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Parental Mental Health and Infant Outcomes in the NICU: A Pilot Study

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by

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Each person whose signature appears below certifies that this thesis, in his/her opinion is adequate, in scope and quality, as a thesis for the degree Doctor of Philosophy.

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ABBREVIATIONS

NICU	Neonatal Intensive Care Unit
VLBW	Very-low-birth-weight
ELBW	Extremely-low-birth-weight
ASD	Acute Stress Disorder
PTSD	Posttraumatic Stress Disorder
MCS	Mental Component Summary
Apgar	Appearance, Pulse, Grimace, Activity, Respiration
LLU	Loma Linda University
QOLI	Quality of Life Inventroy
CES-D	Center for Epidemiological Studies-Depression Scale
SASQ	Stanford Acute Stress Reaction Questionnaire
PIP	Pediatric Inventory for Parenting
PSS: NICU	Parental Stressor Scale: NICU
NTISS	Neonatal Therapeutic Intervention Scoring System
NNNS	NICU Network Neurobehavioral Scale

ABSTRACT OF THE THESIS

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by

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Previous research has shown that having a child in the NICU is stressful for parents and that parents of NICU infants exhibit higher levels of stress compared to parents of healthy infants (Carter, Mulder, & Darow, 2007; MacDonald, 2007; Treyvaud et al., 2010). In addition, studies have found a correlation between improved parental mental health and shorter length of stay for infants in the NICU (Als et al., 2003). However, studies have not investigated the direction of the relationship between parental mental health and infant outcomes in the NICU, specifically whether poor parental mental health is impacting child outcomes such as longer length of stay, whether infant illness severity is impacting the poorer parental mental health, or whether the relationship between these variables is reciprocal. The purpose of this investigation was to implement a pilot study in preparation for a larger longitudinal investigation that will examine the reciprocal relationship between parental mental health and infant outcomes. This pilot study investigated the demographic characteristics of parents and infants in the NICU at the study site, the feasibility of carrying out such a study, as well as preliminary correlations between parental mental health and infant outcome variables. Mental health questionnaires were administered to 30 parents of infants admitted to the NICU at Loma

Linda University Children's Hospital and infant health measures collected by NICU nurses will be used to analyze infant severity. Findings will inform the sample criteria, measures selection, study procedures, and research aims of larger longitudinal study.

CHAPTER ONE

INTRODUCTION

Having a child in the Neonatal Intensive Care Unit (NICU) is highly stressful for parents. Research shows that parents of NICU infants exhibit higher levels of stress, depression, anxiety, and PTSD compared to parents of healthy infants (Carter, Mulder et al. 2007; MacDonald 2007; Lefkowitz, Baxt et al. 2010). Previous research has shown that there is a correlation between decreased parental stress and shorter length of stay for the infant in the NICU (Als et al., 2003). The primary goal of the current investigation was to conduct a pilot study examining the feasibility for a future longitudinal study examining the relationship between parental mental health and infant outcomes at Loma Linda University Children's Hospital.

Typical NICU Outcomes

About 10 to 15 percent of all newborn babies in the US require care in a NICU (Lucile Packard Children's Hospital, 2012). NICUs provide care to infants who are sick or born high-risk. They may also provide intermediate or continuing care for babies who are not as sick, but who need specialized nursing care (American Academy of Pediatrics, 2004). There are three different levels of care provided by NICUs. Level I nurseries care for healthy, term babies who need to be stabilized and made ready to be transferred to specialized facilities for further care (Nemours Foundation, 2012; American Academy of Pediatrics, 2004). Level II nurseries are special care nurseries for babies born more than 32 weeks gestation or who are recovering from more serious conditions and need assisted ventilation (Nemours Foundation, 2012; American Academy of Pediatrics, 2004). Lastly,

level III nurseries care for the greatest variety of support and care for infants with serious illness and congenital defects (Nemours Foundation, 2012; American Academy of Pediatrics, 2004).

Although there are many health risks associated with being admitted to the NICU, due to remarkable improvements in newborn intensive care, a considerable decrease in infant mortality and morbidity has occurred during the last two decades (Lee at al., 2000; Als et al., 2005). Hack et al. (2002) reported that advances in perinatal and neonatal medicine have resulted in increased survival rates of low-birth-weigh infants, such that infants who are classified as low-birth-weight have an 86% chance of survival. Although they account for a small percentage of births, this population of infants comprises a large portion of high rates of mortality, morbidity, cost of medical care and long-term disability that characterize this population (Als et al., 2005). Peterson et al. (2000) found that many infants in this population have developmental issues including cerebral palsy, as well as learning, neurodevelopmental, and school achievement problems. In addition, MacDonald (2000) reported that not only are disabilities such as neurosensory disorder, epilepsy and cerebral palsy constantly seen among former low-birthweight children, other skill challenges and deficits in executive function, attention, language, sensorimotor function, memory, learning, and behavioral adjustment are also a concern. Further research in this population can help cut medical costs and further inform the literature on ways to mediate long-term disabilities.

The population of infants admitted into the NICU varies. Many infants in the NICU are admitted as a result of a low birth weight, defined as less than 2500 grams; a smaller amount are admitted for very low birth weight, defined as weighing less than

1500 grams; and several others are term infants who had congenital anomalies, heart problems, or infections (Lee et al, 2000). Other infants who are admitted had no prenatal care, were born preterm (less than 37 weeks of pregnancy), were delivered via caesarian section, had mothers with hypertension, or were part of a multiple birth (Lucile Packard Children's Hospital, 2012; Lee et al., 2000). The percentage of infants admitted falling into each category vary depending on the hospital and the area of the country. Infants in the NICU present with a variety of problems as shown by one study of NICUs in the Canadian NICU Network that found 7 percent of infants had episodes of bacterial infection, 43 percent of infants received assisted respiratory support, and 11 percent received surgery (Lee et al. 2000). Because there are a large variety of diagnoses in the NICU, it is important that studies sample infants from all different groups in order to make the findings generalize to this diverse population. Moreover, research has found that nearly 13 percent of infants in the United States are born preterm, and many also have low birth weights (Lucile Packard Children's Hospital, 2012), which highlights the urgent need for more research to better understand and assist with this population.

Another area of concern with this population that researchers have been investigating is infant survival rates. Lee et al. (2000) found that overall, in a sample of 20,488 infants admitted to the NICU in the Canadian NICU Network, 96 percent survived until discharge, which is a similar rate found in most developed countries including the United States. The survival rate for this sample was 98 percent for infants less than 1500 grams and only 31 percent for infants less than 500 grams (Lee et al., 2000). Another study found that the survival rate of very-low-birth-weight (VLBW) infants and extremely-low-birth-weight (ELBW) infants were 81 percent and 52 percent

respectively (Sritipsukho, Suarod, & Sritipsukho 2007). Moreover, Larroque et al. (2004) found that survival in NICU infants increased with gestational age and that survival among live births was lower for small gestational age infants, multiple births, and boys. A study investigating the possible ways by which parents can affect infant outcomes may lead to increased survival rates in this population.

Average length of stay in the NICU is another subject of investigation, and has been found to vary depending on severity of diagnosis and type of NICU nursery. A number of hospitals reported an average length of stay between 9 and 20 days (Lee et al, 2000; Aspirus NICU Quality Report, 2007; Nationwide Children's, 2012; Berns, Boyle, Pooper & Gooding, 2007). One study found that the mean length of stay in the NICU until discharge home or transfer to a community hospital was 19 days, with a typical stay for term infants of 9 days and 60 days for infants less than 28 weeks gestation (Lee et al, 2000). In addition, when infants are discharged from the NICU, they can be discharged and sent home, transferred to a community hospital, or transferred to a hospital with a level III NICU for further treatment (Lee et al, 2000). For those infants discharged home, 1% is on some form of further therapy such as supplemental oxygen or assisted respiration (Lee et al., 2000). A significant relationship between parental mental health and child outcomes will inform hospitals about where to allocate their resources, such as better NICU care, which will hopefully lead to a shorter length of stay and better prognosis when infants are discharged from the NICU.

Parental Mental Health in the NICU

Having a child hospitalized is very stressful for parents, no matter what the age of

the child, and having a child in the NICU can be particularly stressful. Studies have investigated parental stress among parents of hospital patients, but psychological research in the parental NICU population is still in its infancy. Studies have found both mothers and fathers of infants in the NICU exhibit a higher percentage of clinical symptomology characteristic of depression and anxiety compared to control parents (Carter et al., 2005). These parents struggle with the unknown and unfamiliar environment of a NICU, which often causes challenges in the development of their role as a parent (Cleveland, 2008). Rather than taking home their child shortly after giving birth, oftentimes the infants are put in incubators and linked to several tubes and medical devices, preventing parents from holding their newborn child. Many of these parents are surprised by the early birth of their infants, resulting in shortened opportunities for planning and preparation, and the upheaval of having a prolonged and unexpected involvement with emergency healthcare, which creates additional stressors (MacDonald, 2007). In addition to giving birth to a sick or premature infant who is at risk for developmental disabilities, the unfamiliar sights, sounds and equipment found in the NICU can be overwhelming. One study found that 35 percent of mothers and 24 percent of fathers in their sample met the criteria for Acute Stress Disorder (ASD) at infant NICU admission and 15 percent of mothers and 8 percent of fathers in the sample met diagnostic criteria for Posttraumatic Stress Disorder (PTSD) 30 days later (Leftkowitz, Baxt, & Evans, 2010). Leftkowitz, Baxt, and Evans (2010) also found that rates of ASD and PTSD in parents of these hospitalized infants were consistent with those in other illness and injury populations who experience traumatic stress. These significant clinical issues lend more evidence for the need to do research with parents of infants in the NICU in order to determine how to intervene with and support them.

Recent literature has focused on predictors of parental stress, particularly among parents of NICU infants. The main general predictors of parental stress and clinical symptomatology in the NICU were dysfunctional personality traits and high anxiety (Carter, Moulder, & Darlow, 2007). Previous studies by Carter, Mulder, Darlow (2007) have shown that family functioning, socioeconomic status, parent perceptions of infant illness, high trait anxiety and available sources of support contribute to parent perception of stress in the NICU as well.

Parents of infants in the NICU, more specifically those of preterm and low-weight infants, have also been shown to experience elevated levels of depression and anxiety compared to parents of healthy infants (Carter, Mulder, & Darow, 2007; MacDonald, 2007; Trevaud, 2010). One study found that 26 percent of parents in the sample who had a child who was born very preterm, reported clinically significant mental health problems (Treyvaud et al., 2010). Moreover, another study revealed that NICU parents' scores on the SF-36 mental component summary (MCS), a multi-purpose, short-form health survey measuring functional health and well-being, mental health, and preference-based health utility, did not vary by any birth-related risk factor such as gestational age, the Appearance, Pulse, Grimace, Activity, Respiration (Apgar) score, multiple birth, presence of major morbidity, or neonatal illness severity score (Klassen et al., 2004; Ware, 2012). However, researchers did find that MCS scores were significantly lower (lower scores meaning worse outcomes) in parents of NICU infants with a congenital anomaly versus those without (Klassen et al., 2004).

Studies have shown that in addition to the infant being preterm and exhibiting a health concern, the NICU environment itself can further exacerbate stress in parents

(Carter, Mulder, & Darlow, 2007). Four specific aspects of the NICU have been found to contribute greatly to the distress experienced by parents: physical environment of the NICU, the infant's physical appearance and behavior, staff and parent interactions, and alterations of the parental role (Miles, 1989). Moreover, MacDonald (2007) has similar findings in that sources of stress of parents in the NICU were attributed to appearance of the infant (having tubes attached to their bodies, being kept in an isolette, etc.), fear that the infant will not survive, modification of the parental role, and separation from the child during hospitalization. Altered parental role was found to be the highest source of stress for mothers and fathers, although mothers reported significantly greater stress in that area compared to fathers (Miles et al. 1992). Investigators have found that distress felt by the parents was comprised of feelings of disappointment, fears concerning their infant's survival, and altered parental role, which included separation and reduced ability to interact with their child (Miles, Funk, & Kasper, 1992). Parents reported that an inability to help, hold, care for their child, protect the infant from pain, and share the infant with family members were among the primary sources of stress and contributed to feelings of inadequacy and helplessness (Cleveland, 2008; Shaw et al., 2006).

Parental Mental Health and Infant Vitality

Studies have shown that correlations exist between infant outcomes in the NICU and parental mental health. Mothers of children admitted to the NICU generally display higher rates of mental health problems and detrimental mental health has been associated with adverse child social-emotional development and increased negative affect (Treyvaud et al., 2010; Caplan et al., 1989; Cummings & Davies, 1994; Halligan et al., 2007; Gao et

al., 2007). More immediate effects of parental mental health have also been studied. An infant's length of stay as well as cardiovascular problems at the time of data collection was found to be associated with parental stress at that point in time (Dudeck-Shriber, 2004). In addition, Dudeck-Shriber (2004) found the infants' length of stay at data collection was also predictive of frequency of stress (determined by the number of items endorsed on the questionnaire which dealt with stress-provoking factors), with longer length of stay resulting in greater frequency. These findings are consistent with other studies that found a correlation between decreases in parents' stress levels and shorter length of stay in the NICU (Browne & Talmi, 2005; Melnyk et al., 2006; McAnulty et al., 2010).

