singer, et al., 2007). Mothers are stressed due to the alteration in their parenting role, which is perceived to be secondary to infant admission to the NICU. As mothers perceive the NICU experience as stressful, they utilize emotion-focused coping strategies more frequently (D'Souza, Karkada, Lewis, Mayya, & Guddattu, 2009). However, the pattern of the maternal coping process during the first few weeks after NICU admission is unclear.

Psychological Well-Being of Mothers with Preterm Infants

Psychological well-being relates to what degree an individual feels he/she is in control of the life (Abbott, et al., 2006). The psychological well-being of mothers with preterm infants is affected by maternal stress (Meijssen, Wolf, Koldewijin, Baar, & Kok, 2011), but social support from family members and friends help to decrease maternal stress and psychological dysfunction, including anxiety and depression (Nkansah-Amankra, Dhawain, Hussey, & Luchok, 2011). Professional support from NICU staff that is perceived to be satisfactory by these mothers also promotes better maternal psychological well-being (Holditch-Davis, 2011).

Although a number of studies have demonstrated that impaired maternal psychological health lasts several weeks to months after the discharge of the preterm infant, how maternal psychological well-being changes during the first few weeks of NICU admission has not been reported (Carter, Mulder, Bartram, & Darlow, 2007; Holditch-Davis, et al., 2007; Shaw, et al., 2006). The first week of NICU admission has a critical impact on maternal psychological

health, as maternal stress is the highest during this period (Lau & Morse, 2003). However, there is controversy regarding whether or not psychological well-being in previous studies was measured using valid instruments (D'Souza, et al., 2009; Traviss, West, & House, 2011; Van Riper, 2001), as psychological well-being has been operationalized as a level of psychological distress, a part of family functioning, or the nurse-family relationship. Different measures used to evaluate psychological well-being across studies make it difficult to generalize conclusions about the psychological status of mothers with preterm infants in the NICU.

Necessity and Significance of the Study

Several gaps exist in the literature related to maternal stress and coping. First, maternal coping strategies used to overcome stress in the NICU are not clearly identified. Second, the impact of maternal stress, coping strategies, as well as possible changes in psychological responses during the first few weeks of NICU hospitalization have not been assessed longitudinally. Third, maternal psychological well-being has been operationalized as levels of negative psychological functioning (i.e., level of parental stress, depression, worry, family functioning and nurse-family relationship), but positive effects on one's life were not incorporated. Lastly, previous studies on maternal stress, coping, and psychological health were conducted in predominantly middle class, Caucasian populations. Consequently, the results are difficult to generalize to minority populations with diverse socioeconomic backgrounds. This study identified maternal stress, type of maternal coping strategies, perceived social support, perceived nursing support, and psychological well-being of mothers with preterm infants admitted to the NICU over the first 2 weeks. These variables were evaluated at admission and at 2 weeks, which has not been reported previously in the literature. The findings from this study will assist healthcare providers and families to better understand the mothers' needs during their infant's hospitalization, and allow NICU nurses to improve their nursing care plan

to better support mothers of preterm infants.

Statement of Purpose

The purpose of this research was to examine the psychological well-being of mothers with preterm infants who were admitted to the NICU, and assess the changes in the relationships among maternal stress, coping strategies, perceived social support, perceived nursing support, and psychological well-being from admission to 2 weeks. A prospective, repeated-measures design was employed with a sample of ethnically diverse mothers of preterm infants in three level III NICUs in the Los Angeles area. The aims and hypotheses of this study were to:

Aim 1: Examine the impact of the level of maternal stress and type of coping strategies on the psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks.

Hypothesis 1: Mothers with decreased stress and increased use of problem-focused coping strategies will have greater improvement in psychological well-being than other mothers from admission to 2 weeks.

Aim 2: Examine the impact of perceived social support and perceived nursing support on the psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks.

Hypothesis 2: Mothers with greater perceived social support and nursing support will have greater improvement in psychological well-being than other mothers from admission to 2 weeks.

Aim 3: Identify maternal sociodemographic characteristics and infant characteristics that may affect the psychological well-being of mothers with preterm infants in the NICU at 2 weeks from admission.

Hypothesis 3a: The maternal characteristics of younger maternal age, lower socioeconomic status, single marital status, non-English speaking, non-Caucasian, a lack of prior NICU experience, lower parity, pregnancy complications, and non-lactating status will be associated with lower psychological well-being of mothers with preterm infants than other mothers in the NICU 2 weeks after admission.

Hypothesis 3b: The infant characteristics of younger gestational age, lower birth weight, higher infant morbidity score, and infant discharge ≥ 2 weeks will be associated with decreased psychological well-being of mothers with preterm infants than other mothers in the NICU 2 weeks after admission.

Content of Dissertation

The content of this dissertation is organized into six chapters, with this chapter presenting an introduction to the dissertation, highlighting the significance of the study and specific aims. Chapter 2 reviews the literature, including a discussion of the emotional and psychological impact of a preterm infant's hospitalization in the neonatal intensive care unit (NICU), stress, coping, psychological well-being of mothers with preterm infants in the NICU, the influence of social and nursing support on maternal stress, and a critical review of the definition of social support and nursing support. Chapter 3 presents the conceptual framework that guides this study. The conceptual framework for this dissertation is modified from Lazarus and Folkman's stress and coping theory (1984) that guides this study. Chapter 4 discusses the research design, sample, instruments, data collection procedure, statistical analysis for the research aims, hypotheses and human subjects. Chapter 5 discusses the results of the data analysis, including maternal and infant characteristics that influence maternal psychological well-being and the relationship between perceived stress and NICU-related stress, perceived

social support, perceived nursing support, coping strategies, and its impact on maternal psychological well-being are discussed. Lastly, chapter 6 provides an interpretation of the findings, clinical implications, limitations, and recommendations for future research.

Chapter Summary

The hospitalization of a preterm infant in the NICU can be stressful for the mother and consequently impact her psychological health and psychological well-being. The effective use of coping strategies, perceived social support and perceived nursing support may reduce the level of maternal stress. The psychological well-being of mothers with preterm infants in the NICU was explored to identify factors that influence well-being during the first two weeks of NICU admission.

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CHAPTER TWO

REVIEW OF THE LITERATURE

This chapter presents a review of the literature on the association between preterm infant NICU hospitalization and maternal anxiety, depression and psychological well-being that are related to maternal stress, coping, perceived social support and perceived nursing support of mothers with preterm infants.

Emotional Response to Preterm Birth

In 1960, Kaplan & Mason (1960) hypothesized that preterm birth is a crisis that may cause emotional distress to the mother, with poor adaptation resulting in failure to respond to the infant's progress. Since this statement, the emotional responses of parents who have infants in the NICU have been cited in the literature (Aagaard & Hall, 2008; Taubman, Findler, & Kuint, 2010; Voegtline & Stifter, 2010). The parental reactions are presented in negative forms including sadness, worry, helplessness, disappointment, anger, fear, frustration, grief, and guilt (Holditch-Davis, Schwartz, Black, & Scher, 2007). Furthermore, the birth of a preterm infant who is not seriously ill has also been shown to be stressful, and may cause emotional upset, disappointment, alienation, resentment, and concern about survival and long-term outcomes (Mackley, Locke, Spear, & Joseph, 2010). However, little is known about the emotional response of mothers of preterm infants over time, or if it varies according to infant's gestational age.

Maternal Stress Related to NICU Hospitalization

Miles et al. (1993) argued that very few studies attempted to measure the sources of parental stress during the NICU hospitalization and developed the Parental Stress Scale (PSS: NICU), a questionnaire that assesses parental perceptions of stressors encountered during the period of neonatal intensive care. Numerous studies using the PSS: NICU demonstrated which

factors of the NICU experience cause stress in the mothers of sick preterm infants (Denney, Okamoto, Singer, Brenner, & Barkley, 2006; D'Souza, et al., 2009; Frank, Cox, Allen, & Winter, 2005; Lau, Hurst, Smith, & Schanler, 2007; Shaw, et al., 2006; Turan, Basbakkal, & Ozbek, 2008). These factors include an infant's illness and vulnerability, changes in the parental role, and the appearance and behavior of the infant (Shah, Clements & Poehlmann, 2011). Particularly, mothers are most stressed by the altered parental role and feelings of powerlessness at their infants' pain (Axelin, Salanterä, Kirjavainen, & Lehtonen, 2009; Frank, et al., 2005).

The PSS: NICU was used successfully to show that not only infant hospitalization but also the NICU environment can cause parental stress in the mothers of preterm infants. However, the majority of studies that utilized the PSS: NICU paid little attention to mothers' personal stress which refers to a stress that poses a challenge or threat to mothers of preterm infants from their general lives, regardless of the birth and infant hospitalization (Lazarus, 2000). Thus, although it is an excellent instrument to measure maternal stress associated with the NICU environment, the tool lacks the ability to capture the life stress of an individual. Consequently, little is known about the personal stress of mothers with preterm infants in the NICU. Examining both maternal personal stress and stress related to the NICU experience will expand our understanding about maternal stress related to NICU hospitalization.

Maternal Coping Strategies

An individual's reaction to a situation is based on the way it is interpreted by him/herself. Lazarus (1993) stated that cognitive appraisal of the situation is the process by which a person categorizes a situation and its aspects in relation to whether it is potentially threatening or not. The cognitive appraisal process is divided into three categories: primary, secondary and reappraisal. In the primary appraisal process, the individual determines the

situation as being irrelevant, benign, or stressful. In the next phase, secondary appraisal, the person evaluates the situation and suitable reactions. The reaction to the situation is decided by carefully analyzing what is at stake and what can be done to reduce negative consequences. Reappraisal is rethinking the strategy to cope with a situation in view of new information provided by circumstances. This may add to or relieve stress depending on what the new information is. Individuals' cognitive interpretation of stressful events is mediated by different coping strategies, which eventually influences psychological outcomes (Herman & Tetrick, 2009).

Coping strategies are classified as problem-focused coping strategies and emotion-focused coping strategies. The person using problem-focused coping strategies focuses on the cause of stress, on finding information about the problem, and learning skills to manage the problem by changing or eliminating the source of the stress. The individual using emotion-focused coping strategies focuses on reducing the emotions resulting from the stress-inducing situation by distraction or using relaxation procedures. Most people possess several coping strategies for dealing with stress-inducing situations but have a preference for one type of coping strategy (Herman & Tetrick, 2009).

Maternal coping strategies are associated with parental stress; mothers with poor coping strategies have higher psychological distress (Treharne, Lyons, Booth & Kitas, 2008). Individuals who have high levels of parental stress, anxiety and depression utilize emotion-focused coping strategies more frequently than problem-focused coping strategies (Herman & Tetrick, 2009). In contrast, individuals who are advanced in age, less anxious, and believe they have more control over stressful situations tend to use more problem-focused coping strategies and are likely to be more involved in problem-solving activities (Herman & Tetrick, 2009). D'Souza and colleagues (2009) identified the most frequently used problem-coping strategies

and emotion-coping strategies in moderately stressed mothers of preterm infants in the NICU. These strategies include utilizing social support, problem solving, and confrontation as problem-focused coping strategies, and positive appraisal, escape-avoidance, and distancing as emotion-focused strategies. However, maternal coping was assessed only once over a broad range of data collection times, from 1 day to 1 month after the NICU admission. In addition, the coping instrument used in the study did not quantify the frequency of each type of maternal coping strategy used, making it difficult to understand the maternal coping strategy pattern. Moreover, the study sample consisted of well-educated, professional, middle-class Caucasian or Asian women. Thus, these findings may not be generalizable to mothers with different sociodemographic backgrounds. There are very few articles in the literature that address stress and coping strategies of mothers with preterm infants in the NICU. Further studies that capture these data and reflect mothers with more diverse sociodemographic and ethnic backgrounds are needed.

Maternal Anxiety and Depression Related to the NICU Experience

An infant's NICU hospitalization is associated with anxiety and depression in mothers of preterm infants compared with mothers of healthy term infants (Friedman, Yang, Parsons, & Amin, 2011). Anxiety and depression for mothers of preterm infants is intense during the first week of the infant's NICU hospitalization, and gradually decreases by 9-12 months post discharge, but the levels remain higher than those of mothers of healthy term infants for 1 year after birth (Lau & Morse, 2003).

Young preterm infant gestational age, low birth weight, young maternal age, low education level, low income, and lack of support from a husband or partner increase maternal anxiety levels, although these findings are inconsistent across various studies (Carvalho, Linhares, Padovani, & Martinez, 2009; Giakoumaki, Vasilaki, Lili, Skouroliakou, & Liosis,

2009; Traviss, et al., 2011). Maternal depression has been known to be elevated in cases of lower parity, lack of social support, young infant gestational age, and preterm infants in more critical conditions, such as having high morbidity scores and spending more days on a ventilator (Carvalho, et al., 2009; Miles, et al., 2007; Traviss, et al., 2011; Vigod, Villegas, Dennis, & Ross, 2010). Ethnicity is also associated with maternal anxiety and depression. Asian immigrant mothers of preterm infants have more depression and anxiety symptoms compared with Caucasian mothers (Traviss, et al., 2011), and postpartum depression is more prevalent in Hispanic and African American women compared to Caucasian women (CDC, 2011). Lactation has been shown to reduce anxiety and depression levels in mothers of preterm infants (Hart, Jackson, & Boylan, 2011; Hill, Aldag, & Demirtas, 2006; Sisk, Lovelady, Dillard, & Gruber, 2006; Lau, et al., 2007; Yalcin & Orun, 2011; Zanardo, et al., 2011). In addition, mothers of preterm infants with low anxiety and depression are more likely to initiate lactation from the first 2 to 6 weeks postpartum (Hart, et al., 2011; Hill, et al., 2006). Moreover, depressed mothers produce low breast milk volume and show less frequent touch of the infant, with poor positioning at breastfeeding (Hart, et al., 2011).

One consideration in regards to depression in mothers of preterm infants is whether the depressive symptoms resulted from the infant's NICU hospitalization or postpartum depression. Postpartum depression begins within 4 to 6 weeks of childbirth and is diagnosed by depressive symptoms that last more than 2 weeks (Pearlstein & Howard, 2009). Although the symptoms are similar, postpartum depression is distinguished from major depression in that it is related to childbirth and the symptoms are milder. Whereas maternal depression is most commonly observed immediately after NICU admission (Lau & Morse, 2003), the onset of postpartum depression variably appears within 4 to 6 weeks after birth. Thus, screening is performed between 4 to 6 weeks after childbirth (Pearlstein & Howard, 2009). It is likely that mothers

who recently delivered a preterm infant may experience postpartum depression as well as depressive symptoms resulted from preterm infant NICU hospitalization. It has been known that postpartum depression may evolve into major depression (Frank, Trupin, Talavera, & Shulman, 2012). However, it is not clearly understood how, if they coexist, postpartum depression and major depression mutually influence each other (Frank, Trupin, Talavera, & Shulman, 2012). As the current study aims to capture changes in depression symptoms during the first 2 weeks of NICU hospitalization, this query may not be answered. A future study with a longer observation period may explain the possible association between the two disorders.

Maternal anxiety and depression are related to poor mother-infant interaction (Carvalho, et al., 2009). In addition, mothers with more depression symptoms during the NICU stay were more stressed in the NICU, tended to worry more about infant health after hospital discharge, and perceived that their infants were in a more critical condition than indicated by the actual infant morbidity scores (Holditch-Davis, et al., 2007). Interestingly, they also provided more interactions than the mothers of term infants to compensate for the NICU stay (Holditch-Davis, et al., 2007). These findings indicate that a NICU experience that is perceived as stressful may have a negative psychological impact represented by maternal depression and anxiety symptoms. These psychological impacts may lead to ineffective mother-infant relationships, including unresponsive or hyper-responsive mother-infant interaction behaviors after hospital discharge.

The long-term effect of maternal stress on anxiety and depression is well documented months to years after hospital discharge (Carvalho, et al., 2009; Realy, Matthey, Ellwood, & Scott, 2010), but few studies have addressed psychological changes over time starting with the acute phase of the NICU hospitalization. Lau and Morse (2003) stated that maternal anxiety is high while the preterm infants are hospitalized in the NICU. However, data were collected at

different time points: at NICU admission, at 1 week, and at hospital discharge, which varied from 9 days to 1 month. Moreover, the data were collected in a level II NICU, a step-down NICU where the patient acuity is lower than in a level III NICU. Therefore, the results may not be generalizable to mothers of preterm infants in critical conditions. In another study, maternal anxiety and depression were measured in only one interview any time within 3 weeks of NICU admission (Carter, et al., 2007). This may provide information that maternal anxiety and depression increase due to NICU admission of their preterm infants but does not identify the impetus for early psychological intervention for mothers during the first few weeks of NICU admission. This warrants further study.

Psychological Well-Being in Mothers of Preterm Infants

The main interest of past research related to stress and psychological health of mothers with preterm infants has been psychological dysfunction. This research has emphasized negative aspects of psychological health; that is, an absence of illness, rather than the presence of wellness. Similarly, there are numerous studies focusing on maternal anxiety and depression that are related to the NICU experience, but the positive meanings of psychological well-being in this population are rarely discussed in related literature (Singer, et al., 2007).

Psychological well-being research pursues the positive mood and emotions that benefit psychological health (Chida & Steptoe, 2008). The psychological well-being tradition emphasizes the formulation of human development and the existential challenges of life (Abbott, et al., 2006). In the 1950s and 1960s, life-span theories and developmental tasks associated with human growth and development provided the foundation of the psychological well-being perspective (Chida & Steptoe, 2008). However, the concept of psychological well-being was difficult to operationalize due to the absence of a valid measure for the construct. Ryff (1989) proposed a multidimensional model of psychological well-being that defines the

constructs of life challenges in six psychological dimensions: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance.

Psychological well-being is higher in individuals who are younger, more educated and more open to new experiences across gender, occupation, and nationality/ethnicity differences (Abbott, et al., 2006; Treharne, et al., 2008). Conversely, psychological well-being is impaired in people with anxiety, psychological distress, or affective disorders (Herman & Tetrick, 2009). Self-esteem, self-determination, and perception of social support are positively related to psychological well-being in the general adult population, whereas anxiety and depression have negative associations with psychological well-being (Vieira, et al., 2011).

In earlier studies, psychological well-being was evaluated in individuals in non-negative (i.e., neutral or positive) or non-stressful situations, or measured after a stress-reducing intervention (Abbott, et al., 2006; Carmody & Baer, 2008; Ruini, et al., 2003). In a recent study, psychological well-being was measured in a group of patients in negative situations represented by chronic illness. It was found that active coping behaviors buffer psychological distress and depression, and that psychological distress strongly predicts psychological well-being and anxiety (Treharne, et al., 2008). This finding indicates that coping and stress impact both negative (i.e., anxiety and depression) and positive (i.e., psychological well-being) aspects of psychological states. Moreover, psychological well-being is detectable and dynamic in negative situations as well as in positive situations.

Mental health research on the population of mothers with preterm infants has widened its perspective to positive aspects of well-being, with the philosophical notion that an individual's life cannot be truly understood without looking at all aspects of his/her life as a whole (Chida & Steptoe, 2008). Despite the few studies addressing the psychological well-being of mothers with preterm infants (D'Souza, et al., 2009; Traviss, et al., 2011; Van Riper,

2001), it is still questionable whether the psychological well-being of mothers has been operationalized appropriately. The operational definition of psychological well-being should embrace both positive and negative impacts, and be measured by tools that are sensitive to psychological dysfunctions, such as anxiety and depression, as well as an instrument developed to measure positive psychological well-being. Currently, there are no studies in the literature that have attempted to measure both positive and negative characteristics of psychological well-being in a single study. The current study measured both negative and positive characteristics of well-being, represented by anxiety symptoms, depression severity, and maternal general well-being, respectively, in one sample, to provide a better understanding of the psychological well-being of mothers with preterm infants.

Social Support and Maternal Stress

Social support that was perceived as positive relieves a mother's stress related to the parenting of preterm infants during NICU hospitalization (Nkansah-Amankra, et al., 2011). Family members are the primary resource that they seek help from, and mothers of preterm infants report that their spouses are the most helpful resources (Traviss, et al., 2011; Zachariah, 2009). In addition, the support from peers is also effective in reducing parental stress. Mothers of preterm infants who received telephone support from other mothers who had experienced similar circumstances had significantly lower levels of anxiety and depression and greater perceived social support than those who did not receive peer support (Preyde & Ardal, 2003).

However, there is still controversy over defining the support provided by professional nurses as a social support because nursing support is distinguished from social support. First, the support provided socially is not limited to certain types of support (e.g., emotional, informational, or esteem support), but is open to include anything that may aid the recipient. In contrast, the support nursing professionals provide includes informational, emotional, and

esteem support, but nurses do not provide financial support. Second, the relationships in a social support network are usually maintained for longer periods; however, nursing professionals provide support during a short period of time, and the relationship is terminated when the patient is discharged from the hospital. Third, reciprocal trust exists between individuals in a personal relationship; however, the relationship between nursing professionals and the patient/family involves a unilateral trust. Lastly, social obligation is another aspect that differentiates social support and nursing support. When the members of one's natural support network provide social support, social obligation or empathy that originates from kinship such as family relation or friendship is usually observed (Hupcey & Morse, 1997). The support provided by professional nurses needs to be conceptualized separately from social support (Finfgeld-Connett, 2005). Therefore, the literature supports the need for better conceptualization and separate measurements of support provided by healthcare professionals versus social support from family or friends. This study operationalized nursing support as a separate factor from social support to assess the influence of each factor on maternal depression symptoms, anxiety and psychological well-being.

