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NICU Parental Mental Health and Infant Outcomes: Effects of Psychological Well-Being and Psychopathology

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NICU Parental Mental Health and Infant Outcomes: Effects of Psychological Well-Being and Psychopathology

by

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Each person whose signature appears below certifies that this dissertation, in his/her opinion is adequate, in scope and quality, as a dissertation 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	Post-Traumatic Stress Disorder
MCS	Mental Component Summary
Apgar	Appearance, Pulse, Grimace, Activity, Respiration
LLU	Loma Linda University
QOLI	Quality of Life Inventory
PWB	Psychological Well-Being
CES-D	Center for Epidemiological Studies-Depression Scale
SASQ	Stanford Acute Stress Reaction Questionnaire
NTISS	Neonatal Therapeutic Intervention Scoring System
TISS	Therapeutic Intervention Scoring System
HLM	Hierarchical linear modeling
NBO	Neurobehavioral Organization
NNBO	Neonatal Neurobehavioral Organization
NNNS	NICU Network Neurobehavioral Scale

ABSTRACT OF THE DISSERTATION

Parental Mental Health and Infant Outcomes in the NICU:
The Moderating Effects of Psychological Well-Being and
Psychopathology

by

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Doctor of Philosophy, Graduate Program in Clinical Psychology
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Previous research has shown that having a child in the Neonatal Intensive Care Unit (NICU) is stressful for parents and that parents of NICU infants exhibit higher levels of stress compared to parents of healthy infants (Carter, Mulder, & Darlow, 2007; MacDonald, 2007; Treyvaud et al., 2010). As a result of these high levels of stress, NICU parents are at risk for developing psychopathology. Studies have found correlations between parental psychopathology and lower scores on measures of psychological well-being such as self-acceptance and autonomy (Bhullar, Hine, & Phillips, 2014; Valiente et al., 2013). Additionally, research has indicated that some well-being characteristics, such as autonomy and increasing perception of control, may be a key buffer in preventing the development of psychopathology (Bhullar et al., 2014). Moreover, findings suggest that both parental psychopathology and well-being have implications for child development. Poor parental mental health has been associated with adverse child social-emotional development and increased negative affect (Gao et al., 2007; Halligan, Murray, Martins, & Cooper, 2007; Treyvaud et al., 2010). In contrast, parental psychological well-being has been linked to positive reciprocal maternal-infant interactions, parental warmth and control, positive parenting, parental responsiveness, and parental involvement and

monitoring of adolescents, all of which are conducive to positive outcomes in children (Hill & Bush, 2001; Izzo, Weiss, Shanahan, & Rodriguez-Brown, 2000; Shumow & Lomax, 2002).

The purpose of this dissertation was to conduct three separate investigations of parental mental health in the NICU, each building on the results of the other. The first investigation examined the effects of parental well-being on the changes in parental psychopathology symptoms in the NICU. The second study investigated how these well-being variables as well as parental psychopathology, specifically depression and acute stress disorder (ASD) symptoms, related to the course of infant illness severity in the NICU. Lastly, indicators of both parental psychopathology and well-being were investigated in relation to indicators of infant neurobehavioral status. Mental health questionnaires were administered to 97 parents of infants admitted to the NICU at Loma Linda University Children's Hospital at two time points. NICU nurses collected measures of infant severity and neurobehavioral status. Results of the investigation showed that specific well-being variables (i.e., personal growth, purpose in life, and environmental mastery) predicted change in depression and ASD symptoms over time. In addition, findings revealed that negative mental health variables were strongly related to the course of infant health compared to well-bing factors. Lastly, results also provide information about parent factors that influence early stages of cognitive development. Findings from this dissertation will inform researchers about aspects of risk and resiliency in parents of this population as well as areas that should be targeted in future interventions to help parents of infants admitted to the NICU. Additionally, results may be used to better inform health care practitioners in the NICU about ways to improve infant outcomes as

well as to improve the experience and well-being of both parents and infants in the NICU.

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 acute stress disorder (ASD)/post-traumatic stress disorder (PTSD) compared to parents of healthy infants (Carter, Mulder, Frampton, & Darlow, 2007; Lefkowitz, Baxt, et al. 2010; MacDonald, 2007). Parental psychopathology is concerning not only because it directly impacts parental health, but because it can also have negative impacts on mother-infant interactions, which, in turn, has negative implications for a child's mental and physical development (Korja et al., 2008; Sohr-Preston & Scaramella, 2006; Weissman et al, 2006). Conversely, parents may have inherent positive qualities, such as effective coping styles and feelings of self-efficacy, which may offset the impact of this mental distress. These positive qualities may facilitate positive interactions with their infants, and, thus, promote healthy adjustment in their children (Shumow & Lomax, 2002; Teti & Gelfand, 1991). The overarching goal of this dissertation was to conduct an in depth investigation of the mental health of parents in the NICU, with the purpose of exploring both positive and negative aspects of mental health as well as investigating how these parental factors may influence infant development. Toward this goal, the three aims were to investigate: 1) the factors that affect changes in parental mental health throughout the NICU stay (i.e., what psychological well-being variables predict the course of parental depression and acute stress over the NICU stay), 2) parental depression, ASD, and psychological well-being variables that moderate the trajectory of infant health severity, and 3) the descriptive

profile of infants' neurobehavioral status in the NICU and the relationship between infant neurobehavioral status and parental mental health factors, specifically depression, acute stress, psychological well-being, coping style, and quality of life.

The Neonatal Intensive Care Unit (NICU)

About 10 to 15 percent of all newborn babies in the United States require care in a NICU (Lucile Packard Children's Hospital, 2012). NICUs provide care to infants who are sick or born high-risk. They 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 (American Academy of Pediatrics, 2004; Nemours Foundation, 2012). 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 (American Academy of Pediatrics, 2004; Nemours Foundation, 2012). Lastly, Level III nurseries care for the greatest variety, providing support and care for infants with serious illness and congenital defects (American Academy of Pediatrics, 2004; Nemours Foundation, 2012).

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 weighing less than 2,500 grams); a smaller amount are admitted for very-low-birth-weight (defined as weighing less than 1,500 grams); and several others are term infants who have congenital anomalies, heart problems, or infections (Lee et al, 2000). Other infants who are admitted

have had no prenatal care, are born preterm (less than 37 weeks of pregnancy), are delivered via caesarian section, have mothers with hypertension, or are part of a multiple birth (Lee et al., 2000; Lucile Packard Children's Hospital, 2012). The percentage of infants admitted falling into each category varies depending on the hospital and the area of the country. Additionally, infants in the NICU may experience a variety of medical concerns. For example, one study of NICUs in the Canadian NICU Network found 7% of infants have episodes of bacterial infection, 43% of infants receive assisted respiratory support, and 11% receive surgery (Lee et al., 2000). Because there are a large variety of diagnoses in the NICU, it is important that current and future studies sample infants from all different groups in order to test for generalizability of previous findings to this diverse population. Moreover, research has found that nearly 13% 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.

Although there are still many health risks associated with the various medical concerns that necessitate an infant's admission into 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 (Als et al., 2005; Lee at al., 2000). Hack et al. (2002) reported that advances in perinatal and neonatal medicine have resulted in increased survival rates of low-birth-weight infants (less than 2,500 grams), 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 (2007) reported that not only are disabilities such as neurosensory disorder, epilepsy and cerebral palsy more often seen among former low-birth weight 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 about factors affecting course of infant health can be used to inform ways to cut medical costs and further inform the literature on ways to mediate long-term disabilities.

Average length of stay in the NICU 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 (Berns, Boyle, Pooper & Gooding, 2007; Lee et al., 2000; Nationwide Children's, 2012; NICU Quality Report, 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). Length of stay is a variable of interest to many given that the average NICU stay costs $3,500 dollars per day and it is not unusual for costs to exceed $1million for a prolonged stay (Muraskas & Parsi, 2008). Although length of stay is largely dependent on infant health status, parent functioning also plays a role. For example, one of the considerations the healthcare team uses in discharge planning is confidence in parental ability to care for the infant at home. Parental distress can impact a parent's ability to adequately respond to their infant's needs, their

confidence in being able to care for their infant independently, as well as their ability to bond with their infant, which can negatively impact readiness to leave the hospital. Better understanding the relationship between parent distress or protective factors and the course of infant health severity can inform targets of parent intervention, which may lead to a shorter length of stay and better prognoses when infants are discharged from the NICU.

An important aspect of an infant's NICU stay is the healthcare team. The people responsible for care of NICU infants and their parents are comprised of a multidisciplinary team of healthcare professionals. The neonatologist is the attending doctor who is mainly responsible for the infant's care and coordinates the daily plan of care. This doctor is a pediatrician with special training in caring for babies who are sick and require intensive care after birth (A.D.A.M. Medical Encyclopedia, 2005). Allied health professionals (e.g., nurse practitioners or physician assistants), neonatology fellows, and medical students work under the supervision of the neonatologist in delivering patient care (A.D.A.M. Medical Encyclopedia, 2005). NICU nurses play an important role in in monitoring the baby and supporting and educating the family. The NICU nurse usually spends the most time at the bedside caring for the baby as well as the family (A.D.A.M. Medical Encyclopedia, 2005). Pharmacists help prepare medications such as antibiotics, immunizations, or intravenous solutions, such as total prenatal nutrition. A dietitian helps monitor what the infants are fed, how they respond to food, and how they grow. A pediatric surgeon is asked to see infants in the NICU who may need surgery for birth defects or conditions that occur after birth. Surgeons might also be asked to place central catheters in babies who need long-term intravenous fluids

(A.D.A.M. Medical Encyclopedia, 2005). Physicians and professionals from other specialties (e.g., audiologist, cardiologist, cardiovascular surgeon, dermatologist, developmental pediatrician, endocrinologist, geneticist, hematologist-oncologist, perinatologist, infectious disease specialist, neurologist, nephrologist, occupational therapist, physical therapist, speech therapist, respiratory therapist, social worker, urologist, x-ray technician, pulmonologist, phlebotomist, pathologist) may be part of the consulting teams involved in caring for babies and their families in the NICU (A.D.A.M. Medical Encyclopedia, 2005). As there are a number of individuals involved in the care of a NICU infant and his family and different components of care for which they are responsible for, keeping track of everyone involved may be overwhelming for parents. Understanding medical jargon used by professionals and being able to communicate with various NICU team members has been found to be one source of parent stress documented in the literature (Lefkowitz, Baxt, Evans, 2010). In addition, part of the job of some members of the team (e.g., social worker, lactation specialist, nurses) is to help parents adjust to having and caring for an infant in the NICU. As a result, a study focusing on infant health, neurobehavioral status, and parental factors affecting them would provide information to the NICU team about how to individualize care in order to optimize functioning for both the infant and family and facilitate better recovery.

Parent Experience and Stressors

Parental distress from infant hospitalization and NICU stay is well documented in the literature. Studies have found both mothers and fathers of infants in the NICU exhibit a higher percentage of clinical symptomology compared to control parents (Carter,

Mulder, Bartram, & Darlow, 2005). Investigators have found that distress experienced by parents is comprised of feelings of disappointment, fears concerning their infant's survival, and altered parental role, which includes separation and reduced ability to interact with their child (Miles, Funk, & Kasper, 1992). Recent literature has focused on predictors of parental stress. Several factors have been cited as potential negative influences on parenting stress in the NICU such as parental dysfunctional personality traits (i.e., high self-transcendence, high harm avoidance, and high novelty seeking, and high anxiety), labor and birth, experience of infant admission to the NICU and the clinical environment, infant illness, concerns about outcome, loss of parental role, and difficulty effectively communicating with NICU staff (Carter, Mulder, Bartram, & Darlow, 2005; Carter, Mulder, & Darlow, 2007; Carter, Mulder, Frampton, & Darlow, 2007; Miles, 1989; Miles, Funk, & Kasper, 1992). As such, a study investigating factors that influence the experience of distress in parents in the NICU will be informative in the development of interventions to help improve the NICU experience and increase healthy adjustment to an infant's hospitalization.

Stressors Related to Infant Health

Studies have shown that factors directly related to infant health in the NICU contribute to parental perception of stress. When parents have a child who is admitted into the NICU, they undergo a number of experiences, which are different than what is expected when delivering a healthy infant. The appearance of the infant in the NICU compared to a healthy infant (e.g. having tubes attached to their bodies, being kept in an isolette) may be upsetting and traumatic for new parents (MacDonald, 2007).

Additionally, the behavior of a NICU infant (e.g., baby looking sad, baby looking in pain, baby's unusual breathing pattern, jerky or restless movements of the baby, baby not being able to cry like other babies) may also be an area of distress (Lefkowitz, Baxt, Evans, 2010; MacDonald, 2007). The threat of potential loss of their child's life, parent perception of infant illness, and separation from the child during hospitalization (Lefkowitz, Baxt, Evans, 2010; MacDonald, 2007) also contribute to parent distress. 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). Moreover, parents of NICU infants may experience distress related to concerns about the future health and development of their infant, developmental disabilities, and their child's future coping (Reid, Bramwell, Booth, & Weindling, 2007).

Research has also shown correlates between infant health and parental endorsement of distress. Parents of preterm and low-weight infants have been shown to experience elevated levels of distress when compared to parents of healthy infants (Carter, Mulder, & Darlow, 2007; MacDonald, 2007; Treyvaud et al., 2010). One study found that 26% of parents in the sample who had a child who was born very preterm (<32 weeks gestation) reported clinically significant mental health problems (Treyvaud et al., 2010). Among NICU parents, mental health challenges were higher amidst those parents of NICU infants born with a congenital anomaly as compared to those without (Klassen et al., 2004). An infant's length of stay as well as cardiovascular problems were also found to be associated with parental stress (Dudeck-Shriber, 2004; Browne & Talmi,

2005; McAnulty et al., 2010; Melnyk et al., 2006). In addition, Dudeck-Shriber (2004) found the infant's length of stay was predictive of frequency of parental stress (determined by the number of items endorsed on the questionnaire which dealt with stress-provoking factors), where longer length of stay was associated with greater stress frequency.

Environmental Stressors in the NICU

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: 1) physical environment of the NICU, 2) the infant's physical appearance and behavior, 3) staff and parent interactions, and 4) alterations of the parental role (Miles, 1989). The unfamiliar sights, sounds, and equipment found in the NICU can be overwhelming. Furthermore, the various monitors, tubes, bandages, and machines connected to an infant are far from the expected appearance of a healthy infant, and thus can cause the NICU experience to be distressing (MacDonald, 2007). Complex medical language and technology used by the NICU physicians, nurses, and staff can also be confusing and hard to understand, causing frustration and stress in parents (Lefkowitz, Baxt, Evans, 2010).