Recent investigations have looked at the effects of interventions to reduce length of stay in the NICU, and many of them have involved ways to incorporate parents into their child's treatment and better inform them about what to expect in the NICU (Altman et al., 1992; Ortenstrand et al., 2010; Merrit, Pillers, & Prows, 2003; Als et al., 2003; McAnulty et al., 2010; Melnyk et al., 2006). One such study found that providing facilities for parents to stay in the neonatal unit from admission to discharge may reduce the total length of stay for infants born prematurely (Ortenstrand et al., 2010). Parents who spend more time with their infants may have a greater opportunity to act on signs of distress compared to what is possible with NICU staff, thereby allowing parents to take a greater role in caring for their infants, and contributing to more specialized care (Ortenstrand et al., 2010). Als and colleagues (2003) implemented a program called individualized developmental care which detailed behavioral observations with subsequent recommendations for individualized caregiving based on the infant's current

functioning. Formal observations of each infant's behavior were regularly conduced and formed the basis for weekly neurobehavioral reports that described current functioning and suggested ways to promote the infant's stability and competence. This program involved parents in NICU care and was found to also reduce infants' length of stay (Als et al., 2003). Another study by McAnulty et al. (2010), found that an intervention called NIDCAP, which requires trained hospital staff to observe neonatal behaviors before, during, and after caregiving interventions (aimed at promoting restfulness; calm breathing and well-modulated color; calm digestive tract; well-modulated face, extremity, and trunk tone; comfortable restful positions; individualized adjustment of all timing and implementation of procedures, and pro-vision of well-supported relaxation periods) and provide recommendations for care by nurses and kinds of parental involvement, also improved infant health outcomes and allowed for shorter stay. Moreover, the intervention was found to have lasting effects into school age such that infants in the experimental group had better right hemisphere and frontal lobe functioning compared to controls at 8 years corrected age which implicates better complex visual spatial processing, as well as visual spatial memory, executive functioning, planning, and organization. (McAnulty et al., 2010).

One process by which parental mental health and infant vitality outcomes may be related is that NICU child health outcomes impact parental mental health, for example longer length of stay seemingly increases parental stress. The very fact that a child needs to stay in the NICU longer is telling of the severity of the child's illness, which probably causes increased distress in parents. In addition, a longer length of stay is reasonably indicative of a child with a more severe diagnosis which may also mean that parents have

less access to their child, and therefore that altered parental role is what is contributing to increased stress and psychopathology (Miles et al. 1992; Shaw et al., 2006). This link from infant vitality to parental stress is supported by interventions that are implemented by hospitals which stress individualized care as well as parent participation in the care of their infants (McAnulty et al., 2010; Melnyk et al., 2006; Als et al., 2003). These interventions have not only been seen to improve the health of the NICU infants, but also show lower levels of stress in their parents (McAnulty et al., 2010; Melnyk et al., 2006; Als et al., 2003).

Conversely, parental mental health may also have an impact on NICU infant outcomes. Another process by which parental mental health and infant vitality are related is that the alteration in parental role which occurs with NICU admission affects the parents' perceptions of their self-efficacy, which in turn puts them at elevated risk for exhibiting higher levels of stress, depression, anxiety, and PTSD (Miles, Funk, & Carlson, 1993). This process can be explained by Bandura's concept of self-efficacy which involves people's beliefs about their abilities to produce certain levels of performance that have influence over events in their lives (Bandura, 1994). These beliefs in turn determine how people think, feel, motivate themselves, and behave. As a result, those who have a strong sense of efficacy in a role such as parenting, are more likely to accomplish tasks and challenges related to that role based on assurance and capabilities (MacDonald, 2007). Having this positive belief in one's abilities is more likely to assist one in reaching goals and accomplishments as well as lower vulnerability toward depression, withdrawal, and burnout (Bandura, 1994). This is applicable especially to mothers whose infants have fragile health issues associated with being admitted into the

NICU. Premature and low-birthweight infants in particular appear inaccessible and less inviting for contact by parents (MacDonald, 2007). As a result, parents with lower self efficacy (resulting from this stressful event) leads parents to behave in a less effective or ideal way (e.g. less effort to hold their baby, more inhibited, more detached, and less engaging), which in turn, negatively impacts the infant outcomes and puts parents at risk for experiencing distress.

Parents' perceptions in their ability to take care of their infant admitted into the NICU contribute to a physician's decision to discharge a patient from the NICU. Discharge criteria for an infant include: cessation of apnea of immaturity, ability to nipple-feed, and proper thermoregulation (Altman et al., 2006). Also of important consideration is the parents' confidence in their ability to take their infant home and care for them (Altman, 2006). If the appearance of a NICU infant and alterations in parental role lead parents to question their abilities in taking care of their infant, this will make them less apt to show the physicians in the NICU that they are ready to take on the responsibility of caring for the infant on their own at home. Parents' lack of confidence in their own ability to care for their child therefore possibly contributes to the infant's longer length of stay or delay in discharge as assessed by the physician. One study reported that changes in clinical practice, including parents taking a more active role and engaging in the care of their infant may be one of the factors responsible for the trend in a quicker discharge from the NICU (Altman et al., 2006).

Parent perception of resources and support is another area of importance as research suggests that failing to address the individual needs of families who have infants in the NICU can have a negative impact on outcomes for parents (Dudeck-Shriber, 2004).

When a child has a chronic illness that requires parents to provide complex health care interventions in the home, the parenting burden, or stress, becomes even greater (Ratliffe, Harrigan, Tse, & Olson,2002; Ray, 2002). This finding applies to not just hospitalized children in general but also to those in the NICU. Parenting stress levels can be increased by limited access or availability of community health services that support parents' psychosocial and child care needs (Floyd & Gallagher, 1997). In a study by Cleveland (2008), six needs were identified for parents who had an infant in the NICU to help them feel more competent as parents and ease their stress. They included: accurate information and inclusion in the infant's care, vigilant watching-over and protecting the infant, contact with the infant, being positively perceived by the nursery staff, individualized care, a therapeutic relationship with the nursing staff (Cleveland, 2008). Interventions that were investigated through recent research provided information about the NICU experience as well as ways parents can be involved in the process. As a result, many of the suggested interventions resulted in decreased stress and decreased parental mental health problems because they knew how to parent their child after participating in such interventions (Als et al., 2003). As a result, mothers and fathers had stronger beliefs about their parental role and what to expect from their infants, which correlated with shorter length of stay (McAnulty et al., 2010; Melnyk et al., 2006). In addition, positive parenting behavior, which resulted from parents being more confident in taking part in the care of their infant also correlated with shorter length of stay (Melnyk et al., 2006). This lends more evidence for the role of the self-efficacy theory of relationship between parental mental health and infant vitality. The reasoning behind why these interventions produced correlations between lower stress and shorter length of stay because

involvement in the NICU process increased parental self-efficacy, which in turn made them less at risk for mental health problems. In addition, increased self-efficacy made parents more confident in their ability to care for infant at home, thus making physicians more confident in discharging infants home with the parents.

Although research has been done revealing that a correlation between parental mental health and NICU infant outcomes exists, studies have not been done to address the direction of the effect. We do not know whether it is the poor health of the child that is causing the parental distress or whether the parental distress is having a negative impact on the child outcomes. The correlation studies tell us that these variables are associated but we do not know the direction of their relationship. Research that has been done shows that having a child in the NICU is stressful for parents (Carter, Mulder et al. 2005; Miles et al. 1992; Miles, Funk, & Kasper, 1992; Board, 2004; Cleveland, 2008). In addition, studies have shown that there is a correlation between decreased parental mental health problems and lower stress levels, and shorter length of stay for the infant in the NICU (Cleveland, 2008; McAnulty et al., 2010; Melnyk et al., 2006; Browne & Talmi, 2005; Melnyk et al., 2006; McAnulty et al., 2010; Dudeck-Shriber, 2004). However, many of these studies used samples of convenience, a restricted range, and only one measure of parental mental health. Our study included both positive and negative measures of parental mental health in order to provide a more in depth assessment of the parental psychological profile in the NICU. In addition, many of the studies were pioneer studies and have yet to be replicated. This study aimed to increase generalizability by including a more heterogeneous sample of the NICU population. Our study included both infants who were born premature and infants with congenital defects who needed surgical

procedures and are admitted into the NICU. Additionally, we collected several measures to assess parental mental health. Moreover, we looked at infant health as an outcome measure rather than length of stay. Previous studies found length of stay to be correlated with parental stress and depression, but there are a variety of factors that affect infant length of stay such as physician variability, lack of incentive to discharge patient, infant illness, insurance coverage, and parental goals, to name a few. Our goal in investigating infant health in relation to parental mental health was to gain a better perspective as to the aspects affecting the previous findings found with length of stay. Further investigation should be done in order to investigate the feasibility of conducting a longitudinal investigation aimed to more fully understand the relationship between parental mental health and infant outcomes in the NICU as well as the direction of effect of that relationship. The findings will lend valuable information about the NICU environment specific to Loma Linda University Medical Center, in addition to the informing a larger longitudinal investigation of this population.

A pilot study investigating the feasibility of carrying out a larger longitudinal exploration looking at parental mental health and infant outcomes would provide copious amounts of useful data. Findings will help researchers understand how to implement the larger study in addition to recruiting the necessary members of a multidisciplinary team in order to collect the needed measures on parental mental health as well as infant health measures of vitality. Significant findings will inform researchers and will assist the refinement of methods and procedures for the larger study. If correlations from previous studies are not replicated using the additional measures of mental health, further consideration of measure selection will need to be done before the larger project is

implemented. Problems with subject recruitment and selection will also lend helpful information in the refinement of procedures for the larger study. In addition, analysis of the overall feasibility of the pilot study will inform whether the larger project should even be implemented.

Characteristics of Loma Linda Medical Center NICU

Loma Linda University (LLU) Children's Hospital was the location of and source for subject recruitment for the current study. Loma Linda's NICU is a Level III NICU that is licensed to care for 84 infants and has an average of 79.4 infants in the NICU on a given day. Of the patients admitted to the NICU in 2011, 58.8% were female and the mean length of stay was 24.01 days (SD = 30.34). Moreover, 9.14% of the patients were inborn patients, 39.89% were transfer patients, and 39.45% were admitted from the regular nursery at LLU. Table 1 depicts the demographics for patients admitted to the LLU NICU in 2011.

The NICU has two different protocols for infants who are admitted for treatment depending on whether the child is born at Loma Linda Medical Center or transferred from another hospital. If the child is born at LLU, NICU nurses will be present at the infant's delivery and the patient's parents will be notified shortly after the delivery that their child will be admitted the NICU. Doctors obtain consent from the parents for the child's treatment and the discussion about the NICU admission happens at the patient's bedside. Front desk staff at the NICU provide the parents with an overview of the NICU's guidelines and policies: (1) Parents can visit anytime with the exception of during nursing staff shift changes (6:30-7:30 am and 6pm-8pm); (2) siblings are allowed

to visit but this must be arranged through a program in the hospital called Child Life and there are no sibling visits allowed during flu season; (3) no visits are allowed while surgeries are being performed in the patient rooms; and (4), only two people are allowed to visit the patient at any given time, one of who must always be a parent.

When a child is admitted to the NICU who is transferred from another hospital, some procedures are slightly varied. In such cases, consent to treat is obtained by the transport team which is composed of a group of LLU NICU nurses who go to transport the infant from the transferring hospital in an ambulance. Before the infant is transported to Loma Linda, the transport team manager informs the parents about Loma Linda's policies and information, as well as the condition of their child and the patient's care plan. When parents arrive at Loma Linda, the same front desk procedures described above are followed.

In both cases, once the infant is admitted to the NICU, the baby is assigned a social worker that meets with the parents in the first 24-48 hours after admission. The social worker conducts an intake interview, which includes a self-report of mental health history and an informal assessment of the parents' mental health and other risk factors that may be a concern. The social worker conducts weekly follow-up meetings with parents and, depending on the family, the social worker may check-in with them more or less frequently. Usually families with less social support and a child with a more severe diagnosis require more social worker involvement. It is common for the social worker to refer the parents to psychiatrists, psychologists, or other mental health professionals as many exhibit post-partum depression and other disorders. Roughly 10-15% of cases in the NICU are referred for counseling (M. Rodriguez, LCSW, personal communication,

Table 1

Loma Linda NICU Patient Demographics (For 2011)

Variable	Patients			
	N	%	M	SD
Number of Patients	1171			
Gestational age			35.78	4.35
Gender				
Female	685	58.8		
Male	480	41.2		
Length of Stay (days)			24.01	30.34
Birth weight				
N/A or 0 - 300g	0	0		
301 – 1000g	87	7.43		
1001 - 1500g	80	6.83		
1501 – 2000g	118	10.08		
2001 - 3000g	356	30.40		
> 3000g	530	45.26		
Admissions				
Inborn	107	9.14		
Transfers	467	39.89		
Regular Nursery	462	39.45		
Emergency Department	94	8.03		
Discharges				
Deaths	59	5.04		
Back transport	20	1.71		
Post Cardiac Surgical Unit	59	5.04		

April 17, 2012). There is also an informal parent support group available to parents in the NICU provided by the social work department. This meeting takes place every Friday from 10am to 11am, but attendance is inconsistent ranging anywhere from two to six to eight different families attending each time. It is more of an open forum for parents to

gather support from one another and share stories, with the social worker providing any referrals for parents particularly in crisis. Moreover, 25% of the patients are referred to Child Protective Services as a result of the mother using drugs, presence of domestic violence in the home, and other parental mental health issues (M. Rodriguez, LCSW, personal communication, April 17, 2012). The social worker assigned to each child plays a role in multidisciplinary team meetings (described in detail below) with the attending, fellow, physical therapist, occupational therapist, and case manager assigned to the child's team.