Nursing Support and Maternal Stress

The nurse is in a position to help parents cope with the hospitalization of preterm infants, and to take the parents' emotional reactions as a normal response and lead parents toward healthy coping behaviors (Turan, et al., 2008). Nurses are constantly present in the NICU, and act as gatekeepers who mediate the relationship between the parents and their infants (Montirosso, Provenzi, Calciolari, & Borgatti, 2011). Holditch-Davis and Miles (2000) interviewed 15 mothers of preterm infants and identified that mothers who had positive experiences with nurses in the NICU expressed positive reinforcement. However, mothers with negative experiences stated that the lack of dialogue with the NICU staff and discordant

information aggravated their emotional distress. This finding provides valuable information that good nursing support is crucial in alleviating maternal emotional distress, but may not be generalizable as it reflects subjective feelings of a small sample in a single hospital.

The most important types of nursing supports perceived by mothers of preterm infants include information about infant condition and treatment, assurance from the NICU staff, unlimited visitation, and the ability to watch the staff provide comfort to their infants (Turan, et al., 2008). When mothers feel that the nurse-family interaction is positive and supportive, they are more satisfied with the care they receive in the NICU and have a greater willingness to seek help from NICU staff. In addition, maternal participation in care and frequent visit can potentially lower maternal stress (Carter, et al., 2007). The literature identifies the impact of good nursing support on maternal stress; however, many of the previous studies that addressed nursing support were single site investigations. A multi-center evaluation utilizing reliable and conceptually based instruments of nursing support is needed to provide a more generalizable evaluation of nursing support related to maternal stress. The current study was conducted in three hospitals in the community using separate scales for perceived social support as well as perceived nursing support.

Gaps in the Literature

A comprehensive review of literature identifies several gaps in our knowledge of maternal stress, use of coping strategies, perceived social support, perceived nursing support and psychological well-being in mothers of preterm infants during NICU hospitalization. First, in the majority of studies, maternal stress was measured using the PSS: NICU, which was designed to measure parental stress related to the NICU experience. Therefore, the mothers' personal stress caused from everyday life stress was not conceptualized in previous research using the PSS: NICU. Second, the pattern of coping strategies or the association between use of

coping strategies and state of psychological well-being in mothers of preterm infants was not clearly identified. Third, maternal psychological well-being was rarely discussed in the related literature. Consequently, the maternal psychological well-being state in the NICU or its association with stress, coping, perceived social support, and perceived nursing support is not well understood. Additionally, although maternal stress has been shown to be high in the NICU, possible changes in maternal stress and psychological well-being during the first few weeks of NICU hospitalization has not been examined. This is an important time period in which nursing interventions may impact maternal psychological well-being. Lastly, nursing support was treated as a part of social support in most previous studies despite the difference between these two concepts. Another important limitation of the previous research is that the study results may not be generalized to all populations, as the study participants were predominantly well-educated, middle-class Caucasian women. Research with a culturally diverse sample is rarely identified in the literature. Given these gaps in the literature, a multi-centered study is necessary to provide more generalizable information on perceived social support, perceived nursing support, and maternal psychological states.

Chapter Summary

Preterm infants' admission to the neonatal intensive care unit causes emotional and psychological distress in mothers of preterm infants. Positive perception of social support and nursing support can alleviate maternal stress. Coping strategies utilized by the mothers also affect maternal stress. Psychological well-being in mothers of preterm infants whose child's outcome is uncertain needs to be explored. In addition, a repeated assessment of the relationship between maternal stress, use of coping strategies, perceived social support, perceived nursing support, and psychological well-being during the first few weeks of NICU hospitalization can demonstrate the psychological dynamics in mothers of preterm infants over

time which may have important influence for nursing care.

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CHAPTER THREE

CONCEPTUAL FRAMEWORK

This chapter presents the theoretical framework of stress and coping that provides the foundation for this study. The first section presents an overview of stress and coping theories and their theoretical assumptions. The second section explains the theoretical concepts of the proposed framework.

Overview of Stress and Coping Theory

Stress theories are classified into two different categories: a systemic stress approach that views stress as a result of nonspecific physiological and psychobiological responses and a psychological stress approach (Krohne, 2002). The systemic stress approach was developed based on animal experiments. Thus, the theory does not include human cognitive mediation. This criticism of the systemic stress theory leads to an argument that the stress theory cannot explain a subjective, human experience of being distressed (Krohne, 2002). On the other hand, the psychological stress theory regards stress as a psychological response associated with individuals' evaluation and their efforts to manage specific demands. In this perspective, the stress response should be explained by a different view that incorporates a coping mechanism (Krohne, 2002).

The stress and coping theory (see Fig. 3-1) developed by Lazarus and Folkman (1984) was modified for the conceptual framework of the present study (see Fig. 3-2). The stress and coping theory is a framework for evaluating one's process of coping with stressful events. The central concepts proposed in Lazarus and Folkman's (1984) stress theory include one's stress appraisal and coping effort. The theory claims that understanding an individual's perception and appraisal of stressors is essential in determining whether they create stress.

Stress is conceptualized as a characteristic of the relationship between the individual

and the environment. A stressor is a stimulus that the individual perceives as negative if the person thinks that he/she is inadequate in terms of being able to react to it, which results in stress. The taxation of a situation is mediated by a two-step process. In the first stage, the primary appraisal, the person classifies the stressful situation as a challenge, threat, or harm/loss. In the next stage, the secondary appraisal, the individual evaluates one's competence, social support, and other resources to determine if he or she can cope with the stressor (Lazarus, 1993). Additionally, in the reappraisal process, the individual re-evaluates new information obtained from the environment during the circumstance and capture more long-term emotional responses. Reappraisal is different from rumination in that reappraisal can be utilized as an "adaptive strategy," while rumination is not (Verduy, Van Mechelen, & Tuerlinckx, 2011).

The response to the stressor and the resulting stress is coping, in which the individual selects a specific manner to deal with the stressor. Coping is described as the constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person. A coherent aggregate of varied coping behavior is known as a coping strategy.

The modification of the stress and coping theory in the current study illustrates the relationship between maternal stress and coping. The theory depicts the mother's psychological stress experience related to her preterm infant's illness, uncertainty, and unexpected hospital admission and her coping process during this crisis period (Lazarus, 2000). Furthermore, the framework will explain how the relationship between maternal stress and coping is influenced by nursing/social support in the NICU. The framework will also determine how these variables influence maternal psychological well-being, which to date have not been clearly identified.

This conceptual framework will provide a new perspective concerning mothers who experience stress due to having a preterm infant in critical condition.

Conceptual Assumptions

The underlying assumptions for the conceptual framework of this study are based on the cognitive development theory developed by Piaget (1962). Piaget (1962) claimed that cognitive development is at the center of the human organism and that human intelligence is adaptive. In other words, humans use already acquired intelligence to adapt to and manipulate the dynamic aspect of reality (Santrock, 2008). A person-situation interaction depends on the subjective cognitive judgment that arises from the interplay between the person and the environment (Zakowski, Hall, Klein & Baum, 2001). The assumptions of this study are as follows: 1) humans have the capacity to engage in cognitive appraisal; 2) humans have continuous and reciprocal interaction with the environment; 3) cognitive appraisal occurs through the interaction between the human and the environment; and 4) humans are able to manage situational demands by using cognitive/behavioral tactics.

Maternal and Infant Characteristics

A stressor refers to any environmental, social, or internal demand that requires the individuals to readjust their usual behavior patterns. Life events that require major behavioral readjustments within a relatively short period of time are stressors (Krohne, 2002). The birth of a preterm infant is a stressor to the mother, as she experiences intense emotions. Fear related to the infant's outcome and the mother's ability to care for the infant, as well as the unfamiliar NICU environment have been identified as stressors (Turan, et al., 2008). In general, negative or threatening life events precipitate psychological distress and psychiatric disorders. Particularly, negative life events produce significant increases in emotional problems when the events generate persistent or recurrent strains. That is, events that are continuously stressful or conflicted can elicit the onset of psychological symptoms (Enlow, et al., 2009).

Previous research found several infant demographic characteristics that may influence

maternal stress levels. These characteristics include young gestational age, low birth weight, and length of stay in the NICU (Carter, et al., 2007; Lau, et al., 2007). Maternal stress is also elevated if infants have increased morbidity or are receiving ventilatory support for a prolonged period (Lefkowitz, Baxt & Evans, 2010). In the present study, maternal and infant characteristics are antecedents to maternal stress associated with preterm infant hospitalization in the NICU. Maternal characteristics include mothers' age, race/ethnicity, education, employment status, income, marital status, speaking English, parity, prior NICU experience, health status during pregnancy, and lactating status at 2 weeks. Infant characteristics include infant gestational age, birth weight, morbidity score, and infant discharge < 2 weeks (Carter, et al., 2007; Lau, et al., 2007; Lefkowitz, et al., 2010).

Maternal Stress

The “stress” in the stress and coping theory refers to psychological stress and is defined as “a relationship with the environment that the person perceives as significant for one’s well-being and in which the demands tax or exceed available coping resources” (Lazarus, 2000). In this conceptual framework, maternal stress is categorized into personal stress and NICU-related stress. Personal stress refers to psychological strains that pose a challenge or threat to mothers of preterm infants from their general lives, regardless of the birth and infant hospitalization. Examples include marital problems, financial constraint, or moving and readjustments. NICU-related stress refers to the stress that is limited to preterm infant NICU admission and the NICU environment. Separate instruments that have been validated for each concept were used to measure personal and NICU-related stress. In this framework, maternal stress is defined as the mother’s personal perception of psychological distress from her life in general, as well as the stress related to the hospitalization of her preterm infant.

Coping Strategies

The stress response is a result of a complex set of interactions between a person and the environment. Mediated by cognitive appraisal, coping processes are an individual's response to stressors (Lazarus, 2000). Coping is defined as "a process of managing demands both external and internal that are appraised as taxing or exceeding the resources of an individual" (Lazarus, 1993). This definition indicates that coping is contextual; individuals use different coping strategies to solve given problems. Thus, coping is not determined solely by personal disposition but also by an individual's appraisal of the demands of a particular situation (Compas, Jaser, Dunn, & Rodriguez, 2011).

Lazarus and Folkman (1984) classify coping as problem-focused and emotion-focused. Problem-focused coping is directed at defining a problem, generating alternative solutions, and weighing the options for action in terms of their costs and benefits. Interpersonal conflict resolution, information gathering, and advice-seeking behaviors are examples of problem-focused coping. People with high self-esteem or perceived control are more likely to use problem-focused coping strategies than emotion-focused coping strategies. Emotion-focused coping is used to minimize anxiety, maintain optimism, and reduce the reality of the fact that the event is harmful. Emotion-focused coping is directed primarily at reducing emotional distress. Therefore, the emotion-focused coping strategies are a range of intrapsychic defensive processes, including denial, suppression, or distancing. Individuals with low self-esteem or low perceived control tend to use passive or avoidant emotion-focused coping (Compas, et al., 2011).

Problem-focused and emotion-focused forms of coping can be mutually facilitative. Coping is a shifting process in which an individual should rely on one form of coping strategy, and then change to another as the demands of the situation change. Problem-focused coping

tends to predominate when people feel that something constructive can be done, whereas, emotion-focused coping tends to predominate when people feel that a stressor is something that must be endured (Herman & Tetrick, 2009).

Effective coping decreases maternal stress (Herman & Tetrick, 2009). Further, the association between maternal stress levels and the coping strategies utilized during the acute phase of infant hospitalization in the NICU has been observed. Parents with increased stress use emotion-focused coping strategies, whereas, less stressed parents use problem-focused coping more frequently (D'Souza, et al., 2009). In this study, coping is defined as a psychological process for managing demands appraised as stressors caused by the NICU experience. The instrument used to measure coping strategies in this study includes both problem-focused coping and emotion-focused coping and has been validated for both concepts.

Social Support and Nursing Support

Social support refers to “the individual belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations” (Cobb, 1976), and is defined as “a function performed for the individuals by significant others, such as family members, friends, and coworkers” (Finfgeld-Connett, 2007). Social support is considered as a coping resource, since it is a mechanism by which interpersonal relationships presumably buffer individuals against stressful environments through various types of assistance provided by significant others (Finfgeld-Connett, 2007).

For the past 2 decades, the concept of social support in terms of its role in protecting people from the pathogenic effects of stressful events has been suggested in multiple studies (Finfgeld-Connett, 2007; Griffin, 2006; Nkansah-Amankra, et al., 2011; Traviss, et al., 2011; Zachariah, 2009). However, social support is not always a positive influence in an individual's coping process. Social support is the process of providing and receiving based on interpersonal

exchange. Therefore, social resources may not be useful if an individual is reluctant or unwilling to engage his or her social network if the individual views the network to be not supportive (Clapp & Beck, 2008).

The concept of social support is one of the most frequently addressed variables in nursing literature. The support from professional nurses is often considered a part of social support, but nursing support needs to be distinguished from social support due to its unique factors (Uchino, 2005). Nurses do not provide material support, and the support lasts a short period of time until the patient is discharged from the hospital. In addition, the relationship in nursing support is unidirectional between the support provider and the recipient, and is based on social and legal obligation (Finfgeld-Connett, 2007). Therefore, the support provided by professional nurses needs to be conceptualized separately from social support (Finfgeld-Connett, 2007).

In this conceptual framework, social support is defined as the assistance provided by significant others, such as family members, friends, and coworkers, to overcome psychological stress. Nursing support is defined as the professional assistance (i.e., informational and emotional support) provided by the neonatal nurses in the NICU through nurse-mother communication. Mothers' perception of social support and nursing support were measured by separate instruments that have been validated for each concept (Canty-Mitchell & Zimet, 2000; Pal, et al., 2007).

Psychological Well-Being

The term "psychological health" has been conceptualized in the literature as a perspective of psychological dysfunction or psychological well-being (Ryff & Singer, 1996). Psychological dysfunction often refers to the persons' mental status whereas psychological well-being refers to positive moods and emotions that affect health (Chida & Steptoe, 2008).

Recent psychological health research has evolved into the theoretical framework that a person's position on the dimension of psychological well-being is seen as a result of the individual's position on two independent dimensions: positive affect and negative affect. These two dimensions are related but independent of one another, making it possible to expect the direction of overall self-ratings of happiness or subjective well-being. The greater the excess of positive affect over negative affect, the higher the overall rating of psychological well-being and vice versa (Ruini, et al., 2003).

Ryff's (1989) theoretical framework of a multidimensional model of psychological well-being has contributed to a new psychological well-being instrument that enables an empirical assessment of the positive aspects of functioning, control, and the meaning of people's lives (Angner, 2010). These dimensions include autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance.

In this conceptual framework, maternal psychological well-being incorporates both negative and positive aspects of life, where anxiety symptoms and levels of depression are manifestations of stress and represent negative psychological impacts, and general well-being is defined as an overall self-appraisal of one's life and represents positive aspects of mental status. An in-depth description of the measures used to explore maternal stress, coping, perceived support, and psychological well-being within this conceptual framework is presented in the following chapter.

Chapter Summary

An infant's hospitalization is a life event that triggers a psychological stress response in the mothers of the infant. Mothers are stressed by their cognitive appraisal of infant hospitalization as a threat. Maternal stress may be reduced by social and nursing support. Nursing support is different from social support, and it needs to be operationalized separately.

An individual's perception of support availability influences the coping strategies that the individual will utilize. Stress and coping theory provided the foundation of the conceptual framework in the current study. Additionally, social support theory and the Stress-Buffering Model have been proposed to describe relationships between social support, nursing support, maternal stress and coping.

Figure 3-1. *Lazarus & Folkman (1984) Stress and Coping Model*

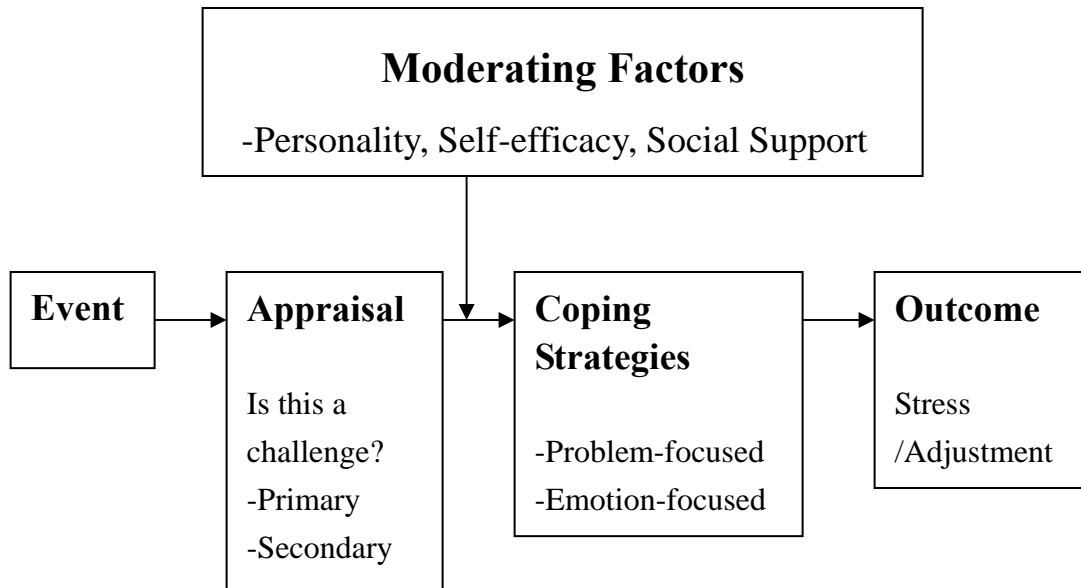
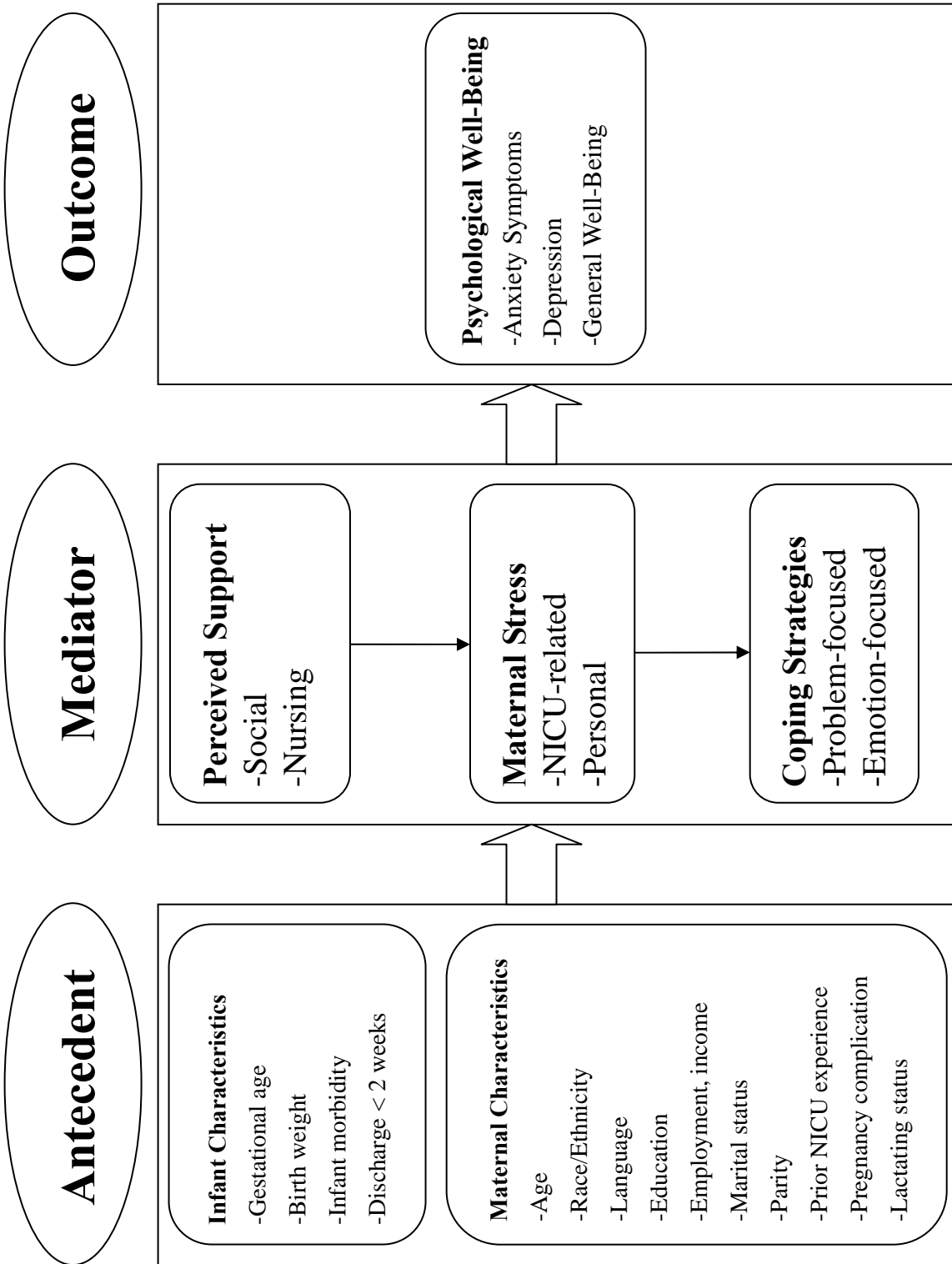


Figure 3-2. Conceptual Framework of the Current Study



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CHAPTER FOUR

METHODS

This chapter presents the methods used to answer the research questions of this study. The study design, study sample and setting, sample selection, protection of human subjects in research, procedure for data collection, study measures, and statistical analysis are described.

Purpose and Aims of the Study

The purpose of the study was to examine maternal stress, coping strategies, perceived social and nursing support, and maternal psychological well-being in mothers of preterm infants admitted to the NICU, and assess the changes in the relationships among these factors from admission to 2 weeks. The major research questions were:

1. How do maternal stress and type of coping strategies influence the psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks?
2. How do perceived social support and perceived nursing support influence the psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks?
3. Which maternal characteristics (i.e., maternal age, socioeconomic status, race/ethnicity, marital status, mother's preferred language, parity, prior NICU experience, mother's pregnancy complication, and mother's lactating status) and infant characteristics (i.e., gestational age, birth weight, infant morbidity, and infant discharge < 2 weeks) influence the psychological well-being of mothers with preterm infants in the NICU?