Parents of infants in the NICU also 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 their child home 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. Altered parental role, which refers to differences in how parents would interact with a healthy infant (e.g., being separated from their child, not feeding their infant on their own, not being able to care for their infant independently, not being able to hold their infant when they want, not being able to protect their infant) was found to be the highest source of stress for mothers and fathers, although mothers reported significantly greater stress in this area when compared to fathers (Lefkowitz, Baxt, Evans, 2010; 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). Difficulties were expressed by mothers about feelings associated with not being able to provide care and their feelings regarding communication with members of staff (e.g., feeling concerns and worries are heard by staff, not knowing who the staff caring for their child is, feeling unable to talk to staff becuae of lack of privacy, feeling that staff does not know them or their family well, feel that nurses are making judgemnts about parents, feeling misunderstood) who were able to do so in their absence (Reid, Bramwell, Booth, & Weindling, 2007). Parents also endorsed perceptions of a sub-optimal relationship with the infant, lacking confidence or parental feelings, and being unsure that their infant knew them (Reid, Bramwell, Booth, & Weindling, 2007).

Social Stressors

Factors related to social and practical difficulties have also been identified as contributors to NICU parental distress (Hughes & McCollum, 1994; Padden, & Glenn,

1997). Parents reported conflicting responsibilities, time pressures, and the emotional and practical costs of worrying about other family members or their own partners (Padden & Glenn, 1997). Not only are these parents' lives interrupted by unexpected prolonged involvement in emergency care, they must tend to their everyday responsibilities as well. Parents have to balance time and energy towards caring for other children, spouses, and work and household responsibilities in addition to being in the NICU to make important medical decisions and participate in their infant's care. Parents may also experience fear or embarrassment about how and what to say to family and friends (Reid, Bramwell, Booth, & Weindling, 2007). Moreover, in the case that the infant 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).

As discussed above, there are several aspects related to NICU involvement that can cause distress in parents. Without adequate treatment or utilization of adaptive coping skills, these parents are at-risk for developing significant mental health problems. However, previous research has found that elevated parenting stress levels are associated with limited access or availability of community health services that support parents' psychosocial and child care needs (Dudeck-Shriber, 2004; Floyd & Gallagher, 1997). Therefore, a study investigating the experience of NICU parental distress as well as the impact of well-being factors can be used to inform health care teams about possible ways they can support parents and make the NICU experience less distressing.

Parental Mental Health in the NICU

The circumstances that parents face while a child is hospitalized in the NICU cause them to experience a variety of emotional reactions including sadness, fear, anxiety, grief, and helplessness (Joseph, Mackley, Davis, Spear, & Locke, 2007; Miles & Holditch-Davis, 1997). Prolonged parental distress experienced by many NICU parents leaves them at risk for developing psychopathology. More specifically, studies have found that NICU parents exhibit higher levels of postpartum depression, Acute Stress Disorder (ASD), and Posttraumatic Stress Disorder (PTSD) compared to parents of healthy infants (Leftkowitz, Baxt, Evans, 2010). In addition, stress from having a premature or sick infant in the NICU has been associated with concurrent parental anxiety and depression (Busse, Stromgren, Thorngate, & Thomas, 2013; Dudek-Shriber, 2004; Holditch-Davis et al., 2009; Leftkowitz, Baxt, & Evans, 2010). Thus, given the high levels of distress in this population, research investigating predictors of mental health difficulties, in addition to the impact of parental mental health on infant outcomes, is warranted.

Mothers in the NICU are at increased risk for developing postpartum depression due to the additional complications of caring for an infant in the NICU, which often leads mothers to experience extreme levels of stress, helplessness, and feelings of inadequacy about how to provide care during the hospitalization (Pinelli, 2000). Postpartum depression is considered the most common mental health complication of childbirth with approximately 8-19% of all mothers in the United States experiencing symptoms of postpartum depression (Centers for Disease Control and Prevention, 2013). In addition, as many as 50-80% of new mothers experience typical postpartum symptoms including

fatigue and mood swings (Blucker et al., 2014). Compared to the general population, parents in the NICU demonstrate an increased risk of postpartum depression with 28-70% of mothers experiencing symptoms (Mounts, 2009). Adverse outcomes of negative mother-child interactions related to experiencing postpartum depression can lead to further maternal mental health problems such as anxiety and mood disorders (Miles, Holditch-Davis, Burchinal, & Nelson, 1999).

Higher rates of depression and anxiety during pregnancy and the postpartum period are well-documented in the literature in relation to concerns about the infant's appearance and condition, feelings of guilt about not carrying to term, fears for the infant's survival, and decreased confidence in their role as mothers (Miller, 2002; Sofronas, Feele, Zelkowitz, & Sabbagh, 2011). Those suffering from depression experience a change in functioning due to depressed mood. Mothers of NICU infants have rates of depression reported as high as 70%, which is higher than rates of major and minor depressive episodes observed in the general population of mothers (e.g., 17% of prenatal and 18% of postpartum women; Horowitz, Briggs-Gowan, Storfer-Isser, & Carter, 2007; Sofronas, Feele, Zelkowitz, & Sabbagh, 2011). Symptoms experienced include weight fluctuation, insomnia or hypersomnia, psychomotor agitation or retardation, fatigue, inappropriate guilt, feelings of worthlessness, reduced ability to concentrate, and recurrent thoughts of death or suicidal ideation (Sofronas, Feele, Zelkowitz, & Sabbagh, 2011). Previous research has shown that NICU mothers also experience symptoms of anxiety, characterized by worry and tension (Zelkowitz & Papageorgiou, 2005). In one sample, 25% of mothers in the NICU reported moderate levels of anxiety while 1% reported severe levels of anxiety (Britton, 2005; Zelkowitz &

Papageorgiou, 2005). Experience of anxiety in this population was related to perinatal medical complications, stressful life events, and perceived stress. More specifically, maternal anxiety was significantly greater when infants had lower birth weight, younger gestational age, and parents had less social support (Zelkowitz & Papageorgiou, 2005).

Further, research has shown that parents of infants in this population are at risk for developing ASD and PTSD (Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Lefkowitz, Baxt, & Evans, 2010; Shaw et al., 2006; Vanderbilt, Bushley, Young, & Frank, 2009). Individuals with ASD and PTSD experience intense fear, horror, or helplessness in response to a traumatic event (i.e., infant NICU admission) and symptoms of re-experiencing (intrusive thoughts, dreams, flashbacks), avoidance (avoiding reminders of the trauma, numbing, restricted affect), and physiological arousal (sleep difficulty, hypervigilance, irritability). ASD describes the presence of these symptoms with onset and duration between 2 days and 4 weeks after the traumatic event whereas PTSD describes the presence of these symptoms persisting beyond one month (American Psychiatric Association, 2013). Moreover, ASD also differs from PTSD in that it includes a greater emphasis on dissociative symptoms, while PTSD does not have a dissociative symptom cluster (American Psychiatric Association, 2013). A diagnosis of ASD without proper intervention appears to be an adequate predictor of subsequent PTSD. Shaw et al. (2006) found that 28% of mothers in a NICU sample (compared to 13-21% in the general population) met criteria for a diagnosis of ASD, which was strongly associated with low cohesion and control in the family and high emotional restraint. Another study found that 35% of mothers and 24% of fathers in the sample met the criteria for ASD at infant NICU admission and 15% of mothers and 8% of fathers in the sample met diagnostic

criteria for 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. As a significant amount of parents in the NICU population exhibit clinical symptoms of distress, a study focusing on predictors of distress can be used to inform interventions that aim to improve the NICU experience and decrease levels of parent distress.

Studies have started to focus on the long-term patterns of distress in these parents. Research by Holditch-Davis and associates (2009) indicated that individual patterns of maternal distress following birth of a preterm infant do not consistently decline over time. In addition, there were different groups of mothers who had varying trajectories of distress over the 24 months following birth (Holditch-Davis et al., 2009). Despite this variability, many mothers of preterm infants demonstrated significant distress reactions six months after the infant's expected due date (Holditch-Davis, Bartlett, Blickman, & Miles, 2003) as well as alterations in parenting up to 24 months after birth (Holditch-Davis et al., 2009). Some longitudinal studies indicate that symptoms of depression and anxiety decrease over time (Miles, Holditch-Davis, Schwartz, & Scher, 2007; Pinelli et al., 2008); however, there is evidence that a significant percentage of parents continue to report concerning levels of depression (Miles et al., 2007; Pinelli et al., 2008). More specifically, Miles and colleagues (2007) found that 63% of parents in their sample reported clinically significant levels of depression 6-months post discharge, and symptoms have been found to remain elevated at 9-months (Pinelli et al., 2008) and 27-months post-NICU stay (Miles et al., 2007). Other research suggests that emotional stress

may not abate over time and that these parents are at risk for a delayed stress response to the experience of having their child hospitalized (Leftkowitz, Baxt, & Evans, 2010; Shaw et al., 2009). Based on this current knowledge, evaluation of parental distress changes over the course of the NICU stay as well as a consideration of the predictors that impact change is important, given these parents typically experience high levels of distress that continues even after their child is discharged home.

Parental Mental Health and NICU Infant Vitality

Psychopathology has negative impacts on overall functioning of parents as well as potential negative implications for infant well-being. Left untreated, parents' symptoms of depression, anxiety, and ASD can lead to problematic parent-infant interactions that have negative implications for cognitive, behavioral, and social-emotional development (Forcada-Guex et al., 2006; Treyvaud et al., 2010). Moreover, parental distress can impact parent's functioning and ability to adequately care for the infant's physiological and medical needs (Altman et al., 2006). Thus, research investigating the moderating factors affecting mental health of parents in the NICU is critical in order to formulate interventions to better help these parents.

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

2007; Halligan et al., 2007; Treyvaud et al., 2010). Short-term effects of parental mental health when the infant is in the NICU and in early infancy have also been studied.

Maternal postpartum depression has been linked to a variety of negative infant outcomes including avoidant attachment, behavioral and emotional difficulties, and cognitive delay (Civic & Holt, 2000; Murray & Cooper, 1997). Infants in the NICU are at particular risk for such outcomes given their increased developmental vulnerability due to prematurity, congenital anomalies, and severe medical illness (Aylward, 2002; Taylor, Klein, & Hack, 2000) as well as factors related to the NICU environment including sensory overstimulation, repeated medical/surgical procedures, pain, and parental separation, all of which negatively affect brain development (Aucott, Donohue, Atkins, & Allen, 2002; Liu et al., 2007).

In addition, maternal depression and anxiety have been found to negatively correlate with cognitive development and behavioral outcomes in preterm infants (McManus & Poehlmann, 2012; Zelkowitz et al., 2011). Anxiety and depression can be detrimental to the initiation of maternal behavior and maintenance of dyadic relationships important for early infant attachment and development (Field, 2010; Forcada-Guex et al., 2011; Hofer, 1994; Meijssen et al., 2011; Tietz et al., 2014). Mothers with depression and anxiety may have difficulty interacting with and responding to cues from their preterm infants (Forcada-Guex et al., 2006). They tend to be less sensitive and responsive to their infants, and touch and speak less to their infants (Feeley et al., 2005; Korja et al., 2008; Zelkowitz et al., 2009; Zelkowitz & Papageorgiou, 2005). Anxious mothers are also less able to provide the necessary autonomy support, sensitivity, contingent responsiveness, and maternal verbal scaffolding (i.e., verbal input providing information about objects

and actions and offering appropriate problem-solving strategies) that has been shown to promote cognitive development in very-low-birth-weight infants (Lowe et al., 2014; Zelkowitz & Papageorgiou, 2005). As a result, infants of depressed mothers have been shown to exhibit poor affect regulation, even after depressive symptoms have resolved (Cohn & Campbell, 1992), while infants of anxious mothers were found to exhibit less mature regulatory behaviors and have high cortisol reactivity compared to those of non-anxious mothers (Feldman et al., 2009).

Parental distress may also play an important factor in determining how long the infant stays in the NICU. Parents' perceptions in their ability to take care of their infant admitted into the NICU contributes 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 et al., 2006). Parental anxiety and depression due to the appearance of a NICU infant and alterations in parental role leads parents to question their abilities in taking care of their infant (Cleveland, 2008; Shaw et al., 2006). This in turn may 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 abilities 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, might be one of the factors responsible for the trend in a quicker discharge from the NICU (Altman et al., 2006). As discussed

above, parent mental health difficulties have negative implications for parent-child interactions as well as infant development. A study investigating the relationship between parental mental health factors and infant neurobehavioral status will further the literature in the field investigating impacts of parent psychopathology on children by adding information about the immediate impact of parental mental health on infants while still in the NICU.

Parental Mental Health and Child Development

Numerous studies have revealed that parental mental health concerns can have adverse long-term impacts on children. Mental health problems not only impact cognitive development (Murray, 1992; Murray, Fiori-Cowley, Hooper, & Cooper, 1996) and later child psychopathology, they also impact how mothers interact with their children. Inconsistent parental behavior and maladaptive parenting patterns, along with insecure parent–child attachment, are factors that have been empirically identified as influential in the development of child and adolescent disorders (Mash & Dozois, 1997). In addition, parental stress is thought to have a spill-over effect in the parent-child relationship. Poor parental mental health has been associated with adverse child social-emotional development and increased negative affect (Caplan et al., 1989; Cummings & Davies, 1994; Gao et al., 2007; Halligan, Murray, Martins, & Cooper, 2007; Treyvaud et al., 2010).

Parental mental health problems exhibited while in the NICU have been shown to impact later parent-child interactions. Increased depressive symptoms, for example, can interfere with a mother's ability to interpret and respond sensitively to her child's

emotional and physiological needs which adversely affects mother-infant interactive behaviors due to the mother being less responsive, affectionate, and less likely to engage in positive reciprocal interactions with her child (Beck, 2003; Korja et al., 2008; Pinelli, 2002; Sohr-Preston & Scaramella, 2006). Additionally, a study investigating early parent attachment in infants and preschoolers found that depressed mothers were less responsive, more helpless, and more hostile and critical in interactions. These mothers were also alternatively disengaged or intrusive, avoidant of confrontation with their children and seemed less competent with regard to caring for their children (Gelfand & Teti, 1990; Goodman, 1992). In addition, mothers who had been more anxious in the NICU were not only less sensitive in their interactions with their infants and less able to provide structure needed to promote cognitive development in preterm babies, but they were also more intrusive and hostile at 24 months corrected age (Zelkowitz, Bargin, & Papageorgiou, 2003; Zelkowitz & Papageorgiou, 2005). Furthermore, mothers with PTSD were observed to be less sensitive and more controlling in interactions with their 6-month old low-birth-weight infant (Zelkowitz,, Papageorgiou, Bardin,, & Wang, 2009).