The Loma Linda NICU offers many resources and programs to encourage parental bonding and enhance care for the infant. While there are no specific designated rooms for parents to stay in the NICU, except for staying awake all night and sitting in chairs at the child's bedside, they are able to stay at the Ronald McDonald house, located minutes away from the hospital, which is arranged by the social worker. Sometimes exceptions are made and parents of new admissions are allowed to stay in the hospital overnight and a room is provided. Additionally, parents of babies who are ready to go home may be permitted to stay overnight and in preparation for their child's discharge. During this time, nurses observe parents to make sure they know how to properly care for their infant. Loma Linda's NICU also has a skin-to-skin program in which they encourage parents who want to hold their babies to hold them on their bare chest. This is the ideal manner for holding any infant of any age in the NICU, but is most strongly encouraged for babies weighing less than 1500g as to help regulate the infant (J. Newbold, personal communication, April 17, 2012; Anderson et al., 2003; Boukydis, 2011). Skin-to-skin contact on the mother's chest provides thermal synchrony as the

temperature of the mother's chest will increase by two degrees Celsius if the baby is too cool and decrease by one degree Celsius if the baby is too hot (Bergman, Linley, & Fawcus, 2004). In addition, skin-to-skin contact has been shown to stabilize infants as defined by physiological parameters such as heart rate, oxygen statistics, and apnea, as well as increasing quiet sleep, REM sleep, and normal sleeping cycles (Bergman, Linley, & Fawcus, 2004). Moreover, skin-to-skin contact with the mother has been shown to increase antibodies in the mother's breastmilk which decreases the incidence of nosocomial infections; increase breastmilk by increasing prolactin levels; and increase duration of breastfeeding (Charpak, Ruiz, Pelaez, Figueroa & Kangaroo Research Team, 2005). Loma Linda's NICU also strongly encourages mothers to breastfeed their child if the child is able. For infants who are not yet able to breastfeed, nurses urge parents to participate in the feeding of infants as long as they are comfortable and know how to respond to the infant's signs of distress.

In terms of discharge, the discharge plan is discussed at multidisciplinary team meetings, which are held for every patient. This meeting consists of the attending physician, resident, NICU fellow, social worker, physical therapist, occupational therapist, and case manager. Discharge may be delayed if additional laboratory tests are needed or if the infant has not fully transitioned from gavage feeding where food is administered through a tube to breast or bottle-feeding. For patients who have more severe illnesses and need medical devices to continue treatment in the home, discharge may be delayed because parents still need to be taught the proper care of their infant in the home with necessary medical equipment and supplies.

The Current Study

In an effort to more directly understand the feasibility of conducting a longitudinal study investigating the correlation between parental mental health and infant vitality outcomes in the NICU, we examined the demographics of parents in the NICU as well as the relationship between parental mental health and measures of infant health outcomes using a variety of questionnaires assessing parental mental health and well-being. Toward this aim, the following hypotheses were investigated: (1) Parents will exhibit more severe scores on assessments of parental mental health compared to normative samples, (2) Poorer parental mental health will be correlated with lower scores on measures of infant vitality in the NICU, and (3) Measures of parental mental health and depression will be inversely related to measures of parental psychological well-being and directly related to NTISS infant severity scores.

CHAPTER TWO

METHOD

Participants

Participants were families recruited from the Loma Linda Children's Hospital Neonatal Intensive Care Unit (NICU) (See Table 2 for demographic information). For the purposes of the pilot study, data from the first 30 families who enrolled in the study were used to investigate the aims of the current study. Nursing and research staff approached and informed parents about the study if they met the selection criteria and signed a consent to be contacted that was collected by NICU administrative staff. Inclusion criteria for the current sample were as follows: (1) all infants admitted to the NICU. Exclusion criteria were as follows: (1) Non-English speaking families. The criteria were chosen in order to provide an accurate and broad representation of characterization of parental mental health at infant NICU admission. Additionally, at the time, we did not have translations of the questionnaires in any other language besides English. We wanted to investigate the feasibility of obtaining the parental mental health assessments in a timely manner in order to assess whether it will be possible to collect longitudinal data investigating the trajectory of mental health in this population. Inclusion and exclusion criteria will be further defined based on the results of the pilot study.

Procedures

Personnel at the front desk in the NICU at Loma Linda Children's Hospital notified the research team about new cases that were admitted into the NICU. A neonatologist or other NICU staff obtained parents' consent to be contacted by the

research team. If consent to contact was obtained, the research team was notified and a member of the research team contacted the family to set up an intake assessment. The intake interview was targeted to be completed within 48 hours of the child being admitted to the NICU. During the intake interview, research staff obtained informed consent and administered the first set of questionnaires to the parent(s). If all questionnaires were not completed at the intake, parents were permitted to take the questionnaires home and asked to return the measures within the next 24 hours. Research staff made phone calls to remind parents to return questionnaires. In addition, infant outcome measures from daily patient records tracked by the nursing staff and physical therapist were obtained at infant NICU admission. Three weeks after packets were returned, a second set of questionnaires was administered in order to clarify the feasibility of collecting longitudinal data. A member of the research team extracted data from PowerChart. All data was entered and stored in SPSS. Data from the first 30 participants were used in order to run preliminary correlations in order to look at the size of the relationship.

Table 2

Loma Linda NICU Subject Recruitment Data

Variable	N	%	M	SD
Number of Patients Expressing Interest	112			
Patients who qualify	106	94.5		
Patients consented	47	44.3		
Completed first assessment	30	63.8		
Completed second assessment	4	13.3		
Race				
Female Parent	30			
African American	2	6.7		
Caucasian	13	43.3		
Hispanic	8	26.7		
Other	1	3.3		
Male Parent	30			
African American	2	6.7		
Caucasian	13	43.3		
Hispanic	7	23.3		
Other	1	3.3		
Marital Status				
Mother				
Married	9	30		
Separated/divorced	7	23.3		
Never Married	8	26.7		
Father				
Married	9	30		
Separated/divorced	2	6.7		
Never Married	11	36.7		
Income				
$0 – 15,000	8	26.7		
$15,001 – 25,000	1	3.3		
$25,001 – 35,000	2	6.7		
$35,001 – 50,000	2	6.7		
$50,001 – 70,000	2	6.7		
$70,001 – 95,000	3	10		
Greater than $95,000	3	10		
Stressfulness of NICU experience			2.39	.92
Quality of Life			55.5	10.32
NTISS	30		13.6	10.5
Score 0-10	17			
Score 11-20	5			
Score 21-30	2			
Score 31-40	2			
Score 41-50	1			

Measures

Demographics

Demographic data was collected by a questionnaire that parents were asked to complete called the Development History Questionnaire. In addition, questions about prenatal history and infant diagnosis were asked. This questionnaire also assessed potential confounding variables such as a history of prenatal counseling, whether or not the infant was a transfer patient, whether the parents have had a previous child in the NICU, if the NICU admission was expected, the appearance of infant, number of parent visitations to NICU, parental feelings of hope, amount of parental participation in their child's care, amount of social support, family financial situation, and family's spirituality and beliefs.

Parent Mental Health Measures

Psychological Well-Being Scales (Ryff & Keys, 1995)

The Psychological Well-Being Scales is a widely used measure that looks at well-being through six dimensions: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. Individuals respond to various statements and indicate on a 6-point Likert scale how true each statement is of them. Higher scores on each scale indicate greater well-being in that dimension. All subscales of this measure were used to assess protective factors in parents in the sample, which may buffer negative outcomes for infants. Studies have shown that the scale is valid and reliable with internal consistencies varying between 0.87 and 0.96 and test-retest reliability coefficients ranging between 0.78 and 0.97 for six subscales (Akin,

2008). Our study yielded the following reliability results for each subscale: autonomy (.90), environmental mastery (.86), personal growth (.85), positive relations with others (.87), purpose in life (.88), and self-acceptance (.84).

Brief COPE Scale (Carver, Scheier, & Weintraub,1989)

The Brief COPE Scale is a 28-item measure used to assess different ways in which people respond to stress. It consists of five scales with four items each measuring distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support); five scales measure aspects of emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measure coping responses that are less useful (focus on and venting of emotions, behavioral disengagement, mental disengagement). Each item was measured using Likert scales ranging from 1 ("I don't do this at all") to 4 ("I do this a lot"). The Brief COPE Scale showed fairly good reliability and validity (Yusoff, Low, & Yip, 2010). Reliability obtained in our study for each subscale was: problem focused coping (.74), emotion-focused coping (.58), and less useful coping (.69). All subscales of this scale were used to screen parents for any protective or risk factors that may make them more or less prone to experiencing high levels of stress.

Quality of Life Inventory (QOLI) (Frisch, 1992)

The QOLI assesses an individual's quality of life through self-report of the importance they attach to each of the 16 domains on a 3- point scale. In addition, it

assesses current satisfaction with each domain on a 6-point rating scale. Importance scores are multiplied by satisfaction scores for each domain, and then these scores are summed to determine an overall current quality of life for each individual. The QOLI possesses good internal consistency (.79) and two week test-retest (.73) reliability. Good convergent validity has been demonstrated between QOLI total score and both the Satisfaction With Life Scale (.56) and the Quality of Life Index scores (.75) (Frisch, 1992). The total scale of this measure was used to look at other aspects of parents' lives that may also contribute to distress. The reliability obtained in our sample for the total scale was (.83).

Center for Epidemiological Studies-Depression Scale (CES-D) (Radloff, 1977)

The CES-D is a 20-item instrument that was developed by the National Institute of Mental Health to detect major or clinical depression in adolescents and adults. It has four separate factors: depressive affect, somatic symptoms, positive affect, and interpersonal relations. The questions cover most of the areas included in the diagnostic criteria for depression and has been used in urban and rural populations, and in cross-cultural studies of depression. Studies using the CES-D indicate that it has very good internal consistency, acceptable test-retest stability, and construct validity (Radloff, 1997). Reliability obtained in our study for each scale is as follows: depressive affect/somatic symptoms (.86), positive affect (.49), and interpersonal relations (.78). The total score of this measure was used to assess the levels of depression of the NICU parents, more specifically, a cut-off score of 16 was used to indicate clinical levels of depression.

Stanford Acute Stress Reaction Questionnaire (SASRQ) (Cardena et al., 2000)

The SASQ is a reliable and valid measure used to evaluate anxiety and dissociation symptoms in the aftermath of traumatic events, following DSM-IV criteria for acute stress disorder (ASD). It has been shown to have good validity and reliability (Cardena et al., 2000). It has 22 items and uses a 5-point Likert scale ranging from 0 (not experienced) to 5 (very often experienced), asking participants to rate how well each statement describes their experience during the stressful event. This measure was used to assess ASD/PTSD clinical criteria for symptoms in parents in the NICU population. A diagnosis of ASD requires at lease 3 symptoms out of the five types of dissociative symptoms, 1 re-experiencing symptoms, 1 avoidance symptom, and 1 marked anxiety/arousal symptom. In order to count as a symptom, circled responses must be 3 or higher. Reliability obtained in our study for each subscale is as follows: dissociative symptoms (.91), re-experiencing symptoms (.82), avoidance (.79), marked anxiety/increased arousal (.86).

The Pediatric Inventory for Parenting (PIP) (Streisand et al., 2001)

The PIP is a 42-item self-report measure of parenting stress related to caring for a child with an illness and has been frequently used in pediatric intensive care unit populations. The PIP measures stress in four domains: (1) medical care, (2) communication (with child and health care team), (3) role functioning, and (4) emotional functioning. Parents rate each item along a 5-point Likert scale (1 = “Not at all,” and 5 = “Extremely”) as to both the item’s frequency over the last week and level of difficulty associated with it. Frequency and difficulty scores are summed separately for each scale

and then the scale scores are added together to form an overall total frequency score (PIP-F) and total difficulty score (PIP-D). Higher scores indicate greater frequency and difficulty. Internal consistency reliability for the PIP is high (Cronbach range: .80-.96) and PIP scores were significantly correlated with a measure of state anxiety and also with parenting stress. Reliability obtained in our study for each subscale was: frequency scales - communication (.71), emotional functioning (.90), role functioning (.69), and medical care (.79); and difficulty scales - communication (.80),emotional functioning (.91), role functioning (.79), and medical care (.71). Both the PIP-F and PIP-D scores were used to look at aspects of the infant's illness and hospitalization which may also contribute to parental stress.

Parental Stressor Scale: NICU (PSS: NICU) (Miles, Funk, & Carlson, 1993)

The PSS: NICU was designed to measure the degree of stress experienced by parents during hospitalization related to alterations in their parental role, the appearance and behavior of their child, and sights and sounds of the unit. Parents are asked to rate items on a 5-point rating scale ranging from "not at all stressful" to "extremely stressful." The PSS: NICU longitudinally predicted depressive symptoms in mothers of prematurely-born-children (Miles et al., 2007). High internal consistency reliability was found (Cronbach = 0.94) in addition to high construct, concurrent and predictive validity. The total scale consisting of one item about the stressfulness of the general experience of having a child in the NICU was used in this study in order to investigate the overall impact of the NICU experience on parental stress.

Child Outcome Measures

Chart Review

Information from patient charts in the program called "Powerchart" were extracted including tracking of respiratory and cardiovascular levels, drug therapy, metabolic/nutrition, transfusion, vascular access, and other vitality measures tracked by NICU staff. This information will be used to calculate the NTISS infant severity score.