The research aims were to:

Aim 1: Examine the impact of the level of maternal stress and type of coping strategies on the psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks.

Hypothesis 1: Mothers with decreased stress and increased use of problem-focused coping strategies will have greater improvement in psychological well-being than other mothers from admission to 2 weeks.

Aim 2: Examine the impact of perceived social support and perceived nursing support on the psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks.

Hypothesis 2: Mothers with greater perceived social support and nursing support will have greater improvement in psychological well-being than other mothers from admission to 2 weeks.

Aim 3: Identify maternal sociodemographic characteristics and infant characteristics that may affect the psychological well-being of mothers with preterm infants in the NICU at 2 weeks from admission.

Hypothesis 3a: The maternal characteristics of younger maternal age, lower socioeconomic status, single marital status, non-English speaking, non-Caucasian, a lack of prior NICU experience, lower parity, pregnancy complications, and non-lactating status will be associated with lower psychological well-being of mothers with preterm infants than other mothers in the NICU 2 weeks after admission.

Hypothesis 3b: The infant characteristics of younger gestational age, lower birth weight, higher infant morbidity score, and infant discharge ≥ 2 weeks will be associated with decreased psychological well-being of mothers with preterm infants than other mothers in the NICU 2 weeks after admission.

Study Design

This study employed a prospective, repeated measures design that compared maternal

psychological states, including perceived stress levels, type of coping strategies used, perceived social support, perceived nursing support, and psychological well-being of mothers with preterm infants in the NICU, at the time of NICU admission and once again at 2 weeks.

Study Sample and Setting

This study was carried out in three level III NICUs across the Los Angeles area. Approval for recruitment was sought prior to data collection from Hollywood Presbyterian Medical Center (HPMC), Good Samaritan Hospital (GSH), and Los Angeles County-University of Southern California (LAC-USC) Medical Center. These three hospitals were selected to provide a diverse ethnic sample for this study. GSH is a mix of Hispanic, Korean, and Caucasian patients, LAC-USC serves predominantly Hispanic and African American patients, and HPMC is a mix of Hispanic and Caucasian patients.

Sample Selection

The calculated sample size was 95 at the confidence interval of 10% and with a 95% confidence level. Additionally, power analysis was performed for medium effect size with a 0.05 Type I error and 80% power. The estimated sample size was 45. This study employed repeated measures; therefore, the risk of dropout at the second data collection point was a concern. We planned to recruit more than the minimum necessary sample size to account for the potential attrition rate. Anticipated drop out was 20. Taking this into account, the target sample size for this study was 100.

There was no age restriction for participating mothers. The inclusion criteria were: 1) preterm infants < 37 weeks' gestation; 2) admitted to the NICU for medical treatment within the past 72 hours; and 3) mothers who spoke English or Spanish. The exclusion criteria were: 1) mothers who had multiple gestations (e.g., twins, triplets); and 2) mothers with severe cognitive impairment.

Protection of Human Subjects in Research

University human subject protection approval was obtained from the University of California, Los Angeles Institutional Review Board and from the three recruitment sites used in this study (see Appendix A). The principal investigator completed the Collaborative Institutional Training Initiative and the Health Insurance Portability and Accountability Act certification.

This is a descriptive, repeated-measures design and was expected to have minimal risk associated with participation in this study. Due to the nature of the questionnaires which may evoke negative emotions, the Principal Investigator (PI) planned to contact a social worker, the primary care physician of the study participant, or the on-call psychiatrist immediately if the mother showed any signs of negative psychological responses (i.e., severe psychological distress, anxiety symptoms, or depression score ≥ 15). None of the participants required psychiatric specialist referral. Each subject received \$30 compensation upon completion of study, which was a minimal amount that reduces the possibility of monetary coercion of study participation. All participants were informed that: 1) study participation was voluntary; 2) information provided in the questionnaires and results of the study would be used solely for scientific purposes; 3) the care of her infant would not be compromised if she refused to participate; 4) they had the right to decline to answer any questions or to withdraw from the study at any time, and 5) their telephone number or address might need to be accessed from the medical records for follow-up of study questionnaire completion or if questionnaires needed to be mailed home. Written explanation of the study objectives, protocol and researcher affiliation was provided in the informed consent process.

All personal information was coded and recorded to protect the patient's anonymity. Electronic data was stored in a computer that has password protection software. A hard copy of

data including personal or private identifiable data was stored in a locked room with limited access by the PI. After the study was completed, all data files were stripped of personal or private identifiers.

Procedure for Data Collection

The General Well-Being Schedule (GWB) and the Nurse Parent Support Tool (NPST) are not available in Spanish and were translated and back-translated independently by two different certified Spanish translation specialists. The population in this study included low-educated mothers. Therefore, the entire questionnaire was reviewed by a group of three Spanish-speaking mothers and two English/Spanish bilingual mothers. The meaning or interpretation of the construct, readability, and cultural appropriateness were assessed and the questionnaires were revised accordingly.

Before data collection, the PI met with neonatologists and nurse practitioners at the recruitment sites to discuss the study protocol and methods for contact regarding potential study subjects. Neonatologists or nurse practitioners provided a verbal study introduction to the mother. In addition, subjects were recruited in response to hospital fliers and brochures placed in the family lounge (see Appendix B). When the mother agreed to meet the PI to discuss the study further, the PI approached her to assess eligibility, discuss the study, and obtain informed consent. If eligible, the PI had a 10- minute meeting with the mother and obtained informed consent. During the informed consent disclosure, all participants were asked if they were able to read and provide written answers to questions in a questionnaire in their primary language of English or Spanish, or if they needed assistance in filling out questionnaires to ensure adequate ability to understand the information disclosed and sign the consent form. Each participant completed a packet of questionnaires within the first 3 days of NICU admission and again at 2 weeks. Each set of questionnaires took approximately 30 to 60 minutes to complete.

If the infant was discharged prior to the second data collection, the PI called the mother and mailed the questionnaires with a self-addressed, stamped envelope. The PI gave the mother a reminder call in a week if the questionnaires were not returned. All questionnaires were checked for completeness upon return. The PI called the mother again for the missing items when unanswered items were found. Upon completion of both sets of questionnaires, the mothers received a \$30 gift card in appreciation of their time and participation. The PI collected the infant data from the medical records at 2 weeks to obtain the full spectrum of infant morbidity over 2 weeks. Clinical data for infant demographic characteristics, gestational age, birth weight, diagnosis, and clinical condition were obtained from the bedside chart, progress notes, and nursing flow sheet review (see Appendix C-1).

Study Measures

Infant morbidity.

The Expanded Neonatal Morbidity Scale is an instrument used to measure preterm infant' severity of illness by the most common disease or pathophysiological states in the NICU (see Appendix C-2). Fifteen infant medical conditions are assessed (e.g., intracranial hemorrhage, convulsion, pneumothorax, sepsis, etc.), and the severity of each condition is rated on a 3-point scale. Possible scores range from 0 to 45, with higher scores indicating that the preterm infant is in a more critical condition. For example, sepsis is scored as 0 for either not having the disease or antibiotics given only for suspected infection, 1 for mild infection with positive cultures or severe infection well controlled with antibiotics, and 2 for sepsis confirmed by positive blood cultures with elevated white blood cells. The instrument was evaluated for reliability ($\alpha = .87$), and predictability ($r = .57, p < .001$) in 89 preterm infants born between 24 to 36 weeks' gestation, assessing infant outcomes (i.e., completion of immunization course without complication, weight gain, and hospital readmission rate) 6 months after hospital

discharge (Pleasure, Gennaro, Cnaan, & Wolf, 1997). In this study, the tool had good reliability (Cronbach's α .733).

Sociodemographic data.

Maternal and infant demographic background was obtained by a standardized form structured by the PI (see Appendix D-1). Maternal age, race/ethnicity, education, employment status, income, mother's language, marital status, parity, prior NICU experience, and mother's health status related to this pregnancy were included in the form. Maternal demographic data were collected once at the time of NICU admission. Additionally, mothers' lactating status, defined as whether the mother was breastfeeding or pumping breast milk for her preterm infant, was checked once at 2 weeks after NICU admission. Maternal perception of stress, type of coping strategies, perception of social support, perception of nursing support, and psychological well-being of mothers with preterm infants was collected by repeated measurements (i.e., at NICU admission and at 2 weeks after NICU admission). Maternal psychological well-being was operationalized as anxiety symptoms, depression severity, and general well-being, measured by instruments for each concept. A questionnaire packet in either English or Spanish was provided depending on respondent preference.

Psychological well-being.

Anxiety symptoms - Brief Symptom Inventory (BSI).

The original BSI (Derogatis & Melisaratos, 1983) is a 53-item scale to evaluate typical symptoms of psychiatric disorders, which was later modified by Lange et al. (2009) for anxiety symptom screening in the primary care setting (see Appendix D-2). It is a self-administered questionnaire that comprises six items (i.e. three general anxiety and three phobic anxiety items) with a 5-point Likert-scale (0 = not at all, 1 = a little bit, 2 = moderately, 3 = quite a bit, and 4 = extremely). This tool has been tested for its good internal consistency (α = .85) and

high test-retest reliability ($r = .91$) in 18-60 year-old adult patients in a psychiatric clinic (Lange, Norman, Means-Christensen, & Stein, 2009). Scores range from 0 to 24, with higher scores indicating more anxiety. This tool is popular in mental health research, and is used in various populations. In relation to the present study, the scale was tested in mothers of healthy term and preterm infants for its high internal consistency ($\alpha = .83$) (Farrow & Blissett, 2006). The scale is available in English and Spanish; the Spanish version has been validated with moderate to high internal consistency ($\alpha = .72$ to $.84$) (Pereda, Forns, & Pero, 2007). In this study, the instrument showed high reliability (Cronbach's $\alpha .89$).

Depression symptoms severity - Patient Health Questionnaire mood scale (PHQ-9).

This scale is designed based on Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition criteria to evaluate severity of depressive symptoms during the prior 2 weeks (see Appendix D-3). It is a 9-item, 4-point Likert scale self-report (0 = not at all, 1 = several days, 2 = more than half the days, and 3 = nearly every day), with higher scores indicating more depressive symptoms. Each item can score from 0 to 3 with possible sum scores from 0 to 27. The total scores are interpreted by using the guide that: 1) the patient may not need treatment with scores of 4 or less; 2) the physician uses clinical judgment for treatment of scores of 5 to 14; and 3) the patient warrants treatment for depression for scores of 15 or higher. The scale has been validated in 506 mothers who were 12 years of age or older and had given birth within a month, and showed good sensitivity (82%) and specificity (84%) for major depression (Gjerdingen, Crow, McGovern, Miner & Center, 2009). The Spanish version has also been validated and had excellent sensitivity (77%) and specificity (100%) in Hispanic adult women with diverse backgrounds (Wulsin, Somoza & Heck, 2002). In this study, the instrument had reliability (Cronbach's $\alpha .74$).

Psychological well-being - General Well-Being Schedule (GWB).

The GWB, originally developed by Dupuy (1978) and modified to a shorter version of 10 items by Ulin (1981), is a broad-ranging indicator of subjective feelings of psychological well-being and distress (see Appendix D-4). The instrument has 10 items, with 6-point Likert-type scale with various scale anchors on each question. The scale reflects six dimensions of positive and negative feelings: positive well-being (two items), depression (two items), anxiety (three items), and behavioral-emotional control (three items). Scores range from 0 to 60, with higher scores indicating more positive psychological well-being. Ulin (1981) suggested the cutting points to represent three levels of psychological well-being: 1) scores of 0 to 30 reflect severe distress; 2) 31 to 38 as moderate distress; and 3) 39 to 60 reflect psychological well-being. The instrument was validated in an adult population (age range: 20-69 years) at a psychiatric outpatient clinic (McDowell, 2009). Internal consistency of the GWB is moderate to high with Cronbach's alpha coefficient range of .69 to .85 (McDowell, 2009). The GWB schedule has not been tested in women of preterm infants, and is available only in English. Therefore, the tool was translated from English version to Spanish, and back-translated from Spanish into English by two different certified translators, and the meaning of the construct was checked with a group of five Spanish-speaking mothers in the community prior to data collection. In this study, the instrument showed reliability, with Cronbach's α of .81 for the English version and Cronbach's α of .80 for the Spanish version.

Stress.

Perceived stress from NICU environment - Parental stress scale: NICU (PSS:NICU).

The PSS: NICU (Miles, Funk, & Carlson, 1993) is a 26-item, self-report scale that assesses parental perceptions of stressors arising from the physical and psychosocial environment of the NICU (see Appendix D-5). The scale comprises three dimensions of the NICU environment: 1) sights and sounds in the NICU, 2) infant appearance, and 3) parent role

and relationship with baby. The parent is asked to rate each item on a 5-point Likert-type scale (1 = not at all stressful, 2 = a little stressful, 3 = moderately stressful, 4 = very stressful, and 5 = extremely stressful). The sum of total responses on the items is divided by the items that have been responded to. Possible scores range from 1 to 5, with higher scores indicating greater stress. The PSS: NICU has been used in numerous studies of 20-45 year-old Caucasian and Asian mothers of preterm infants (Frank, et al., 2005; Reid & Bramwell, 2003; Shaw, et al., 2006; Turan, et al., 2008). The scale has demonstrated moderate to excellent internal consistency, with Cronbach's alpha ranging from .77 to .96 and a test-retest reliability from .69 to .87 (Miles, et al., 1993; Frank, et al., 2005; Shaw, et al., 2006). The PSS: NICU has both English and Spanish versions. In this study, the instrument showed excellent reliability (Cronbach's α .90).

Personal stress from life - Perceived stress scale (PSS).

The PSS (Cohen, 1983) is a 4-item, self-report instrument measuring the degree to which situations in one's life are appraised as stressful (see Appendix D-6). The scale comprises four items with a 5-point Likert-type scale (0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, and 4 = very often). Scoring is the sum of the rated items with reversing positive items (0 = 4, 1 = 3, 2 = 2, 3 = 1, and 4 = 0) indicating overall stress levels. Possible scores range from 0 to 16, with high scores indicating a greater stress level. The PSS was tested in postpartum women between 18 to 42 years of age for its internal consistency, with Cronbach's ranging from .73 to .86 (Miura & Griffiths, 2004). The PSS is available in multiple languages and is used globally. The Spanish version has high reliability, with Cronbach's of .81 in general adult populations (Remor, 2006). In this study, the instrument showed good reliability (Cronbach's α .70).

Coping strategies.

Brief COPE inventory.

The Brief COPE is a revised version of the COPE inventory (Carver, Scheier, & Weintraub, 1989). It is a multidimensional, 28-item, 4-point Likert scale measure of coping strategies (1 = I haven't been doing this at all, 2 = I've been doing this a little bit, 3 = I've been doing this a medium amount, and 4 = I've been doing this a lot) (see Appendix D-7). The scale comprises 14 problem-focused coping strategies (i.e., active coping, planning, using instrumental support, acceptance, positive reframing, humor, and venting) and 14 emotion-focused coping strategies (i.e., using emotional support, behavioral disengagement, denial, religion, substance use, self-distraction, and self-blame). The scores range from 14 to 56 for both problem-focused and emotion-focused coping strategies. The scale is interpreted by summing the scores of answered items in each dimension (i.e. problem-focused versus emotion-focused), with higher scores indicating greater intensity of use of the coping strategy (Schnider, Elhai, & Gray, 2007). The scale has good internal consistency, with Cronbach's α ranging from .80 to .88, although it has not been evaluated in mothers of preterm infants (Schnider, et al., 2007). The tool also is available in Spanish and was tested in 17-35 year-old English-Spanish bilingual college students. The Spanish version was adequate to use, with 78% correlation with the English version (Perczek, Carver, Price, & Pozo-Kaderman, 2000). In this study, the instrument showed high reliability (Cronbach's α .88).

Support.

Social support - The Multidimensional Scale of Perceived Social Support (MSPSS).

This is a 12-item scale (Zimet, Powell, Farley, Werkman, & Berkoff, 1990) to measure perceived support from family, friends, and significant others (see Appendix D-8). Each item is on a 7-point Likert scale (1 = very strongly disagree, 2 = strongly disagree, 3 = mildly disagree, 4 = neutral, 5 = mildly agree, 6 = strongly agree, and 7 = very strongly agree). Scores are

calculated the by sum of responses on the items and divided by the items responded to. Possible scores range from 1 to 7, with higher scores indicating more perceived support. The scale has previously been tested for validity and reliability in pregnant women and adolescents. The internal consistency is well established, with Cronbach's from .85 to .91 and test-retest reliability from .72 to .85 (Canty-Mitchell, & Zimet, 2000). The Spanish version was tested in Mexican-American high school students and has been validated for internal consistency ($\alpha = .86$) (Edwards, 2004). In this study, the instrument had excellent reliability (Cronbach's $\alpha .93$).

Nursing Support - The Nurse Parent Support Tool (NPST).

This tool was developed by Mile and colleagues (1999) to measure parental perception of nursing support during child hospitalization (see Appendix D-9). It consists of 21 items and a 5-point Likert rating classified into four subscales, including: 1) information giving and communication support (nine items); 2) emotional support (three items); 3) esteem support (four items); 4) quality care-giving support (five items). Scores are obtained by summing the items that were responded to and then dividing by the number of items answered. Possible scores range from 1 to 5, with higher scores reflecting greater perceived support from the nursing staff. The tool has been tested in parents of preterm infants hospitalized in the NICU in several studies, and has shown good internal consistency ($\alpha = .85$ to $.96$) (Davis, Edwards, Mohay & Wollin, 2003; Mok & Leung, 2006; Pal, et al., 2007). The NPST is not available in Spanish and no reliability report for a Spanish version has been evaluated in prior studies. Therefore, the original tool was translated and back-translated from English to Spanish by two independent translators and reviewed by a group of five Spanish-speaking mothers in the community prior to data collection. In this study, the instrument showed the reliability, with Cronbach's α of .93 for the English version and .90 for the Spanish version.

Statistical Analysis

The statistical analyses used for this study include descriptive statistics, chi-square tests, multivariate analysis of variance, general linear model repeated-measures analysis of covariance, and multiple linear regression models. Data were analyzed with SPSS 19.0 (IBM, 2011). Descriptive statistics of frequency and percentage were used for categorical variables (i.e., maternal education, employment status, income, marital status, mother's language, parity, prior NICU experience, mother's health status during pregnancy, and lactating status), and mean and standard deviation was used for continuous variables (i.e., infant gestational age, birth weight, infant morbidity scores, maternal age, maternal perceived stress, perceived social support, perceived nursing support, and psychological well-being including anxiety symptoms, depression severity and general well-being scores). All data were checked for assumptions of each analysis model to verify that the data were appropriately analyzed. Multivariate analysis of variance and chi-square tests were used to check statistical differences in demographic variables for mothers and infants among the three hospitals. General linear model repeated-measures analysis of covariance, with hospitals as a covariate was used to assess changes in outcome variables, including maternal psychological well-being, perceived social support, perceived nursing support, and types of coping strategies over 2 weeks.

Preterm infants' severity of illness increases with lower gestational age (Darnall, Ariagno & Kinney, 2006), and late preterm infants born at 34 to 36 weeks gestation have been reported to have lower morbidity and mortality compared to infants younger than 34 weeks' gestation (Darnall, et al., 2006). Therefore, the sample was further divided into two groups and compared as mothers of infants < 34 weeks' gestation and infants born at 34-36 weeks' gestation. These two groups were considered as a factor and analyzed by a general linear model repeated-measures analysis of variance. Aims 1 through 3 were analyzed by multiple linear

regression models. Variables that were found to have bivariate significance of $p < .05$ or variables that were considered theoretically important were included in a multivariate analysis using a forward entry method.

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CHAPTER FIVE

RESULTS

This chapter presents the results of this study which include the sample characteristics of the mother and infant, mean scores for psychological well-being (anxiety symptoms, depression severity and general well-being) and other independent variables (maternal stress, maternal coping strategies and perceived social support, and perceived nursing support), and changes in maternal psychological well-being over two time periods (i.e., at admission and at 2 weeks follow-up) during the preterm infant's NICU hospitalization. The results of testing each hypothesis were examined using correlations and general linear model repeated-measures analysis to identify predictors of psychological well-being in mothers of preterm infants on admission and at 2 weeks, and identified which predictors change over time.

Sample Description

One hundred and eighty-eight mothers of NICU infants were identified as eligible for the study. Of these, 127 mothers agreed to participate and provided written informed consent between April 12, 2011 and September 26, 2011 (68% consent rate). Sixty-one mothers declined to participate due to various reasons, which included: lengthy questionnaires, emotionally overwhelmed, or lack of time to participate in the study. Out of the 127 subjects that consented to participate, one subject was excluded due to infant death before 2 weeks, eight subjects withdrew study participation during the first round of data collection or before the second data collection time point, and 18 mothers did not complete the required study materials because they were lost to follow-up after hospital discharge (21% attrition rate). A total of 100 subjects completed both data time points: 40 from the GSH, 33 from the LAC-USC, and 27 from the HPMC (see Fig. 5-1).

The 27 subjects that withdrew (n = 8) or dropped out (n = 19) had a mean maternal age

of 28.8 ± 5.9 years, were predominantly Hispanic (72%) and low income (77.8%), unemployed (55.6%), educated at the 12th grade or less (61.1%), and single (66.7%). Their infants had a gestational age of 34.8 ± 0.9 weeks and a mean birth weight of 2532 ± 460.6 grams. Independent *t*-test and chi-square test showed no significant differences in maternal demographic variables and infant morbidity scores compared to the 100 study participants. However, the 26 infants, excluding the one infant who died, were more likely to be older than 34 weeks' gestation and had a higher mean birth weight than the entire sample. In addition, these infants were more likely to be discharged before the 2-week follow-up time point. Consequently, gestational age and birth weight were significantly higher in these 27 subjects than in the study sample (see Table 5-1).