Parent dysfunctional interactions that result from the experience of depression have adverse impacts on infant and child development. A study investigating early parent attachment in infants and preschoolers found that parenting characteristics of depressed mothers were found to be associated with early insecure attachment, which has negative implications for later socio-emotional development in the child (Murray & Cooper, 1997). Lyons-Ruth and colleagues (1986) found that increased levels of maternal depression were significantly related at one year of age to poorer infant mental health and motor development using the Bayley scales. Another study showed that maternal

depression lasting through the first year postpartum and beyond was related with delayed infant cognitive and psychomotor development (Cornish, McMahon, Ungerer, Barnett, Kowalenko, & Tennant, 2005). Specific to infant populations, severity of maternal depression has been related to delayed child development in very-low-birth-weight children (Singer, Salvator, Guo, Lilien, & Bailey, 1999). Additionally, preliminary investigations by the author found differences in the trajectory of infant illness over 5 consecutive days in the NICU between parents endorsing clinical symptoms of depression versus those who did not (Parker, Xu, Neece & Tagge, 2014). More specifically, infants of parents endorsing clinical symptoms of depression showed less improvement in illness severity over the 5-day snapshot.

Other symptoms of parental psychopathology also have negative implications for children. Children of mothers who experienced anxiety while in the NICU were seen to have more internalizing problems at 24-months-old and to be rated with less satisfactory cognitive development according to the Mental Development Index on the Bayley Scales of Infant Development (Zelkowitz & Papageorgiou, 2005). In addition, the toddlers of more anxious mothers were less responsive to their mothers, and less likely to engage them in interaction (Zelkowitz, Bargin, & Papageorgiou, 2003). Moreover, maternal PTSD symptoms have been found to be an important predictor of toddler sleep problems (Muller-Nix et al., 2004; Pierrehumbert et al., 2003).

Distress that parents experience impacts their thinking and interactions, which can lead to less prosocial behaviors and parent-infant interactions that subsequently increases their child's risk for experiencing negative outcomes, such as insecure attachment, leading to decreased self-esteem, and negatively impacting their expectations of others as

well as ability to maintain successful adult relationships. For example, stress in mothers can affect their ability to provide necessary socio-emotional cues and responses necessary for a secure attachment (Benn, 1986; Jarvis & Creasey, 1991). As parents experience higher rates of stress, they may become more behaviorally and emotionally withdrawn, which may lead them to be less supportive in response to their child's negative emotions, perpetuating their infant's development of a less secure attachment (Stelter & Halbertstadt, 2011). Moreover, poor parental mental health can lead to poor mental and physical health outcomes in children. For example, parents who are highly anxious may be impaired in their ability to judge situational demands and neglect to behave in a way that enhances a child's sense of mastery and self confidence, thus putting their child at higher risk for developing anxiety as compared to non-anxious parents (Rutherford, 2004).

An investigation of how parental factors in the NICU are related to infant neurobehavior is important, as these parents have been shown to evidence significant depression and ASD, which has been indicated to negatively impact children over the course of development. Parent mental health concerns have been shown to have implications for infant development both in the short-term (during the NICU stay) as well as over the long-term, in addition to having continuous and far-reaching impacts on children's development. Therefore, identifying mental health concerns early, knowing how these impact infant development, and, ultimately developing and testing effective interventions for these parents' mental health problems may have significant implications for child development.

Parental Mental Health and Protective Factors

Much of the discussion thus far has focused on parental distress in the NICU and the implications of parental mental health on infant and child development. While parents in the NICU are at high risk for developing mental health problems, which negatively impact their functioning as well as that of their infants, a growing body of research in the area of positive psychology suggests that aspects of psychological well-being may protect these parents from the adverse impacts of NICU distress. This research focuses on resilience, or factors that could reduce stress and enhance well-being and happiness.

Resilience refers to a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar, Cicchetti, & Becker, 2000). It has been studied in the context of chronic illness and mental illness and has been associated with personal characteristics such as an optimism, active or adaptable coping style, ability to elicit social support, higher levels of intelligence and education, goal orientation, and wide-ranging interests (Antoni & Goodkin, 1988; Edward et al., 2005; Edward et al., 2009; Rabkin et al., 1993). On average, resilient individuals are good learners and problem solvers, able to engage other people, and have areas of efficacy perceived as valuable to the community (Edward, 2013; Garmezy, 1985). In addition, factors such as acceptance of self, others, and the situation, having hope and faith, being spiritual, having courage, being optimistic and at times being naïve in situations have been identified as integral to transcending adversity (Edward et al., 2009). Aspects of resiliency can be applied to parents in the NICU, as it has been shown that the NICU is a distressing experience for parents. An investigation of parental psychological well-being and its

impact on distress will inform the literature about any protective factors these parents possess that may mitigate the development of later pathology.

Models of Resilience in Parents

Resilience has also been investigated in the context of pediatric psychology regarding family adaptation and resilience in the face of having a child with a chronic health condition. Given that there is no empirically supported model for understanding resiliency in NICU parents, models of resilience in parents of children with chronic health conditions were chose as a frame of reference. While a majority of infants in this population do not have a chronic illness and do not have prolonged time in hospital care as in pediatric populations, parents in both populations must face alterations in their role as parents. In addition, both parent populations must adjust to having a child with an illness, deal with multiple social stressors (e.g., finances, caring for other children at home), face the chance that their child may die, and must navigate the hospital environment and learn to effectively communicate with the hospital teams. Therefore, the protective factors that parents of chronically ill children possess that contribute to their resilience may provide insight as to mechanisms of resiliency in parents of NICU infants.

Three predominant models of parental resilience have been widely studied in pediatric psychology. All the models have roots in Bronfenbrenner's social ecology model (1979) suggesting that the surrounding ecological environment significantly affects individual development: Wallander and Varni's risk-resistance model (Wallander, Varni, Babani, Tweddle, Banis, & Wilcox, 1989), Thompson et al.'s (Thompson, Gil, Burbach, Keith, & Kinney, 1993) transactional stress and coping model, and Kazak et

al.'s (2006; Kazak, Segal-Andrews, & Johnson, 1995) social ecological model. The models characterize parent and child adjustment to chronic illness as an ongoing transactional process within a family systems framework. One of these models may also apply to parent experience of stress and coping in the NICU environment.

Wallander and Varni's (Wallander et al., 1989) disability-stress-coping model suggests that child and parent psychosocial adjustment to chronic illness are affected by numerous biopsychosocial risk and resistance factors. An increase in risk factors (e.g., poverty, lack of social support, low socioeconomic status) leads to worse psychosocial adjustment while increases in resistance factors (e.g., family cohesion, adaptive coping styles, high self-esteem, social support) lead to better psychosocial adjustment. It has been found that adequate family cohesion (e.g., closeness, dependability, and support), social supports, and problem-focused coping strategies can contribute to decreased parental stress (Duffy, 2011).

According to Thompson and Gustafson's (1996) model, adjustment outcomes are impacted by variables directly related to illness (e.g., disease type, diagnosis, and illness severity), demographic variables (e.g., socioeconomic status, gender, and age), and various intrapersonal adjustment processes. Within this model, the child's chronic illness and its treatment are viewed as a potential stressor to which the individual and family system strive to adapt (Thompson et al., 1993). Specifically, illness factors, demographic factors, cognitive processes, and social support have the potential to significantly attenuate the stress of a chronic illness and hence the subsequent psychosocial outcomes. This model places a strong emphasis on the transactions that take place between child and parent adjustment, with reciprocal influence taking place (i.e., child adjustment

influences parent adjustment, and in turn, parent adjustment influences child adjustment). In support of this model, studies examining families of pediatric cancer, diabetes, sickle cell, and asthma patients have demonstrated that parent distress ratings are a highly consistent predictor of child adjustment as measured by internalizing and externalizing problems (Colletti et al., 2008; Mullins et al., 2004; Mullins et al., 2007; Mullins et al., 2015; Thompson et al., 1993)

Lastly, Kazak and colleagues' (Kazak, 2006; Kazak et al., 1995) social ecological model suggests that the many systems (i.e., child, family, social group, school, community, and culture) in which the child and parent reside have the potential to significantly affect child and parent adjustment to a chronic illness. This model emphasizes the importance of a constant interplay between systems levels. Each ecological system includes a unique relationship or influence from several subsystems within the child and family systems, which are continually interconnected and represent various relationships, community, school, and hospital influences. This includes microsystems such as schools, family, and the health care system. At the next level (mesosystem), interplays of interactions with broader relationships, such as the health care team and family-school interactions, are the focus (Kazak et al., 2009). At this level, influences on treatment decisions and choices, educational maturation, as well as perceived level of quality of care can become targets for treatment or support. At the second-most exterior level (exosystem), an interworking of parental networks (e.g., social) and parental employment is the focus. Lastly, at the outer most level (macrosystem), culture and subculture influences play a significant role in shaping values and beliefs (Kazak et al., 2009). Applications of this resiliency model in parents of

children with chronic illness revealed a decrease in endorsement of depressive symptoms and perceived burden when parents rated improvements in the microsystem of family functioning since diagnosis of illness (Shapiro, Perez, & Warden, 1998). In addition, similar results were found when parents rated positive relationships in the mesosystem created by the family-healthcare relationship, such that good perceived relationships with the child's doctor were related to lower endorsement of depressive symptoms and perceived burden (Shapiro, Perez, & Warden, 1998). Moreover, post-traumatic stress in parents of pediatric cancer survivors was correlated with parent's anxiety symptoms, perceptions of threat to the child's life, perception of treatment intensity, and social support (Kazak et al., 1998).

While the three models differ in their conceptualization of parental stressors and adjustment to illness, they all converge on the idea that adjustment to illness for parents occurs as a transactional process within the family network. All models discuss how parental mental health problems can be exacerbated by lack of social support, ineffective coping, increased stress related to demographic variables and interpretation of illness severity. They diverge, however, in the framework with which they understand these stressors and risk factors. Both Wallander and Varni (1989) and Thompson and Gustafson's models involve various risk factors (e.g., social economic status, social support, coping skills) that impact a parent's adjustment to illness; however, Thompson and Gustafson's model (1996) places high emphasis on the transactions that take place between child and parent adjustment. Kazak and colleagues' model on the other hand places emphasis on the stressors that arise from various systems (i.e., child, family, social group, school, community, and culture) and how stressors from those systems (e.g.,

depressive symptoms, perceived burden, and doctor-parent relationship) affect coping and adjustment. All three models of resilience have aspects that can inform how NICU parents experience distress. While parents may not be able to relate to their child's coping and adjustment to the NICU as in Thompson and Gustafson's model, similar to parents of children with chronic illness, they have biopsychosocial risk factors that can predispose them to experiencing higher levels of distress. In addition, they also exist in a similar framework to that discussed in Kazak et al.'s model (2009), such that parents in the NICU may exhibit stressors from relations with hospital staff and their family, as well as to perceptions of their child's illness. Taken together, these models lend information about risk factors and sources of stress in various groups of parents of children chronic illness that may also apply to NICU parents.

Well-Being in the NICU

While no specific model about resilience in the NICU has been formulated, NICU parents exhibit similar qualities to both individuals undergoing distress as well as parents of chronically ill children in their experience of distress related to having an infant in the NICU. Most parents in the NICU do not experience prolonged involvement in health care nor are they as greatly impacted by their child's adjustment to illness; however, they may possess similar biopsychosocial risk factors and exist in similar social systems that can significantly affect adjustment. A small body of research has begun to investigate aspects of resiliency and psychological well-being in relation to the NICU. One recent study by the author found that although parents in the NICU population exhibit a significant amount of distress (i.e., stress, depressive symptoms, and anxiety symptomatology),

parents also reported higher than average levels of quality of life indicating that on average, these parents endorsed life satisfaction similar to or better than their peers (Parker, 2014). In addition, many parents endorsed use of positive coping strategies. Even more so, parents also endorsed average to higher than average ratings of psychological well-being (e.g., self-acceptance, positive relations, autonomy, environmental master, purpose in life, and personal growth), indicating various levels of agreement in mastering specific areas that contribute to positive psychological health (Parker, 2014).

Still much is unknown about parental psychological well-being in the NICU as many studies focus on parent psychopathology. More specifically, what has not been done is an investigation of the positive psychological qualities that parents possess which may buffer the stressfulness of the NICU experience and moderate the course of parental distress. As such, it would be important to investigate protective factors that parents may possess in buffering risk for developing later clinical symptomatology. In addition, qualities that may mitigate the impact of stress on parents in the NICU can be used to inform intervention to improve the experience of parents in this population.

Implications of Psychological Well-Being

Psychological well-being not only has implications for better psychological adjustment to stressors, but also has positive implications for parental role function and child competence. Maternal feelings of efficacy have been associated with many adaptive parental outcomes, such as an easier transition to motherhood (Williams et al., 1987), lower maternal depression, and perceptions of the child as less temperamentally difficult (Gross, Conrad, Fogg, & Wothke, 1994; Teti & Gelfand, 1991). Moreover, parental self-

efficacy has been linked to parental warmth and control, positive parenting, parental responsiveness, and parental involvement and monitoring of adolescents, which are conducive to positive outcomes in children (Bogenschneider, Small, & Tsay, 1997; Bohlin & Hagekull, 1987; Coleman & Karraker, 1998; Dumka et al., 1996; Gondoli & Silverberg, 1997; Hill & Bush, 2001; Izzo, Weiss, Shanahan, & Rodriguez-Brown, 2000; Shumow & Lomax, 2002). Parents who are well adjusted are better able to model appropriate behaviors and emotional responses for their children, in addition to having positive interactions with their children. Specific to the NICU, improved parental mental health has been associated with better infant outcomes, including shorter length of stay for infants in the NICU (Als et al., 2003).

Psychological well-being has positive implications for parental adjustment during a stressful time, in addition to impacting positive and adaptive child development and outcomes (Coleman & Karraker, 1998). As such, it is important to include positive psychological attributes of parents in the NICU in a study investigating both protective factors against parent psychopathology as well as the impacts of parent variables on infant health and neurobehavior as positive attributes can be used in intervention to safeguard against the development of psychopathology and negative childhood outcomes.

Overview of Dissertation

In an effort to build upon current literature as well as investigate relationships between positive and negative parental mental health variables and infant outcomes characteristic to the NICU population, which are less well-known, the aims of this dissertation are as follows: 1) To examine the effects of parental well-being on changes in

psychopathology in the NICU, 2) To examine well-being variables and psychopathology in relation to the course of infant illness severity in the NICU, and 3) To investigate both parental mental health and well-being in relationship to specific indicators of severity as measured by neurobehavioral status.