Neonatal Therapeutic Intervention Scoring System (NTISS) (Gray et al., 1992)

The NTISS is a scoring system for ICU and surgery patients in the NICU. It is a therapy-based severity of illness assessment index with scores ranging from 0 to 47 and is a modification of the TISS score of Cullen et al (1974) suitable for use in neonatal intensive care. NTISS measures severity by quantifying the intensity and complexity of care received by a patient by assigning score points from 1 to 4 for various intensive care therapies including respiratory, drug therapy, cardiovascular, monitoring, transfusion, metabolic/nutrition, and vascular access. As such, the minimum score for a NICU infant at Loma Linda University Medical Center is 4 because there are 4 procedures mandated for NICU admission there (NTISS): frequent vital signs, cardiorespiratory monitoring, noninvasive oxygen monitoring, quantitative intake and output, each of which is one point. It is based on the assumption that given similar philosophies or styles of care, that therapeutic intensity is a direct correlate of illness severity. High internal consistency reliability was found (Cronbach = 0.84) in addition to high validity. This measure was used to assess for infant severity.

Data Analytic Plan

Descriptive statistics were analyzed in order to gain a better understanding of the parent characteristics of Loma Linda Medical Center's NICU. Preliminary correlations were run in order to investigate the hypothesis whether poorer parental mental health was correlated with lower scores of infant vitality in the NICU. A sample of 82 participants was needed in order to detect a medium effect size of 0.3 with a power of 0.8 and alpha level of 0.05. Due to the fact that our sample only had 30 participants, the power of our study (Power = 0.24) was significantly lower than expected and therefore our results may have failed to detect a relationship between variables when there actually is one present.

CHAPTER THREE

RESULTS

Development of the Research Team

In order to carry out the procedures outlined above, collaboration between the pediatrics, pediatric surgery, nursing, and psychology departments was necessary. A multidisciplinary team was established consisting of neonatologists, neonatology fellows, pediatric surgeons, NICU nurses, a NICU physical therapist, a clinical psychologist, psychology doctoral students, and NICU administrative assistants. The original research team and current Project Investigators included a psychology doctoral student, clinical psychologist, and pediatric surgeon, and this team was established the lab in the fall of 2011. Since its establishment, the research team has expanded in order to obtain additional expertise to make this project feasible and effective. Once the literature review was complete and the research questions were finalized, it was necessary to consult a team of neonatologists in order to refine the methods and identify the inclusion and exclusion criteria that would yield the appropriate participants. The neonatologists were also important in providing consultation with regard to selecting validated measures to assess infant severity and neuropsychological functioning. Additionally, it was also necessary to involve the head of nursing research with the project after concluding that a majority of the infant measures would need to be collected by NICU nursing staff.

As a result of this collaboration, the NICU nursing department chose 5 nurses and a physical therapist to be trained in the NICU Network Neurobehavioral Scale (NNNS) (Lester & Tronick, 2004), which is a standardized tool that examines the neurobehavioral organization, neurological reflexes, motor development of the at-risk and drug-exposed

infant and will be helpful in providing more information about infant functioning in the NICU. In order for the nurses to be trained in the neurobehavioral tool, the team had to meet with the head of Neonatology as well as the nursing research coordinator in order to obtain funding of about $12,000 for the training. Additionally, the head of nursing research was contacted in order to identify potential nurses to be specialized with this training, in addition to how they would be compensated for implementing the assessments as part of our study. Moreover, the nursing department and nursing team had to coordinate a week long training session with Brown University, each day last 8-9 hours, in order to learn how to administer the instrument as well as ensure reliability of their technique. This tool will be used as another measure to assess severity of infant illness and track infant functioning in the aforementioned areas.

In terms of data collection, it was vital to recruit NICU administrative staff who could contact the research team and inform them when possible new subjects were admitted. Moreover, several neonatologists and their residents became involved with the project in order to better identify which patients would meet the eligibility criteria for our study and obtain consent to be contacted. As the number of participants grew, it was also necessary to recruit more psychology doctoral students to aid in the consenting and data collection of subjects.

The research team has made a considerable amount of progress in the year since it has been established. Not only has the research team grown from its original three members to include a number of staff in both medicine and psychology, in addition to various relationships in nursing and Loma Linda Children's Hospital, but it moved from sharing lab space with another psychology research team to acquiring its own established

lab space complete with computers and data filing system. Moreover, the NICU research team was able to obtain funding from various members of Loma Linda Medical Center in order to train nursing staff in the NTISS tool.

Team Roles

The research team met once weekly in order to discuss specifics of how to carry out study procedures and how best to identify and recruit patients. Each member of the team was assigned a distinct role to carry out. The main role of the neonatologists and neonatology fellows on the team consisted of identifying eligible patients and obtaining the initial consent to contact the parents. In addition, the pediatric surgeon (also a co-PI) took on the role of collecting patient data from PowerChart in order to calculate NTISS scores, while also being in charge of facilitating communication between the Psychology Department and various departments in the Children's Hospital. The role of the NICU administrative staff included collecting consent to contact forms from the medical staff who originally contact the patients, as well as contacting psychology students who are part of the research team when identified patients check-in. The clinical child psychologist on the team (also a co-PI) and was in charge organizing the psychological aspects of the study which mostly focus on the parental evaluations of mental health, in addition to creating the statistical model for analyzing the data from the larger study. Each of the psychology students on the project were assigned specific cases for which they must contact the patient, informed them of the study, obtained consent, and scheduled and administered assessments. In addition, the psychology students were also in charge of managing the data once it was been collected.

Study Participants and Recruitment

Current Participants

Currently 30 parents are enrolled in the study. Results indicated that a majority of parents identified as Caucasian (43.3%). Additionally, most of the patient's parents were married (30%) and fell in the low income level ($0 to $15,000) (26.7%). Moreover, a majority of parents endorsed high school diploma as their highest degree attained (43.3% of mothers and 33.3% of fathers). In terms of infant demographics, 60% were male while 40% were female, with the mean gestational age being 34.7 weeks (SD = 4.97) and the mean birth weight of 5 pounds and 5 ounces (SD = 2 lbs. 3oz.).

Recruitment Strengths

The study has progressed greatly from an idea to a fully functioning research lab with data collection in progress. A major strength of the study was the ability to recruit an interdisciplinary team of medical and psychology staff from the several departments at Loma Linda University. In addition, the delegation of roles for each team member was very helpful in terms of organization. Having the neonatologists identify the patients who will meet inclusion criteria has decreased extra expenditure of time and resources on parents of patients who are interested in the study but who will not have a length of stay long enough to complete the study. Refinement in the organization and delegation of duties has been greatly beneficial as well. The implementation of a NICU visit schedule to ensure that doctoral students visit several times a day has allowed for an increase in ability to contact potential subjects. Case assignments and daily communication about subjects have also been utilized, creating more accountability on the part of subject

recruitment. Furthermore, the formation of strong relationships with NICU administration staff and recruiting them as part of the research team was essential in coordinating the recruitment of eligible patients. Moreover, the procedure of the administrative staff notifying psychology personnel on the study via a pager was very helpful in terms of contacting and finding parents of patients who qualify for the study in a timely and efficient manner.

Recruitment Limitations

Presently**,** 112 parents have expressed interest in participating the in NICU study, four of which did not meet eligibility criteria because they were non-English speakers or were transferred several months after being at another hospital. Forty-seven of the above parents gave consent to participate in the study and 30 of those participants filled out and returned the first set of questionnaires. Only four of the parents of those 30 patients filled out the second set of questionnaires for the second assessment.

Although this research program has progressed from a research idea to a large-scale project that has a multidisciplinary team who are currently recruiting patients and collecting data, there are still several areas where the research protocol requires further refinement. The greatest barrier to subject participation has been obtaining consent from parents who express interest in the study. The researchers have found that although many of the parents expressed interest in the study to NICU hospital staff, many of the times parents are difficult to reach or do not visit the NICU often enough to be consented within the 48 hour deadline. Actual time to obtain consent ranged from one to three weeks after admission. Additionally, it has also been difficult to collect the first

assessment questionnaire packets back from parents within the 72 hour deadline. Most parents returned their packets between three days and three weeks later. Many times the parents were busy attending to their child when a researcher obtained consent, so the parent completed the assessment packet later. As a result, many parents forgot to bring the packets back to the NICU in a timely manner, or they forgot to fill out the packets entirely. Additionally, the time difference between birth of the infant and time of first assessment, the mean number of days was 19.13 (*SD* = 20.23). This great variability may be attributed the fact that our sample consisted of both infants born at Loma Linda and those transferred from other hospitals. In terms of scheduling second assessments, we have found that many of the patients did not stay long enough to be administered the second assessment packet three weeks after collection of the first packet. As a result, we refined the inclusion criteria to include infants 30 weeks or those whom the research team neonatologists identified as having diagnoses that will cause them to be in the NICU three weeks or more. Another barrier of concern was that for many of the patients who did stay in the NICU during their scheduled second assessment time, their parents forgot to turn in the questionnaires in a timely manner and therefore rendered their results invalid for the study.

Parental Descriptive

Descriptive Experiences

In terms of the pregnancy, 54.5% of the patients' parents reported that the child was unplanned, 31.8% reported that they received prenatal counseling, and 100% reported receiving some degree of prenatal care during the length pregnancy. With

regards to patient characteristics, 63% were born premature, 44.4% were transferred from another hospital, and 96.3% were the first child of their parents to be in the NICU. Many of the parents (80.8%) report that they visit their child everyday and 48% report having physical contact with their infant several times a day, with the majority of the contact being skin to skin (56%). Most of the parents also endorsed that hey have emotional support from family and friends (88.9%) and endorsed some degree of spirituality (88.9%).

Parental Stress and Mental Health Findings

While 23.3% of parents reported that the financial aspect of their child's NICU stay is not stressful, the mean rating of overall stress related to the NICU experience was 2.39 (SD = .916) on a 0-4 point scale, showing that the experience has been classified as moderately to very stressful by parents. Parents who reported higher levels of stress were seen to endorse clinical levels of re-experiencing ($r = 0.43$, $p < .05$) and avoidance ($r = 0.43$, $p < .05$) symptoms which are part of the criteria considered in diagnosing Acute Stress Disorder (ASD). Of the whole sample, 1 out of the 30 parents endorsed enough symptoms to qualify them for a diagnosis of ASD (3.3.%). Although stress was not significantly correlated with quality of life or mastery in well-being areas ($p > .05$), it was associated with difficulty and frequency of problems related to communication and emotional distress connected to the NICU, as well as difficulty in dealing with problems regarding medical care (see Table 3).

Table 3

Correlations between Parent Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
1. ASD dissociative	1																							
2. ASD reexperiencing	.51**	1																						
3. ASD avoidance	.80**	.54**	1																					
4. ASD marked anxiety	.88**	.52**	.61**	1																				
5. Depression	.83**	.58**	.74**	.81**	1																			
6. COPE problem focus	-.03	-.02	-.01	.11	-.01	1																		
7. COPE emotion focus	.14	.11	.03	.15	.04	.45*	1																	
8. COPE less useful	.86**	.45*	.69**	.70**	.70**	.32	.35	1																
9. Well-being: self acceptance	-.55*	-.37	-.38	-.62**	-.75**	.05	.03	-.43**	1															
10. Well-being: positive relations	-.30	-.20	-.25	-.30	-.49*	.20	.38	-.21	.77**	1														
11. Well-being: autonomy	-.58**	-.32	-.46*	-.58**	-.62**	.21	.18	-.48*	.72**	.72**	1													
12. Well-being: environmental mastery	-.57**	-.14	-.46*	-.60**	-.66**	.24	.29	-.37	.87**	.73**	.78**	1												
13. Well-being: purpose in life	-.14	-.18	.03	-.24	-.22	52**	.18	.18	.54*	.50*	.60**	.67**	1											
14. Well-being: personal growth	-.32	-.08	-.26	-.32	-.33	.40*	.10	-.24	.65**	.72**	.76**	.75**	.68**	1										
Frequency of problems																								
15. Communication	.61**	.37	.68**	.60**	.63**	.31	.24	.56**	-.38	.09	-.20	-.33	.12	-.04	1									
16. Emotional Distress	.64**	.73**	.81**	.57**	.67**	.22	.18	.62**	-.32	-.10	-.39	-.23	.07	-.09	.78**	1								
17. Role Function	.54**	.49*	.55**	.46*	.55**	.05	.10	.46*	-.54*	-.22	-.36	-.40	-.07	-.24	.75**	.66**	1							
18. Medical Care	.48*	.57**	.50**	.51**	.49*	.12	.03	.43*	-.19	.06	-.19	-.16	.03	.12	.73**	.74**	.69**	1						
Difficulty of problems																								

19. Communication	.72**	.39	.82**	.66**	.74**	.17	.13	.54**	-.47*	-.23	-.32	-.46*	-.05	-.23	.81**	.75**	.51**	.46*	1					
20. Emotional Distress	.61**	.64**	.76**	.61**	.64**	.31	.17	.57**	-.31	-.05	-.33	-.23	.09	-.02	.81**	.96**	.54**	.70**	.80**	1				
21. Role Function	.65**	.41*	.68**	.62**	.71**	.04	.08	.50**	-.55**	-.24	-.25	-.49*	-.06	-.23	.67**	.59**	.68**	.54**	.71**	.57**	1			
22. Medical Care	.62**	.64**	.72**	.59**	.54**	.05	.13	.44*	-.23	.05	-.22	-.14	-.04	.02	.68**	.81**	50*	.71**	.73**	.82**	.64**	1		
23. QOLI	-.13	-.05	.07	-.50	-.17	.12	.05	.18	.65*	.64*	.52	.70**	.67**	.78**	.05	.12	.06	.06	-.14	.06	.01	.03	1	
24. Stress	.33	.43*	.43*	.34	.39*	.21	.06	.36	-.16	.01	-.16	-.07	.11	.07	.52**	.60**	.35	.41*	.44*	.61**	.39	.49*	.06	1

Note. * $p < .05$,
** $p < .01$,

Demographics variables such as prenatal care, prenatal counseling, knowing that their child would be transferred to the NICU beforehand, infant being transferred from another hospital, etc. were investigate in relation to both the positive and negative aspects of mental health. Findings showed that prenatal counseling and prenatal care were not significantly related to stress, ASD/PTSD symptoms, depressive symptoms, or cooping style, (all $p > .05$). On the other hand, there was a significant difference between having a child that was full term or premature and endorsement of criteria meeting clinical levels of ASD, ($t(26) = 2.56$, $p < .05$), suggesting that having a child that is full-term was related to endorsement of higher levels of symptoms associated with ASD.