The study sample was further analyzed to assess for homogeneity across the three hospital sites using chi-square test and analysis of variance. There were no significant differences found in maternal and infant characteristics among the three study sites (see Table 5-2).

Maternal characteristics.

Demographic characteristics of the mothers who participated in the study are listed in Table 5-3. Mean maternal age was 29.8 ± 6.4 with a range of 17 to 44 years of age. The sample was mostly Hispanic (62%), unemployed (59%), with low income (67%), high school education or higher (67%), and English speaking (67%). Seventy-four percent were married or living with partners, and 44% experienced pregnancy complications. In addition, 55% had parity > 1 (i.e., one or more prior children) and 16% had prior experience in the NICU. The majority of mothers (74%) practiced breastfeeding at 2 weeks.

Infant characteristics.

The preterm infants' clinical characteristics in this study are listed in Table 5-4.

Preterm infants were born at a mean gestational age of 31.7 ± 3.3 weeks with a mean birth weight of 1848 ± 731.1 grams. Nearly half of the infant sample was male (56 %), and born by Caesarian section (51%). The infant sample had moderately high Apgar scores at both 1 minute (6.7 ± 2.2) and 5 minutes (7.9 ± 1.8). The infants had a low mean morbidity score at admission (4.7 ± 3.1) with scores ranging from 0 to 14, and at 2 weeks (2.0 ± 2.4) with scores ranging from 0 to 12, out of a possible morbidity score range of 0 to 45. In addition, the majority of the infants (81%) was hospitalized for greater than 2 weeks and completed the second data collection while in the hospital.

Descriptive Statistics at NICU Admission and at 2 Weeks

The dependent variables (i.e., maternal anxiety symptoms, depression severity, and general well-being), and independent variables (i.e., NICU-related stress, perceived personal stress, problem-focused coping, emotion-focused coping, perceived social support, and perceived nursing support) were measured at two time points (i.e., NICU admission and again at 2 weeks). Means, standard deviations, percentages, score ranges and general linear models for repeated measures were calculated for the 100 subjects that completed both data time points.

Dependent variables (anxiety, depression, and general well-being).

The BSI- anxiety subscale was used to measure anxiety symptoms (score range of 0 to 24). The mean maternal anxiety symptoms score was mildly elevated at admission (6.5 ± 5.3), and significantly reduced at 2-week time point (4.0 ± 4.2 , $p = .008$). The PHQ-9 was used to measure depression severity (score range of 0 to 27, with 4 or less = mild depression; 5-14 = moderate depression; and scores ≥ 15 severe depression). Mild depression was identified on

admission (4.3 ± 3.6) and decreased at 2 weeks ($3.9 \pm 2.3, p = .065$). Despite mild anxiety symptoms and depression identified in these mothers on admission, GWB (score range of 0 to 60, with score > 39 indicates positive psychological well-being) remained positive at admission (47.2 ± 9.1) and further improved at 2 weeks ($49.8 \pm 7.3, p = .004$) (see Table 5-5).

Independent variables (maternal stress, coping strategies, and perceived social / nursing support).

Maternal stress was differentiated between NICU-related stress (score range of 1 to 5) and personal stress (score range of 0 to 16). NICU-related stress significantly decreased from admission (2.6 ± 0.8) to 2 weeks ($2.2 \pm 0.7, p = .000$), but personal stress did not improve over time (4.7 ± 3.0 at admission vs. 4.4 ± 2.9 at 2 weeks, $p = .325$).

Use of problem-focused coping strategies and emotion-focused coping strategies were measured using the Brief COPE inventory, with possible scores ranging from 14 to 56 for each type of coping. On admission, mothers were found to use more emotion-focused coping (27.4 ± 6.4) than problem-focused coping ($25.9 \pm 6.1, p = .000$). However, at 2 weeks mothers used more problem-focused coping (31.2 ± 7.8) than emotion-focused coping ($23.7 \pm 7.0, p = .000$).

Perceived social support (MSPSS) scores and perceived nursing support (NPST) scores can range from 1 to 7 and 1 to 5, respectively. Compared to the level of perceived social support at admission (5.7 ± 1.0), mothers perceived significantly more social support at 2 week-time point ($6.2 \pm 0.6, p = .000$). The same was true for perceived nursing support at admission (4.1 ± 0.6) and at 2 weeks ($4.4 \pm 0.6, p = .008$) (see Table 5-5).

Comparison between gestational age groups.

The study sample was further analyzed by stratifying the groups into gestational age groups to assess for differences in psychological well-being in mothers with preterm infants < 34 weeks' gestation (n = 60) compared to mothers with preterm infants \geq 34 weeks gestation (n = 40).

When analyzing for changes over time in the dependent variables, mothers of infants \geq 34 weeks' gestation experienced higher anxiety symptom scores at admission than mothers of infants < 34 weeks (8.0 \pm 6.4 vs. 5.6 \pm 4.1, respectively, $p = .002$). Anxiety symptom score significantly decreased in both groups at 2 weeks, but the score did not differ between two groups (3.8 \pm 4.4 vs. 4.1 \pm 4.0, respectively, $p = .243$). Depression scores were higher in mothers of infants < 34 weeks' gestation than in those of older infants both at admission (4.7 \pm 3.7 vs. 3.9 \pm 2.3, $p = .150$) and at 2 weeks (4.0 \pm 2.4 vs. 3.8 \pm 2.3, $p = .150$), but no statistical significance was found between the groups. Although not statistically significant, general well-being scores were higher in mothers of infants \geq 34 weeks gestation than in those of infants < 34 week's gestation both at admission (45.9 \pm 9.9 vs. 49.3 \pm 6.4, respectively, $p = .312$) and at 2 weeks (49.3 \pm 6.4 vs. 50.7 \pm 8.4, respectively, $p = .312$).

Specific Aim 1

Aim 1: To examine the impact of the level of maternal stress and type of coping strategies on the psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks.

Correlations of maternal stress, coping and psychological well-being.

Pearson's product moment correlation coefficients were computed on the dependent variables of psychological well-being (i.e., anxiety, depression, and general well-being) and the

independent variables of stress and coping strategies to determine the strength and direction of the relationship (see Table 5-6).

At admission, anxiety symptoms score was positively related to depression ($r = .460, p < .01$), personal stress ($r = .640, p < .01$), and NICU-related stress ($r = .464, p < .01$). Depression was positively related to personal stress ($r = .460, p < .01$) and NICU-related stress ($r = .337, p < .01$), while general well-being was negatively related to depression ($r = -.306, p < .01$) and NICU-related stress ($r = -.325, p < .01$). At the 2-week time point, anxiety symptoms score was positively related to depression ($r = .320, p < .01$) and NICU-related stress ($r = .470, p < .01$). Depression was also positively related to personal stress ($r = .292, p < .01$), while general well-being was negatively related to anxiety ($r = -.391, p < .01$), depression ($r = -.374, p < .01$), NICU-related stress ($r = -.345, p < .01$), and emotion-focused coping ($r = -.241, p < .05$).

Overall, maternal anxiety symptoms, depression severity, and general well-being were significantly related to NICU-related stress, personal stress, problem-focused coping strategies, and emotion-focused coping strategies. Therefore, these variables were entered as predictors for maternal psychological well-being (i.e., anxiety, depression, and general well-being) in the multiple linear regression models.

Maternal stress, coping, and psychological well-being.

A multiple linear regression model was used to examine stress and coping as predictors for psychological well-being, and to assess a possible association between changes in maternal stress, coping, and psychological well-being at 2 weeks from admission to the NICU (see Table 5-7).

Predictors of two time points.

Maternal psychological well-being (i.e., anxiety symptoms, depression severity, and

general well-being) was affected by both NICU-related stress and personal stress over 2 weeks. At admission, the predictive model associated with maternal anxiety symptoms and depression was NICU-related stress and personal stress, accounting for 43% ($F = 38.726, p = .000$) and 22% ($F = 14.953, p = .000$) of the variance, respectively. However, general well-being was not significantly associated with stress or coping.

At 2 weeks, 25% of the variance in maternal anxiety symptom was explained by NICU-related stress and personal stress ($F = 27.792, p = .000$). NICU-related stress, personal stress and emotion-focused coping accounted for 16% of the variance in depression ($F = 7.433, p = .000$) and 31% of the variance in general well-being ($F = 15.863, p = .000$), respectively (see Table 5-7).

Predictors of change over time.

Changes in anxiety symptoms, depression severity, general well-being, NICU-related stress, personal stress, and coping strategies over time were examined by calculating the difference between scores at admission and the 2-week follow-up. This created a new variable that was coded and entered into the regression model.

A decrease in maternal anxiety symptoms was predicted by a decrease in emotion-focused coping with only 5% of the variance explained ($F = 6.009, p = .016$). That is, compared to others, mothers who used less emotion-focused coping at 2 weeks had greater improvement in anxiety symptoms at 2 week-time point. The model predicting a decrease in maternal depression severity was predicted by a decrease in personal stress and emotion-focused coping accounting for 10% of the variance ($F = 6.745, p = .022$). That is, compared to others, mothers who had less personal stress levels and used more problem-focused coping at 2 weeks had greater improvement in depression severity at 2 week-time point. An increase in general well-being was predicted by an increase in problem-focused coping ($F = 3.928, p$

= .049), but only 3% of the variance was explained. That is, compared to others, mothers who used more problem-focused coping at 2 weeks had greater improvement in general well-being at 2 week-time point (see Table 5-7).

Hypothesis.

Hypothesis 1: Mothers with decreased stress and increased use of problem-focused coping strategies will have greater improvement in psychological well-being than other mothers from admission to 2 weeks.

Hypothesis results.

As NICU-related stress and personal stress decreased at 2 weeks compared to admission, the maternal anxiety symptom score was decreased and general well-being score was increased at 2 weeks. The depression score decreased over 2 weeks without statistical significance. Maternal stress predicted maternal psychological well-being at both time points. Although coping strategies did not predict maternal psychological well-being at admission, emotion-focused coping strategies predicted depression severity and general well-being at 2 weeks. Interestingly, a decrease in emotion-focused coping strategies predicted decreased anxiety symptoms and depression severity. An increase in problem-focused coping strategies predicted increased general well-being. These results suggest that decreased maternal stress and increased use of problem-focused coping strategies improve maternal psychological well-being, which supports hypothesis 1.

Specific Aim 2

Aim 2: To examine the impact of perceived social support and perceived nursing support on the psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks.

Correlations of maternal perceived support and psychological well-being.

Pearson's product moment correlation coefficients were computed on the dependent variables of psychological well-being (i.e., anxiety, depression, and general well-being) and the independent variables of perceived social support and perceived nursing support to determine the strength and direction of the relationship (see Table 5-6).

At admission, anxiety symptoms score was not significantly correlated with perceived social support or perceived nursing support. Depression severity was negatively related to perceived social support ($r = -.220, p < .05$), while general well-being was positively related to perceived social support ($r = .201, p < .05$). At the 2 week-time point, neither anxiety symptom score nor depression severity had a significant relationship with perceived social support or perceived nursing support. General well-being was positively related to perceived social support ($r = .200, p < .05$).

These findings demonstrate that maternal depression and perceived social support have time-specific correlations with perceived social support, which disappears at the 2-week follow-up. Maternal general well-being was significantly correlated with perceived social support at both admission and 2 weeks. Although there was no significant correlation between maternal anxiety symptoms and perceived social support, the perceived social support variable was entered as a predictor for maternal psychological well-being (i.e., anxiety symptoms, depression severity, and general well-being) in multiple linear regression models due to its theoretical importance. Similarly, perceived nursing support showed no significant correlation with maternal psychological well-being, but this variable was entered into the predictive model for maternal psychological well-being.

Maternal perceived support and psychological well-being.

Multiple linear regression models were used to examine perceived social support and perceived nursing support as predictors for psychological well-being, and possible association

between changes in perceived support and maternal psychological well-being over 2 weeks (see Table 5-8).

Predictors of two time points.

Perceived social support was a predictor of anxiety symptoms, depression severity, and general well-being both at admission and at the 2-week time point. At admission, perceived social support predicted anxiety symptoms ($F = 3.213, p = .045$), depression severity ($F = 5.226, p = .024$), and general well-being ($F = 4.122, p = .045$). However, only 3% to 4% of the variance could be explained by these models. At 2 weeks, perceived social support had an extremely weak but significant association with maternal psychological well-being. That is, perceived social support predicted anxiety symptoms ($F = 4.075, p = .046$), depression severity ($F = 5.006, p = .028$) and general well-being ($F = 4.116, p = .045$) but only explained 3% of the variance (see Table 5-8).

Predictors of change over time.

Changes over time in perceived social support and perceived nursing support were computed and entered as predictors for change in maternal psychological well-being in the multiple regression models. A decrease in maternal anxiety symptoms was predicted by an increase in perceived social support ($F = 3.312, p = .048$), however, only 3% of the variance can be explained. That is, compared to others, mothers who perceived more social support at 2 weeks had greater improvement in anxiety symptoms at 2 week-time point. Change in maternal depression severity or general well-being was not significantly associated with a change in perceived social or nursing support (see Table 5-8).

Hypothesis.

Hypothesis 2: Mothers with greater perceived social support and nursing support will have greater improvement in psychological well-being than other mothers from admission to 2

weeks.

Hypothesis results.

Perceived social support showed a significant association with maternal psychological well-being over time. More specifically, anxiety symptoms and depression severity were predicted by perceived social support, with a negative association at both time points. General well-being was predicted by perceived social support, with a positive association at both times. Perceived nursing support had no significant association with maternal psychological well-being variables at either time points. A decrease in maternal anxiety symptoms was predicted by an increase in perceived social support; however, neither depression nor general well-being was significantly associated with change in perceived social or nursing support. Therefore, hypothesis 2 is only partially supported.

Specific Aim 3

Aim 3: To identify maternal sociodemographic characteristics and infant characteristics that may affect the psychological well-being of mothers with preterm infants in the NICU at 2 weeks from admission.

Correlations of maternal and infant characteristics and psychological well-being.

Pearson's product moment correlation coefficient for continuous variables and Spearman's rank correlation coefficients for categorical variables were computed on the dependent variables of psychological well-being (i.e., anxiety, depression, and general well-being) to determine the strength and direction of the relationship with maternal and infant characteristics (see Table 5-6).

At admission, anxiety symptoms score was negatively related to employment status ($r = -.354, p < .01$). Depression severity was negatively related to gestational age ($r = -.203, p < .05$), birth weight ($r = -.256, p < .05$), morbidity ($r = -.209, p < .05$) and education ($r = -.205,$

$p < .05$). General well-being was positively related to gestational age ($r = .235, p < .01$), discharge < 2 weeks ($r = .293, p < .01$), and negatively related to morbidity ($r = -.222, p < .05$). At the 2-week time point, anxiety symptom was negatively related to employment status ($r = -.306, p < .00$) and infant discharge < 2 weeks ($r = -.254, p < .05$), and positively related to morbidity score ($r = .232, p < .05$). Depression severity was negatively related to education ($r = -.232, p < .05$) and positively related to morbidity ($r = .259, p < .01$).

These findings indicate that maternal education, employment status, infant gestational age, birth weight, morbidity score, and discharge before 2 weeks were significantly related to maternal anxiety, depression, and general well-being. Therefore, these variables were entered as predictors for maternal psychological well-being (i.e., anxiety symptoms, depression severity, and general well-being) in multiple linear regression models. Although not found to be statistically significant here, based on the literature review and observational experience, income, marital status, mother's preferred language, prior NICU experience, pregnancy complications, and lactating status at the 2 week-time point were also entered as predictor variables in the regression models. Infant characteristics that were entered into the regression model included gestational age, birth weight, morbidity score, and infant discharge < 2 weeks.

Maternal and infant characteristics and psychological well-being.

Multiple linear regression models using a stepwise method examined maternal and infant characteristics as predictors for maternal psychological well-being at both time points and changes in maternal psychological well-being over time (see Table 5-9).

Predictors of two time points.

At admission, anxiety symptoms score was negatively predicted by employment status ($F = 9.048, p = .004$), accounting for 15% of the variance. That is, unemployed mothers had higher anxiety symptom scores than mothers working full-time or part-time at admission.

Depression severity was positively predicted by pregnancy complications and negatively predicted by maternal education ($F = 6.259, p = .003$), accounting for 10% of the variance. That is, mothers who had pregnancy complications and lower education levels had more severe depressive symptoms than mothers without pregnancy complications and with higher education levels at admission. General well-being was positively predicted by gestational age ($F = 4.556, p = .036$), accounting for 4% of the variance. That is, mothers of preterm infants born at older gestational age had higher general well-being scores than mothers of preterm infants born at younger gestational age at admission (see Table 5-9).

At 2 weeks, anxiety symptoms score was negatively predicted by employment status, infant discharge < 2 weeks, education, lactating at 2 weeks, and prior NICU experience ($F = 8.972, p = .000$), explaining 47 % of the variance. That is, mothers who were unemployed, non-lactating, and with lower education levels, no prior NICU experience and preterm infants who were not discharged from the NICU at 2 week-time point had worsening anxiety symptoms at 2 weeks, compared to mothers working full-time or part-time, lactating, with higher education levels, prior NICU experience, and preterm infants who were discharged from the NICU < 2 weeks. Depression severity was negatively predicted by income and infant gestational age, and positively predicted by race/ethnicity and infant morbidity ($F = 12.792, p = .000$), with 51% of the variance explained. That is, maternal depressive symptom was worsening in Hispanic mothers with lower income, and preterm infants of younger gestational age and higher morbidity score, compared to non-Hispanic mothers with higher income, and preterm infants with older gestational age and lower morbidity scores. General well-being was positively predicted by education, employment status and infant discharge < 2 weeks ($F = 7.406, p = .000$), accounting for 17% of the variance. That is, general well-being score was higher in mothers who were working full-time or part-time, with higher education levels, and preterm

infants who were discharged from the NICU < 2 weeks, compared to mothers who were unemployed, with lower education levels, and preterm infants who were not discharged at 2 week-time point (see Table 5-9).

Predictors of change over time.

Predictors for change in maternal psychological well-being over 2 weeks were identified. A decrease in anxiety symptoms score was negatively predicted by the mother's preferred language, prior NICU experience, gestational age, and positively predicted by race/ethnicity ($F = 6.939, p = .000$), accounting for 21% of the variance. That is, at 2 week-time point maternal anxiety symptom was improved more significantly in Hispanic mothers who preferred Spanish as their primary language, with prior NICU experience, and preterm infants of older gestational age, compared to non-Hispanic mothers who preferred English as their primary language, with no prior NICU experience and preterm infants of younger gestational age. A decrease in depression severity was negatively predicted by pregnancy complications and marital status, and positively predicted by mother's preferred language ($F = 4.116, p = .006$), with 10% of the variance explained. That is, at 2 week-time point depression severity was improved more significantly in mothers who were married or single living with a partner, without pregnancy complications, and preferred English as their primary language, compared to mothers who were single living without a partner, with pregnancy complications, and preferred Spanish as the primary language. Change in general well-being was positively predicted by employment status and education ($F = 8.054, p = .001$), accounting for 14% of the variance. That is, at 2 week-time point general well-being score was improved more significantly in mothers working full-time or part-time and with higher education levels, compared to unemployed mothers with lower education levels (see Table 5-9).

Hypothesis.

Hypothesis 3a: The maternal characteristics of younger maternal age, lower socioeconomic status, single marital status, non-English speaking, non-Caucasian, a lack of prior NICU experience, lower parity, pregnancy complications, and non-lactating status will be associated with lower psychological well-being of mothers with preterm infants than other mothers in the NICU 2 weeks after admission.

Hypothesis 3b: The infant characteristics of younger gestational age, lower birth weight, higher infant morbidity score, and infant discharge ≥ 2 weeks will be associated with decreased psychological well-being of mothers with preterm infants than other mothers in the NICU 2 weeks after admission.

Hypothesis results.

Maternal characteristics that were identified as predictors of psychological well-being at admission were employment status, education, and pregnancy complications. Maternal characteristics that were found as predictors of psychological well-being at 2 weeks include employment status, income, race/ethnicity, education, prior NICU experience, and lactating status at 2 weeks. Maternal characteristics that were identified as predictors for 2-week changes of psychological well-being include education, employment status, race/ethnicity, language, prior NICU experience, marital status, and pregnancy complications.

Employment status was negatively associated with anxiety symptoms and depression severity scores both at admission and 2 weeks, indicating that unemployed mothers experienced worsening anxiety and depression symptoms at admission and 2 weeks, compared to mothers working full-time or part-time. However, employment status was positively associated with general well-being at 2 weeks, indicating full-time or part-time working mothers experienced more improved general well-being at 2 weeks. Similarly, education was negatively associated with anxiety symptoms and depression severity both at admission and 2 weeks, but positively

associated with general well-being at 2 weeks. This indicates that women with a lower education level experienced worsening anxiety symptoms and more severe depression at admission and 2 weeks, but women with higher education levels experienced more improved general well-being at 2 week-time point. In addition, employment status and education were positively associated with 2-week change in general well-being, indicating that mothers working full-time or part-time and with higher education levels experienced a greater improvement in general well-being over two weeks than unemployed mothers with lower education levels. Income was negatively associated with depression severity at 2 weeks, indicating mothers who had lower income had worsening depression severity at 2 weeks, compared to mothers with higher income.