Research to date shows that having a child in the NICU is stressful for parents (Board, 2004; Carter et al., 2005; Cleveland, 2008; Miles et al., 1992; Miles, Funk, & Kasper, 1992). In addition, studies have shown that there is a correlation between decreased parental mental health problems, lower stress levels, and shorter length of stay for the infant in the NICU (Cleveland, 2008; Dudeck-Shriber, 2004; McAnulty et al., 2010; Browne & Talmi, 2005; Melnyk et al., 2006). However, many of these studies stop at just providing profiles of single mental health variables or investigate the course of mental health at NICU intake and months after NICU discharge. An investigation exploring the course of parental mental health during the NICU stay and protective factors that may impact that course would provide information on how to better serve this population. Additionally, although studies have focused on the negative implications of parental psychopathology on child emotional and physical well-being, the literature has not adequately explored the relationship between positive and negative parent variables that may impact the course of infant severity while in the NICU. As such, an investigation of the moderating effects of parental mental health variables on the course of infant illness during the NICU stay will inform interventions that can be made to better serve not only the parent population, but also improve NICU outcomes. These data can be used to inform NICU treatment and patient care, which can lead to shorter length of stay and therefore decrease cost for parents and hospitals with regard to long-term

treatment. Lastly, the literature has not addressed the specifics of NICU infant variables impacted by parent mental health, which could lead to longer or shorter length of stay. An examination of the relationship between specific infant neurobehavioral variables and parental mental health variables would lend more specifics to the literature findings of correlations between better mental health in parents and decreased stay in the NICU.

The following chapters discuss how the studies of this dissertation address the above aims. The next chapter provides an overview of the methods that are relevant to all three investigations of the dissertation. Chapter 3 discusses the investigation of the relationship between psychological well-being (PWB), depression, and ASD, more specifically, which aspects of PWB impact change in depression and ASD over time. The study investigates the impact of the PWB dimensions in relation to infant illness severity in the NICU in Chapter 4. Specifically, the study explores the association between changes in parental ASD and depression symptoms over time and the trajectory of infant illness severity in the NICU. The final investigation is discussed in Chapter 5. This study explores the relationship between parental distress and well-being factors and their relation to infant neurobehavioral status evaluated through the NICU Network Neurobehavioral Scale (NNNS). Lastly, Chapter 6 discusses the limitations and contributions of this dissertation.

CHAPTER TWO

OVERARCHING METHOD

Participants

Participants were families recruited from the Loma Linda University (LLU) Children's Hospital NICU (See Table 1 for demographic information). All families of infants admitted to the NICU who spoke English and had a NICU stay of at least three weeks were eligible for the study. Broad inclusion criteria were chosen in order to provide an accurate and broad representation of characterization of parental mental health at infant NICU admission. However, parent questionnaires were only available in English. A minimum length of stay was chosen in order to ensure that there would be enough time between questionnaires to assess changes in parental mental health variables. At the end of this study, 97 families had complete time 1 parental measures and infant Neonatal Therapeutic Intervention Scoring System (NTISS) scores and therefore were used in the dissertation's analyses.

Table 1. *Loma Linda NICU Parent Subject Data*

Variable	N	%	M	SD
Race				
Female Parent	97			
African American	7	7.2		
Caucasian	43	44.3		
Hispanic	32	33.0		
Asian	1	1.0		
Other	4	4.1		
Not Answered	9	9.3		
Male Parent	97			
African American	9	9.3		
Caucasian	37	38.1		
Asian	2	2.1		
Hispanic	27	27.8		
Other	7	7.2		
Not Answered	14	14.4		
Marital Status				
Mother				
Married	39	40.2		
Separated/divorced	9	9.3		
Never Married	40	41.2		
No Answer	9	9.3		
Father				
Married	40	41.2		
Separated/divorced	6	6.2		
Never Married	36	37.1		
No Answer	8	8.2		
Income				
$0 – 15,000	21	21.6		
$15,001 – 25,000	9	9.3		
$25,001 – 35,000	11	11.3		
$35,001 – 50,000	12	12.4		
$50,001 – 70,000	8	8.2		
$70,001 – 95,000	8	8.2		
Greater than $95,000	9	9.3		
No Answer	19	19.6		
Stressfulness of NICU experience			2.88	1.0
Quality of Life			52.9	11.8

Table 2. *Loma Linda NICU Infant Subject Data*

Variable	N	%	M	SD
Age (weeks)			33	4.2
Length of Stay			30	23
Gender				
Female	40	41.4		
Male	57	58.6		
Race				
African American	7	7.2		
Caucasian	43	44.3		
Hispanic	32	33		
Asian	2	2		
Other	4	4.1		
Not Answered	9	9.3		
Non-surgery	67	69		
Surgery	30	31		
NTISS	95		12.3	7.8
Score 0-10	58	61.1		
Score 11-20	23	24.2		
Score 21-30	12	12.6		
Score 31-40	1	.01		
Score 41-50	1	.01		

Procedures

Personnel at the front desk in the NICU at LLU 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 interview. 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 (time 1) to the parent(s). If all questionnaires were not

completed at the intake, parents were permitted to take the questionnaires home and were asked to return the measures within the next 24 hours. Research staff made phone calls to remind parents to return questionnaires. Three weeks after the packets were returned, a second set of questionnaires (time 2) was administered in order to measure changes in parental mental health status. The target completion for this packet was within one week of receiving the questionnaires. Questionnaires that were returned after one week were ineligible for the study as all data needed to be reflective of a change in scores over a uniform length of time between questionnaires. All data were entered and stored in SPSS.

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.

Parent Mental Health Measures Used in All Studies

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 responded to various statements and indicated on a 6-point Likert scale how true each statement was of them. Higher scores on each scale indicated greater well-being on 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). The present 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).

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 relation; all are combined into a total score. The questions cover most of the areas included in the diagnostic criteria for depression and have been used with 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). The total score of this measure, which was found to have adequate reliability (.90), 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 SASRQ is a reliable and valid measure used to evaluate anxiety and dissociation symptoms in the aftermath of traumatic events, following the Diagnostic and

Statistical Manual of Mental Disorders (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 clinical criteria for symptoms in parents in the NICU population. Clinical levels of ASD symptoms were indicated by at least three out of the five dissociative symptoms, one re-experiencing symptoms, one avoidance symptom, and one marked anxiety/arousal symptom. In order to count as a "symptom" for the above criteria, responses must be three or higher on the 5-point Likert scale. Reliability obtained in our current sample for each subscale is as follows: dissociative symptoms (.91), re-experiencing symptoms (.82), avoidance (.79), marked anxiety/increased arousal (.86).

CHAPTER THREE

PSYCHOLOGICAL WELL-BEING PREDICTORS OF THE COURSE OF PARENT PSYCHOPATHOLOGY IN THE NICU

Introduction

Earlier, it was discussed that parents of infants in the NICU exhibit higher levels of symptomatology characteristic of depression, anxiety, and ASD when compared to parents of healthy infants (Carter, Mulder, Bartram, & Darlow, 2005; Leftkowitz, Baxt, Evans, 2010; Treyvaud et al., 2010) and that while distress decreases post-NICU stay, some parents still express significant levels of symptomatology (Pinelli et al., 2008). As reviewed earlier, psychological resources such as relational support, optimism, and self-acceptance are important factors that may buffer the development of psychopathology in these parents. Although some research has investigated parental distress in NICU populations, previous research has not investigated the course of parental mental health over the course of the NICU stay or possible factors that protect mental health challenges experienced in this population. The goal of the current study was to investigate the impact of psychological well-being (PWB) on changes in parental depression and ASD symptoms during the NICU stay. More specifically, the purpose was to explore which aspects of PWB impact changes in depression and ASD over time.

Relationship Between Psychological Well-Being and Parental Mental Health

The introduction of the field of positive psychology has promoted the study of resiliency or psychological characteristics presumed beneficial to PWB. Carol Ryff (1989) designed a theory and measurement scales meant to combine various concepts of

well-being into one factor describing the core dimensions of well-being. The dimensions of PWB describe different challenges individuals face as they strive to function positively: 1) autonomy (being able to evaluate oneself according to personal standards and not look to others for approval), 2) environmental mastery (being able to choose and create environments that meet one's specific needs), 3) personal growth (being open to new experiences and considering the self as growing and expanding over time), 4) positive relations with others (having warm and trusting interactions with other people and being able to display empathy, affection, and intimacy), 5) purpose in life (having goals, intentions and a sense of direction, which contributes to the feeling that life is meaningful), and 6) self-acceptance (being able to positively evaluate oneself and one's past life, acknowledging the presence of good and bad qualities in the self; Edmondson & MacLeod, 2014). .

Each of the dimensions of PWB is an aspect of life that could bring happiness and fulfillment if mastered appropriately. However, the absence of psychological distress does not adequately reflect positive mental health or PWB. Psychological well-being, however, has been associated with resiliency in the face of life stressors (Zautra, Arewasikporn, & Davis, 2010). A three-way cross-lagged panel analysis found that distress and well-being (positive outcome expectancies, perceived control, social relationship quality, social support) significantly predicted each other over time in a sample of cancer patients (Hou & Lam, 2014). Various studies investigating the mental health of parents of children with chronic illness have shown that PWB is negatively associated with distress in these populations. Specifically, coping skills and social support were found to regulate the impact of stress in parents of children with chronic

illness (Streisand, Mackey, & Herge, 2010; Tak, 1995). In addition, self-efficacy, optimism, life satisfaction, and open and frequent family communication were found to be related to less distress in parents of children with cancer (Cessna, Pidala, & Jacobsen, 2015; Fotiadou, Barlow, Powell, & Langton, 2008; Lou, 2006; Shapiro & Shumaker, 1987). Moreover, PWB has been associated with meaning in life (i.e., purpose in life), a constructive adaptation to coping with chronic illness or stressors (Dezutter, 2013). As such, an investigation of the impact of PWB on the course of psychological distress in the stressful environment of the NICU is important, as it would inform ways to prevent and treat the development of psychopathology in this population.

Psychological well-being as defined by Ryff (1989) has been found to be negatively correlated with depression in both non-clinical samples as well as in people in remission from mental illness (Edmondson & MacLeod, 2014). Interestingly, each of the dimensions of PWB has been found to correlate differently with depression, with some dimensions being related more complexly than simple negative correlations (Ruini et al., 2003). For example, Nierenberg et al. (2010) found that PWB scores in people suffering from clinical levels of depression were extremely low for environmental mastery and self-acceptance, low for purpose in life and positive relations with others, but were still within the normal range for personal growth and autonomy. Valiente and colleagues (2013) in another study comparing depressed individuals to healthy controls and individuals with persecutory delusions, found that participants with depression had significantly lower scores in self-acceptance, environmental mastery, autonomy, and personal growth than participants in the persecutory beliefs or healthy group. Those in the depressed group also scored significantly lower than individuals with persecutory beliefs

on the self-acceptance and autonomy scales (Valiente et al., 2013). Bhullar, Hine, and Phillips (2014) found that those with high scores on the PWB scale had the lowest levels of depression. The study furthermore revealed that autonomy and increasing perception of control may be a key buffer in preventing depression because those dimensions of PWB were most related with lower depression scores (Bhullar, Hine, & Phillips, 2014). As such, it is important to explore how different dimensions of PWB relate to the course of depression in parents of NICU infants where distress levels are high. Findings that specific dimensions are related to lower depression scores will be useful in developing and tailoring interventions for these parents.

Aspects of PWB have also been widely investigated in relation to stress and ASD and PTSD symptoms. Similarly to its relation to depression, dimensions of PWB have been shown to be negatively correlated with anxiety. More specifically, in a sample of patients with rheumatoid arthritis, those who endorsed higher scores on a self-acceptance rating scale also had lower scores on an anxiety and automatic thoughts questionnaire (Paloș & Vîșcu, 2014). Other studies have shown that interventions focused on increasing PWB are related to a decrease in ASD/PTSD and depression symptoms (Goldsmith et. al., 2014). Since the NICU experience has been shown to be related to stress and ASD symptoms in parents it is important to investigate if these same PWB factors are associated with resilience in this population as well. Replication of previous studies' findings using a new population, parents of infants in the NICU, will increase the generalizability and utility of interventions used to increase PWB.

The Current Study

In an effort to more directly understand the course of parental depression and ASD in the NICU as well as how PWB may impact that course, the study examined whether dimensions of PWB defined by Ryff predict changes in parental depression and ASD symptoms over the course of infant NICU stay. The hypothesis was that the dimensions of PWB would predict changes in depression and ASD symptoms. More specifically, while the study planned to investigate the effect of all PWB variables, based on previous research in parent populations, it was predicted that environmental mastery (related to self-efficacy), positive relations, and purpose in life would significantly predict changes in depression and/or ASD symptoms over the three-week period such that parents who endorse higher mastery of environmental mastery, positive relations, and purpose in life will have lower depression scores and number of ASD symptoms at time 2.

Data Analysis Plan for Aim 1

To examine whether the dimensions of PWB affect changes in depression and ASD scores of parents in the NICU, a multiple linear regression analysis was conducted to assess if PWB variables (i.e., autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance) predicted ASD symptoms and depression at time 2. Data were examined to determine whether they met the assumptions of multiple linear regression prior to analysis. Correlation analyses were completed between demographic variables, other health-related factors (e.g., surgery vs. non-surgery, LOS, infant severity, prenatal counseling, previous child in the NICU, full-

term birth, and knowledge of NICU admission beforehand), and the independent and dependent variables to determine if they should be included as covariates. Significant results indicated that the variable would be used as a covariate in the analyses (Cohen, Cohen, West, & Aiken, 2013). A multiple linear regression was conducted with each PWB variable being entered in separately into a different regression analysis. The independent variables of the regression were depression or ASD at time 1, and the PWB variable. The dependent variable of the regression was depression or ASD at time 2. By controlling for depression and ASD at time 1, changes in depression and ASD from times 1 to 2 were able to be examined. If the PWB coefficient significantly predicted depression or ASD at time 2, controlling for time 1, then it could be concluded that the PWB variable significantly predicted changes in ASD or depression scores over time. At the end of data collection, 30 families had complete time 1 and time 2 data and were included in the analyses. Power calculations indicated that given our sample, there was 8.24% power to detect a small effect size (.02), 34.86% for medium (.15), and 71.30% for large (.35).

Preliminary Analyses

Tests of normality, linearity, and homoscedasticity of errors were examined using residual scatterplots. Scatterplots indicated that the data did not violate assumptions of normality, linearity, and homoscedasticity of errors. Tests of collinearity for PWB variables, ASD symptoms at time 1, and depression at time 1 indicated no multicollinearity as all variables had VIF that were not substantially greater than 1 (Bowerman & O'Connell, 1990) and all Tolerance statistics were greater than .2

(Menard, 1995). Tests for discrepancy indicated that standardized residuals were not +/-3, more than 1% of the sample, did not have standardized residuals greater than +/- 2.5, and no more than 5% of cases had standardized residuals greater than +/-2 (Field, 2009). Tests for leverage indicated that no cases were three times or more than the average leverage value (Stevens, 2002) and tests of influence indicated that Cook's distance statistics were not greater than 1 (Cook & Weisberg, 1982). As such, there were no extreme outliers in these data. Demographic variables in addition to other health-related factors (e.g., surgery vs. non-surgery, LOS, infant severity, prenatal counseling, previous child in the NICU, full-term birth, and knowledge of NICU admission beforehand) were not significantly related (using correlations and ANOVAs) to the PWB subscales, total depression scores at time 2, or ASD symptoms at time 2, all $p > .05$. Thus, no covariates were included in analyses.