Parents who were stressed reported higher levels of depression ($r = 0.39$, $p < .05$), more specifically, 34.8% of parents scored above the cut-off score of 16 on the CES-D. Parents endorsing depression symptoms were also more likely to exhibit clinical levels of Acute Stress Disorder symptoms ($r = 0.72$, $p < .01$), although only one of the participants met the clinical criteria of Acute Stress Disorder according to the SASQ. In addition, these parents were also found to use less useful coping skills ($r = 0.70$, $p < .01$) such as venting, behavioral disengagement, denial, self-blame, and substance abuse; and to have acquired less mastery in the areas of self-acceptance ($r = -0.75$, $p < .01$), positive relations ($r = -0.49$, $p < .05$), environmental mastery ($r = -0.66$, $p < .01$), and autonomy ($r = -0.62$, $p < .01$). Moreover, parents with more depressive symptoms endorsed more difficulty and higher frequency of problems related to communication, emotional distress, role function, and medical care in relation to the NICU experience (see Table 3).

Overall, parents in the sample used emotion focused and problem focused coping significantly more than less useful coping responses, ($t(28) = 20.30$, $p < .01$; $r = 0.35$, $p >$

.06); $t(28) = 11.50$, $p < .01$; $r = 0.32$, $p > .05$), and emotion focused coping significantly more than problem focused coping, ($t(28) = 5.68$, $p < .01$; $r = 0.45$, $p < .05$). The use of types of emotion focused and problem focused coping did not significantly differ from each other, $p > .05$, however, there was a significant difference in the use of different types of less useful coping mechanisms such that venting, self distraction, and self blame were significantly more used than denial, behavioral disengagement, and substance use (see Table 4). Less useful coping responses were correlated with higher frequency and more difficulty with problems related to the NICU experience as well as endorsement of more clinical symptoms of Acute Stress Disorder, $p < .05$ (see Table 3).

Table 4

Differences Between Levels of COPE Variables

Variable	df	M	SD	t	r
Venting	28	3.59	1.59		
Behavioral	28	2.21	.56	4.54**	.10
Disengagement					
Denial	28	2.41	1.01	3.83**	.63
Self Distract	28	3.28	1.58	.69	-.17
Self Blame	28	3.07	1.65	1.41	.26
Substance use	28	2.00	0	5.36**	--
Behavioral Disengagement	28	2.21	.56		
Denial	28	2.41	1.01	-1.54	.72**
Self Distract	28	3.28	1.58	-3.81**	.30
Self Blame	28	3.07	1.65	-3.43**	.64**
Substance use	28	2.00	0	1.99	--
Denial	28	2.41	1.01		
Self Distract	28	3.28	1.58	-2.54*	.06
Self Blame	28	3.07	1.65	-2.63*	.58**
Substance use	28	2.00	0	2.19*	--
Self Distract	28	3.28	1.58		
Self Blame	28	3.07	1.65	.59	.31
Substance use	28	2.00	0	4.35**	--
Self Blame	28	3.07	1.65		
Substance use	28	2.00	0	3.50**	--

Note. * $p < .05$, ** $p < .01$,

Although parents in this sample endorsed moderate to high levels of stress, the majority of them did not meet the criteria for Acute Stress Disorder (96.7%). More specifically, 6.7% of parents met the criteria for dissociative symptoms, 16.7% of parents met the criteria for re-experiencing symptoms, 20% met clinical criteria of avoidance symptoms, and 70% endorsed clinical levels of marked anxiety/increased arousal symptoms. Their stress most frequently came from problems arising from medical care (M = 2.95, SD = 1.02) and least frequently from changes in their role function (M = 2.54, SD = .68), ($t(25) = 2.67$, $p < .05$), while the most difficulty in problems related to emotional distress (M = 2.49, SD = 1.03) from the NICU and the least difficulty from communication with staff in the NICU (M = 1.83, SD = .76). In terms of mastery in areas of positive well-being, no area was significantly more mastered than others, $p > .05$.

The overall quality of life as reported by parents in the sample fell in the Average range (M = 55.5, SD = 10.3). In particular, 6.3% of the sample fell in the Low category, people who are generally unhappy, unfulfilled, and unable to get basic needs met; 62.5% of the sample in the Average category, people who are generally successful at getting what they want out of life and are able to get their basic needs met and achieve goals in most areas of life ; and 31.3% in the High category, people who report being largely free from psychological distress because their most cherished needs, wishes and goals have been fulfilled. The area in which parents endorsed the highest satisfaction was with regards to children (M = 5.0, SD = 1.63) and love (M = 4.5, SD = 3.06), while the lowest areas of satisfaction were in regards to work (M = 2.0, SD = 3.36) and money (M = 1.1, SD = 2.02). It is interesting to note that quality of life was significantly positively

correlated with all aspects related to positive well-being, with the exception of autonomy (see Table 3).

Association between Parental Stress and Infant Severity

Infant severity ranged from 0 to 48 with an average severity score of 13.6 (*SD* = 10.5). Severity of infant illness was shown to be significantly correlated with frequency of stress related to problems with communication ($r = 0.44$, $p < .05$) and stress related to changes in role functioning ($r = 0.53$, $p < .01$), such that higher frequency of stress related to problems with communication and changes in role function were associated with more severity of illness. More specifically, parents endorsed that communication problems with regard to speaking with their child's doctor (*M* = 3.54, *SD* = 1.29), nurses (*M* = 4.11, *SD* = 1.37), and with family members (*M* = 4.11, *SD* = 1.11), regarding their child's illness were the most stressful in that area. Additionally, infant illness severity was also significantly associated with endorsement of ASD re-experiencing symptoms ($r = 0.43$, $p < .05$). All other parental mental health variables were shown to not be significantly correlated with infant severity (Table 5). In terms of parental mental health related to birth of the infant, it was found that a greater time between infant birth and first assessment was related to greater endorsement of ASD dissociative symptoms ($r = .43$, $p < .03$) as well as higher use of less useful coping mechanisms ($r = .42$, $p < .02$).

Table 5

Correlations between Parent and Child Variables

Variable	NTISS	M	SD	Questionnaire Option Range
1. ASD dissociative	.25	.51	.78	0-5
2. ASD reexperiencing	.43*	.56	.78	0-5
3. ASD avoidance	.36	.60	.81	0-5
4. ASD marked anxiety	.20	1.7	1.2	0-5
5. Depression	.31	17.4	11.7	0-60
6. COPE problem focus	-.01	5.59	1.37	1-4
7. COPE emotion focus	-.17	7.00	1.16	1-4
8. COPE less useful	.17	2.76	.69	1-4
9. Well-being: self acceptance	-.29	4.66	.82	1-6
10. Well-being: positive relations	-.15	4.75	.9	1-6
11. Well-being: autonomy	-.15	4.72	.99	1-6
12. Well-being: environmental mastery	-.14	4.73	.81	1-6
13. Well-being: purpose in life	.03	4.89	.71	1-6
14. Well-being: personal growth	-.08	4.8	.74	1-6
Frequency of problems				1-5
15. Communication	.44*	2.73	.64	
16. Emotional Distress	.40	2.45	.85	
17. Role Function	.53**	2.57	.68	
18. Medical Care	.22	2.88	1.02	
Difficulty of problems				1-5
19. Communication	.34	1.82	.76	
20. Emotional Distress	.29	2.37	1.03	
21. Role Function	.21	2.16	.77	
22. Medical Care	.16	2.23	.98	
23. QOLI (T score)	-.12	55.5	10.32	
24. Stress	.25	2.39	.92	0-4

Note. * $p < .05$, ** $p < .01$,

CHAPTER FOUR

DISCUSSION

The present study advances our understanding of the feasibility of conducting a longitudinal investigation of the relationship between parental mental health and infant outcomes in the NICU. A large team had to be recruited in order to put the idea of this study into practice. In addition, trial and error had to be employed in terms of trouble-shooting recruitment problems related to indentifying potential subjects, contacting parents of children who qualify, and obtaining the necessary data during the needed time points. In particular, we learned how difficult it is to obtain data from the subjects in our study in a timely manner. In addition, we also learned that our inclusion criteria needed to be children in the NICU who would remain for at least 3 weeks, otherwise, it would not be possible to collect multiple assessments on both the child and parent.

The present study also lends valuable information about the demographic characteristics of parents in the NICU. Not only does the study replicate findings from previous literature which found that parents in the NICU are significantly stressed and exhibit depressive symptoms (Carter, Mulder et al. 2007; MacDonald 2007; Lefkowitz, Baxt et al. 2010), but it also reveals valuable information about protective factors. Our study showed that those parents who were endorsing higher levels of stress and clinical levels of depression employed less useful coping skills and experienced a majority of stress from communication problems, emotional distress, role function and medical care in the NICU. Additionally, these parents were also found to be lacking in mastery of self-acceptance and environmental mastery. Moreover, it is interesting to mention that while our study was not able to replicate the results of Miles et al. (1992) in finding alterations

in parental role as the highest source of stress, this area was one of the few areas that was significantly correlated with infant severity. The other area significantly related to infant severity was re-experiencing symptoms, characteristic of clinical criteria for ASD and PTSD. This finding is interesting in that re-experiencing symptoms are one of the hallmark symptoms of PTSD and of all the PTSD symptoms surveyed, it was the most associated with having a child with a more severe illness. This finding may suggest that there is something about having a more severely ill child in the NICU that is somewhat traumatic for parents. Lastly, greater time between infant birth and first assessment was related to more severe dysfunction in terms of parental mental health, which may be a function of more impaired parents taking longer to complete and return the assessment questionnaires or may represent a decline in parental mental health over the course of the NICU stay. Future longitudinal research is needed to address this question.

On the alternative side, despite the fact that parents were stressed and depressed to some degree, our results also show that parents exhibited a number of strengths as they scored in the average or above ranges on positive psychological measures. More specifically, parents on average endorsed a score of 4 or higher in rating self-acceptance, positive relations, autonomy, environmental master, purpose in life, and personal growth, indicating various levels of agreement in mastering the aforementioned areas of positive well-being (see Table 5). Parents also rated their quality of life higher than average (M = 55.5, SD = 10.32), indicating, that on average, parents endorsed life satisfaction similar to or better than peers.

Results of the study highlight the importance of conducting research in this population as the findings show that parents are highly distressed and lack successful use

of coping strategies. In addition, our findings support the future study to look at both positive as well as negative mental health outcomes because our study showed that they are not mutually exclusive. The positive outcomes in our study suggest that despite, the stress of having a child in the NICU, there may be something inherently positive about having a new baby that exists simultaneously with stress. These strengths may be important for future interventions to build on.

Information provided by this study will used in designing a longitudinal study in order to investigate the direction of effect of the relationship between parental mental health and child outcomes in the NICU, which will later be used to improve the NICU experience. The results of this study also lend more evidence for the need to use a more comprehensive measure to assess infant severity as well as infant neurobehavioral functioning. It would be important to note, that as mentioned in the introduction, Loma Linda Children's Hospital is the only Level III NICU in the Inland Empire, and as such, infants in this NICU will have more severe diagnosis which consequently will cause them to have a longer length of stay than infants in a lower grade NICU. The lack of significance in finding an association between parental mental health and severity of infant illness may be due to the fact that infant severity changes daily as a surgery one day can elevate scores comparably higher than the day after surgery. The one score of infant severity may not have been the most accurate representation of infant severity in relation to the recorded parental health at infant admission. Daily record of NTISS scores and correlating the average over a time period may provide a better representation of the relationship to parental mental health functioning. In addition, we may need to add another measure of infant severity, which more accurately captures variables that will be

impacted by parent interaction with the child, such as the NICU Network Neurobehavioral Scale (NNNS). The use of this additional infant measure, in addition to the improvements in the methodology learned from this study will be used in the design of the larger study in pursuit of investigating a temporal relationship between parental mental health and infant outcomes with a future direction of using those results to inform practitioners about where intervention is needed—at the level of parental mental health or at the level of infant care or both.

Next Steps

This pilot study has been very informative in terms of refining research protocol as well as establishing the necessary relationships in order to implement the larger project, which will consist of a longitudinal analysis of the relationship between parental mental health and infant health outcomes in the NICU. The refinement of team member roles as well as flow of communication in terms of procedures for identifying, contacting, and consenting eligible patients will allow for a more efficient way of recruiting larger samples of subjects. The study results also indicate that more specific inclusion and exclusion criteria need to be established. More specifically, only infants projected to stay in the NICU a minimum of three weeks will be included in the future study. Infants whose length of stay is less than three weeks, in addition to infants whose parents are not contacted within one week of admission will be excluded retroactively. This will be implemented in order to maintain that levels of stress reported by parents are more representative of their experience at infant NICU admission. Additionally, from this pilot study, it became apparent that the parents needed a form of motivation to return their

questionnaires in a timely manner. After looking at the preliminary data and finding that much of the subject pool comes from a low socioeconomic status, it was decided that a small monetary compensation may decrease the amount of participants lost due to questionnaires being turned in too late. Preliminary data also indicated that many of the NICU parents did not qualify because they were primarily Spanish speaking, as such it was decided that Spanish versions of the questionnaires would be obtained or translated in order to enhance recruitment. Findings have also led the team to consider the possibility of adding a trait anxiety measure, due to high rates of anxiety symptoms, in order to gain a more in depth idea of the psychological profile of NICU parents and whether higher stress levels are a result of parents being anxious people already. It was also decided that daily measures of infant severity, which will be averaged and then correlated with parental health measures may provide a more accurate representation of the relationship between those variables. In researching and consulting with experts in the field, we decided that it would be highly beneficial to include the NICU Network Neurobehavioral Scale (NNNS) in our next study (Lester & Tronick, 2004). The NNS examines the neurobehavioral organization, neurological reflexes, motor development of the at-risk and drug-exposed infant. This is a standardized tool that looks at active and passive tone, signs of stress, and withdrawal in infants, which will be helpful in providing more information about infant functioning in the NICU. Moreover, due to the large backing of the study from both the nursing and neonatology departments, enough funding has been gathered in order to train 6 nurses in the NNNS, which will provide more comprehensive information on how the infants are functioning at both assessments.