Minority race/ethnicity was associated with depression at 2 week-time point, revealing that Hispanic mothers experienced worsening depression at 2 weeks compared to non-Hispanic mothers. Additionally, the mother's preferred language was associated negatively with 2-week change in anxiety symptoms, and positively with 2-week change in depression severity. That is, Spanish-speaking mothers experienced greater improvement in anxiety symptoms at 2 weeks, whereas English-speaking mothers experienced greater improvement in depression severity at 2 weeks. Along with mother's preferred language, race/ethnicity was positively associated with the 2-week change in anxiety symptom score. That is, Hispanic mothers experienced greater improvement in anxiety symptoms at 2 weeks compared to non-Hispanic mothers.

Pregnancy complications and marital status were negatively associated with a 2-week change in depression severity. That is, compared to others, mothers who were married or living with a partner and with no pregnancy complications experienced greater improvement in depression severity over 2 weeks. Lactating status at 2 weeks was negatively associated with anxiety symptoms, indicating that non-lactating mothers had worsening anxiety symptoms than

lactating mothers at 2 weeks. However, maternal age did not predict maternal psychological well-being. Taken together, the results demonstrated that hypothesis 3a was partially supported.

Infant characteristic that was identified as predictors of maternal psychological well-being at admission include infant gestational age. However, more infant characteristics were identified as predictors of maternal psychological well-being. These predictors include gestational age, infant morbidity score and infant discharge < 2 weeks. Infant characteristic that was found as predictors of 2-week change in maternal psychological well-being include gestational age.

Gestational age was associated positively with general well-being at admission, and negatively with depression severity at 2 weeks. That is, mothers with preterm infants of older gestational age experienced higher levels of general well-being at admission, and their depression severity was improved at 2 weeks, compared to mothers with preterm infants of younger gestational age. Infant discharge < 2 weeks was associated negatively with anxiety symptoms and positively with general well-being at 2 weeks. This indicates that at 2-week time point mothers with preterm infants who were not discharged from the NICU at 2 weeks experienced worsening anxiety symptoms and general well-being, compared to mothers with preterm infants who were discharged from the NICU < 2 weeks. Infant morbidity was positively associated with depression severity at 2 weeks, suggesting that mothers of preterm infants with lower morbidity score experienced more significant improvement in depression severity at 2 weeks, compared to mothers of preterm infants with higher morbidity score. Additionally, gestational age was negatively associated with a 2-week change in anxiety symptoms, indicating that mothers with preterm infants of older gestational age experienced a greater improvement in anxiety symptoms over the 2 weeks.

Maternal characteristics, such as employment status, income, education, marital status

race/ethnicity, mother's preferred language, pregnancy complications, prior NICU experience, and lactating status at 2 weeks were identified as predictors for maternal anxiety symptoms, depression severity, and general well-being. Infant gestational age, morbidity score, and hospital discharge < 2 weeks were also identified as predictors of maternal anxiety symptoms, depression severity and general well-being. However, birth weight did not predict maternal psychological well-being. Taken together, these results indicate that hypothesis 3b was partially supported.

Chapter Summary

This chapter presents the finding of the study. Hypotheses were tested using correlations, multivariate analysis of variance repeated measures, multiple linear regression models using 3 outcome variables and predictor variables.

Study Aim 1 examined the impact of the level of maternal stress and type of coping strategies on psychological well-being of mothers with preterm infants in the NICU from admission to 2 weeks. Hypothesis 1 was supported with maternal stress (i.e. NICU-related and personal) being positively associated with worsening maternal anxiety and depression severity at admission and 2 weeks, and negatively associated with improved general well-being at 2-week time point. In addition, a decrease of emotion-focused coping strategies was a positive predictor for improved anxiety symptom and depression severity over 2 weeks. An increase of problem-focused coping strategies was a positive predictor for improved general well-being over 2 weeks.

Study Aim 2 examined the association between perceived social support and perceived nursing support with maternal psychological well-being. Hypothesis 2 was partially supported by the significant negative association between perceived social support and anxiety symptoms and depression severity both at admission and 2 weeks, and positive association between

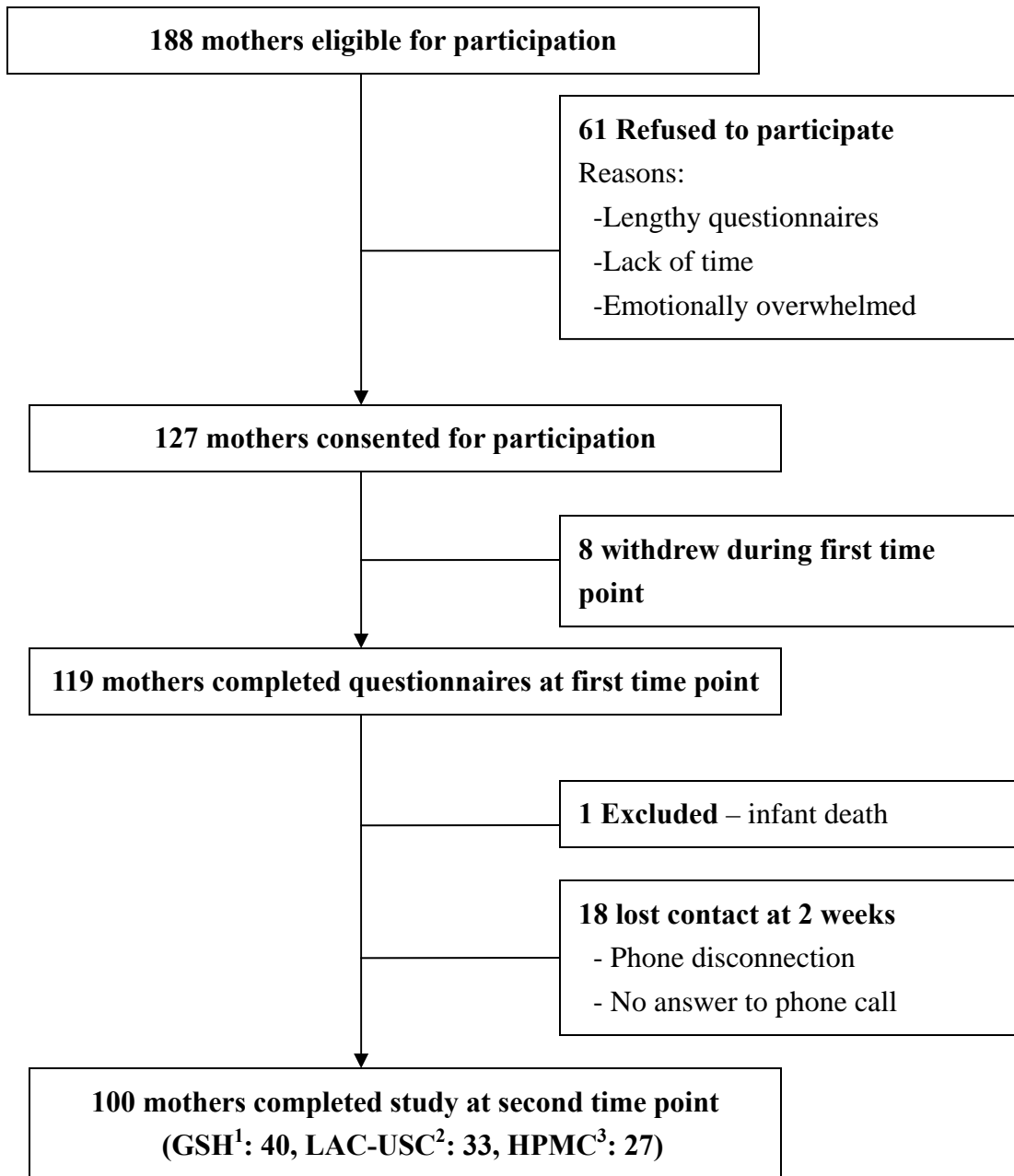
perceived social support and general well-being at admission and 2 week-time point. Perceived social support accounted for 3 to 4 % of the variance in anxiety symptoms, depression severity and general well-being both at admission and 2 weeks.

Study Aim 3 consisted of two hypotheses related to the possible predictive relationship between 1) maternal characteristics and maternal psychological well-being, and 2) infant characteristics and maternal psychological well-being. Hypothesis 3a was partially supported by identifying maternal characteristics predictors accounting for 10% to 51% of the variance in maternal psychological well-being: 1) employment as a negative predictor for anxiety symptoms and depression severity, and positive predictor for general well-being at admission and 2 weeks, 2) income was a negative predictor for depression severity at 2 weeks, 3) education as a negative predictor for anxiety symptoms and depression severity, and positive predictor for general well-being both at admission and 2 weeks, 3) race/ethnicity (i.e., Hispanic) as a positive predictor for depression severity at 2 weeks, 4) pregnancy complications as a positive predictor for depression at admission, 5) lactating at 2 weeks as a negative predictor for anxiety symptom at 2 weeks, 6) prior NICU experience as a negative predictor for anxiety symptom at admission, and 7) marital status as a negative predictors for a decrease in depression severity. Additionally, mother's preferred language was a predictor for 2 weeks change: Spanish-speaking mothers had more significantly decreased anxiety symptom scores, and English-speaking mothers had more significantly decreased depression severity score.

Hypothesis 3b was partially supported by identifying infant characteristics predictors contributing approximately 4% to 10% of the variance in maternal psychological well-being: 1) infant gestational age as a positive predictor for anxiety symptoms at admission, and also a positive predictor for depression severity at 2 weeks, 2) morbidity as a positive predictor for

depression severity at 2 weeks, and 3) infant discharge < 2 weeks as a negative predictor for anxiety symptom and a positive predictor for general well-being at 2 weeks.

Figure 5-1. Study Sample Recruitment Flow Diagram



¹Good Samaritan Hospital, ²Los Angeles County-University of Southern California, ³Hollywood Presbyterian Medical Center

Table 5-1. Maternal/Infant Characteristics between Study Sample and Sample of Attrition

Variable	n (%) or mean \pm SD ¹		F	p	Pearson's χ^2	df	Asymp.Sig. (2 sided)
	Study Sample (n = 100)	Attrition (n = 27)					
Maternal age	29.8 (\pm 6.4)	28.8 (\pm 5.9)	0.586	0.446			
Race/Ethnicity							
Hispanic	62 (62%)	25 (96%)					
Asian/Pacific Islander	20 (20%)	1 (0.4%)			3.399	4	0.493
Black	9 (9%)	-					
White	7 (7%)	-					
Other	2 (2%)	-					
Employment					4.282	4	0.369
Unemployed	59 (59%)	11 (42%)					
Full-time	20 (20%)	5 (19%)					
Part-time	14 (14%)	4 (15%)					
Other	7 (7%)	8 (24%)					
Education					6.114	4	0.191
< 12 th grade	33 (33%)	10 (38%)					
High school/GED	29 (29%)	7 (27%)					
1-3 years college	15 (15%)	6 (23%)					
\geq Bachelors degree	23 (23%)	3 (12%)					
Income					10.064	5	0.073
< \$30,000	67 (67%)	14 (53%)					
\$30,000 – \$49,999	17 (17%)	7 (27%)					
\$50,000 – \$79,999	5 (5%)	5 (20%)					
\geq \$80,000	11 (11%)	-					
Language					0.236	1	0.602
English	67 (67%)	15 (58%)					
Spanish	33 (33%)	11 (42%)					
Marital Status					1.322	1	0.250
Married	52 (52%)	10 (38%)					

(table continues)

¹ Standard deviation

Table 5-1. (continued)

Variable	n (%) or mean \pm SD ¹		F	p	Pearson's χ^2	df	Asymp.Sig. (2 sided)
	Study Sample (n = 100)	Attrition (n = 27)					
Single with a partner	22 (22%)	7 (27%)					
Single without a partner	18 (18%)	6 (23%)					
Separated/divorced	8 (8%)	3 (12%)					
Prior preterm - Yes	16 (16%)	4 (15%)			0.200	1	0.655
Prior NICU²	16 (16%)	4 (15%)			3.868	2	0.268
Experience -Yes							
Pregnancy							
Complication -Yes	44 (44%)	12 (26%)			0.001	1	0.972
Gestational age	31.7 (\pm 3.2)	34.8 (\pm 0.9)	23.597	0.000*			
Birth weight	1848.5 (\pm 731.0)	2532.3 (\pm 460.6)	5.110	0.026*			
Morbidity score³	4.6 (\pm 3.1)	2.0 (\pm 2.4)	0.512	0.475			
DC < 2 weeks⁴	19 (19%)	26 (100%)			46.498	1	0.000*

* $p < 0.05$

¹Standard deviation, ²Neonatal Intensive Care Unit, ³Morbidity score range 0-45, ⁴discharged before 2 weeks

Table 5-2. Maternal and Infant Characteristics across Three Study Sites

Variable	n (%) or mean \pm SD ¹			F	p	Pearson's χ^2	df	Asymp.Sig. (2 sided)
	GSH ² (n=40)	LAC-USC ³ (n=33)	HPMC ⁴ (n=27)					
Race/Ethnicity						10.620	8	0.224
Hispanic	23 (23%)	21 (21%)	18 (18%)					
Asian/Pacific Islander	10 (10%)	5 (5%)	5 (5%)					
Black	4 (4%)	5 (5%)	-					
White	3 (3%)	1 (1%)	3 (3%)					
Other	-	1 (1%)	1 (1%)					
Employment						2.061	8	0.979
Unemployed	24 (24%)	28 (18%)	17 (17%)					
Full-time	7 (7%)	7 (7%)	6 (6%)					
Part-time	7 (73%)	5 (5%)	2 (2%)					
Other	2 (2%)	3 (3%)	2 (2%)					
Education						10.242	8	0.248
< 12 th grade	15 (15%)	15 (15%)	3 (3%)					
High school/GED	9 (9%)	9 (9%)	11 (11%)					
1-3 years college	6 (6%)	3 (3%)	6 (6%)					
\geq Bachelors degree	10 (10%)	-	1 (1%)					
Income						5.081	8	0.886
< \$30,000	27 (27%)	24 (24%)	16 (16%)					
\$30,000 - \$49,999	6 (6%)	6 (6%)	5 (5%)					
\$50,000 – \$79,999	2 (2%)	1 (1%)	2 (2%)					
\geq \$80,000	3 (3%)	1 (1%)	3 (3%)					

(table continues)

¹ Standard deviation, ²Good Samaritan Hospital, ³ Los Angeles County-University of Southern California,

⁴Hollywood Presbyterian Medical Center

Table 5-2. (continued)

Variable	n (%) or mean \pm SD ¹			F	p	Pearson's χ^2	df	Asymp.Sig. (2 sided)
	GSH ² (n=40)	LAC-USC ³ (n=33)	HPMC ⁴ (n=27)					
Maternal age	30.1 \pm 6.4	28.9 \pm 6.9	30.3 \pm 5.9	0.385	0.68			
Language						0.923	2	0.630
English	27 (27%)	23 (23%)	17 (17%)					
Spanish	13 (13%)	10 (10%)	10 (10%)					
Marital Status						0.798	4	0.671
Married	20 (20%)	17 (17%)	11 (11%)					
Single with a partner	8 (8%)	11 (11%)	3 (3%)					
Single without a partner	9 (9%)	5 (5%)	4 (4%)					
Separated/divorced	2 (2%)	1 (1%)	4 (4%)					
Prior preterm - Yes	4 (4%)	6 (6%)	6 (6%)			0.776	2	0.644
Prior NICU⁵	4 (4%)	6 (6%)	6 (6%)			8.292	2	0.166
Experience - Yes								
Pregnancy	13 (13%)	21 (21%)	10 (10%)			7.842	2	0.2
Complication -Yes								
Gestational age	32.25 (\pm 0.49)	30.93 (\pm 0.64)	32.07 (\pm 0.55)	1.618	0.20			
Birth weight	1959.2 (\pm 109.89)	1643.0 (\pm 137.59)	1935.8 (\pm 130.71)	1.995	0.14			
Morbidity Score:	4.7 (\pm 0.53)	4.5 (\pm 0.48)	4.7 (\pm 0.62)	0.057	0.94			
Admission								
Morbidity Score:	1.8 (\pm 0.39)	2.6 (\pm 0.46)	1.5 (\pm 0.35)	1.865	0.16			
2 weeks								
DC < 2 wks⁶	9 (9%)	7 (7%)	3 (3%)			1.769	2	0.413
BF⁷ at 2 weeks -Yes	31 (31%)	20 (20%)	23 (23%)			4.737	2	0.194

¹Standard deviation, ²Good Samaritan Hospital, ³Los Angeles County-University of Southern California,

⁴Hollywood Presbyterian Medical Center, ⁵Neonatal Intensive Care Unit, ⁶discharge < 2 weeks, ⁷breastfeeding

Table 5-3. Maternal Demographic Characteristics (N =100)

Demographic	n (%) or mean \pm SD¹
Age	29.8 \pm 6.4
	17-19 years old
	10 (10%)
	20-29 years old
	35 (35%)
	30-39 years old
	50 (50%)
	\geq 40 years old
	5 (5%)
Race/Ethnicity	Hispanic
	62 (62%)
	Asian/Pacific Islander
	20 (20%)
	Black
	9 (9%)
	White
	7 (7%)
	Other
	2 (2%)
Employment	Unemployed
	59 (59%)
	Working full-time
	20 (20%)
	Working part-time
	14 (14%)
	Other
	7 (7%)
Education	< 12 th grade
	33 (33%)
	High school/GED
	29 (29%)
	1-3 years college
	15 (15%)
	\geq Bachelor's degree
	23 (23%)
Household income	< \$30,000
	67 (67%)
	\$30,000 – \$49,999
	17 (17%)
	\$50,000 – \$79,999
	5 (5%)
	\geq \$80,000
	11 (11%)
Marital status	Married
	52 (52%)
	Single living with a partner
	22 (22%)
	Single living without a partner
	18 (18%)
	Separated/divorced
	8 (8%)

*(table continues)*¹standard deviation

Table 5-3. (continued)

Demographic		n (%) or mean \pm SD¹
Preferred language	English	67 (67%)
	Spanish	33 (33%)
Parity >1		55 (55%)
Prior NICU² experience with mother's own child	Yes	16 (16%)
Pregnancy complication Complications	Yes	44 (44%)
	Hospital bed rest > 2 days	26 (26%)
	Hypertension before pregnancy	4 (4%)
	Hypertension from pregnancy	8 (8%)
	Diabetes from pregnancy	4 (4%)
	Infection requiring antibiotics	2 (2%)
Available baby sitter	Yes	85 (85%)
Breastfeeding at 2 weeks	Yes	74 (74%)

¹standard deviation, ²Neonatal Intensive Care Unit

Table 5-4. Preterm Infant Characteristics (N =100)

Demographic	n (%) or mean \pm SD¹ (range)
Gestational age	31.7 \pm 3.3 (24-36 weeks)
24 weeks – 29 weeks	26 (26%)
30 weeks – 33 weeks	34 (34%)
34 weeks – 36 weeks	40 (40%)
Birth weight	1848 \pm 731.1 grams (560-3688 grams)
Gender	
Male	56 (56%)
Female	44 (44%)
Delivery method	
Caesarean section	51 (51%)
Vaginal delivery	49 (49%)
1 minute Apgar²	6.7 \pm 2.2
5 minute Apgar	7.9 \pm 1.8
Morbidity score³: Admission	4.7 \pm 3.1
Morbidity score: 2 weeks	2.0 \pm 2.4
Discharge < 2 weeks	19 (19%)

¹standard deviation, ²Apgar score range 0-10, ³morbidity score range 0-45

Table 5-5. Repeated Measures Multivariate Analysis of Covariance for Maternal Psychological State Variables of Overall Sample and by Study Sites at Admission and 2 Weeks (N =100)

Variable	Admission				2 weeks				F	P
	Score \pm SD ¹				Score \pm SD					
	Total (n = 100)	GSH ² (n = 40)	LAC-USC ³ (n = 33)	HPMC ⁴ (n = 27)	Total (n = 100)	GSH (n = 40)	LAC-USC (n = 33)	HPMC (n = 27)		
BSI⁵	6.5 \pm 5.3	6.5 \pm 5.3	7.7 \pm 5.7	5.8 \pm 4.5	4.0 \pm 4.2	3.6 \pm 3.8	4.6 \pm 4.8	4.0 \pm 4.2		
Time									7.255	0.008*
PHQ⁶	4.3 \pm 3.6	3.6 \pm 3.0	5.0 \pm 3.8	4.7 \pm 3.9	3.9 \pm 2.3	3.6 \pm 2.2	4.2 \pm 2.2	3.8 \pm 2.3		
Time									3.488	0.065
GWB⁷	47.2 \pm 9.1	47.2 \pm 10	47.2 \pm 5.9	47.1 \pm 11.2	49.8 \pm 7.3	50 \pm 7.1	49.2 \pm 7.6	50.1 \pm 7.3		
Time									8.890	0.004*
PSS-NICU⁸	2.6 \pm 0.8	2.5 \pm 0.8	2.7 \pm 0.8	2.8 \pm 0.7	2.2 \pm 0.7	2.1 \pm 0.7	2.3 \pm 0.8	2.4 \pm 0.6		
Time									18.567	0.000*
PSS⁹	4.7 \pm 3.0	4.7 \pm 3.1	4.4 \pm 3.2	5.1 \pm 2.8	4.4 \pm 2.9	4.0 \pm 2.9	4.1 \pm 2.6	5.1 \pm 3.0		
Time									0.979	0.325

(table continues)

¹ standard deviation,, ²Good Samaritan Hospital, ³ Los Angeles County-University of Southern California, ⁴Hollywood Presbyterian Medical Center, ⁵BSI = Brief Symptom Inventory (score range 0-24), ⁶PHQ = Patient Health Questionnaires (score range 0-27), ⁷GWB = General Well-Being Schedule (score range 0-60), ⁸PSS-NICU = Parental Stress Scale-NICU (score range 1-5), ⁹PSS=Perceived Stress Scale (score range 0-16)