In addition, descriptive statistics were calculated investigating rates of depression and ASD in the sample. At time 1, 56.7% (17/30) of parents endorsed clinical symptoms of depression while 63.3% (19/30) of parents endorsed clinical symptoms of depression time 2. Scores at time 1 and time 2 were not significantly different, ($t = -1.16$, $p > .05$). With regard to ASD, 6 out of 30 parents (20%) endorsed 3 or more symptoms of ASD at time 1 while 8 out of 30 parents (27%) endorsed 3 or more symptoms of ASD at time 2. Scores from time 1 to time 2 were not significantly different, ($t = -1.16$, $p > .05$). In terms of PWB, parents endorsed high mastery in well-being areas with mean scores ranging from 4.39- 4.82 on a 6 point scale. Correlations among PWB subscales were calculated in order to investigate convergent and discriminant validity, and indicated intercorrelations ranging from .41-.78 (see table 2). All well-being areas were shown to

be significantly negatively correlated with depression and ASD symptoms at time 2 (all $p < .05$), with the exception of autonomy (see table 3). Parents endorsed the most mastery in personal growth ($M = 4.82$, $SD = .59$) and purpose in life ($M = 4.71$, $SD = .79$) and the least mastery in environmental mastery ($M = 4.39$, $SD = .76$).

Table 3. *Correlations Between PWB Variables*

Variable	1	2	3	4	5	6
1. Autonomy	--					
2. Environmental Mastery	.53**	--				
3. Personal Growth	.45*	.58**	--			
4. Positive Relations	.41*	.72**	.47**	--		
5. Purpose in Life	.50**	.75**	.63*	.50**	--	
6. Self-Acceptance	.50**	.77**	.55*	.71**	.78**	--

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

Table 4. *Correlations Between PWB Variables and Time 2 Depression and ASD Symptoms*

Variable	Depression Time 2	ASD Symptoms Time 2
Autonomy	-.32	-.30
Environmental Mastery	-.58**	-.52**
Personal Growth	-.54**	-.50**
Positive Relations	-.63**	-.42**
Purpose in Life	-.64**	-.61**
Self-Acceptance	-.62**	-.56**

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

Results

Ten multiple regression models were constructed to evaluate whether (1) the various PWB variables significantly predicted later depression and (2) whether the PWB

variables significantly predicted later ASD symptoms. Autonomy was not included in the analyses as it was not significantly correlated with time 2 depression and ASD scores. First, in order to test whether PWB (i.e., environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance) predicted later parental depression, depression at baseline was entered in Block 1 of the regression model, and each PWB variable was entered into a separate regression in Block 2 of the model, with depression at time 2 as the dependent variable. Results indicated that positive relations, and self-acceptance did not significantly account for changes in parental depression in the model (all $p > 0.05$; See tables 3, and 4). Environmental mastery and personal growth marginally accounted for changes in parental depression, explaining 6% and 5% of the variance in later parental depression respectively ($\Delta R^2 = .06$ $p = .07$; $\Delta R^2 = .05$, $p = .08$; See tables 5 and 6). Purpose in life significantly accounted for changes in parental depression over time, explaining 10% of the variance in later parental depression, ($\Delta R^2 = .10$; See table 7).

Table 5. *Multiple Regression Analysis Predicting Later Parental Depression from PWB Positive Relations*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.51**			
Depression at Baseline		.71	5.3	[0.50, 1.12]
Block 2	.04			
Depression at Baseline		.53	.60	[.20, 1.01]
PWB Positive Relations		-.27	-3.5	[-8.14, 1.05]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 6. *Multiple Regression Analysis Predicting Later Parental Depression from PWB Self-Acceptance*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.51***			
Depression at Baseline		.71	.81	[.50, 1.12]
Block 2	.02			
Depression at Baseline		.56	.64	[.18, 1.10]
PWB Self-Acceptance		-.21	-3.12	[-9.25, 3.01]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 7. *Multiple Regression Analysis Predicting Later Parental Depression from PWB Environmental Mastery*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.51***			
Depression at Baseline		.71	.81	[.50, 1.12]
Block 2	.06			
Depression at Baseline		.56	.64	[.29, .99]
PWB Environmental Mastery		-.28	-4.25†	[-8.94, .44]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
† $p < .10$
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 8. *Multiple Regression Analysis Predicting Later Parental Depression from PWB Personal Growth*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.51***			
Depression at Baseline		.71	.81	[.50, 1.12]
Block 2	.05			
Depression at Baseline		.59	.67	[.33, 1.01]
PWB Personal Growth		-.26	-5.12†	[-10.96, .73]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
† $p < .10$
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 9. *Multiple Regression Analysis Predicting Later Parental Depression from PWB Purpose in Life*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.51***			
Depression at Baseline		.71	.82	[.50, 1.12]
Block 2	.10*			
Depression at Baseline		.52	.60	[.26, .93]
PWB Purpose in Life		-.36	-5.31*	[-9.59, -1.03]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
* $p < .05$, ** $p < .01$, *** $p < .001$

Second, in order to test whether PWB (i.e. environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance) predicted later parental ASD symptoms, total ASD symptoms at baseline was entered in Block 1 of the regression model, and each PWB variable was entered into a separate regression in Block 2 of the model, with total ASD symptoms at time 2 as the dependent variable. Positive relations, self-acceptance, and environmental mastery did not significantly account for changes in parental ASD symptoms in the model (all $p > 0.05$; See tables 8, 9, and 10).

Personal growth and purpose in life significantly accounted for changes in parental ASD symptoms over time. More specifically, personal growth explained 6% of the variance in later parental ASD symptoms, (ΔR^2 = .06; See table 11), while purpose in life explained 7% of the variance in later parental ASD symptoms, (ΔR^2 = .07; See table 12).

Table 10. *Multiple Regression Analysis Predicting Later Parental ASD Symptoms from PWB Positive Relations*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.61***			
Total ASD Symptoms at Baseline		.78	.87	[.59, 1.13]
Block 2	.00			
Total ASD Symptoms at Baseline		.78	.87	[.54, 1.19]
PWB Positive Relations		.004	.01	[-.43, .44]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 11. *Multiple Regression Analysis Predicting Later Parental ASD Symptoms from PWB Self-Acceptance*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.61***			
Total ASD Symptoms at Baseline		.78	.87	[.60, 1.13]
Block 2	.04			
Total ASD Symptoms at Baseline		.67	.74	[.44, 1.05]
PWB Self-Acceptance		-.22	-.38	[-.86, .10]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 12. *Multiple Regression Analysis Predicting Later Parental ASD Symptoms from PWB Environmental Mastery*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.61***			
Total ASD Symptoms at Baseline		.78	.87	[.59, 1.13]
Block 2	.02			
Total ASD Symptoms at Baseline		.69	.77	[.46, 1.07]
PWB Environmental Mastery		-.18	-.31	[-.79, .17]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 13. *Multiple Regression Analysis Predicting Later Parental ASD Symptoms from PWB Personal Growth*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.61***			
Total ASD Symptoms at Baseline		.78	.87	[.60, 1.13]
Block 2	.06*			
Total ASD Symptoms at Baseline		.69	.77	[.50, 1.03]
PWB Personal Growth		-.27	-.61*	[-1.15, -.06]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 14. *Multiple Regression Analysis Predicting Later Parental ASD Symptoms from PWB Purpose in Life*

Predictor Variable	ΔR^2	β	B	95% CI (B)
Block 1	.61***			
Total ASD Symptoms at Baseline		.78	.87	[.60, 1.13]
Block 2	.07*			
Total ASD Symptoms at Baseline		.633	.70	[.42, .98]
PWB Purpose in Life		-.31	-.52*	[-.95, -.09]

Note. ΔR^2 = R squared change; β = standardized regression coefficient; B = unstandardized regression coefficient; 95% CI (B) = the 95% confidence interval associated with the unstandardized regression coefficient.
* $p < .05$, ** $p < .01$, *** $p < .001$

Discussion

The present study advances our understanding of the relationship between parental PWB variables and parents' experience of ASD and depressive symptoms while their infant is in the NICU. Previous resiliency models have shown that PWB in light of medical illness can mitigate the effects of stressors as well as serve as protective factors that buffer the development of severe psychopathology (Bhullar, Hine, & Phillips, 2014; Zautra, Arewasikporn, & Davis, 2010), yet to date, there is not a model specific to NICU parents. While most parents in the NICU do not develop severe psychopathology, the NICU experience is very stressful and happens at a time when mothers are already more prone to distress and development of post-partum depression and baby blues. The presence of parental distress in the NICU is concerning as mental health difficulties impact parent-child interaction and early infancy is a time when positive parent-child interaction is critical for optimizing infant development (Athanasopoulou & Fox, 2014; Chiang, Lin, Lee, & Lee, 2015; McManus & Poehlmann, 2012; van Ee, Kleber, & Mooren, 2012). The results of the current study indicated that while parent report of

distress did not significantly change over time (i.e., changes were not statistically significant), parents in our samples were reporting clinically elevated depressive and ASD symptoms at time 2. It may be that for parents whose children are in the NICU for an extended period of time (e.g., 3 weeks or more), parental mental health does not improve (or regress to the mean as expected), and thus the need for intervention is warranted. Based on the study sample, parents in the NICU seem to continue to endorse clinical levels of symptomatology for an extended period of time and thus are in need of intervention to address their distress.

Parent report of distress (e.g., depressive and ASD symptoms) in the sample did not change significantly over time, and appears to be buffered by aspects of psychological well-being. Aspects of PWB were predictive of later ASD and depressive symptoms, with higher levels of PWB being associated with lower levels of ASD and depressive symptoms. More specifically, personal growth and purpose in life impacted the change in both parental depression and ASD symptoms over time. Additionally, environmental mastery was found to significantly impact changes in parental depression. Future research should examine factors that maintain the stability of distress in the sample. Moreover, the presence of distress in parents at a later time in the NICU lends further justification for the need to provide intervention to parents while their child is in the NICU. Additionally, the well-being characteristics found to help parents the most in this population can serve as the basis for which intervention is targeted.

Providing NICU parental mental health support in a way that capitalizes on PWB areas would be important as those endorsing high mastery in PWB areas (i.e., environmental mastery, personal growth, positive relations with others, purpose in life,

and self-acceptance) endorsed lower levels of distress. Allowing parents to be involved in their child's care in a meaningful way that taps into these mastery areas (e.g., allowing parents to assist nurses in feeding or bathing their infant, regular communication with NICU staff about the care of their child, involving parents in decision making of their child's care) may help alleviate their distress faster (Shellabarger & Thompson, 1993). In addition, parent supports in the hospital in the form of psychological therapy or group therapy would also be warranted. More specifically, approaches employing mindfulness, cognitive behavioral therapy, or logotherapy, which have been actively used in addressing depression and ASD would be beneficial (Cheraghi, Kalantari, Moulavi, & Shafti, 2009; Pearson, Brown, Bravo, & Witkiewitz, 2014; Robatmili et al., 2015). Treatment could focus on building environmental mastery, an area of weakness in the sample parents, by enhancing coping skills, highlighting purpose in life, normalizing their experience, and building a sense of community.

The study of positive protective factors in the NICU population is still a relatively new area of research. This study sheds light on parental resiliency and the need for further investigation into the specific effects of well-being in order to create a model of resiliency in this population. Personal growth and purpose in life were consistent and robust predictors of both depression and ASD symptoms in the study sample. When investigating parent characteristics further, results indicated that both of these PWB areas were the two highest areas of reported mastery among parents in the sample. In addition, purpose in life and personal growth have been shown in the literature to improve psychological symptoms through interventions such as mindfulness (Blackburn & Owens, 2015; Goldsmith et. al., 2014; Haugan, 2014). Being able to maintain a sense of

meaning in life after a traumatic event (Frazier, Conlin, & Glaser, 2001; Krause, 2007; Steger et al., 2006; Updegraff, Silver, & Holman, 2008) as well as being open to new possibilities and spiritual growth has been shown to protect against development of mental health problems (Soo & Sherman, 2015; Tedeschi & Calhoun, 1996). As such, it may be that since parents in the sample endorsed higher mastery in purpose in life and personal growth, they are endorsing that they are able to find meaning in life despite the stressors of having a child in the NICU. They are also open to growing in the face of the challenges that come with having a child in the NICU. These characteristics serve to protect them from developing further mental health problems over the course of NICU stay. Future studies should include more in depth analysis of the impacts of well-being on distress experienced in the NICU by including more longitudinal data throughout the whole NICU stay as well as up to 6 months post discharge. This research would allow one to decipher whether parental distress continues to remain unchanged throughout NICU involvement and build a stronger case for the need for intervention in this population. It would also be informative to investigate if the highest areas of mastery also impact later experience of distress in other NICU populations as found in the study sample.

Future research should also further investigate the impact of environmental mastery in this population. While environmental mastery predicted later depression, it did not predict later ASD symptoms. Environmental mastery was also the area least mastered by parents in the study sample. Environmental mastery through the ability to create an environment to fulfill one's own needs as well as the state of mind that one is able to have an influence on the events in life has been found to buffer against distress in parents

of children with cancer (Cessna, Pidala, & Jacobsen, 2015; Ryff, 1989). While many ASD symptoms are physiological in nature, depressive disorders have a cognitive component characterized by a negative view of oneself, one's experiences, and one's life leading to a negative view of the self and helplessness (Bryant, 2006; Seligman, 1975). As such, it may be that environmental mastery has a much larger impact on depression due to its cognitive components rather than ASD, which comprises mostly of physiological symptoms. A person who is high on environmental mastery feels he can act on his own behalf even though he is not able to actually be in control of the situation, and therefore he is at lower risk for feelings of helplessness and resulting depression (Ryff, 1989; Sin & Lyubomirsky, 2009). In a future study, a brief screening could be used to identify parents with lower environmental mastery and an intervention could be delivered targeting those parents. The intervention could be delivered during a NICU stay and focus on teaching parents adaptive coping skills as well as empowerment and advocacy in ways to have a larger role in their child's care. Levels of depression and ASD could be measured throughout the NICU stay and investigated in relation to the intervention.