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APPENDIX A

LIST OF MEASURES

Measures for NICU Project			
Measure	**Description**	**Type of Measure**	**Variable**
Process Variables			
Demographics questionnaire	Demographic data was collected by a questionnaire that parents will be asked to complete called the Development History Questionnaire. In addition, questions about prenatal history and infant diagnosis will be asked.	Parent Interview	This questionnaire assessed potential confounding variables such as a history of prenatal counseling, whether or not the infant is a transfer patient, whether the parents have had a previous child in the NICU, if the NICU admission expected, the appearance of infant, number of parent visitations to NICU, parental feelings of hope, amount of parental participation in their child's care, amount of social support, family financial situation, and family's spirituality and beliefs.

Independent Variable Measures of Parental Stress and Overall Parental Functioning			
Psychological Well-Being Scale	The Psychological Well-Being Scales is a widely used measure which looks at well-being through six dimensions: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. Individuals respond to various statements and indicate on a 6-point Likert scale how true each statement is of them. Higher scores on that scale indicate greater well-being on that dimension.	Parent Report	All subscales of this measure was used to assess protective factors in parents in the sample which may buffer negative outcomes for infants.
Brief COPE Scale	The Brief COPE Scale is a 28-item measure used to assess different ways in which people respond to stress. It consists of five scales with four items each measuring distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support); five scales measure aspects of emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measure coping responses that are less useful (focus on and venting of emotions, behavioral disengagement, mental disengagement). Each item was measured using Likert scales ranging from 1 ("I don't do this at all") to 4 ("I do this a lot"). The Brief COPE Scale showed fairly good reliability and validity (Yusoff, Low, & Yip, 2010).	Parent Report	All subscales of this scale was used to identify coping styles used by parents in the NICU.

Quality of Life Inventory (QOLI)	The QOLI assesses an individual's quality of life through self-report of the importance they attach to each of the 16 domains on a 3- point scale. In addition, it assesses current satisfaction with each domain on a 6-point rating scale. Importance scores are multiplied by satisfaction scores for each domain, and then these scores are summed to determine an overall current quality of life for each individual. The QOLI possesses good internal consistency (.79) and two week test-retest (.73) reliability. Good convergent validity has been demonstrated between QOLI total score and both the Satisfaction With Life Scale (.56) and the Quality of Life Index scores (.75) (Frisch, 1992).	Parent Report	The total scale of this measure was used to look at other aspects of parents' lives that may contribute to or protect from distress.
Center for Epidemiological Studies-Depression Scale (CES-D)	The CES-D is a 20-item instrument that was developed by the National Institute of Mental Health to detect major or clinical depression in adolescents and adults. It has four separate factors: depressive affect, somatic symptoms, positive affect, and interpersonal relations. The questions cover most of the areas included in the diagnostic criteria for depression and has been used in urban and rural populations, and in cross-cultural studies of depression. Studies using the CES-D indicate that it has very good internal consistency, acceptable test-retest stability, and construct validity (Radloff, 1997).	Parent Report	The total score of this measure was used to assess the levels of depression of the NICU parents.

The Stanford Acute Stress Reaction Questionnaire (SASQ)	The SASQ is a reliable and valid measure used to evaluate anxiety and dissociation symptoms in the aftermath of traumatic events, following DSM-IV criteria for acute stress disorder. It has been shown to have good validity and reliability (Cardena et al., 2000). It has 22 items and uses a 5-point Likert scale ranging from 0 (not experienced) to 5 (very often experienced), asking participants to rate how well each statement describes their experience during the stressful event.	Parent Report	This measure was used to assess ASD/PTSD symptoms in parents in the NICU population.
The Pediatric Inventory for Parents (PIP)	The PIP is a 42-item self-report measure of parenting stress related to caring for a child with an illness. The PIP measures stress in four domains: (1) medical care, (2) communication (with child and health care team), (3) role functioning, and (4) emotional functioning. Parents rate each item along a 5-point Likert scale (1 = "Not at all," and 5 = "Extremely") as to both the item's frequency over the last week and level of difficulty associated with it. Frequency and difficulty scores are summed separately for each scale and then the scale scores are added together to form an overall total frequency score (PIP-F) and total difficulty score (PIP-D). Higher scores indicate greater frequency and difficulty. Internal consistency reliability for the PIP is high (Cronbach range: .80-.96) and PIP scores were significantly correlated with a measure of state anxiety and also with parenting stress.	Parent Report	Both the PIP-F and PIP-D scores was used to look at aspects of the infant's illness and hospitalization which may also contribute to parental stress.

Parental Stressor Scale :NICU (PSS: NICU)	The PSS: NICU was designed to measure the degree of stress experienced by parents during hospitalization related to alterations in their parental role, the appearance and behavior of their child, and sights and sounds of the unit. Parents are asked to rate items on a 5-point rating scale ranging from "not at all stressful" to "extremely stressful." The PSS: NICU longitudinally predicted depressive symptoms in mothers of prematurely-born-children (Miles et al., 2007). High internal consistency reliability was found (Cronbach = 0.94) in addition to high construct, concurrent and predictive validity.	Parent Report	The total scale consisting of one item about the stressfulness of the general experience of having a child in the NICU was used in this study in order to investigate the overall impact of the NICU experience on parental stress.
Outcome Measures of Infant Vitality			
Chart Review	Information from patient charts in the program called “Powerchart” will be extracted including weight, temperature, length of stay, head circumference, length, and other vitality measures tracked by NICU staff.	NICU staff Observation which are charted daily for all patients	Information was used to calculate the NTISS score.

NTISS	The NTISS is a scoring system for ICU and surgery patients in the NICU. It is a therapy-based severity of illness assessment index with scores ranging from 0 to 47 and is a modification of the TISS score of Cullen et al (1974) suitable for use in neonatal intensive care. The minimum score for a NICU infant is 4 because there are 4 procedures mandated for a NICU baby at Loma Linda Medical Center (NTISS), each of which is one point. The NTISS measures severity by quantifying the intensity and complexity of care received by a patient by assigning score points from 1 to 4 for various intensive care therapies including respiratory, drug therapy, cardiovascular, monitoring, transfusion, metabolic/nutrition, and vascular access.	Chart Review	This measure was used to assess for infant severity.

The NICU Network Neurobehavioral Scale (NNNS)	The NNS examines the neurobehavioral organization, neurological reflexes, motor development of the at-risk and drug-exposed infant. This tool looks at active and passive tone, signs of stress, and withdrawal in infants. The NNNS is applicable to term, normal healthy infants, preterm infants and infants at risk due to factors such as prenatal substance exposure and suited for infants as young as 30 weeks gestational age through 46-48 weeks corrected conceptional age (up to a full-term infant who is about 2 months old). It is a standardized tool with established test-retest reliability and strong psychometric properties. The NNNS is comprised of 115 items broken down into 3 categories: 1) neurological items that assess active and passive muscle tone, primitive reflexes, and central nervous system integrity, 2) behavioral state, sensory, and interactive response, and 3) stress/abstinence items and takes 25-30 minutes to administer. Outcome variables that are measured include: Habituation, Orientation, Amount of Handling, State, Self-Regulation, Hypotonia, Hypertonia, Quality of Movement, Number of Stress Abstinence Signs, and Number of Non-optimal Reflexes.	Nurse evaluation	This tool was added as a result of the findings of this study. It will be used in the longitudinal investigation to assess the psychosocial functioning of the infants.

APPENDIX B

PARENT MEASURES

1. COPE
2. CES-D
3. SASQ
4. Psychological Well-Being Scales
5. Pediatric Inventory for Parents
6. PSSI: NICU
7. Developmental History Questionnaire

Measures not included due to copyright protection

1. QOLI

Brief COPE

These items deal with ways you've been coping with the stress in your life since you found out your child would be in the NICU. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. 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. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

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
4 = I've been doing this a lot

____1. I've been turning to work or other activities to take my mind off things.
____2. I've been concentrating my efforts on doing something about the situation I'm in.
____3. I've been saying to myself "this isn't real."
____4. I've been using alcohol or other drugs to make myself feel better.
____5. I've been getting emotional support from others.
____6. I've been giving up trying to deal with it.
____7. I've been taking action to try to make the situation better.
____8. I've been refusing to believe that it has happened.
____9. I've been saying things to let my unpleasant feelings escape.
____10. I've been getting help and advice from other people.
____11. I've been using alcohol or other drugs to help me get through it.
____12. I've been trying to see it in a different light, to make it seem more positive.
____13. I've been criticizing myself.
____14. I've been trying to come up with a strategy about what to do.
____15. I've been getting comfort and understanding from someone.
____16. I've been giving up the attempt to cope.
____17. I've been looking for something good in what is happening.
____18. I've been making jokes about it.
____19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
____20. I've been accepting the reality of the fact that it has happened.
____21. I've been expressing my negative feelings.
____22. I've been trying to find comfort in my religion or spiritual beliefs.
____23. I've been trying to get advice or help from other people about what to do.
____24. I've been learning to live with it.
____25. I've been thinking hard about what steps to take.
____26. I've been blaming myself for things that happened.
____27. I've been praying or meditating.
____28. I've been making fun of the situation.

CENTER FOR EPIDEMIOLOGIC STUDIES—DEPRESSION SCALE

	Rarely or none of the time (less than 1 day)	**Some or a little of the time (1-2 days)**	**Occasionally or a moderate amount of the time (3-4 days)**	**Most or all of the time (5-7 days)**
During the past week:	0	1	2	3
1) I was bothered by things that usually don't bother me	0	1	2	3
2) I did not feel like eating; my appetite was poor	0	1	2	3
3) I felt that I could not shake off the blues even with help from my family and friends	0	1	2	3
4) I felt that I was just as good as other people	0	1	2	3
5) I had trouble keeping my mind on what I was doing	0	1	2	3
6) I felt depressed	0	1	2	3
7) I felt that everything I did was an effort	0	1	2	3
8) I felt hopeful about the future	0	1	2	3
9) I thought my life had been a failure	0	1	2	3
10) I felt fearful	0	1	2	3
11) My sleep was restless	0	1	2	3
12) I was happy	0	1	2	3
13) I talked less than usual	0	1	2	3
14) I felt lonely	0	1	2	3
15) People were unfriendly	0	1	2	3
16) I enjoyed life	0	1	2	3
17) I had crying spells	0	1	2	3
18) I felt sad	0	1	2	3
19) I felt that people disliked me	0	1	2	3
20) I could not get "going"	0	1	2	3

Stanford Acute Stress Reaction Questionnaire

<u>DIRECTIONS</u>: Below is a list of experiences people sometimes have during and after a stressful event. Please read each item carefully and decide how well it describes *your* experience during and immediately following your child's admission/stay in the NICU. Refer to this event in answering the items below. Use the 0-5 point scale shown below and circle the number that best describes your experience.

0----------1----------2----------3----------4----------5

not very rarely rarely sometimes often very often
experienced experienced experienced experienced experienced experienced

1. I had difficulty falling or staying asleep.
0 1 2 3 4 5

2. I felt restless.
0 1 2 3 4 5

3. I felt a sense of timelessness.
0 1 2 3 4 5

4. I was slow to respond.
0 1 2 3 4 5

5. I tried to avoid feelings about my child's NICU admission/stay.
0 1 2 3 4 5

6. I had repeated distressing dreams about my child's NICU admission/stay.
0 1 2 3 4 5

7. I felt extremely upset if exposed to events that reminded me of an aspect of my child being admitted to/staying in the NICU.
0 1 2 3 4 5

8. I would jump in surprise at the least thing.
0 1 2 3 4 5

9. My child's NICU admission made it difficult for me to perform work or other things I needed to do.
0 1 2 3 4 5

10. I did not have the usual sense of who I am.
0 1 2 3 4 5

0----------1----------2----------3----------4----------5

not experienced	very rarely experienced	rarely experienced	sometimes experienced	often experienced	very often experienced

11. I tried to avoid activities that reminded me of my child's NICU admission/stay.
0 1 2 3 4 5

12. I felt hypervigilant or "on edge".
0 1 2 3 4 5

13. I experienced myself as though I were a stranger.
0 1 2 3 4 5

14. I tried to avoid conversations about my child's NICU stay.
0 1 2 3 4 5

15. I had a bodily reaction when exposed to reminders of my child's NICU stay.
0 1 2 3 4 5

16. I had problems remembering important details about my child's NICU stay.
0 1 2 3 4 5

17. I tried to avoid thoughts about my child's NICU stay.
0 1 2 3 4 5

18. Things I saw looked different to me from how I know they really looked.
0 1 2 3 4 5

19. I had repeated and unwanted memories of my child's NICU stay.
0 1 2 3 4 5

20. I felt distant from my own emotions.
0 1 2 3 4 5

21. I felt irritable or had outbursts of anger.
0 1 2 3 4 5

22. I avoided contact with people who reminded me of my child's NICU stay.
0 1 2 3 4 5

23. I would suddenly act or feel as if my child's NICU admission/stay was happening again.
0 1 2 3 4 5

24. My mind went blank.
0 1 2 3 4 5

0----------1----------2----------3----------4----------5

not experienced	very rarely experienced	rarely experienced	sometimes experienced	often experienced	very often experienced

25. I had amnesia for large periods of my child's NICU admission/stay.
0 1 2 3 4 5

26. My child's NICU admission/stay caused problems in my relationships with other people.
0 1 2 3 4 5

27. I had difficulty concentrating.
0 1 2 3 4 5

28. I felt estranged or detached from other people.
0 1 2 3 4 5

29. I had a vivid sense that my child's sickness happening all over again.
0 1 2 3 4 5

30. I tried to stay away from places that reminded me of my child's NICU stay.
0 1 2 3 4 5

On how many days did you experience any of the above symptoms of distress? (Please mark one):
No days ____
One day ____
Two days ____
Three days ____
Four days ____
Five or more days ____

Psychological Well-Being Scales

The following set of questions deals with how you feel about yourself and your life. Please remember that there are no right or wrong answers.