Table 5-5. (continued)

Variable	Admission				2 weeks				F	p
	Score ± SD ¹				Score ± SD					
	Total (N = 100)	GSH ² (n = 40)	LAC-USC ³ (n = 33)	HPMC ⁴ (n = 27)	Total (N = 100)	GSH (n = 40)	LAC-USC (n = 33)	HPMC (n = 27)		
Pcope⁵	25.9 ± 6.1	21.9 ± 4.6	27.1 ± 5.3	30.0 ± 5.7	31.2 ± 7.8	29.3 ± 8.4	32.2 ± 7.8	32.5 ± 6.7		
Time									19.992	0.000*
Ecope⁶	27.4 ± 6.4	26.3 ± 6.8	28.2 ± 6.9	27.9 ± 5.0	23.7 ± 7.0	21.5 ± 5.8	25.0 ± 7.4	26.0 ± 7.1		
Time									14.868	0.000*
MSPSS⁷	5.7 ± 1.0	5.7 ± 0.9	5.8 ± 1.1	5.6 ± 1.0	6.2 ± 0.6	6.1 ± 0.5	6.2 ± 0.6	6.2 ± 0.6		
Family	6.0 ± 1.1				6.5 ± 0.6					
Friend	5.9 ± 1.1				6.1 ± 1.0					
Sig.Others ⁸	5.3 ± 1.3				6.0 ± 0.8					
Time									33.039	0.000*
NPST⁹	4.1 ± 0.6	4.0 ± 0.6	4.3 ± 0.6	4.0 ± 0.7	4.4 ± 0.6	4.4 ± 0.5	4.5 ± 0.6	4.3 ± 0.5		
Time									7.383	0.008*

¹standard deviation,, ²Good Samaritan Hospital, ³ Los Angeles County-University of Southern California, ⁴Hollywood Presbyterian Medical Center,

⁵Pcope = problem-focused coping (score range 14-56), ⁶Ecope = emotion-focused coping (score range 14-56), ⁷ MSPSS = multi-dimensional perceived social support (score range 1-7), ⁸Sig.Others = significant others, ⁹NPST = nurse parent support tool (score range 1-5)

Table 5-6. Correlation Coefficients for Maternal Psychological Well-Being Variables and Maternal/Infant Characteristics Variables

Variable	Correlation Coefficient
BSI⁵ 1	PHQ 1 .460**, PSS 1 .640**, PSS-NICU 1 .464**, Employment -.354**
BSI 2	PHQ 2 .320**, GWB2 -.391**, PSS-NICU 2 .470**, Employment -.306**, DC<2 wks -.254*, Morbidity 2 .232*
PHQ⁶ 1	BSI 1.460**, GWB 1-.306**, PSS 1 .446**, PSS-NICU 1 .337**, MSPSS 1 -.220*, GA ¹ -.203*, BW ² -.256*, Morbidity 1 .209*, Education -.205*
PHQ 2	BSI 2 .320**, GWB 2 -.374**, PSS 2 .292**, Education -.232*, Morbidity 2 .259**
GWB⁷ 1	PHQ 1-.306**, PSS-NICU 1 -.325**, MSPSS 1 .201*, GA 0.235*, DC<2wks ⁴ 0.293**, Morbidity 1 -.222*
GWB 2	BSI 2 -.391**, PHQ 2 -.374**, PSS-NICU 2 -.345**, Ecope -.241*, MSPSS 2 .200*, Employment .251*, Education .230*, Preg.com ³ -.208*, GA .231*
PSS⁸ 1	BSI 1 .640**, PSS-NICU 1 .470**, MSPSS 2 -.393**, BW -.205*, Employment -.316**, Education -.207*
PSS 2	PHQ 2 .292**, PSS-NICU 2 .278**, MSPSS 2 -.331**, NPST 2 -.201*, Marital status -.283*, Preg.com .306**
PSS-NICU⁹ 1	PSS 1 .470**, Ecope 1 .266**, BW -.197*, Employment -.220*
PSS-NICU 2	GWB -.345**, PSS 2 .278**, Ecope 2 .348**, NPST 2 -.364**
Pcope¹⁰ 1	NPST 1 .308**, MSPSS 1 .400**, Prior NICU experience .220*
Pcope 2	Ecope 2 .451**, GA -.201*
Ecope¹¹ 1	NPST 1 .200*, BW -.313**, Morbidity 1 .251*, Employment -.236*
Ecope 2	BSI 2 .226*, PHQ 2 -.241*, PSS-NICU 2 .348**, Pcope 2 .451**, BW -.357**, Morbidity .340**, Marital status -.216*
MSPSS¹² 1	Pcope 1 .400**, DC<2wks .230*, Morbidity 1 .209*, Maternal age -.197*
MSPSS 2	PSS 2 -.331**, BW .207*, DC<2wks .201*, Marital status .230*
NPST¹³ 1	Pcope 1 .308**, Ecope 1 .200*, Maternal age -.292**, Race/Ethnicity -.207*, Marital status .348**, Prior NICU experience .325**
NPST 2	PSS 2 -.201*, PSS-NICU 2 -.364**, DC<2 wks .201*, Marital status -.438**

* $P < 0.05$, ** $P < 0.01$

¹ gestational age, ² birth weight, ³ pregnancy complications, ⁴ discharge <2 weeks, ⁵ Brief Symptom Inventory, ⁶ Patient Health Questionnaires, ⁷ General Well-Being Schedule, ⁸ Perceived Stress Scale, ⁹ Parental Stress Scale-NICU, ¹⁰ problem-focused coping, ¹¹ emotion-focused coping, ¹² multi-dimensional perceived social support, ¹³ NPST = nurse parent support tool

Table 5-7. Multiple Linear Regression Models of Stress, Coping, and Maternal Psychological Well-Being Over 2 Weeks

Dependent variable	Independent variable	β	R ²	Adjusted R ²	p	F
<u>Admission</u>						
Model*					0.000	38.726
Anxiety	PSS ¹ 1	0.640	0.410	0.404	0.001	
	PSS-NICU ² 1	0.208	0.444	0.433	0.017	
Model*					0.000	14.953
Depression	PSS1	0.344	0.199	0.191	0.001	
	PSS-NICU1	0.217	0.236	0.220	0.034	
Model					0.470	3.470
General Well-Being	Pcope ³ 1	0.079	0.065	0.026	0.470	
	PSS-NICU1	-0.101	0.065	0.026	0.391	
	PSS1	-0.123	0.065	0.026	0.279	
	Ecope ⁴ 1	-0.143	-1.326	0.026	0.188	
<u>2 weeks</u>						
Model*					0.000	27.792
Anxiety	PSS-NICU2	0.344	0.364	0.351	0.001	
	PSS2	0.508	0.258	0.250	0.042	
Model*					0.000	7.433
Depression	PSS-NICU2	0.337	0.114	0.105	0.011	
	Ecope2	0.211	0.149	0.131	0.033	
	PSS2	0.214	0.188	0.163	0.045	
Model*					0.000	15.863
General Well-Being	PSS2	-0.342	0.228	0.220	0.007	
	PSS-NICU2	-0.248	0.299	0.284	0.009	
	Ecope2	-0.188	0.331	0.311	0.024	

(table continues)

* model significant at the .05 level, ¹Perceived Stress Scale, ¹Parental Stress Scale-NICU, ³problem-focused coping, ⁴emotion-focused coping

Table 5-7. (continued)

Dependent variable	Independent variable	β	R^2	Adjusted R^2	<i>p</i>	F
<u>Changes over 2 weeks</u>						
Model*					0.016	6.009
Anxiety	Ecopediff ⁵	0.240	0.058	0.048	0.016	
Model*					0.022	6.745
Depression	PSSdiff ⁶	0.267	0.073	0.064	0.006	
	Ecopediff	0.220	0.122	0.104	0.023	
Model*					0.049	3.928
General Well-Being*	Pcopediff ⁷	0.196	0.039	0.029	0.049	

* model significant at the .05 level, ⁵2 weeks change in emotion-focused coping ⁶2 weeks change in perceived stress scale, ⁷2 weeks change in problem-focused coping

Table 5-8. Multiple Linear Regression Models of Perceived Social/Nursing Support and Maternal Psychological Well-Being Over 2 Weeks

Dependent variable	Independent variable	β	R ²	Adjusted R ²	<i>p</i>	F
<u>Admission</u>						
Model*					0.045	3.213
Anxiety	MSPSS ¹	-0.242	0.062	0.043	0.045	
Model*					0.024	5.226
Depression	MSPSS1	-0.225	0.051	0.041	0.024	
Model*					0.045	4.122
General Well-Being	MSPSS1	0.201	0.040	0.031	0.045	
<u>2 weeks</u>						
Model*					0.046	4.075
Anxiety	MSPSS2	-0.200	0.040	0.030	0.046	
Model*					0.028	5.006
Depression	MSPSS2	-0.220	0.049	0.039	0.028	
Model*					0.045	4.116
General Well-Being	MSPSS2	0.201	0.040	0.031	0.045	
<u>Changes over 2 weeks</u>						
Model*					0.048	3.312
Anxiety	MSPSSdiff ²	-0.175	0.027	0.030	0.048	
Model					0.524	0.650
Depression	MSPSSdiff	-0.078	0.006	0.004	0.438	
	NPSTdiff ³	-0.075	0.006	0.005	0.459	
Model					0.802	0.221
General Well-Being	MSPSSdiff	0.021	0.000	0.000	0.837	
	NPSTdiff	0.012	0.000	0.000	0.904	

* model significant at the .05 level

¹Multidimensional Scale of Perceived Social Support, ²2 weeks change in Multidimensional Scale of Perceived Social Support, ³2 weeks change in Nurse Parent Support Tool

Table 5-9. Multiple Linear Regression Models of Maternal/Infant Characteristics and Maternal Psychological Well-Being Over 2 Weeks

Dependent variable	Independent variable	β	R²	Adjusted R²	p	F
<u>Admission</u>						
Model*					0.004	9.048
Anxiety	Employment	-0.357	0.174	0.155	0.004	
Model*					0.003	6.259
Depression	Preg.com ¹	0.256	0.065	0.055	0.004	
	Education	-0.243	0.125	0.105	0.026	
Model*					0.036	4.556
General Well-Being	GA ²	0.221	0.049	0.038	0.036	
<u>2 weeks</u>						
Model*					0.000	8.972
Anxiety	Employment	-0.375	0.098	0.077	0.001	
	DC < 2wks ³	-0.291	0.189	0.150	0.030	
	Education	-0.266	0.292	0.240	0.000	
	BF ⁴ at 2wks	-0.212	0.473	0.420	0.028	
	NICU exp ⁵	-0.192	0.535	0.475	0.000	
Model*					0.000	12.792
Depression	Income	-0.551	0.282	0.265	0.000	
	Morbidity 2	0.751	0.369	0.339	0.000	
	GA	-0.482	0.476	0.438	0.007	
	Race/ethnicity	0.305	0.561	0.517	0.008	
Model*					0.000	7.406
General Well-Being	Education	0.366	0.071	0.061	0.001	
	Employment	0.309	0.154	0.135	0.001	
	DC < 2wks	0.222	0.203	0.176	0.045	

(table continues)

* model significant at the .05 level, ¹pregnancy complications, ²gestational age, ³discharge < 2 weeks, ⁴breastfeeding, ⁵prior Neonatal Intensive Care Unit experience

Table 5-9. (continued)

Dependent variable	Independent variable	β	R²	Adjusted R²	<i>p</i>	F
<u>Changes over 2 weeks</u>						
Model*					0.000	6.939
Anxiety	Language	-0.401	0.087	0.076	0.001	
	NICU exp ¹	-0.236	0.149	0.129	0.009	
	GA ²	-0.249	0.194	0.166	0.012	
	Race/Ethnicity	0.247	0.244	0.209	0.021	
Model*					0.006	4.116
Depression	Preg.com ³	-0.264	0.048	0.037	0.009	
	Language	0.236	0.092	0.071	0.019	
	Marital status	-0.204	0.132	0.102	0.026	
Model*					0.001	8.054
General Well-Being	Employment	0.393	0.094	0.084	0.005	
	Education	0.261	0.155	0.136	0.036	

* model significant at the .05 level, ¹prior Neonatal Intensive Care Unit experience, ²gestational age, ³pregnancy complications

CHAPTER SIX

DISCUSSION

This study examined psychological well-being (i.e., anxiety symptoms, depression severity, and general well-being) of mothers with preterm infants over the first 2 weeks after NICU admission. Maternal stress (i.e., NICU-related and personal) was negative predictors of maternal psychological well-being. Perceived social support was positively associated and predicted maternal psychological well-being, whereas perceived nursing support was not significantly associated with three psychological well-being outcome variables. Maternal education, employment status, pregnancy complications, infant gestational age were identified as predictors for maternal psychological well-being at admission. At 2 week-time point, education, employment status, income, race/ethnicity, prior NICU experience, lactating status, infant morbidity score, and infant discharge < 2 weeks were identified as predictors for maternal psychological well-being.

Maternal Anxiety, Depression, and General Well-Being

The result of this study showed that the initial anxiety symptoms and depression severity in culturally diverse mothers of preterm infants improved at the 2 week time point. These findings are consistent with previous reports using similar measures of psychological well-being at two time points (Hill, et al., 2006; Lau & Morse, 2003; Miles, et al., 2007). However, our study identified that mothers maintained positive general well-being states over the 2 weeks despite the mild anxiety and depression upon admission, which has not been documented in the literature.

In previous studies, the instruments used to measure anxiety symptoms (i.e., State-Trait Anxiety Inventory and the Brief Symptom Inventory) and depression (i.e., Center for Epidemiologic Studies Depression Scale, Beck Depression Inventory, Edinburg Postnatal

Depression Scale) varied, making it difficult to generalize the findings. However, the comparison of BSI scores in studies of predominantly Caucasian subjects were similar to our findings in a more ethnically diverse sample (62% Hispanic, 20% Asian, 9% African American, and 7% Caucasian) (Cho, Holditch-Davis & Miles, 2008; De Paz, et al., 2011; Field, et al., 2003; Zelkowitz, et al., 2011). These findings show that anxiety symptoms and depression severity in mothers of preterm infants can affect all ethnicities. According to the CDC, depression is more prevalent in Hispanic and African American women compared to Asian or Caucasian women (CDC, 2010). Our findings support this prevalence as race/ethnicity was a significant predictor of psychological well-being. Additional maternal characteristics that are associated with maternal anxiety symptoms and depression severity are explained in later section of this chapter.

This study showed a significant improvement in anxiety symptoms and general well-being from admission to 2 weeks, but did not observe significant changes in depression severity. Both maternal anxiety and depression have been previously shown to decrease over time in the NICU (Hill, et al., 2006; Lau & Morse, 2003; Miles, et al., 2007); however, these findings are not generalizable due to the various time points at which anxiety and depression were measured, and the level of the NICU in which the data were collected. For example, maternal psychological symptoms were re-assessed at various time points from 9 days to 1 month, and one study was conducted in a level II special care nursery (Lau & Morse, 2003). Data from our study were collected in three level III NICUs during a specific time period (i.e. at admission and at 2 weeks), which enables measurement of the maternal psychological well-being state more precisely. Moreover, 2 weeks of observation can eliminate controversy over whether the observed maternal depression severity was derived from the infant's NICU admission or postpartum depression, since postpartum depression typically begins in the 4-6 weeks

postpartum period and lasts more than 2 weeks (Pearlstein & Howard, 2009). Elevated depression level is associated with maternal perception of the infant to be in a more critical condition than the actual condition indicated by the morbidity scale (Holditch-Davis, et al., 2007). Our study showed mild maternal depression that did not change over 2 weeks with our sample of mothers whose infants had fairly low infant morbidity scores. A replicated study with mothers of infants with higher morbidity scores could identify change in depression severity in mothers of preterm infants in the NICU.

Interestingly, maternal general well-being was positive throughout the two data collection time points, despite the presence of mild anxiety and depression. There are a few plausible explanations for this finding. The first is that the GWB may not have been as sensitive enough to assess mild changes in psychological well-being compared to a more disease-specific or symptom-focused instrument measuring anxiety symptoms and depression in our population. The GWB comprises six dimensions of subscales (i.e., anxiety, depression, positive well-being, self-control, vitality, and general health) and was validated for the reliability and validity in comparison to mental health scales such as the Symptom Checklist-90 Revised and the BDI (Samuel-Hodge, DeVellis, Ammerman, Keyserling, & Elasy, 2002; Taylor, et al., 2003). However, to date, the validity and reliability of the GWB has not been evaluated in mothers of reproductive age with preterm infants in the NICU, although the general well-being score in this study was comparable to those in predominantly Caucasian pregnant women with respiratory distress, as measured by the same general well-being instrument (Cohen, Freyer & Johnson, 2009). However, a more plausible explanation for positive general well-being may be related to the concept of psychological well-being. Psychological well-being embraces both the positive and negative psychological aspects of an individual (Treharne, et al., 2008). Therefore, psychological well-being is detectable in individuals not only in non-stressful

or normal circumstances, but also negative situations, such as the birth of a preterm infant and hospitalization immediately afterwards (Abbott, et al., 2006; Treharne, et al., 2008).

Secondly, the maternal sample had high school or higher educational level (67%), and more social support either from a husband or designated partner (74%), all of which may contribute to positive psychological well-being. Subjective well-being is higher in young adults who are more educated and more open to new experiences (Abbott, et al., 2006; Treharne, et al., 2008). In addition, taking into consideration that the study sample was predominantly English speaking (67%) and predominantly Hispanic (62%), our findings could imply that this multicultural maternal sample may have been more acculturated, although this concept was not directly measured. Mothers who have higher education levels and better communication with NICU staff via English language may have contributed to better understanding of their infant's condition in the NICU, leading to positive general well-being. Although this was not measured, a positive marital relationship and marital satisfaction can be a significant buffer for psychological symptoms in mothers of preterm infants (Evans, Whittingham & Boyds, 2011). Furthermore, mothers in this study used effective coping strategies both at admission and at 2 weeks, and use of appropriate coping strategies is associated with positive psychological well-being (Herman & Tetrick, 2009; Outten, Schmitt, Garcia & Branscombe, 2009; Treharne, et al., 2008).

Lastly, another plausible explanation for positive psychological well-being in mothers of preterm infants is the level of acuity of the infant, which was assessed based on the infant's clinical condition upon admission and at 2 weeks. The three hospitals used for subject recruitment were all level III NICUs, which admit infants with a high level of acuity. However, the infant morbidity scores at both time points reflected a low level of patient acuity. The mother's psychological well-being could have been influenced by having an infant that was not

critically ill after birth but still required neonatal intensive care. Previous studies have shown that preterm infants with high acuity were associated with high maternal depression, anxiety, and stress during NICU hospitalization and 6 months after discharge (Carvalho, et al., 2009; Miles, et al., 2007; Morrison-Beedy, Melnyk, & Feinstein, 2011).

Mothers of preterm infants often experience ambivalence and difficulty in decision-making after hospital discharge, which affects maternal mental health (Feldman, et al., 2009). These authors identified a decrease in maternal anxiety and depression from NICU to 6, 9, and 18 month after discharge, but 29% of mothers still had major depression and anxiety disorders at 6 to 9 month.

In our study, the positive psychological well-being at 2 weeks may be attributed to a lack of maternal understanding of the complications and medical needs of a preterm infant. This understanding may not become a reality until the parent is responsible for all of the infants care and specialist follow-up after hospital discharge. Previous studies have shown that lower parity with a lack of child care experience is associated with maternal anxiety and depression during the first year after delivery (Sayil, Gure & Ucanok 2007). Anxiety symptoms, depression severity, and general well-being scores may have changed if measured months after hospital discharge. Further longitudinal studies are needed to assess changes in psychological well-being months after hospital discharge.

Maternal Stress, Coping, and Psychological Well-Being

Among all predictors studied, NICU-related stress and personal stress explained the highest percent of the variance for psychological well-being upon admission (anxiety 43%, depression 22% and general well-being 24%) and at 2 weeks (anxiety 25%, depression 16% and general well-being 31%). Women with anxiety symptoms are often diagnosed with other psychological dysfunctions; during pregnancy, anxiety, depression and stress are particularly

high co-morbidities (Fortner, Pekow, Dole, Markenson & Chasan-Taber, 2011).

NICU-related maternal stress has been reported to be a strong predictor for anxiety symptoms and depression (Carvalho, et al., 2009; Carter, et al., 2007; Friedman, et al., 2011; Miles, et al., 2007). This study supports previous findings that maternal NICU-related stress was a negative predictor of psychological well-being. Further, this study identified that perceived personal stress also affects psychological well-being in mothers of preterm infants. Additional stress that occurs to individuals with pre-existing psychological distress can cause delayed recovery from psychological distress, which can lead to psychiatric disorders (Wisely, Wilson, Duncan & Tarrier, 2010). Previous research has emphasized the association between NICU-related stress and maternal psychological health, but little was discussed concerning the impact of maternal personal stress on maternal mental health in the NICU (Carvalho, et al., 2009; Carter, et al., 2007; Friedman, et al., 2011; Denny, et al., 2006; D'Souza, et al., 2009; Miles, et al., 2007). This study is one of few studies demonstrating that maternal psychological well-being is affected by maternal personal stress as well as NICU-related stress.

Mothers used more emotion-focused coping strategies at the time of NICU admission when the preterm infant is more critical and maternal anxiety and depression scores were elevated. Conversely, mothers used more problem-focused coping strategies at the 2 week time point when maternal anxiety, depression, and general well-being scores were improved. This finding is consistent with previous reports showing that elevated psychological distress is related to emotion-focused coping, and positive psychological health status is related to problem-focused coping (Herman & Tetrick, 2009). Our findings are particularly important to NICU staff in setting up discharge care plans for mothers of preterm infants, since the majority of preterm infants are ready to be discharged from the hospital 2 weeks after NICU admission. Mothers of preterm infants need to learn their new role as a care taker and they can achieve

their new responsibilities more successfully via using problem-focused coping strategies (i.e., planning, using instrumental support, and active coping) (Verhaeghe, Defloor & Grypdonck, 2005).