Limitations and population factors of the study likely had an impact on explaining the resulting outcomes. It was predicted that social support would be highly predictive of later depression and ASD scores, given social support was shown in the literature to buffer against distress in parents of sick children. However, parents in the sample reported higher mastery in other areas of PWB (e.g., personal growth and purpose in life), which were shown to significantly predict later distress in the sample. In addition, the study only consisted of longitudinal data from 30 parents in the NICU and 10 multiple regression analyses were run. The low number of cases and multiple analyses decreases

the power and increases the Type I error such that there is 40% chance of making a Type I error or a 40% chance that one of the significant findings is due to chance. It was important to run 10 analyses because the researcher wanted to investigate which well-being resources impacted distress in the study population. Knowing that the NICU population has not been as widely studied as other illness populations, the researcher did not want to limit the investigation to specific variables found in previous literature. While the limitations of the study can skew the results and cause them to not be generalizable to other NICUs, it is still important to know about parental experience of distress over the course of their child's NICU stay, as well as any protective factors they may inherently have that mitigate impacts of NICU related stress. A study using a much larger sample with more longitudinal data points, extending to 6 months post discharge would give more power to investigate how parental experience of distress changes over the course of NICU stay as well as the impact of parental psychological well-being on the course of distress.

The results of this study also lend valuable information for the LLU hospital staff. Results provide a frame of reference with which to understand the experience of parents in the NICU who are distressed, whose distress levels do not abate over time, but who have inherent characteristics that significantly impact their experience of later distress in the NICU. These considerations would be beneficial in thinking about patient health care satisfaction and how to improve it, as well as its implications about the overall NICU experience of these clients. Specific to the sample, while environmental mastery was one of the few PWB variables to predict later distress, this construct was also the area least

mastered by parents in the study sample, which lends support for the need to provide intervention focusing on building environmental mastery in these parents.

CHAPTER FOUR

MODERATING EFFECTS OF PARENTAL MENTAL HEALTH ON COURSE OF INFANT SERVERITY IN THE NICU

Introduction

As discussed in Chapter One, parents of infants in the NICU are often distressed and exhibit levels of ASD and PTSD consistent with those in other illness and injury populations who experience traumatic stress (i.e. 35% of mothers and 24% of fathers in the sample met the criteria for ASD at infant NICU admission and 15% of mothers and 8% of fathers in the sample met diagnostic criteria for PTSD 30 days later; Shaw et al., 2006). Poor parental mental health has been shown to lower parents' responsiveness to child behavior and leads to fewer positive interactions with their children, thus having negative implications for child social, emotional, and cognitive development (Beck, 1995; Caplan et al., 1989; Cummings & Davies, 1994; Gao et al., 2007; Halligan et al., 2007; Pinelli, 2002; Treyvaud et al., 2010). Conversely, improved parental mental health has been associated with better infant outcomes, including shorter length of stay for infants in the NICU (Als et al., 2003). The purpose of this study was to conduct an investigation of the association between parental ASD and depression symptoms and the trajectory of infant health severity in the NICU. In addition, the impact of PWB dimensions on NICU severity was explored.

NICU Infant Illness

As reviewed earlier, infants in the NICU present with various health difficulties including prematurity, congenital anomalies, and low-birth-weight. Infant illness severity

can be measured in a variety of ways. One method used by researchers is length of stay (LOS) as it takes into account both course of illness but also the need for physiologic maturation (Gray et al., 1992). Other studies have used birth weight and gestational age as measures of infant illness severity, however, these do not account completely for variations such as differences in rates of bronchopulmonary dysplasia, intraventricular hemorrhage, and neonatal mortality (Gray et al., 1992). Another type of severity assessment is therapy-based-severity-of-illness assessment such as the Neonatal Therapeutic Intervention Scoring System (NTISS), which quantifies illness severity by tabulating the intensity of therapies (e.g., respiratory therapies, drug therapies, metabolic/nutrition interventions, procedures, transfusion, cardiovascular interventions, monitoring) received by the patient. The benefit of this assessment is that it is more detailed given it accounts for more factors affecting illness severity than gestational age and birth weight alone. Studies using the NTISS have found that this illness severity scoring system is strongly associated with in-hospital mortality and clinician estimates of mortality risk, in addition to being a strong predictor of total hospital charges (Gray et al., 1992). As a result, use of this scoring system was chosen for evaluation of infant illness severity over the course of NICU stay in the current study.

Parental Distress in Relation to Infant Health

Psychopathology has negative impacts on overall functioning of parents and has been investigated in relation to infant health. Left untreated, parents' symptoms of depression, anxiety, and acute stress disorder can lead to problems such as physical health problems (e.g., stroke or coronary artery disease), changes in sleep patterns,

cognitive dysfunction, and prolonged experiencing of symptoms (Austin, Mitchell, & Goodwin, 2001; Crocker et al., 2013; Gudmundsson et al., 2006). Studies have found differences in parental distress based on health severity of infants. In one study, mothers of high risk infants (very low birth weight infants diagnosed with bronchopulmonary dysplasia) had lower levels of distress at the end of the study than at the start, but still experienced more symptoms of distress at two years post discharge compared to mothers of low-risk infants (Singer et al., 1999). An infant's length of stay and diagnosis at the time of data collection were found to be associated with parental stress at that point in time. More specifically, a longer length of stay and cardiovascular complications were associated with higher stress scores in parents at the time of data collection (Dudeck-Shriber, 2004). In addition, Dudeck-Shriber (2004) found the infants' length of stay at data collection was also predictive of frequency of stress, with longer length of stay resulting in greater frequency.

Numerous studies have revealed that poor parental mental health can have adverse impacts on child outcomes. Increased levels of maternal depression have been shown to be significantly related at one year to poorer infant mental health and motor development (Lyons-Ruth et al., 1986). Cornish and colleagues (2005) found that maternal depression lasting through the first year postpartum and beyond was related with lower infant cognitive and psychomotor development. Severity of maternal depression has been related to delayed child development in very-low-birth-weight children (Singer et al., 1999). Woodward and colleagues (2014) found that NICU-related stress in parents was associated with child anxiety and poorer language development at four years post-NICU stay. Moreover, depression, parenting stress and weak sense of

coherence were found to be associated with more behavioral and emotional problems in very-low-birth-weight children at age three (Huhtala et al., 2012).

NICU parents have been shown to evidence significant depression and ASD, which has been shown to have negative impacts on children later in life. Thus, an investigation of parental mental health in the NICU in relation to the course of infant health severity is important. Research on the immediate impacts of parental distress on the course of infant health while still in the NICU is limited and thus warrants further investigation. In addition, the use of the NTISS in relation to parental mental health has never been done before. The NTISS provided a more detailed measure of infant illness severity compared to previous studies, which used singular factors such as gestational age, birth weight, or length of stay. These findings provide more information for how to better serve this population and address not only health of NICU infants, but also socio-emotional and developmental implications that could result from poor parental mental health later on.

Parental Well-being in Relation to Infant Health

Healthy parental psychological adjustment has positive implications for parental functioning and child competence. One example highlights the importance of 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). 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). Specifically, high parental self-efficacy has been linked

with competent and positive parenting practices, strategies, and behaviors (Coleman & Karraker, 1998). Parents in the NICU experience stress related to changes in their parental role functioning. Thus parents who have a strong sense of self-efficacy may be better able to adapt to the stressful NICU environment and confidently take on the role of learning to care for their infant. This is especially significant because it is one of the considerations of neonatologists in deciding whether an infant is ready to be discharged from the NICU (Altman et al., 2006).

Studies investigating infant outcomes in relation to parental well-being have shown that better adjustment in parents yields positive results for infant development and adjustment. Davis, Edwards, and Mohay (2003) found that mothers who coped better while their preterm infant was in the NICU also had infants who were more responsive at three months after infant discharge from the hospital. Studies on more immediate impacts of parental well-being have found a correlation between lower parental stress levels and shorter length of stay in the NICU (Browne & Talmi, 2005; McAnulty et al., 2010; Melnyk et al., 2006). Even more so, researchers have found that parents who have effective social support systems are better adjusted and interact in more optimal ways with their child (Dunst, Trivette, & Cross, 1986). A mother's satisfaction with the intimate support provided by her significant other has been shown to have a positive effect on the quality of mother-infant interaction (Crnic, Greenberg, Robinson, & Ragozin, 1984). Nevertheless, the literature is less informative about the immediate impacts of parental well-being on the course of infant health severity while the infant is in the NICU. As such, a study investigating parent well-being factors (autonomy, self-acceptance, positive coping skills, and social support) that have a significant relationship

to course of infant severity provides valuable information about parent characteristics that can be strengthened through intervention.

The Current Study

The purpose of this investigation was to more directly understand the relationship between parental mental health and the course of infant illness severity while in the NICU. As such, the study examined the course of illness severity over the NICU stay as well as parental well-being characteristics (e.g. psychological well-being, coping style, quality of life) and distress (depression and ASD) that may act as moderators of these infant illness trajectories. Toward this aim, the following hypotheses were investigated: (1) Infants of parents with higher depression and ASD scores will exhibit smaller changes in illness severity over time compared to those with lower scores, and (2) Infants of parents with higher PWB and quality of life scores as well as those who endorse more effective coping strategies (e.g., emotion focused coping style and problem-focused coping style) will exhibit greater changes in illness severity over time compared to those who endorse lower scores. More specifically, based on previous research, it was predicted that self-acceptance and autonomy on PWB, positive coping strategies (emotion focused coping and problem focused coping subscales of the Brief COPE), and higher quality of life would be associated with greater changes in scores of infant illness severity.

Method

Additional Procedures

In addition to the procedures discussed in Chapter Two, infant illness severity was calculated by the Neonatal Therapeutic Intervention Scoring System (NTISS) using information from daily patient records (e.g., use of respiratory therapy, medication use, type of transfusion, feeding method, cardiovascular therapy). This information was tracked by the nursing staff and a physical therapist and was obtained at infant NICU admission, 5 days surrounding parent intake, and at discharge. A member of the research team extracted data from PowerChart, the electronic medical record system used by LLU Medical Center. Information on vitals, therapies provided, lab results, treatments, medications, diagnostics, and nursing and physician notes on patient progress are charted daily. A pediatric surgeon trained medical students on how to extract information about the therapies a patient received and enter them into the NTISS scoring sheet (e.g., therapy received or not) in order to obtain a total illness severity score calculated by the program.

Additional Measures

Parent Mental Health Measures

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); the 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 in earlier studies (Yusoff, Low, & Yip, 2010). Reliability obtained in the current sample for each subscale was: problem focused coping (.80), emotion-focused coping (.64), and less useful coping (.64).

Quality of Life Inventory (QOLI) (Frisch Cornell, Villanueva, & Retzlaff, 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 current sample for the total scale was (.83).

Child Outcome Measures

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

The NTISS is a scoring system for intensive care 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 Therapeutic Intervention Scoring System (TISS) score of Cullen et al. (1974) suitable for use in neonatal intensive care. The TISS is a scoring system consisting of 57 items of therapeutic interventions scored on a 1 to 4 basis according to intensity of involvement. The points acquired per patient per day are summated into a total score. The number and type of therapeutic interventions were used rather than diagnosis since a more critically ill patient should require more therapeutic interventions (Cullen et al., 1974; Keene & Cullen, 1983).

NTISS measures severity of illness 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 NTISS score for a NICU infant at LLU Medical Center is 4 because there are 4 procedures mandated for NICU admission: Frequent vital signs, cardiorespiratory monitoring, noninvasive oxygen monitoring, quantitative intake and output—each of which is one point. The severity score is based on the assumption that given similar philosophies or styles of care, therapeutic intensity is a direct correlate of illness severity (Cullen et al., 1974; Gray et al., 1992). High internal consistency reliability was found (0.84) in addition to high validity. Inter-rater reliability for the study ranged from .95-.98. Reliability in the current

study for repeated NTISS scores ranged from .83-.97. This measure was used to assess for infant illness severity.

Data Analysis for Aim 2

Hierarchical linear modeling (HLM) was used to examine changes in infant illness severity scores over the course of the NICU stay (5 time points) (Raudenbush & Bryk, 2002). HLM analysis was used to examine (a) whether there was a significant change in infant illness severity scores over the course of five days during NICU stay, and (b) to determine whether parental depression, ASD, PWB, coping style, and quality of life moderated the trajectory of infant illness severity over the time points.

Demographic variables and other health-related factors (e.g., LOS, prenatal counseling, previous child in the NICU, full-term birth, and knowledge of NICU admission beforehand) were not significantly related (using correlations and ANOVAs) to any of the independent or dependent variables, ($p > .05$) and therefore were not tested as covariates in the conditional growth analyses. Data were examined for outliers and for violations of the assumptions of hierarchical linear modeling (normality, linearity, independence, and homoscedasticity of errors) prior to analysis (Raudenbush et al., 2004). Tests of normality, linearity, and homoscedasticity of errors were examined using residual scatterplots (Field, 2009). Due to violations of the normality assumption (all Kolmogorov-Smirnov & Shapiro Wilk $p <$ 05; see Appendix A for Q-Q plots; Field, 2009), the robust standard errors correction was used. Tests for leverage, discrepancy and influence were used for detecting outliers. Tests for discrepancy indicated that standardized residuals were not +/-3, more than 1% of the sample did not have

standardized residuals greater than +/- 2.5, and no more than 5% of cases had standardized residuals greater than +/-2 (Field, 2009). Tests for leverage indicated that no cases were three times or more than the average leverage value (Stevens, 2002) and tests of influence indicated that Cook's distance statistics were not greater than 1 (Cook & Weisberg, 1982), and as such there were no extreme outliers in the data. Analyses were performed using HLM software (Raudenbush et al., 2004).

Table 15. *Normality Tests for NTISS Scores*

Variable	Kolmogorov-Smirnov Statistic	Shapiro-Wilk Statistic
Infant Illness Severity Day 1	.17***	.83***
Infant Illness Severity Day 2	.21***	.67***
Infant Illness Severity Day 3	.25***	.75***
Infant Illness Severity Day 4	.24***	.75***
Infant Illness Severity Day 5	.25***	.70***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

To examine significant change over time, first the unconditional growth model was examined. Only the linear model fit and no other growth functions (i.e., quadratic or cubic models) were examined because graphical representation of the data looked linear (Figure 1). In addition, the data only had 60 degrees of freedom for data analysis, which was too small for model comparison statistics. To examine whether parental depression, ASD, PWB, coping style, and quality of life moderated changes in infant severity over the NICU stay, parental depression, ASD, PWB, coping style, and quality of life were added as a level – 2 predictor. A significant finding indicated that trajectories of infant illness severity change as a function of the aforementioned parental variables. Level 1/Level 2 equations for the final model are as follows:

Level 1: $NTISS_{ti} = \pi_{0i} + \pi_{1i}*(TIME_{ti}) + e_{ti}$

Level 2: $\pi_{0i} = \beta_{00} + \beta_{01}*(PARENT\ VARIABLE_i) + r_{0i}$

$\pi_{1i} = \beta_{10} + \beta_{11}*(PARENT\ VARIABLE_i) + r_{1i}$

*Note: PARENT VARIABLE = parental depression, ASD, PWB, coping style, and quality of life

At the end of data collection, 74 families had both complete infant data and complete time 1 measures and were included in the analyses. Power calculations indicated that given size of the sample and number of observations, we obtained 70% power.