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
1. Most people see me as loving and affectionate.	1	2	3	4	5	6
2. Sometimes I change the way I act or think to be more like those around me.	1	2	3	4	5	6
3. In general, I feel I am in charge of the situation in which I live.	1	2	3	4	5	6
4. I am not interested in activities that will expand my horizons.	1	2	3	4	5	6
5. I feel good when I think of what I've done in the past and what I hope to do in the future.	1	2	3	4	5	6
6. When I look at the story of my life, I am pleased with how things have turned out.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
7. Maintaining close relationships has been difficult and frustrating for me.	1	2	3	4	5	6
8. I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.	1	2	3	4	5	6
9. The demands of everyday life often get me down.	1	2	3	4	5	6
10. In general, I feel that I continue to learn more about myself as time goes by.	1	2	3	4	5	6
11. I live life one day at a time and don't really think about the future.	1	2	3	4	5	6
12. In general, I feel confident and positive about myself.	1	2	3	4	5	6
13. I often feel lonely because I have few close friends with whom to share my concerns.	1	2	3	4	5	6
14. My decisions are not usually influenced by what everyone else is doing.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
15. I do not fit very well with the people and the community around me.	1	2	3	4	5	6
16. I am the kind of person who likes to give new things a try.	1	2	3	4	5	6
17. I tend to focus on the present, because the future nearly always brings me problems.	1	2	3	4	5	6
18. I feel like many of the people I know have gotten more out of life than I have.	1	2	3	4	5	6
19. I enjoy personal and mutual conversations with family members or friends.	1	2	3	4	5	6
20. I tend to worry about what other people think of me.	1	2	3	4	5	6
21. I am quite good at managing the many responsibilities of my daily life.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
22. I don't want to try new ways of doing things - my life is fine the way it is.	1	2	3	4	5	6
23. I have a sense of direction and purpose in life.	1	2	3	4	5	6
24. Given the opportunity, there are many things about myself that I would change.	1	2	3	4	5	6
25. It is important to me to be a good listener when close friends talk to me about their problems.	1	2	3	4	5	6
26. Being happy with myself is more important to me than having others approve of me.	1	2	3	4	5	6
27. I often feel overwhelmed by my responsibilities.	1	2	3	4	5	6
28. I think it is important to have new experiences that challenge how you think about yourself and the world.	1	2	3	4	5	6
29. My daily activities often seem trivial and unimportant to me.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
30. I like most aspects of my personality.	1	2	3	4	5	6
31. I don't have many people who want to listen when I need to talk.	1	2	3	4	5	6
32. I tend to be influenced by people with strong opinions.	1	2	3	4	5	6
33. If I were unhappy with my living situation, I would take effective steps to change it.	1	2	3	4	5	6
34. When I think about it, I haven't really improved much as a person over the years.	1	2	3	4	5	6
35. I don't have a good sense of what it is I'm trying to accomplish in life.	1	2	3	4	5	6
36. I made some mistakes in the past, but I feel that all in all everything has worked out for the best.	1	2	3	4	5	6
37. I feel like I get a lot out of my friendships.	1	2	3	4	5	6
38. People rarely talk to me into doing things I don't want to do.	1	2	3	4	5	6
39. I generally do a good job of taking care of my personal finances and affairs.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
40. In my view, people of every age are able to continue growing and developing.	1	2	3	4	5	6
41. I used to set goals for myself, but that now seems like a waste of time.	1	2	3	4	5	6
42. In many ways, I feel disappointed about my achievements in life.	1	2	3	4	5	6
43. It seems to me that most other people have more friends than I do.	1	2	3	4	5	6
44. It is more important to me to "fit in" with others than to stand alone on my principles.	1	2	3	4	5	6
45. I find it stressful that I can't keep up with all of the things I have to do each day.	1	2	3	4	5	6
46. With time, I have gained a lot of insight about life that has made me a stronger, more capable person.	1	2	3	4	5	6
47. I enjoy making plans for the future and working to make them a reality.	1	2	3	4	5	6
48. For the most part, I am proud of who I am and the life I lead.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
49. People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6
50. I have confidence in my opinions, even if they are contrary to the general consensus.	1	2	3	4	5	6
51. I am good at juggling my time so that I can fit everything in that needs to be done.	1	2	3	4	5	6
52. I have a sense that I have developed a lot as a person over time.	1	2	3	4	5	6
53. I am an active person in carrying out the plans I set for myself.	1	2	3	4	5	6
54. I envy many people for the lives they lead.	1	2	3	4	5	6
55. I have not experienced many warm and trusting relationships with others.	1	2	3	4	5	6
56. It's difficult for me to voice my own opinions on controversial matters.	1	2	3	4	5	6
57. My daily life is busy, but I derive a sense of satisfaction from keeping up with everything.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
58. I do not enjoy being in new situations that require me to change my old familiar ways of doing things.	1	2	3	4	5	6
59. Some people wander aimlessly through life, but I am not one of them.	1	2	3	4	5	6
60. My attitude about myself is probably not as positive as most people feel about themselves.	1	2	3	4	5	6
61. I often feel as if I'm on the outside looking in when it comes to friendships.	1	2	3	4	5	6
62. I often change my mind about decisions if my friends or family disagree.	1	2	3	4	5	6
63. I get frustrated when trying to plan my daily activities because I never accomplish the things I set out to do.	1	2	3	4	5	6
64. For me, life has been a continuous process of learning, changing, and growth.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
65. I sometimes feel as if I've done all there is to do in life.	1	2	3	4	5	6
66. Many days I wake up feeling discouraged about how I have lived my life.	1	2	3	4	5	6
67. I know that I can trust my friends, and they know they can trust me.	1	2	3	4	5	6
68. I am not the kind of person who gives in to social pressures to think or act in certain ways.	1	2	3	4	5	6
69. My efforts to find the kinds of activities and relationships that I need have been quite successful.	1	2	3	4	5	6
70. I enjoy seeing how my views have changed and matured over the years.	1	2	3	4	5	6
71. My aims in life have been more a source of satisfaction than frustration to me.	1	2	3	4	5	6
72. The past had its ups and downs, but in general, I wouldn't want to change it.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
73. I find it difficult to really open up when I talk with others.	1	2	3	4	5	6
74. I am concerned about how other people evaluate the choices I have made in my life.	1	2	3	4	5	6
75. I have difficulty arranging my life in a way that is satisfying to me.	1	2	3	4	5	6
76. I gave up trying to make big improvements or changes in my life a long time ago.	1	2	3	4	5	6
77. I find it satisfying to think about what I have accomplished in life.	1	2	3	4	5	6
78. When I compare myself to friends and acquaintances, it makes me feel good about who I am.	1	2	3	4	5	6
79. My friends and I sympathize with each other's problems.	1	2	3	4	5	6
80. I judge myself by what I think is important, not by the values of what others think is important.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
81. I have been able to build a home and a lifestyle for myself that is much to my liking.	1	2	3	4	5	6
82. There is truth to the saying that you can't teach an old dog new tricks.	1	2	3	4	5	6
83. In the final analysis, I'm not so sure that my life adds up to much.	1	2	3	4	5	6
84. Everyone has their weaknesses, but I seem to have more than my share.	1	2	3	4	5	6

Pediatric Inventory for Parents

Below is a list of difficult events which parents of children who have (or have had) a serious illness sometimes face. Please read each event carefully, and circle HOW OFTEN the event has occurred for you <u>in the past 7 days</u>, using the 5 point scale below. Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale. <u>Please complete both columns for each item.</u>

EVENT	**HOW OFTEN?** 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often	**HOW DIFFICULT?** 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely
1. Difficulty sleeping	1 2 3 4 5	1 2 3 4 5
2. Arguing with family member(s)	1 2 3 4 5	1 2 3 4 5
3. Learning upsetting news	1 2 3 4 5	1 2 3 4 5
4. Being unable to go to work/job	1 2 3 4 5	1 2 3 4 5
5. Speaking with doctor	1 2 3 4 5	1 2 3 4 5
6. Watching my child have trouble eating	1 2 3 4 5	1 2 3 4 5
7. Waiting for my child's test results	1 2 3 4 5	1 2 3 4 5
8. Having money/financial troubles	1 2 3 4 5	1 2 3 4 5
9. Trying not to think about my family's difficulties	1 2 3 4 5	1 2 3 4 5
10. Feeling confused about medical information	1 2 3 4 5	1 2 3 4 5
11. Being with my child during medical procedures	1 2 3 4 5	1 2 3 4 5
12. Trying to attend to the needs of other family members	1 2 3 4 5	1 2 3 4 5
13. Talking with the nurse	1 2 3 4 5	1 2 3 4 5
14. Making decisions about medical care or medicines	1 2 3 4 5	1 2 3 4 5
15. Being far away from family and/or friends	1 2 3 4 5	1 2 3 4 5
16. Feeling numb inside	1 2 3 4 5	1 2 3 4 5
17. Disagreeing with a member of the health care team	1 2 3 4 5	1 2 3 4 5
18. Worrying about the long term impact of the illness	1 2 3 4 5	1 2 3 4 5
19. Having little time to take care of my own needs	1 2 3 4 5	1 2 3 4 5
20. Feeling helpless over my child's condition	1 2 3 4 5	1 2 3 4 5

EVENT	HOW OFTEN? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often	HOW DIFFICULT? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely
21. Feeling misunderstood by family/friends as to the severity of my child's illness	1 2 3 4 5	1 2 3 4 5
22. Handling changes in my child's daily medical routines	1 2 3 4 5	1 2 3 4 5
23. Feeling uncertain about the future	1 2 3 4 5	1 2 3 4 5
24. Being in the hospital over weekends/holidays	1 2 3 4 5	1 2 3 4 5
25. Thinking about other children who have been seriously ill	1 2 3 4 5	1 2 3 4 5
26. Having my heart beat fast, sweating, or feeling tingly	1 2 3 4 5	1 2 3 4 5
27. Feeling scared that my child could get very sick or die	1 2 3 4 5	1 2 3 4 5
28. Speaking with family members about my child's illness	1 2 3 4 5	1 2 3 4 5
29. Watching my child during medical visits/procedures	1 2 3 4 5	1 2 3 4 5
30. Missing important events in the lives of other family members	1 2 3 4 5	1 2 3 4 5
31. Worrying about how friends and relatives interact with my child	1 2 3 4 5	1 2 3 4 5
32. Noticing a change in my relationship with my partner	1 2 3 4 5	1 2 3 4 5
33. Spending a great deal of time in unfamiliar settings	1 2 3 4 5	1 2 3 4 5

PSSI: NICU

Total Stress Scale:

How stressful has the experience of having your baby hospitalized been for you?

	1	2	3	4	5
N/A	Not at all Stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful

Other Sources of Stress

Please rate how stressful the following are:

1) Being separated from your baby as a result of him/her being admitted into the NICU

	1	2	3	4	5
N/A	Not at all Stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful

2) Having to travel in order to get to the hospital to visit your baby

	1	2	3	4	5
N/A	Not at all Stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful

3) Having other children that need care at home

	1	2	3	4	5
N/A	Not at all Stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful

4) Finding childcare for other children while you are at the hospital

	1	2	3	4	5
N/A	Not at all Stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful

5) Keeping your job while taking time off to be at the hospital

	1	2	3	4	5
N/A	Not at all Stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful

6) Financial concerns

	1	2	3	4	5
N/A	Not at all Stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful

Please rate how much you agree with the following statements:

1) I fear that my baby is currently having pain

	1	2	3	4	5
N/A	Not at all Stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressfuL

2) I fear that my baby may die

	1	2	3	4	5
N/A	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

3) I fear that my baby may have long-term disabilities

	1	2	3	4	5
N/A	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

4) I feel that I have good communication with my baby's nurse

	1	2	3	4	5
N/A	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

5) I feel that I have good communication with my baby's NICU doctor

	1	2	3	4	5
N/A	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

6) I feel that I have good communication with my baby's surgeon or other specialist

	1	2	3	4	5
N/A	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

7) I feel that I have had all my questions answered satisfactorily

	1	2	3	4	5
N/A	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

8) For mothers—I am having difficulty with breastfeeding or pumping milk for my baby

	1	2	3	4	5
N/A	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

9) For mothers—I feel that I am getting enough help from Lactation Specialists or bedside nurses

	1	2	3	4	5
N/A	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Demographics Questionnaire

I will be asking you some specific questions about yourself as well as your child's early history, as we would like as accurate a picture as possible. Remember, this information is strictly confidential and it will not be shared with anyone outside of this project.