Coping was not a significant predictor for maternal psychological well-being at either time points. However, the difference in psychological well-being over the two time points was predicted by the type of coping strategy employed by the mother. This may be explained by the notion that coping is not a static psychological state, but rather, a dynamic process (Treharne, et al., 2008). Furthermore, change of emotion-focused coping predicted negative psychological dysfunctions such as anxiety and depression, whereas change in problem-focused coping predicted a change in the general well-being score (i.e. positive psychological well-being), which supports previous findings in the literature (Herman & Tetrick, 2009).

Perceived Support and Psychological Well-Being

This study is one of only a few to report on how nursing support affects psychological well-being in mothers of preterm infants from an ethnically diverse sample in comparison to other forms of social support. Perceived social support has been shown to improve psychological well-being (Nkansah-Amankra, et al., 2011; Traviss, West & House, 2011; Zachariah, 2009). Although perceived social support was significantly related to all outcome variables of psychological well-being at both time points, surprisingly, it only accounted for 3-4% of the variance related to psychological well-being. However, perceived nursing support was not significantly related to maternal psychological well-being. The perceived nursing support scores at both time points were comparable to findings from a prior study using the same instrument in Italian mothers of preterm infants that were admitted to the NICU (Montiroso, et al., 2011).

The association between nursing support and maternal stress has been well

documented in the literature, but the influence of nursing support on maternal anxiety symptoms, depression severity or general well-being is not well understood (D'Souza, et al., 2009; Montiroso, et al., 2011; Turan, et al., 2008). Our finding showed that perceived nursing support scores were relatively high at both time points but nursing support was not predictive of maternal psychological well-being. A plausible explanation for this finding may be related to the study sample, which was predominantly Hispanic (62%). Hispanic culture is one of the ethnic groups characterized by a strong sense of family and respect for extended family members (Russell & Taylor, 2009). This family support can often buffer the effect of stress exposure on psychological distress. Hispanic women often prefer family members to healthcare professionals when seeking support or information (Russell & Taylor, 2009). With the majority of Hispanic women in this study, the cultural aspect of family support as being more valued than nursing support from non-family members could explain these findings.

Another explanation for the non-significant relationship between perceived nursing support and maternal psychological well-being may be the difference in perception (i.e., mother versus nurse) in what is viewed as an important nursing task in the care of preterm infant. Nurses perceive expressive activities such as establishing trusting relationships, cheerful behavior, and offering support as important components to nursing care. In contrast, patients perceive the technical skills or tasks as more important (Papastavrou, Efstathiou & Charalambous, 2011). This means that the patients may not be open or receptive to the expressive caring behaviors until basic physical needs are met by the nurse (Clark, et al., 2009; Papastavrou, et al., 2011). The perceived nursing support tool used in this study is conceptualized based on the nurse-patient relationship (Miles, 1999). However, the mother may not have had enough time (i.e., 2 weeks) to establish a relationship with a specific nurse due to nurses changing shifts every 12 hours, potential language barriers or mother's lack of daily

presence at the bedside after childbirth. The concept of perceived nursing support may have been more prominent in a NICU environment where primary nurses are assigned, or there are more high-acuity infants where the parents' daily presence is required to make critical medical decisions on behalf of their infant.

Maternal and Infant Characteristics and Psychological Well-Being

Many maternal and infant characteristics were predictors of psychological well-being. Upon NICU admission, the mother's employment status, pregnancy complication and education were identified as significant predictors, representing only 15% of the variance for psychological well-being. However, at 2 weeks, employment status, income, education, race/ethnicity, infant discharge < 2 weeks, infant morbidity, prior NICU experience, and breastfeeding were additional maternal predictors of psychological well-being representing 17-51% of the variance.

The literature has identified a variety of socioeconomic variables such as employment status, education, income, and breastfeeding as predictors of psychological well-being but inconsistencies exist across studies (Carvalho, et al., 2009; Giakoumaki, et al., 2009; Miles, et al., 2007; Traviss, et al., 2011). The inconsistency in socioeconomic predictors for anxiety and depression severity may be attributed to the time points at which maternal anxiety and depression were assessed. Maternal socioeconomic factors were not identified as predictors of anxiety symptoms or depression when measured only once during the NICU hospitalization (Carvalho, et al., 2009; Giakoumaki, et al., 2009). This study found different maternal socioeconomic factors that predicted maternal anxiety and depression at NICU admission and at the 2-week time point. Pregnancy complication was a predictor for depression severity upon admission which supports prior research showing that depression is associated with pregnancy complications (Katon, Russo, Melville, Katon & Galvin, 2011). However, infant discharge < 2

weeks, prior NICU experience, and breastfeeding, which are more associated with infant care, were predictors of psychological well-being at the 2-week time point.

Lactation is known to benefit maternal mental health (Hill, et al., 2006; Sisk, et al., 2006; Yalcin & Orun, 2011). Mothers of preterm infants with low anxiety and depression are more likely to initiate lactation in the early postpartum period (Hart, et al., 2011; Hill, et al., 2006). Furthermore, lactating mothers were found to have low levels of stress, anxiety and depression in the NICU (Zanardo, et al., 2011). This study, in predominantly low-income and unemployed mothers, identified high lactation rates at 2 weeks (74%) compared to the national average for all gestational ages in the United States (55.6%), and to preterm infants admitted to the NICU (69%) (Bartick & Reinhold, 2010; Colaizy & Morris, 2008). We also found a significant association between lactation and maternal anxiety at the 2-week time point, which is consistent with findings in the literature (Hill, et al., 2006; Yalcin & Orun, 2011; Zanardo, et al., 2011). The high lactation rate in this study may reflect the high desire of low income mothers to breastfeed as a more affordable and healthier option to feed their infant. Furthermore, a decrease in anxiety at 2 weeks may have been a result of the high lactation rate at 2 weeks, since lactation leads to the release of oxytocin, an anxiolytic neurotransmitter that calms mothers and promotes the maternal-infant bond, which could potentially impacts all aspects of psychological well-being (Ring, et al., 2006).

Infant characteristics that were examined in this study include gestational age, birth weight, morbidity scores, and early hospital discharge < 2 weeks. Gestational age, morbidity, and discharge < 2 weeks were significant predictors of maternal psychological well-being, which supports the literature (Traviss, et al., 2011; Vigod, et al., 2010). Interestingly, this study found that mothers of preterm infants ≥ 34 weeks' gestation (also known as late preterm infants) had higher anxiety scores at admission compared to mothers of infants < 34 weeks'

gestation. This could represent sample attrition reflecting a study sample with more mothers of infants older than 34 weeks with anxiety symptoms compared to the 27 subjects who withdrew or dropped out of the study. The 27 subjects who withdrew or dropped out were predominantly mothers of infants older than 34 weeks' gestation with higher birth weights. One would presume these mothers to be less anxious. However, other maternal characteristics such as being a single mother, first time mother or having had a caesarian section could be other factors for heightened anxiety symptoms.

A potential biologic explanation is the hormonal changes during pregnancy. A dramatic increase in estrogen, progesterone, and cortisol levels occurs after 34 weeks of gestation compared to preterm births before 34 weeks and is associated with hyperactive states of neurotransmitter pathways processing emotional stimuli (Pearson, Lightman & Evans, 2009). The surge in hormones during late pregnancy results in hyper-vigilant processing of emotional signals, which can lead to increased anxiety scores (Pearson, et al., 2009). However, because this study did not measure pregnancy hormones or cortisol levels, it is difficult to conclude whether the high anxiety in mothers of late preterm infants was the result of hormonal changes.

Clinical Implications

This study identified elevated maternal anxiety and depression symptoms immediately after NICU admission and improved at 2 weeks. There is currently no routine screening of maternal mental health as part of routine family-centered care in the majority of NICUs. Though this data showed improvement in anxiety and depression at the second time point, these symptoms can persist and warrants follow-up assessment in all mother's of preterm infants. Earlier detection of depressive symptoms and follow-up assessment of mother's at risk can not only have a positive benefit for the mother but also the infant. Furthermore, maternal characteristics of unemployment, low income, low education, Hispanic ethnicity, no prior

NICU experience, no lactation, younger gestational age, infant remaining in the hospital at 2 weeks, and higher infant morbidity scores were predictive of anxiety and depression symptoms at different time points. A NICU nursing staff and social services lead-hospital-based parent support group can provide a venue to support mothers and identify families that need resources and counseling during the infant's hospitalization and after discharge. In addition, the study identified Hispanic mothers with worse psychological well-being than Caucasian mothers. This calls for heightened awareness of the nursing and medical staff to worse mental health in this minority and to possibly assign Spanish speaking nursing staff (if needed) to care for the infant and family.

An interesting finding to this study was that perceived nursing support did not improve maternal psychological well-being although the perception was positive and significantly increased over 2 weeks. This finding may prompt institutional assessment of routine nursing support to mothers of preterm infants and ways to improve the quality of support. This institutional assessment could be an anonymous questionnaire or survey given to mothers upon discharge from hospital. The result could be incorporated into improving nursing support once change has been implemented with follow-up data collection to assess maternal satisfaction.

The data in this study shows that coping styles switch from emotion-focused to problem-focused coping from admission to 2 weeks. This is an important finding for the health care team when imparting clinical information to families and assessing readiness for discharge teaching. The concept of "normalization" and repeating important clinical information are useful techniques when mothers are using emotion-focused coping strategies. Teaching the nursing staff how to identify the mother's coping style and the use of the 2 week time point for the transition to problem-focused coping as a "bench mark" for the start of didactic instruction.

Limitations

The results of this study must be viewed in light of some limitations. The convenience sampling is subject to selection bias and the mothers who volunteer to participate may have been mentally healthier than those who did not enroll. Therefore, findings cannot be generalized to all mothers of preterm infants.

Another limitation in the study is that the sample primarily reflects English-speaking, Hispanic mothers and acculturation was not measured in this study. In addition, the infant sample had low acuity which could result in the findings of only mild maternal anxiety and depression upon NICU admission.

Another limitation in the study was the exclusion of fathers of preterm infants. Fathers were excluded because of the reported low rates of participation in prior research and lack of easy accessibility (Nepomnyaschy & Garfinkel, 2010). A future study that includes fathers' assessment of psychological well-being is needed.

From a methodological standpoint, most of the data were self-reported which could result in possible reporting bias. There might have been confusion by the participants in the demographic descriptions of maternal marital status as the categories provided were not mutually exclusive. Furthermore, the conceptual model of this study defined maternal stress, coping and perceived social/nursing support as mediators, but these variables were analyzed as predictors. An analysis model to examine stress, coping and perceived social support/nursing support as mediators for maternal psychological well-being is necessary. Additionally, three outcome variables were used to measure psychological well-being (anxiety, depression and general well-being) as there is no "gold standard" for measurement. However, the instruments used in this study were congruent with operational definitions of anxiety, depression and general well-being. Lastly, maternal cognitive appraisal or personal characteristics (i.e. self-

efficacy) were not measured and could potentially affect subjective well-being responses. A future study may further evaluate the association between maternal stress and the appraisal process. Despite these limitations, the findings of this study contribute to and extend the literature on psychological well-being in mothers of preterm infants.

Conclusion

Psychological well-being in mothers of preterm infants continues to be a concern for the health and well-being of the mothers and infants. This study demonstrated that predominantly Hispanic mothers with low income and lack of experience with a preterm infant had overall positive psychological well-being upon admission to the NICU and at 2 weeks after admission, despite mild anxiety and depression at admission. Maternal stress was a negative predictor which worsened psychological well-being, and perceived social support was a positive predictor which improved psychological well-being. Mothers used more emotion-focused coping strategies at admission, and used more problem-focused coping strategies at two weeks, which most likely contributed to improve maternal psychological well-being. Infant characteristics (i.e., gestational age, infant morbidity score, and hospital discharge < 2 weeks) and maternal characteristics (i.e., race/ethnicity, language, education, marital status, income, employment status, pregnancy complications, and breastfeeding at 2 weeks) were identified as predictors of maternal psychological well-being.

Findings of this study warrant the development of maternal screening of psychological well-being as part of family-centered care in NICUs and awareness to mothers of Hispanic culture with worse depressive symptoms. The assessment of “nursing support” in relation to meeting maternal needs during hospitalization is needed and to implement ways for improvement. Furthermore, the nursing staff needs to be more aware of coping strategies in relation to providing clinical updates in infant condition and comprehension or readiness for

discharge teaching. Future research is needed on infants with higher acuity, the father's psychological well-being, collecting data past 2 weeks, and the impact of negative maternal mental health on the maternal-infant bond and infant growth parameters.

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APPENDIX A
HUMAN SUBJECTS CONSENT FORM

CONSENT TO PARTICIPATE IN RESEARCH

Psychological well-being of mothers with preterm infants

You are asked to participate in a research study conducted by Keejeong Cheon PhD(c) (Principal Investigator) and Dr. Nancy Pike (Faculty Sponsor) from the School of Nursing at the University of California, Los Angeles. You were selected as a possible participant in this study because your baby was born at less than 37 weeks and admitted to neonatal Intensive Care Unit. Your participation in this research study is voluntary.

Why is this study being done?

When preterm infants are admitted to the neonatal intensive care unit (NICU), mothers can experience stress and poor coping that can affect their psychological well-being. The purpose of this study is to inform participants that the study is voluntary and not part of their treatment and that the decision about participation will have no impact on the receipt of that treatment.

What will happen if I take part in this research study?

If you volunteer to participate in this study, the principal investigator or the research assistant will ask you to complete a packet of questionnaires twice (within 3 days after NICU admission and 2 weeks after NICU admission). If you are not comfortable in completing written questionnaires, the principal investigator or research assistant will read the questions to you and record your answers. If your baby is discharged earlier than two weeks after NICU admission, the principal investigator or research assistant will mail you the questionnaires with pre-stamped envelope or complete over the telephone. If there is any unanswered item, the principal investigator or research assistant will call you and ask you whether it was omitted on purpose. This study includes screening tools for anxiety and depression. Therefore, if your anxiety or depression levels are high enough to be treated, the principal investigator or research assistant will refer you to appropriate specialists, such as social worker or psychiatrist. At two weeks after NICU admission, the principal investigator or research assistant will obtain your baby's demographic information and clinical information from chart review.

How long will I be in the research study?

Participation requires completion of two sets of questionnaires that take approximately 40 to 60 minutes to complete. Total participation time will be two weeks.

Are there any potential risks or discomforts that I can expect from this study?

Some questions may trigger negative emotions or thoughts from prior experiences.

Are there any potential benefits if I participate?

You will not directly benefit from your participation in the study. The results of this study may provide valuable information in caring for mothers of preterm infants in the NICU.

Will I receive any payment if I participate in this study?

You will receive a \$30 gift card after completion of the two sets of questionnaires. If you discontinue your participation after completion of the first questionnaires, you will receive a \$15 gift card.

Will information about me and my participation be kept confidential?

Any information that is obtained in connection with this study and that can identify you will remain confidential. Confidentiality will be maintained by means of labeling your questionnaires with a code number instead of your name. The information will be entered as a code in a computer that is kept in a private locked place using access security ID and password. Paper hard copies will be placed in a locked private place. All research-related information will be accessed only by the principal investigator and research assistant. It will be disclosed only with your permission or as required by law. Under California law, the privilege of confidentiality does not extend to information about sexual or physical abuse of a child or elder. If any member of the program staff has or is given such information, he or she is required to report it to the authorities. The obligation to report includes alleged or reasonably suspected abuse as well as known abuse. Additionally, if there are significant psychological risks that may threaten to participant self or others, the research team needs to be reported to authorities.

Withdrawal of participation by the investigator

The investigator may withdraw you from participating in this research if circumstances arise which warrant doing so. In the unforeseen event that your child dies during study participation, the principal investigator will withdraw you from the study and will not approach you for completion of the last set of questionnaires.

What are my rights if I take part in this study?

You may withdraw your consent at any time and discontinue participation without penalty or loss of benefits to which you were otherwise entitled.

You can choose whether or not you want to be in this study. If you volunteer to be in this study, you may leave the study at any time without consequences of any kind. You are not waiving any of your legal rights if you choose to be in this research study. You may refuse to answer any questions that you do not want to answer and still remain in the study.

If you choose not to participate, that will not affect your relationship with Good Samaritan Hospital, Hollywood Presbyterian Medical Center, LAC-USC NICU or your right to health care or other services to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice to your future care at Good Samaritan Hospital, Hollywood Presbyterian Medical Center, or LAC-USC NICU.

Who can answer questions I might have about this study?

In the event of a research related injury, please immediately contact one of the researchers listed below. If you have any questions, comments or concerns about the research, you can talk to the one of the researchers. Please contact:

Principal Investigator: Keejeong Cheon Phone: 267-968-2873

Faculty Sponsor: Dr. Nancy Pike Phone: 310-206-3683

Address: UCLA School of Nursing
3938 Factor Building
Los Angeles, CA 90095

If you wish to ask questions about your rights as a research participant or if you wish to voice any problems or concerns you may have about the study to someone other than the researchers, please call the Office for Protection of Research Subjects at (310) 825-7122 or write to Office for Protection of Research Subjects, UCLA, 11000 Kinross Avenue, Suite 102, Box 951694, Los Angeles, CA 90095-1694.

SIGNATURE OF STUDY PARTICIPANT

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant

Date

SIGNATURE OF PERSON OBTAINING CONSENT

In my judgment the participant is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.

Name of Person Obtaining Consent

Contact Number

Signature of Person Obtaining Consent

Date

University of California
Permission to Use Personal Health Information for Research

Study Title (or IRB Approval Number if study title may breach subject's privacy):

Psychological well-being of mothers with preterm infants

Principal Investigator Name:

Keejeong Cheon

Sponsor/Funding Agency (if funded):

N/A

A. What is the purpose of this form?

State and federal privacy laws protect the use and release of your health information. Under these laws, the University of California or your health care provider cannot release your health information to the research team unless you give your permission. The research team includes the researchers and people hired by the University or the sponsor to do the research. If you decide to give your permission and to participate in the study, you must sign this form as well as the Consent Form. This form describes the different ways that the researcher, research team and research sponsor may use your health information for the research study. The research team will use and protect your information as described in the attached Consent Form. However, once your health information is released it may not be protected by the privacy laws and might be shared with others. If you have questions, ask a member of the research team.

B. What Personal Health Information will be released?

If you give your permission and sign this form, you are allowing: LAC-USC/Good Samaritan Hospital/Hollywood Presbyterian Medical Center to release the following medical records containing your Personal Health Information. Your Personal Health Information includes health information in your medical records and information that can identify you. For example, Personal Health Information may include your name, address, phone number or social security number.

Entire Medical Record

Laboratory Reports

Emergency Medicine Center
Reports

- | | | |
|--|--|---|
| <input type="checkbox"/> Outpatient Clinic Records | <input type="checkbox"/> Dental Records | <input type="checkbox"/> Health Care Billing Statements |
| <input type="checkbox"/> Pathology Reports | <input type="checkbox"/> Operative Reports | <input type="checkbox"/> Diagnostic Imaging Reports |
| <input type="checkbox"/> EKG | <input type="checkbox"/> Radiology Reports | <input type="checkbox"/> History & Physical Exams |
| <input type="checkbox"/> Progress Notes | <input type="checkbox"/> Radiologic & MR Scans | <input type="checkbox"/> Consultations |
| | <input type="checkbox"/> Discharge Summary | <input type="checkbox"/> Psychological Tests |
| <input type="checkbox"/> Other (describe): <u>nursing record</u> | | |

C. Do I have to give my permission for certain specific uses?

Yes. The following information will only be released if you give your specific permission by putting your initials on the line(s).

___ I agree to the release of information pertaining to drug and alcohol abuse, diagnosis or treatment.

___ I agree to the release of HIV/AIDS testing information.

___ I agree to the release of genetic testing information.

___ I agree to the release of information pertaining to mental health diagnosis or treatment as follows:

D. How will my Personal Health Information be used?

Your Personal Health Information may be released to these people for the following purposes:

1. To the research team for the research described in the attached Consent Form;
2. To others at UC who are required by law to review the research;
3. To others who are required by law to review the quality and safety of the research, including: U.S. government agencies, such as the Food and Drug Administration, the research sponsor or the sponsor’s representatives, or government agencies in other countries. These organizations and their representatives may see your Personal Health Information. They may not copy or take it from your medical records unless permitted or required by law.

E. How will my Personal Health Information be used in a research report?

If you agree to be in this study, the research team may fill out a research report. (This is sometimes called “a case report”.) The research report will **not** include your name, address, or telephone or social security number. The research report may include your date of birth, initials, dates you received medical care, and a tracking code. The research report will also include

information the research team collects for the study. The research team and the research sponsor may use the research report and share it with others in the following ways:

1. To perform more research;
2. Share it with researchers in the U.S. or other countries;
3. Place it into research databases;
4. Use it to improve the design of future studies;
5. Use it to publish articles or for presentations to other researchers;
6. Share it with business partners of the sponsor; or
7. File applications with U.S. or foreign government agencies to get approval for new drugs or health care products.

F. Does my permission expire?

This permission to release your Personal Health Information expires when the research ends and all required study monitoring is over. Research reports can be used forever.

Can I cancel my permission?

You can cancel your permission at any time. You can do this in two ways. You can write to the researcher or you can ask someone on the research team to give you a form to fill out to cancel your permission. If you cancel your permission, you may no longer be in the research study. You may want to ask someone on the research team if canceling will affect your medical treatment. If you cancel, information that was already collected and disclosed about you may continue to be used. Also, if the law requires it, the sponsor and government agencies may continue to look at your medical records to review the quality or safety of the study.