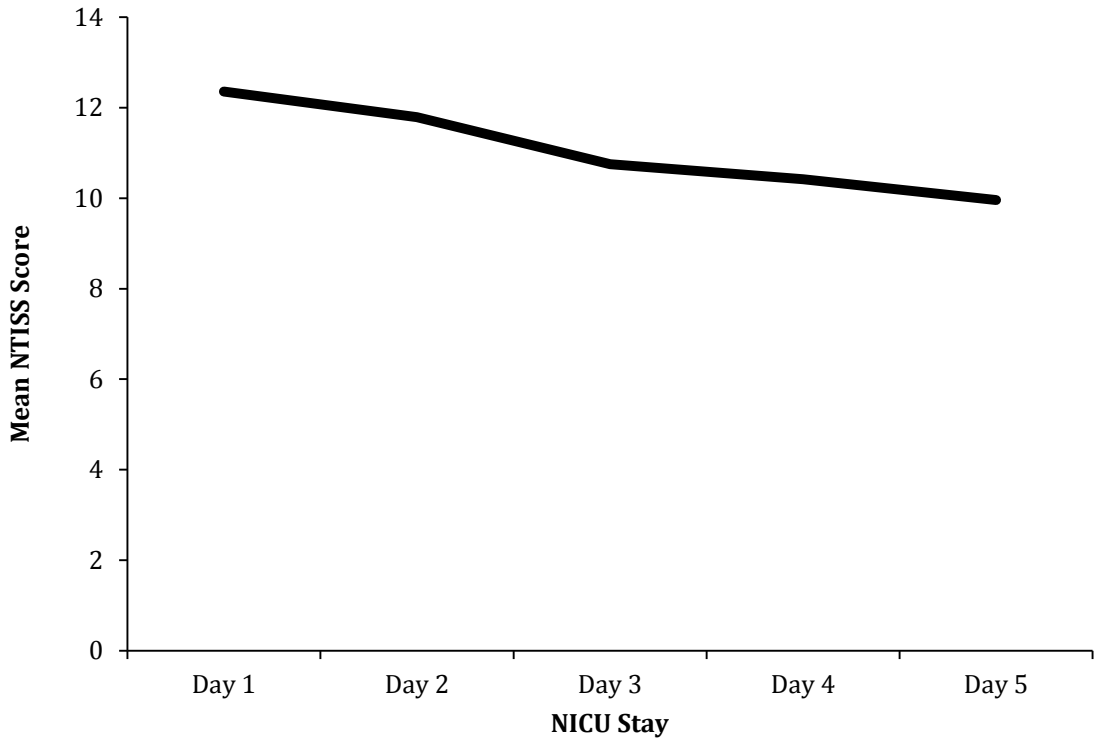

Figure 1. Mean NTISS Scores During NICU Stay

Results

Unconditional Growth Model

First the unconditional growth model was tested in order to examine whether there was a significant change in infant severity scores over the five day assessment period during NICU stay. Results indicated that there was a significant effect of time. More specifically, on average, infant severity scores started at 13.29 and significantly decreased (improved) by 0.5 points everyday ($p < .01$).

Table 16. *HLM of Unconditional Growth Model of NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	60	13.29 (1.05)**
	Time	60	-.50 (.14)**

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

Conditional Growth Model

Parental Mental Health

Next, analyses tested whether negative aspects of parental mental health (depression and ASD) moderated the trajectory of infant severity scores over time. Depression, total number of ASD symptoms, and each of the subscales of the ASD measure were entered separately into the Level 2 equation.

Depression did not significantly predict the intercept, but it was found to have a marginal effect on change over time. Regardless of whether the infant's parents endorsed depression, their severity score on average still started at 13; however, there was a

marginally significant difference with regard to how quickly infants of parents who endorsed depression improved. More specifically, infants whose parents endorsed higher scores on the CES-D improved at a slower rate (.02 points slower on average), but this was only marginally significant (p = .095).

Table 17. *HLM of Depression Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.05 (.92)**
	Depression	59	.11 (1.31)
Rate of change/slope (π_{1i})	Intercept	59	-.54 (.14)**
	Depression	59	.02 (.01) †

Note. † p < .10, * p < .05, ** p < .01

Total number of clinical ASD symptoms endorsed did not significantly predict the intercept, but significantly predicted the rate of change of infant severity over time. Parents who endorsed more clinical ASD symptoms had infants who still started with a severity score of 13, but improved at a significantly slower rate, .33 points per day on average (p < .05). Specific symptoms of ASD were then investigated in relation to their impact on rate of change of infant severity. Parental endorsement of more re-experiencing symptoms of ASD did not predict the intercept and only marginally significantly predicted the rate of change in infant severity over time, such that their infants still started with a severity score of 13, but improved at a rate of .32 points per day on average (p = .07). Additionally, parental endorsement of avoidant symptoms of ASD did not predict the intercept, but very highly significantly predicted the rate of change in infant illness severity, such that parents who endorsed more avoidant symptoms had

children who still started with a severity score of 13, but improved at a rate of .15 points per day on average ($p < .001$). Endorsement of anxiety symptoms of ASD did not significantly predict the initial infant severity score or the rate of change of infant severity ($p > .05$). Moreover, total number of dissociative symptoms of ASD did not predict the intercept, but was highly predictive of the rate of change in infant severity, such that parents who endorsed more dissociative symptoms of ASD had infants who still started with a severity score of 13, but improved at a rate of .27 points per day on average ($p < .001$).

Table 18. *HLM of Total ASD Symptoms Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.18 (1.02)**
	Total ASD	59	.56 (.76)
Rate of change/slope (π_{1i})	Intercept	59	-.53 (.13)**
	Total ASD	59	.20 (.09)*

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

Table 19. *HLM of ASD Re-experiencing Symptoms Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.26 (1.03)**
	Re-experiencing	59	.22 (.23)
Rate of change/slope (π_{1i})	Intercept	59	-.53 (.14)**
	Re-experiencing	59	.20 (.11) †

Note. † $p < .10$, * $p < .05$, ** $p < .01$

Table 20. *HLM of ASD Avoidance Symptoms Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.25 (1.06)**
	Avoidance	59	.29 (1.04)
Rate of change/slope (π_{1i})	Intercept	59	-.55 (.13)**
	Avoidance	59	.40 (.11)**

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

Table 21. *HLM of ASD Anxiety Symptoms Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.11 (.99)**
	Anxiety	59	1.00 (.78)
Rate of change/slope (π_{1i})	Intercept	59	-.52 (.14)**
	Anxiety	59	.10 (.09)

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

Table 22. *HLM of ASD Total Dissociative Symptoms Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.27 (1.04)**
	Total Dissociative	59	.26 (.78)
Rate of change/slope (π_{1i})	Intercept	59	-.55 (.13)**
	Total Dissociative	59	.28 (.07)**

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

Further analysis investigated the moderating effects of specific dissociative symptoms (i.e., encompassing subjective sense of numbing, detachment and emotional unresponsiveness, reduced awareness of the surroundings, derealization, depersonalization, and dissociative amnesia) on the rate of change in infant illness severity. Results indicated that derealization and dissociative symptoms (i.e. related to dissociative amnesia) of the subscale did not significantly predict the initial infant severity score or rate of change in infant severity ($p > .10$ and $p > .50$ respectively). Symptoms of depersonalization did not predict the initial infant severity score, but were significantly predictive of change in infant severity evidenced by improvement by .29 points per day on average ($p < .01$). Similarly, symptoms of decreased awareness also did not predict initial infant severity, but significantly predicted the rate of change in infant severity, with higher endorsement of symptoms resulting in a rate of change of improvement of .34 points per day on average ($p < .05$). Lastly, endorsement of symptoms of detachment did not predict the initial infant severity, but highly significantly predicted rate of change of infant severity such that the more parents endorsed detachment, the slower their infants improved (.26 points per day on average, $p < .001$).

Table 23. *HLM of ASD Derealization Symptoms Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})			13.13 (.98)**
	Intercept	59	
	Derealization	59	.73 (.76)
Rate of change/slope (π_{1i})			
	Intercept	59	-.52 (.14)**
	Derealization	59	.11 (.08)

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

Table 24. *HLM of ASD Dissociative Symptoms Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.09 (.97)**
	Dissociative	59	1.92 (1.54)
Rate of change/slope (π_{1i})	Intercept	59	-.52 (.14)**
	Dissociative	59	.15 (.15)

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

Table 25. *HLM of ASD Depersonalization Symptoms Predicting Rate of Change in* NTISS *Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.25 (1.04)**
	Depersonalization	59	.17 (.81)
Rate of change/slope (π_{1i})	Intercept	59	-.52 (.14)**
	Depersonalization	60	.24 (.08)**

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

Table 26. *HLM of ASD Decreased Awareness Symptoms Predicting* Rate *of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.11 (1.04)**
	Decreased Awareness	59	.63 (.78)
Rate of change/slope (π_{1i})	Intercept	59	-.55 (.13)**
	Decreased Awareness	59	.21 (.09)*

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

Table 27. *HLM of ASD Detachment Symptoms Predicting Rate of Change in* NTISS *Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.39 (1.07)**
	Detachment	59	-.41 (.66)
Rate of change/slope (π_{1i})	Intercept	59	-.57 (.13)**
	Detachment	59	.31 (.09)**

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

In summary, while none of the negative mental health variables significantly predicted the intercept, certain variables predicted a slower decrease (improvement) in infant illness severity scores compared to the effect of time alone. In other words, regardless of whether the infant's parents endorsed symptoms of depression or ASD, their NTISS score on average still started at 13; however, rate of change in severity scores differed based on select variables. More specifically, endorsement of more clinical ASD symptoms, ASD avoidant symptoms, higher number of total ASD dissociative symptoms, and specific ASD dissociative symptoms of depersonalization, decreased awareness, and detachment predicted a slower improvement in NTISS scores over time. Depression and ASD re-experiencing symptoms also predicted a slower improvement in NTISS score, but their effect was only marginally significant. Lastly, ASD anxiety symptoms and specific ASD dissociative symptoms of derealization and dissociation did not significantly predict changes in NTISS score over time.

Positive Protective Factors

This study also investigated whether positive aspects of well-being (coping style, quality of life, and PWB) moderated the trajectory of infant severity over the five days assessment during NICU stay. The various coping styles, quality of life, and each of the subscales of the PWB measure were entered separately into the Level 2 equation.

With regard to coping style, both emotion-focused coping and problem-focused coping did not significantly predict the initial infant severity score or rate of change of infant illness over time ($p > .40$ and $p > .30$ respectively). On the other hand, although less useful coping did not predict the initial infant severity score, it was found to significantly moderate the course of infant severity over time. Specifically, parents who endorsed more use of less useful coping strategies had infants who improved at a significantly slower rate (.44 points per day on average) than those who did not ($p < .01$).

Table 28. *HLM of Emotion-Focused Coping Predicting Rate of Change in NTISS Scores*

	Variable	Df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.28 (1.04)**
	Emotion-Focused Coping	59	-.10 (.18)
Rate of change/slope (π_{1i})	Intercept	59	-.50 (.14)**
	Emotion-Focused Coping	59	.02 (.02)

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

Table 29. *HLM of Problem-Focused Coping Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.31 (1.05)**
	Problem-Focused Coping	59	-.09 (.17)
Rate of change/slope (π_{1i})	Intercept	59	-.51 (.14)**
	Problem-Focused Coping	59	.03 (.03)

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

Table 30. *HLM of Less Useful Coping Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.27 (1.05)**
	Less Useful Coping	59	-.01 (.29)
Rate of change/slope (π_{1i})	Intercept	59	-.51 (.14)**
	Less Useful Coping	59	.07 (.03)**

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

Quality of life and PWB (self acceptance, positive relations, autonomy, environmental mastery, purpose in life, and personal growth) did not significantly predict the initial infant severity score or the rate of change in infant severity score over time (all $p > .05$).

Table 31. *HLM of Quality of Life Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept			13.27
(π_{0i})	Intercept	59	(1.04)**
	Quality of Life	59	-.20 (.53)
Rate of change/slope			
(π_{1i})	Intercept	59	-.50 (.14)**
	Quality of Life	59	.02 (.09)

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

Table 32. *HLM of PWB Self Acceptance Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept			13.17
(π_{0i})	Intercept	59	(1.02)**
	PWB Self Acceptance	59	-1.06 (1.17)
Rate of change/slope			
(π_{1i})	Intercept	59	-.49 (.15)**
	PWB Self Acceptance	59	.10 (.20)

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

Table 33. *HLM of PWB Positive Relations Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept			13.18
(π_{0i})	Intercept	59	(.99)**
	PWB Positive Relations	59	-.83 (1.43)
Rate of change/slope			
(π_{1i})	Intercept	59	-.52 (.14)**
	PWB Positive Relations	59	-.14 (.17)

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

Table 34. *HLM of PWB Autonomy Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.37 (1.10)**
	PWB Autonomy	59	-1.45 (1.87)
Rate of change/slope (π_{1i})	Intercept	59	-.49 (.14)**
	PWB Autonomy	59	-.10 (.22)

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

Table 35. *HLM of PWB Environmental Mastery Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.24 (1.03)**
	PWB Environmental Mastery	59	-.55 (1.04)
Rate of change/slope (π_{1i})	Intercept	59	-.52 (.14)**
	PWB Environmental Mastery	59	-.19 (.14)

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

Table 36. *HLM of PWB Purpose in Life Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.29 (1.08)**
	PWB Purpose in Life	59	-.01 (1.49)
Rate of change/slope (π_{1i})	Intercept	59	-.51 (.14)**
	PWB Purpose in Life	59	-.12 (.16)

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

Table 37. *HLM of PWB Personal Growth Predicting Rate of Change in NTISS Scores*

	Variable	df	Coefficient
Fixed Effects			
Initial status/y-intercept (π_{0i})	Intercept	59	13.29 (1.02)**
	PWB Personal Growth	59	-.18 (1.72)
Rate of change/slope (π_{1i})	Intercept	59	-.50 (.14)**
	PWB Personal Growth	59	-.06 (.17)

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

Discussion

The present study advances our knowledge of the relationship between parental mental health and changes in infant health status in the NICU by shedding light on specific parent variables that are associated with changes in infant health over time. As expected, the rate of change of infant health severity was significantly different based on certain parent variables. More specifically, consistent with previous literature, negative parental mental health variables were shown to be related to certain infant health trajectories (Dudeck-Shriber, 2004). However, positive protective factors were not shown to have any significant association. Parents who endorsed more ASD symptoms had infants whose health improved at a slower rate compared to others. Endorsement of ASD symptoms that would lead to emotional unresponsiveness and detachment (e.g., re-experiencing, avoidance, dissociation, depersonalization, detachment, and decreased awareness) were associated with a slower rate of improvement of infant health. Possible reasons for slower rate of infant improvement being associated with distress symptoms related to emotional unresponsiveness and detachment is that these parents may be less able to identify and attend to their child's needs than healthy parents. In addition, previous studies have shown that parental mental distress is related to poorer cognitive,

emotional, and motor development (Cornish et al., 2005; Lyons-Ruth et al., 1986; Singer et al., 1999; Woodward et al., 2014), and similarly, parents with heightened distress in the NICU may impact the way that parents interact with their children, making them less responsive and less attuned to their child, which may lead to slower recovery of an infant in the NICU. It is important to note that although this study found that parent variables are associated with particular infant trajectories, what is still unknown is the direction of effect among these variables. It is possible, and probably likely, that infant health status would also predict changes in parent MH over time (e.g., those infants whose health concerns are more severe might improve less quickly compared with infants with less severe health concerns and may also have parents that come in more depressed and anxious and exhibit higher levels of these symptoms over time). Future research could focus on examining the direction of the effect between parental mental distress and infant health severity in order to determine if the relationship is transactional (i.e., is it that infant health severity is causing parents to experience more distress in addition to parental distress causing infants to improve at a slower rate?). A longitudinal study with a larger sample as well as 3 or more data points (admission, every 2 weeks, discharge) of both parent distress and well-being and infant severity scores would allow for such analyses to be done.