I. Child's Information

1. Child's Full Name:
_____
(Last, First, Middle)

2. Child's Birthdate: ___ ___ / ___ ___ / ___ ___

3. Sex: (Please circle one)
1 = Female
2 = Male

4a. Child's race: (Please circle one)
1 = African American
2 = Asian
3 = Caucasian (White)
4 = Hispanic
5 = Native American
6 = Other (Please specify: _____)

II. Female Parent's Information

5. Full Name:
_____
(Last, First, Middle)

6. Race: (Please circle one)
1 = African American
2 = Asian
3 = Caucasian (White)
4 = Hispanic
5 = Native American
6 = Other (Please specify: _____)

7. Birthdate: ___ ___ / ___ ___ / ___ ___

8. Monolingual Spanish-Speaking?
1 = Yes 0 = No

III. Male Parent's Information

9. Full Name:
_____
(Last, First, Middle)

10.Race: (Please circle one)
1 = African American
2 = Asian
3 = Caucasian (White)
4 = Hispanic
5 = Native American
6 = Other (Please specify: _____)

11. Birthdate: ___ ___ / ___ ___ / ___ ___

12. Monolingual Spanish-Speaking?
1 = Yes 0 = No

IV. Current Family Living Arrangements

13. Home Address:
_____
(Street Address)

_____
(City) (State) (Zip)

14a. Home
Phone:_____

14b. Work Phone:
(Dad)_____

(Mom) _____

14c. Mobile Phone:
(Dad)_____

(Mom) _____

14d. Email:

(Dad)_____

(Mom) _____

14e. Preferred Method of Contact:_____

V. Emergency Contact

15. In case you move or change your phone number before the project is completed, we would like to have the name, address, and phone number of two people who will always know where you are.

Contact 1: _____ _____
(Last, First, Middle) (Relation to interviewee)

_____
Street Address City

_____
State Zip Area Code + Phone Number

Contact 2: _____ _____
(Last, First, Middle) (Relation to interviewee)

_____
Street Address City

_____
State Zip Area Code + Phone Number

I give permission to The NICU Study staff to contact the persons listed above in order to locate me.

_____
PRINT NAME (Last, First, Middle)

_____ _____
SIGNATURE DATE

VI. Mother's Employment and Education Information:

16. Current marital status: (Please circle one)

1 = Married
2 = Separated/Divorced
3 = Widowed
4 = Never Married

17a. Currently (or during the last 12 months) employed full-time or part-time outside of the home: (Please circle one)

1= YES
2 = NO

17b. What is the longest period of time worked at the same job in the last 12 months? (If at the same job for longer than one year, please enter 12) _____
(# of months)

17c. Please describe the kind of work, including job title/position, name of company/employer, job responsibilities, and what employer makes or sells:

_____
_____
_____
_____
_____

17d. Number of hours worked per week, on average: _____ (# of hours)

17e. What are the work hours: (Please circle one)

1 = DAY (8 am to 5 p.m.)
2 = EVENING (after 5 p.m.)
3 = NIGHT (after 11 p.m.)
4 = VARIABLE (hours change)

18. Highest educational degree attained: (Please circle one)

1 = None
2 = High School Diploma or GED
3 = Associate's Degree
4 = Vocational Degree
5 = Bachelor's Degree
6 = Master's Degree
7 = Ph.D., M.D., J.D., etc

19. Highest grade completed in school: (Please circle highest on scale)

5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Or fewer High School College Or more

VII. Father's Information:

20. Current marital status: (Please circle one)

1 = Married
2 = Separated/Divorced
3 = Widowed
4 = Never Married

21a. Currently (or during the last 12 months) employed full-time or part-time outside of the home: (Please circle one)

1= YES
2 = NO

21b. What is the longest period of time worked at the same job in the last 12 months? (If at the same job for longer than one year, please enter 12)_____
(# of months)

21c. Please describe the kind of work, including job title/position, name of company/employer, job responsibilities, and what employer makes or sells:

_____
_____
_____
_____
_____

21d. Number of hours worked per week, on average: _____ (# of hours)

21e. What are the work hours: (Please circle one)

1 = DAY (8 am to 5 p.m.)
2 = EVENING (after 5 p.m.)
3 = NIGHT (after 11 p.m.)
4 = VARIABLE (hours change)

22. Highest educational degree attained: (Please circle one)

1 = None
2 = High School Diploma or GED
3 = Associate's Degree
4 = Vocational Degree
5 = Bachelor's Degree
6 = Master's Degree
7 = Ph.D., M.D., J.D., etc

23. Highest grade completed in school: (Please circle highest on scale)

5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Or fewer High School College Or mor

VIII. Family Information:

24. What is the total gross annual income for your household, considering all sources of income and support together (e.g., job earnings, interest from savings, investment or rent income, unemployment or disability insurance, alimony, child support, and support from extended family)?

Please Circle One:

	Yearly	Monthly Estimates	Weekly Estimates
01/A=	$0 to 15,000	0 to 1250	0 to 288
02/B=	$15,001 to 25,000	1251 to 2083	289 to 480
03/C=	$25,001 to 35,000	2084 to 2916	481 to 673
04/D=	$35,001 to 50,000	2917 to 4166	481 to 961
05/E=	$50,001 to 70,000	4167 to 5834	962 to 1346
06/F=	$70,001 to 95,000	5835 to 7917	1347 to 1827
07/G=	> $ 95,000	> 7918	> 1828

25. Parents are currently: (Please circle one)

1 = Married (Number of years married? _____ / _____)
Years Months

2 = Living Together (Length of time together? _____ / _____)
Years Months

IX. Pregnancy

1. Was the pregnancy planned? 1 = Yes 0 = No
2. How was the mother's health during the pregnancy?

   1 = Poor 2 = Fair 3 = Good 4 = Very Good
3. How much prenatal care did the mother receive during pregnancy?

   1 = None 2 = Some 3 = A Lot
4. Did mother receive prenatal counseling?

   1 = Yes 0 = No
5. How much (if at all) did the mother smoke during pregnancy?

   _____
6. How much (if at all) did the mother drink during pregnancy?

   _____

7. Were any medications/drugs taken during pregnancy?

   _____

X. Birth

1. Was the baby full-term? 1 = Yes 0 = No

   If not, how many weeks early was the baby? _____

2. Would you say the delivery was:

   1 = Easy 2 = Average 3 = Difficult

3. Were there any complications during delivery?

   _____

   _____

4. What was the baby's weight at birth? _____lbs _____ozs
5. Reason for NICU admission?

   _____

   _____

6. Did you know beforehand that your infant would be admitted to the NICU?

   1 = Yes 0 = No

7. Infant's diagnosis

   _____

8. Have you had any previous children in the NICU before?

   1 = Yes 0 = No

9. Was your child transferred to Loma Linda Medical Center from another hospital's NICU?

   1 = Yes 0 = No

   If you answer to the above is yes, please answer the following questions:

   9a.Which hospital was your child transferred from?

   _____

   9b. What was the reason for the transfer?_____

   9c. How old was your child when he/she was transferred to Loma Linda Medical Center? _____

10. Baby is:

    1 = Bottle fed 2 = Breast-fed (on breast)

    3 = Breast-fed (through bottle) 4 = Mixed

XI. Other

1. How many times (on average) have you visited your infant in the NICU since your child was admitted to the NICU?

    1 = Once a week
    2 = Twice a week
    3 = Almost everyday of the week
    4 = Every day of the week

2. How will you being paying for your child's NICU stay?

    1 = Insurance
    2 = Medicaid
    3 = Out of pocket
    4 = Loans
    5= Unsure
    6 = Other

3. How stressful is the financial aspect of your child's NICU stay?

    1 = Not at all stressful
    2 = A little stressful
    3 = Moderately stressful
    4 = Very stressful
    5 = Extremely stressful

4. How much physical contact do you get to experience with your infant?

    1= I have no physical contact with my infant
    2 = I have physical contact with my infant a 1-2 times a day
    3 = I have physical contact with my infant several times a day.

5. What kind of physical contact are you able to have with your infant?

    1 = I am only able to touch my infant through the isolette
    2 = I am able to hold my infant
    3 = I am able to hold my infant and also have skin-to-skin contact with my infant

How much do you agree with the following statements:

6. "I get the emotional help and support I need from family and friends."

   1 = Strongly agree
   2 = Agree
   3 = Slightly agree
   4 = Slightly disagree
   5 = Disagree
   6 = Strongly disagree

7. Which of the following describes how your baby looks and behaves? Circle all that apply.

   1 = My baby has tubes or equipment on or near him/her
   2 = My baby has bruises, cuts, or surgical incisions
   3 = My baby has unusual color (for example looks pale or jaundiced)
   4 = My baby has unusual or abnormal breathing patterns
   5 = My baby is small in size
   6 = My baby has a wrinkled appearance
   7 = My baby has a machine (respirator) breathing for him/her
   8 = My baby has a swollen or enlarged body part, such as abdomen, head, limb

8. Which of the following describes your role in the care of your infant in the NICU? Circle all that apply.

   1 = I participate in the feeding of my infant by myself
   2 = I am not able to participate in the feeding of my infant by myself
   3 = I am able to participate in the bathing of my infant
   4 = I am able to participate in the diapering of my infant
   5 = I am not able to bathe my infant
   6 = 5 = I am not able to diaper my infant
   7 = I am able to hold my infant when I want
   8 = I am not able to hold my infant when I want
   9 = I am able to have alone time with my infant
   10 = I do not get to have alone time with my infant
   11 = I am able to take my infant's temperature

9. Even when others get discouraged, I know I can find a way to solve the problem.

    1 = Definitely False
    2 = Mostly False
    3 = Somewhat False
    4 = Slightly False
    5 = Slightly True
    6 = Somewhat True
    7 = Mostly True
    8 = Definitely True

10. I consider myself a spiritual person.

    1 = Definitely False
    2 = Mostly False
    3 = Somewhat False
    4 = Slightly False
    5 = Slightly True
    6 = Somewhat True
    7 = Mostly True
    8 = Definitely True

APPENDIX C

INFANT MEASURES

NTISS

Ressources et utilitaires

Scoring systems for ICU and surgical patients:

NTISS (Neonatal Therapeutic Intervention Scoring System)

Respiratory	Subscore		Cardiovascular	Subscore	
Supplemental oxygen[a]	1	yes	Indomethacin administration	1	yes / no
C.P.A.P.[a]	2	yes	Volume expansion (>=15 mL/kg)[c]	1	yes / no
Mechanical ventilation[a]	3	yes / no	Volume expansion (>15 mL/kg)[c]	2	yes / no
Mechanical ventilation with muscle relaxation[a]	4	yes	Vasopressor administration (1 agent)[d]	2	yes / no
High frequency ventilation[a]	4	yes	Vasopressor administration (>1 agent)[d]	2	yes / no
Surfactant administration	1	yes / no	Cardiopulmonary resuscitation	4	yes / no
Endotracheal intubation	2	yes / no	Pacemaker on standby[e]	3	yes / no
Tracheostomy care[b]	1	yes / no	Pacemaker used[e]	4	yes / no
Tracheostomy placement[b]	1	yes			
Extracorporeal membrane oxygenation	4	yes / no			
Drug therapy			**Monitoring**		
Antibiotic administration (<= 2 agents)[f]	1	yes / no	Frequent vital signs	1	yes / no
Antibiotic administration (> 2 agents)[f]	2	yes	Phlebotomy (5-10 blood draws)[h]	1	yes
Diuretic administration (enteral)[g]	1	yes / no	Extensive phlebotomy (> 10 blood draws)[h]	2	yes / no
Diuretic administration (parenteral)[g]	2	yes	Cardiorespiratory monitoring	1	yes / no
Anticonvulsant therapy	1	yes / no	Thermoregulated environment	1	yes / no
Aminophylinne administration	1	yes / no	Noninvasive oxygen monitoring	1	yes / no
Other unscheduled medication	1	yes / no	Arterial pressure monitoring	1	yes / no
Steroid administration (postnatal)	1	yes / no	Central venous pressure monitoring	1	yes / no
Potassium binding resin administration	2	yes / no	Urinary catheter	1	yes / no
Treatment of metabolic acidosis	2	yes / no	Quantitative intake and output	1	yes / no
Metabolic / nutrition			**Transfusion**		
Gavage feeding	1	yes / no	Intravenous gamma globulin	1	yes / no
Phototherapy	1	yes / no	Double volume exchange transfusion	3	yes / no
Intravenous fat emulsion	1	yes / no	Partial volume exchange transfusion	2	yes / no
Intravenous amino acid solution	1	yes / no	Red blood cell transfusion (>=15 ml/kg)[i]	2	yes / no
Insulin administration	2	yes / no	Red blood cell transfusion (>15 ml/kg)[i]	3	yes / no
Potassium infusion	3	yes / no	Platelet transfusion	3	yes / no
			White blood cell transfusion	3	yes / no
Procedural			**Vascular access**		
Transport of patient	2	yes / no	Peripheral intravenous line	1	yes / no
Dialysis	4	yes / no	Arterial line	2	yes / no
Single chest tube in place[j]	2	yes / no	Central venous line	2	yes / no
Multiple chest tubes in place[j]	3	yes			
Thoracentesis	3	yes / no			
Pericardial tube in place[j]	4	yes / no			
Pericardiocentesis[j]	4	yes			
Minor operation[k]	2	yes / no			
Major operation[k]	4	yes			

Clear

NTISS = SUM (points for activities performed) = 0 Abstraction guidelines

Superscript letters represent mutually exclusive variables.