G. Signatures

Subject

If you agree to the use and release of your Personal Health Information, please print your name and sign below. You will be given a signed copy of this form.

Subject's Name (print)--*required*

Subject's Signature

Date

Parent or Legally Authorized Representative (where IRB approved)

If you agree to the use and release of the above named subject's Personal Health Information, please print your name and sign below.

Parent or Legally Authorized Representative's Name
(print)

Relationship to the Subject

Parent or Legally Authorized Representative's Signature

Date

Witness

If this form is being read to the subject because s/he cannot read the form, a witness must be present and is required to print his/her name and sign here:

Witness' Name (print)

Witness' Signature

Date

APPENDIX B
RECRUITMENT MATERIALS

RESEARCH STUDY PARTICIPANTS WANTED

Psychological Well-Being of Mothers with Preterm Infants

Participants will receive \$30 gift card upon completion.

Are you a mom of a preterm baby?

Have you delivered a preterm baby within the last 3 days?

Is your baby in the neonatal intensive care unit (NICU) now?

If you answered YES to ALL of the above questions, you may be eligible
to
participate in a study examining mothers' psychological well-being.

Participants will be required to complete survey questionnaires twice
(within 3 days of NICU admission and 2 weeks later), and agree to allow
the principal investigator to review participants' phone number, address,
and the preterm baby's medical records.

The questionnaires will take approximately 40 to 60 minutes.

If interested, please contact Keejeong Cheon: (267) 968-2873

Research Study

Psychological well-being of Mothers with Preterm Infants

Contact: Keejeong Cheon

267-968-2873

What is this study about?

This study is to examine psychological well-being of mothers with preterm infants who are admitted to the NICU, and assess the changes in the relationships among maternal stress, coping strategies, perceived social and nursing support and psychological well-being over two weeks.

Who are eligible to participate?

- 1) Mothers of preterm infants born less than 37 weeks gestation
- 2) Mothers who delivered a preterm infant within the last 3 days and admitted to neonatal intensive care unit (NICU)
- 3) English or Spanish speaking mothers

How can I participate?

Participants will need to complete a packet of questionnaires twice (once within 3 days of NICU admission, and 2 weeks later).

I am not comfortable reading and writing for personal/health reasons. Can I participate?

Yes, we will read the questionnaires in person or on the phone as an interview.

How long does it take to complete a set of questionnaires?

It takes approximately 40 to 60 minutes.

What rewards will I get if I participate?

Participants will receive compensation after completion of two sets of questionnaires.

What if my baby is discharged earlier than 2 weeks?

We will mail you a packet of questionnaires with a pre-stamped envelope for the second survey follow up. We will call you if there are unanswered items.

Who will see my responses to the questionnaires?

The principal investigator only has access to the survey questionnaires. Participants' responses are confidential and will be kept in a secured place. The survey will be used only for this research.

Is there anything else I need to know?

Participants will need to allow the principal investigator to obtain phone number, home address, and preterm baby's medical record from the chart. If your depression score is high enough to be treated, we will refer you to social worker or a psychiatrist for treatment.

APPENDIX C
CHART REVIEW FORM

Appendix C-1. Infant Data Sheet

The PI will complete this infant information at two weeks after NICU admission.

Data collection site:

1. Study subject ID	
2. Medical record number	
3. Date of birth	
4. Gestational age	
5. Birth weight	
6. APGAR scores	1) 1 min () 2) 5 min ()
7. Obstetric History	1) Gravida () 2) Para () 3) Term () 4) Preterm () 5) Spontaneous abortion () 6) Therapeutic abortion () 7) Live birth () 8) Death after birth () 9) Living children ()
8. Admitting diagnosis of the infant	
9. Is the mother currently breastfeeding or pumping breast milk at two weeks after NICU admission?	1) Yes () 2) No ()

Appendix C-2. The Expanded Neonatal Morbidity Scale

Score for each period within 3 days of life and at 2 weeks. Mark 0 if not applicable or absence of guided symptoms.

	Day 1-3	Day 14
	Score	Score
<p>1. Convulsion</p> <p>3- Frequent (>6/day)</p> <p>2- 1-5 convulsions/day or abnormal EEG</p> <p>1- Anticonvulsant therapy but no seizures or normal EEG</p>		
<p>2. Hydrocephalus or poor head growth (microcephaly)</p> <p>3- Shunted but head size still increasing rapidly- repeat shunt required Or rapidly increasing head size- still to be shunted Or ultrasound, CT scan Or MRI findings of severe hydrocephalus or porencephaly Or poor head growth (microcephaly)</p> <p>2- Hydrocephalus with good shunt function of US, CT Or MRI findings of mild, progressive hydrocephalus prior to shunt</p> <p>1- Arrested hydrocephalus requiring no shunt, ventriculomegaly only</p>		
<p>3. Intracranial hemorrhage (ICH)</p> <p>3- Massive ICH and major symptoms such as convulsions, apnea-confirmed on lumbar puncture or CT scan or US</p> <p>2- Moderate ICH with less serious physical findings Or uni or bilateral grade III IVH</p> <p>1- ICH confirmed on CT scan or US with some deterioration in condition Or uni or bilateral grade II IVH</p>		
<p>4. Perinatal asphyxia</p> <p>3- Cardiac arrest or prolonged attempts at resuscitation at birth or during transfer. Or severe neurological signs, or apnea Or frequent seizures, or Apgar < 3 at 5 minutes</p> <p>2- Lesser neurological abnormalities or transient myocardial or transient renal ischemic effects, or Apgar 3-5 at 5 minutes</p> <p>1- Lack of prompt breathing or depression at birth, only requiring naloxone or intubation and stimulation or Apgar score 5-7 at 5 minutes</p>		

<p>5. NEC</p> <p>3- surgery or very poor condition and still NPO, or during period of short bowel syndrome (diarrhea and failure to thrive)</p> <p>2- no surgery but x-ray evidence of NEC or strong clinical suspicion based on bloody stools, distention or ileus; or postoperative and feeding</p> <p>1- NEC “scare” – during period infant is NPO</p>		
<p>6. Sepsis and/or meningitis or other major infection (Bacterial, fungal or viral)</p> <p>3- Very poor condition, or shock, of hypotension (requiring pressors) or DIC Or meningitis or repeated apnea, or requiring ventilation</p> <p>2- Sepsis confirmed by positive blood culture- condition fair Or during first 7 days of therapy, osteomyelitis, UTI, or actual signs of congenital syphilis (i.e., hepatomegaly, conjugated hyperbilirubinemia, bone lesions)</p> <p>1- Sepsis unconfirmed but well controlled and in good condition On antibiotics- 3, 5 days, 7 or 10 days</p>		
<p>7. Pneumothorax</p> <p>3- Bilateral, within 2 hours of placement or replacement of either drainage tube</p> <p>2- Unilateral, within 24 hours of tube placement</p> <p>1- Tube(s) in, and stable after first 24 hours</p>		
<p>8. Apnea (apnea of prematurity or other CNS disturbance)</p> <p>3- Requiring ventilation (Do not score if on ventilator for reasons other than apnea)</p> <p>2- Requiring respiratory therapy other than artificial ventilation (nasal CPAP, extra oxygen, “bumpered bed” or having more than 12 significant spells per day (uncontrolled)</p> <p>1- Requiring caffeine but fewer than 12 significant spells/day (controlled)</p>		
<p>9. Respiratory distress- Use for infants < 4 weeks old or still < 36weekks postconceptional age at time of scoring (RDS) or other acute pulmonary problems beginning at birth such as amniotic fluid aspiration, transient tachypnea of the newborn or pulmonary insufficiency of prematurity.</p> <p>3- Requiring ventilation (if still continuously ventilated until after 4 weeks of age, use chronic lung disease)</p> <p>2- Requiring nasal CPAP for RDS (not therapy for apnea)</p> <p>1- Requiring extra oxygen Or intubated at or shortly after birth for transient respiratory distress with prompt extubation in delivery room or within first 24 hours of life</p>		

<p>10. Chronic lung disease (BPD), use for infants > 3 weeks old AND > 36 weeks postconceptional age at time of scoring</p> <p>3- Confirmed on x-ray, requiring repeated or continuous intubation or tracheostomy and ventilation</p> <p>2- nasal catheter oxygen and negative pressure box</p> <p>1- Extra oxygen- only remaining therapy for BPD (via oxyhood, tent or nasal cannula)</p>		
<p>11. Cardiac failure</p> <p>3- Intractable cardiac failure despite vigorous treatment Or scheduled for surgery (PDA ligation or other), Or day of surgery or post operative day 1-7</p> <p>2- with symptoms requiring lasix and responding to indomethacin</p> <p>1- requiring digoxin (or diuretics) but condition stable (do not rate PDA without failure)</p>		
<p>12. Hyperbilirubinemia</p> <p>2- with each exchange transfusion</p> <p>1- requiring phototherapy</p>		
<p>13. Hypoglycemia (with laboratory glucose < 40mg/dL)</p> <p>3- Producing apnea or convulsions</p> <p>2- Requiring glucose intravenous infusion</p> <p>1- Transient and easily corrected with frequent feeds</p>		
<p>14. Bleeding and anemia-and volume expansion-score each transfusion</p> <p>3- fulminating DIC Or isolated pulmonary hemorrhage, platelet transfusion, or requiring blood transfusion for active bleeding</p> <p>2- Saline, albumin, blood transfusion for hypotension, poor perfusion or other signs of volume depletion</p> <p>1- anemia requiring top-up transfusion-non-emergent</p>		
<p>15. Surgery-including tracheostomy, ileostomy, herniorrhaphy, PDA ligation, VP shunt placement or simply central line placement- score each operation</p> <p>3- Surgery-score on day of surgery</p> <p>2- Problems with surgical result (e.g., bleeding, dehiscence)</p> <p>1- Satisfactory result but still requiring care- e.g., while tracheostomy tube still in or an intestinal “ostomy” is still in use</p>		
<p>Total</p>		

APPENDIX D
QUESTIONNAIRE PACKET

Appendix D-1. Maternal Sociodemographic Data

Please mark in the box for the following questions.

1. What is your age?	()
2. What is your race/ethnicity?	<input type="checkbox"/> White <input type="checkbox"/> Black/African American <input type="checkbox"/> Asian or Pacific Islander <input type="checkbox"/> Hispanic <input type="checkbox"/> Other, explain:
3. What is your employment status?	<input type="checkbox"/> Working full-time <input type="checkbox"/> Working part-time <input type="checkbox"/> Homemaker <input type="checkbox"/> Unemployed <input type="checkbox"/> Other, explain:
4. What is your highest education completed?	<input type="checkbox"/> < 12 th grade <input type="checkbox"/> High school/GED <input type="checkbox"/> 1-3 years college <input type="checkbox"/> Bachelors degree <input type="checkbox"/> Masters degree <input type="checkbox"/> PhD / MD
5. What is your household annual income?	<input type="checkbox"/> < \$30,000 <input type="checkbox"/> \$30,000 – less than \$50,000 <input type="checkbox"/> \$50,000 – less than \$80,000 <input type="checkbox"/> \$ 80,000 – less than \$100,000 <input type="checkbox"/> \$100,000 or above
6. Is your primary language English or Spanish?	<input type="checkbox"/> English <input type="checkbox"/> Spanish

<p>7. What is your current marital status? If married, please go to question 8. If not married, please answer to 7-b), then go to 8.</p>	<p><input type="checkbox"/> Married <input type="checkbox"/> Not married</p>
<p>7-b) If not married, what is the relationship with your partner?</p>	<p><input type="checkbox"/> Single living without a partner <input type="checkbox"/> Single living with a partner <input type="checkbox"/> Separated/Divorced <input type="checkbox"/> Widowed</p>
<p>8. Is this baby your first baby? If yes, please go to question 9. If no, please answer 7-b), then go to 9.</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>8-b) How many child(ren) were you with before having this baby?</p>	<p>()</p>
<p>9. Is this your first preterm baby? If yes, please go to question 10. If no, please answer 9-b), then go to 10.</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>9-b) Was your previous preterm baby admitted to baby intensive care unit?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>10. Did you have pregnancy complication(s)? If yes, please answer 10-b), then go to 11. If no, please go to question 11.</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>10-b) Please check all you had during <u>THIS</u> pregnancy.</p>	<p><input type="checkbox"/> Bed rest in the hospital more than 2 days <input type="checkbox"/> High blood pressure before pregnancy <input type="checkbox"/> High blood pressure from pregnancy <input type="checkbox"/> Diabetes before pregnancy <input type="checkbox"/> Diabetes from pregnancy <input type="checkbox"/> Infection to take antibiotics</p>
<p>11. Is there anyone who will help you to take care of your child(ren)?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>

Appendix D-2. Brief Symptom Inventory

Below is a list of problems people sometimes have. Please read each one carefully, and circle the number to the right that best describes **how much the problems has distressed or bothered you during the past three days, including today**. Circle only one number for each problem. Your responses will remain completely confidential.

How much were you distressed by:	Not at All	A Little Bit	Moderately	Quite a bit	Extremely
1. Nervousness or shakiness inside	0	1	2	3	4
2. Suddenly scared for no reason	0	1	2	3	4
3. Feeling fearful	0	1	2	3	4
4. Feeling tense or keyed up	0	1	2	3	4
5. Spells of terror or panic	0	1	2	3	4
6. Feeling so restless you couldn't sit still	0	1	2	3	4

Appendix D-3. Patient Health Questionnaire Mood Scale (PHQ-9)

1. **Over the last three days**, how often have you been bothered by any of the following problems? Read each item carefully, and circle your response.

	Not at all	Several days	More than half the days	Nearly every day
	0	1	2	3
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling asleep, staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself - or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

2. If you checked off **any** problem on this questionnaire so far, **how difficult** have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
0	1	2	3

Appendix D-4. General Well-Being Schedule

This section of the examination contains questions about how you feel and how things have been going with you **DURING THE LAST THREE DAYS**. For each question, **mark (X)** in the box.

<p>1. How have you been feeling in general?</p>	<p><input type="checkbox"/> In excellent spirits <input type="checkbox"/> In very good spirits <input type="checkbox"/> In good spirits mostly <input type="checkbox"/> I have been up and down in spirits a lot <input type="checkbox"/> In low spirits mostly <input type="checkbox"/> In very low spirits</p>
<p>2. Have you been bothered by nervousness or your “nerves”?</p>	<p><input type="checkbox"/> Extremely so – to the point where I could not work or take care of things <input type="checkbox"/> Very much so <input type="checkbox"/> Quite a bit <input type="checkbox"/> Some – enough to bother me <input type="checkbox"/> A little <input type="checkbox"/> Not at all</p>
<p>3. Have you been in firm control of your behavior, thoughts, emotions, or feelings?</p>	<p><input type="checkbox"/> Yes, definitely so <input type="checkbox"/> Yes, for the most part <input type="checkbox"/> Generally so <input type="checkbox"/> Not too well <input type="checkbox"/> No, and I am somewhat disturbed <input type="checkbox"/> No, and I am very disturbed</p>
<p>4. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile?</p>	<p><input type="checkbox"/> Extremely so – to the point that I have just about given up <input type="checkbox"/> Very much so <input type="checkbox"/> Quite a bit <input type="checkbox"/> Some – enough to bother me <input type="checkbox"/> A little bit <input type="checkbox"/> Not at all</p>
<p>5. Have you been under or felt you were under any strain, stress, or pressure?</p>	<p><input type="checkbox"/> Yes – almost more than I could bear or stand <input type="checkbox"/> Yes – quite a bit of pressure <input type="checkbox"/> Yes – some, more than usual <input type="checkbox"/> Yes – some, but about usual</p>

	<input type="checkbox"/> Yes – a little <input type="checkbox"/> Not at all
6. How happy, satisfied, or pleased have you been with your personal life?	<input type="checkbox"/> Extremely happy – could not have been more satisfied or pleased <input type="checkbox"/> Very happy <input type="checkbox"/> Fairly happy <input type="checkbox"/> Satisfied – pleased <input type="checkbox"/> Somewhat dissatisfied <input type="checkbox"/> Very dissatisfied
7. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory?	<input type="checkbox"/> Not at all <input type="checkbox"/> Only a little <input type="checkbox"/> Some – but not enough to be concerned or worried about <input type="checkbox"/> Some and I have been a little concerned <input type="checkbox"/> Some and I am quite concerned <input type="checkbox"/> Yes, very much so and I am very concerned
8. Have you been anxious, worried, or upset?	<input type="checkbox"/> Extremely so – to the point of being sick or almost sick <input type="checkbox"/> Very much so <input type="checkbox"/> Quite a bit <input type="checkbox"/> Some – enough to bother me <input type="checkbox"/> A little bit <input type="checkbox"/> Not at all
9. Have you felt down-hearted and blue?	<input type="checkbox"/> All the time <input type="checkbox"/> Most of the time <input type="checkbox"/> A good bit of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> A little of the time <input type="checkbox"/> None of the time
10. Have you been feeling emotionally stable and sure of yourself?	<input type="checkbox"/> All the time <input type="checkbox"/> Most of the time <input type="checkbox"/> A good bit of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> A little of the time <input type="checkbox"/> None of the time

Appendix D-5. Parental Stress Scale: NICU (PSS: NICU)

We would like to know what aspects of your experience as a parent are stressful to you. **By stressful, we mean that the experience has caused you to feel anxious, upset, or tense DURING THE LAST THREE DAYS.**

Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in a NICU. Circle the number that best represents your level of stress.

	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
	1	2	3	4	5
1. The presence of monitors and equipment.	1	2	3	4	5
2. The constant noises of monitors and equipment.	1	2	3	4	5
3. The sudden noises of monitor alarms.	1	2	3	4	5
4. The other sick babies in the room.	1	2	3	4	5
5. The large number of people working in the unit.	1	2	3	4	5
6. Having a machine (respirator) breathe for my baby.	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. Circle the number that best represents your level of stress.

	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
	1	2	3	4	5
1. Tubes and equipment on or near my baby.	1	2	3	4	5
2. Bruises, cuts or incisions on my baby.	1	2	3	4	5
3. The unusual color of my baby (for example looking pale or yellow jaundiced).	1	2	3	4	5
4. My baby's unusual or abnormal breathing patterns.	1	2	3	4	5
5. The small size of my baby.	1	2	3	4	5
6. The wrinkled appearance of my baby.	1	2	3	4	5
7. Seeing needles and tubes put in my baby.	1	2	3	4	5
8. My baby being fed by an intravenous line or tube.	1	2	3	4	5
9. When my baby seemed to be in pain.	1	2	3	4	5
10. When my baby looked sad.	1	2	3	4	5
11. The limp and weak appearance of my baby.	1	2	3	4	5
12. Jerky or restless movements of my baby.	1	2	3	4	5
13. My baby not being able to cry like other babies.	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**. Circle the number that best represents your level of stress.

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

Appendix D-6. Perceived Stress Scale (PSS)

The questions in this scale ask you about your feelings and thoughts **DURING THE LAST THREE DAYS**. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

	Never	Almost never	Sometimes	Fairly often	Very often
	0	1	2	3	4
1. In the last three days, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
2. In the last three days, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
3. In the last three days, how often have you felt that things were going your way?	0	1	2	3	4
4. In the last three days, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

Appendix D-7. Brief COPE Inventory

These items deal with ways you've been coping with the stress in your life. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Make your answers as true **FOR YOU NOW** as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
	1	2	3	4
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real."	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5. I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10. I've been getting help and advice from other people.	1	2	3	4
11. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
13. I've been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

Appendix D-8. The Multidimensional Scale of Perceived Social Support (MSPSS)

We are interested in how you feel about the following statements **DURING THE LAST THREE DAYS**. Read each statement and indicate how you feel about each statement.

	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
	1	2	3	4	5	6	7
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7

	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can take about my problems with my friends.	1	2	3	4	5	6	7

Appendix D-9. The Nurse Parent Support Tool (NPST)

We are interested in learning your views about how much the nursing staff caring for your child has been supportive to you during your child's hospitalization. For each question below, please circle the response that best indicates how often the nurses have helped you **DURING THE LAST THREE DAYS**.

THE NURSING STAFF AT THIS HOSPITAL, IN GENERAL, HAS

	Almost never	Not very often	Some of the time	Most of the time	Almost always
	1	2	3	4	5
1. Helped me talk about my feelings, worries, or concerns.	1	2	3	4	5
2. Helped me understand what is being done to my child (for example: tests, treatments, medicines, etc.).	1	2	3	4	5
3. Taught me how to give care to my child.	1	2	3	4	5
4. Made me feel important as the parent.	1	2	3	4	5
5. Let me decide whether to stay or leave during medical procedures.	1	2	3	4	5
6. Answered my questions satisfactorily or find someone who could.	1	2	3	4	5
7. Told me about changes/improvements in my child's condition.	1	2	3	4	5
8. Included me in discussions when decisions were made about my child's care.	1	2	3	4	5
9. Helped me understand my child's behavior and reactions.	1	2	3	4	5
10. Helped me know how to comfort my child during or after procedures.	1	2	3	4	5
11. Let me know I am doing a good job in helping my child.	1	2	3	4	5

	Almost never	Not very often	Some of the time	Most of the time	Almost always
12. Responded to my worries or concerns.	1	2	3	4	5
13. Showed concern about my well-being (for example, sleeping, eating, etc).	1	2	3	4	5
14. Helped me know the names and roles of the staff caring for my child.	1	2	3	4	5
15. Gave good care to my child.	1	2	3	4	5
16. Encouraged me to ask questions about my child.	1	2	3	4	5
17. Were sensitive to my child's special needs.	1	2	3	4	5
18. Allowed me to be involved in my child's care whenever possible.	1	2	3	4	5
19. Showed that they like my child.	1	2	3	4	5
20. Responded to my child's needs in a timely fashion.	1	2	3	4	5
21. Were optimistic about my child.	1	2	3	4	5