In addition to significant parental distress being related to certain trajectories of infant improvement in the NICU, the study also revealed that negative coping skills carried more weight than positive protective factors. Specifically, less useful coping skills were significantly related to a slower rate of change in infant severity. This is consistent with literature findings that parents who cope well have infants who are more responsive

and better adjusted after being discharged from the NICU (Davis, Edwards, & Mohay, 2003). Parents who have less adaptive coping strategies likely are more at risk for higher rates of distress, leaving them vulnerable to developing psychopathology, and having less responsive and positive interactions with their infants. It is interesting to note that in this study, the most frequently used less useful coping skills for parents were venting, self-blame, and self-distraction. It would be interesting for future investigations to take a more in depth survey of the types of coping strategies parents in the NICU use. These coping styles could be investigated in relation to how parents interact with their infants both in the NICU (frequency of NICU visits, amount of interaction with their infant, type of interaction) and with regard to parenting style assessed at a later time. This would allow for further investigation of why less useful coping strategies in the study were found to be more related to infant health severity compared to more adaptive coping.

The results of the present study reveal that parental mental health is related to negative outcomes in children as early as infancy. The negative relationship between ASD symptoms and slower rate of change of infant severity while in the NICU provides rationale for the need to address parental mental health as part of medical treatment. The findings also showed that it is more important to address parental coping as well as psychopathology for parents in this population, since those were found to have the most significant relationship to infant health. Teaching parents healthier coping skills as well as addressing ways to decrease symptoms of ASD and depression may mitigate the negative relationships between psychopathology and infant health found in the present study. Future research investigating the use of an intervention (e.g., counseling services, coping skills workshops, parenting support groups) to address these parental needs during

the NICU stay is needed in order to further investigate the impacts of negative mental health on the course of infant health severity in the NICU. This lends more justification for the need to provide intervention in this population. While we do not know if the relationship between parental distress, well-being, and infant health severity is transactional, we do know that distress is related to changes in infant illness severity, and so is negative coping. An intervention that aims to teach parents more productive coping skills in an effort to not only impact their experience of distress during the whole NICU stay, but also impact the infant's health progress, could be beneficial for parents of infants in the NICU.

CHAPTER FIVE

NICU INFANT NEUROBEHAVIORAL HEALTH AND RELATIONSHIP TO PARENTAL MENTAL HEALTH

Introduction

Studies have indicated that the NICU experience is stressful for parents. As discussed earlier, previous studies by the author have found that in addition to stress, parents in the NICU exhibit a number of positive psychological attributes, which the literature has shown to be negatively related to psychopathology (Parker, 2014). The preceding studies of this dissertation found that some of these positive psychological attributes make the NICU experience less distressing and predict later experiences of NICU related parental distress. Additionally, similar to the author's preliminary investigations, poor mental health in NICU parents was found to be related to slower improvements in infant illness over the NICU stay (Parker, Xu, Neece, & Tagge, 2014a; Parker, Xu, Neece, & Tagge, 2014b).

As a result, the current study aimed to investigate specific aspects of infant illness that may be more directly related to parental mental health variables. The purpose of this final investigation was to explore the relationship between parental distress and well-being factors and their relation to specific infant health/functioning variables used to evaluate infant neurobehavioral status through the NICU Network Neurobehavioral Scale (NNNS). The investigation of parental mental health and infant neurobehavioral status is still in its infancy and thus further studies on this population are needed. Results lend more information on the specific immediate impacts of parent factors on infants in the NICU. The relationships between these variables can be used to inform the type of care

or services in the NICU, what is already in place that enhances these characteristics, and what types/targets of intervention would be helpful but are not yet in place.

Infant Neurobehavioral Health

During the neonatal period (first 28 days after birth), a neonate undergoes a series of milestones, which include abilities for interacting with the environment while maintaining internal stability also known as neurobehavioral organization (NBO; Bell, Lucas, & White-Traut, 2008). Internal stability is the foundation from which the neonate is able to socially interact and learn from the environment indicated by both neurological and behavioral assessment (Andre-Thomas & Anne Dargassies, 1960; Bell, Lucas, & White-Traut, 2008; Rosenblith, 1959). Researchers in the field of clinical psychology and developmental psychology established the foundation of our understanding of neonatal NBO. They recognized that infants are active participants in their own development, which is sculpted by sensory experience. As such, NBO occurs in a hierarchical manner as the infant's capacity for stability increases in a constantly changing environment. Researchers in the discipline of medicine (e.g. T. Berry Brazelton) emphasized the infant's neurologic integrity as the basis of NBO (Bell, Lucas, & White-Traut, 2008; Brazelton & Nugent, 1995). The attributes of NBO are defined as the capacity of the neonate to use goal-directed states of consciousness in reciprocal interaction with the caregiving environment to facilitate the emergence of differentiating, hierarchical, and coordinated neurobehavioral systems (Bell, Lucas, & White-Traut, 2008). Thus, according to this definition, maturation of NBO is evidenced by the neonate's ever-increasing resiliency and the capacity to learn from complex stimuli. Several disciplines

including nursing, developmental neurology and physiology, physical and occupational therapy, pediatrics, and developmental psychology study various aspects that compose neonatal neurobehavioral organization (NNBO). These areas include the measurement of sleep and alert states, breastfeeding behaviors, sucking parameters, movement patterns, event-related potentials of auditory stimulated brain activity and heart rate variability (deRegnier, 2005; Holdisth-Davis & Thoman, 1987; Majnemer & Snider, 2005; Porges, 2007; Radzyminksi, 2005; White-Traut et al., 2002).

The NICU Network Neurobehavioral Scale (NNNS; Lester & Tronick, 2004), is a standardized tool developed in order to examine neurologic integrity and behavioral function characteristic of NBO. It examines the neurobehavioral organization, neurological reflexes, and motor development of infants at risk. Risk as defined by the NNNS developers may be characterized as biological risks (e.g., prematurity, intrauterine growth restriction), medical risk (e.g., illness or injury at birth), or social risks (e.g., poor nutrition inadequate prenatal care, excessive maternal stress, poverty), which may have biological and neurobehavioral consequences for an infant (Boukydis, Bigsby, & Lester, 2004). The NNNS is applicable for assessing term normal healthy infants, infants at risk as a result of factors such as prenatal substance exposure, and preterm infants (Lester & Tronick, 2004). See Measures section for more details of the NNNS instrument.

Comparisons of Infant NNNS Performance

Studies have found differences in NBO as assessed by the NNNS in various groups of infants. Moraes Barros and colleagues (2008) focused on normal healthy infants and found that they displayed certain characteristics upon examination with the

NNNS specific to their group. In particular, normal healthy infants habituated to stimuli after 5-6 repetitions of exposure, displayed moderate spontaneous and reactive activity, were only occasionally irritable, were able to self soothe, and were easily comforted by examiners when distressed (Moraes Barros et al., 2008). Healthy infants were also constantly alert throughout the evaluation and attended to both visual and auditory stimuli (Moraes Barros et al., 2008). Lastly, Moraes Barros and associates (2008) found that healthy infants had no abnormal movements (e.g., tremors), muscle tone (i.e. hypotonicity, hypertonocity), or asymmetry in reflexes (e.g., one side of the body responding significantly stronger than the other). Pineda and colleagues (2013) focused on preterm infants and found that they have altered neurobehavior in a broad number of domains at term equivalent. More specifically, at term equivalent, preterm infants exhibited altered behavior compared to full-term infants, with poorer orientation, lower tolerance of handling, lower self-regulation, poorer reflexes, more stress, hypertonicity, hypotonia, and more excitability (Pineda et al., 2013). Researchers also found that cerebral injury altered neurobehavior but did not appear to impair early neurobehavioral changes as cerebral injury was associated with more excitability (Pineda et al., 2013). Preterm infants from 34 weeks gestation to term equivalent, demonstrated changes in motor functions with declining quality of movement, increasing hypertonia, decreasing hypotonia, and changes in behavior with increasing arousal, increasing excitability, and decreasing lethargy. Moreover, research has found that children prenatally exposed to cocaine score lower on the motor portion of the NNNS (Miller-Loncar et al., 2005). As such, the NNNS appears to be sensitive in assessing differences in NBO in differing types of infants.

Implications of NNNS Findings

Various studies have investigated the relation of NNNS scores to later development in children. A study of preterm infants showed that NNNS scores were related to brain volumes of white matter, basal ganglia, and total brain tissue and that impaired neurobehavioral findings on the NNNS were associated with decreased regional brain volumes (Brown et al., 2005; Brown et al., 2006). NNNS scores have also been found to be predictive of motor outcome on the Bayley scales at 24 months (Brown et al., 2006). Moreover, Miller-Loncar et al. (2005) found that motor scores on the NNNS were related motor outcomes at 18 months. Infants with a specific profile (poor attention that required extensive handling, poor regulation, were highly aroused and excitable, and exhibited poor quality of movement and a high number of stress signs) were more likely to show abnormalities between 2 and 4½ years on the Bayley Scales, behavior problems on the Child Behavior Checklist, deficits in school readiness, and low IQ (Lester et al., 2011). These findings are important because they suggest that infant neurobehavioral status in the NICU may be related to long-term neurobehavioral outcome. If our findings show that certain parental characteristics are associated with specific dimensions of the NNNS, interventions could be put in place to maximize the developmental outcome of NICU graduates.

Infant Neurobehavioral Status and Parental Variables

Research consistently shows that parental mental health impacts infant development. Research cited in the previous investigation showed that maternal distress was related to lower infant psychomotor, cognitive, and language development in the

years after birth (Cornish et al., 2005; Singer et al., 1999; Sohr-Preston & Scaramella, 2006). Infants of depressed mothers have also been shown to exhibit poor affect regulation, even after depressive symptoms have resolved (Cohn & Campbell, 1992). Additionally, infants of anxious mothers were found to exhibit less mature regulatory behaviors and have high cortisol reactivity compared to those of non-anxious mothers (Feldman et al., 2009). Additionally, the results of study 2 further supported these literature findings. Specifically, the results showed that parental depression and ASD symptoms are related to slower improvement in infant illness severity. In addition, less useful coping was also found to significantly moderate the course of infant severity over time.

Research has also started to investigate implications of parental well-being with regard to impact on infants, although research in the NICU population is limited. As stated in the previous chapters of this dissertation, parents who are high on self-efficacy have been shown to exhibit parenting behaviors that foster positive outcomes in children (Bohlin & Hagekull, 1987; Dumka et al., 1996; Izzo, Weiss, Shanahan, & Rodriguez-Brown, 2000; Shumow & Lomax, 2002). Recent successful interventions in the NICU aimed at decreasing length of stay have focused on increased parental involvement in infant care and individualized treatment (Als et al., 2003; McAnulty et al., 2010; Melnyk et al., 2006; Merrit, Pillers, & Prows, 2003; Ortenstrand et al., 2010). The goal of many of these interventions is to decrease parenting stress by enhancing parental self-efficacy (e.g., incorporating parents into their child's treatment and informing parents about what to expect in the NICU; Als et al., 2003; Altman et al., 1992; McAnulty et al., 2010; Melnyk et al., 2006; Merrit, Pillers, & Prows, 2003; Ortenstrand et al., 2010).

Researchers have begun to investigate the impact of such interventions on infant neurobehavioral status. Montirosso and colleagues (2012) found that infants at hospitals with more infant centered care (care involving parent involvement and other developmental interventions) evidenced higher attention and regulation, less excitability and hypotonicity, and lower stress/abstinence NNNS scores than infants from low care units. Based on the results of this study and assumptions of the epigenetic model, if certain aspects of parental well-being were related to infant improvements in neurobehavior, we would expect those parental variables to be related to more modulated and better organized neurobehavior. In other words, they should be related to less reactive, less stressed, less excitable and aroused infants that show better self-regulation and better attention.

The Current Study

In an effort to more directly understand the relationship between parental mental health and infant neurobehavior, the study examined the neurobehavioral characteristics of NICU infants in the LLU NICU as well as the relationship between parental mental health and infant neurobehavioral status using a variety of questionnaires assessing parental mental health and well-being. Toward this aim, the following hypotheses were investigated: (1) Infant neurobehavioral status in the LLU NICU population will exhibit more severe scores compared to the normative population, (2) Parental depression and ASD will be correlated with increased arousal, lower motor scores, and lower regulation scores on the NNNS, and (3) Parental well-being will be associated with less reactivity,

less stress, less excitability and arousal, high self-regulation and high attention scores on the NNNS.

Method

Additional Procedures

Before data collection on the NNNS was initiated, the director of NNNS training at Brown University, Lynne Andreozzi Fontaine, Ph.D., was flown out to LLU in order to train the NICU team. Six members of the NICU team were selected to be trained in NNNS administration and consisted of two NICU nurses, a NICU physical therapist, the NICU nursing supervisor, a NICU lactation specialist, and NICU developmental coordinator, all of whom possess an associates, registered nurse, or master's of science in nursing degree. Training was split over a six day period in May 2013, with three members trained on the first three days and the remaining three members trained on the last three days. Before training seminars began, an overview of the NNNS, its development, and its uses was presented. The training process consisted of an introductory session, in which the trainees observed the trainer administer and score the NNNS and then practiced with supervision by the trainer. The trainees then practiced on their own time and then were observed by the trainer for additional feedback. Some trainees worked in pairs, watching the trainer administer the NNNS, scoring alongside her, and then comparing scores. Trainees worked with 4-5 babies each day for 8-9 hours in order to achieve competence and reliability in scoring. In order for certification, reliability required that examiners must be within one point on items with ≥9 scoring options with no more than two two-point disagreements, which is 93% agreement. In

addition for items with 5 or fewer scale points, agreement had to be exact with no more than 5 disagreements (Lester & Tronick, 2004). At the end of training, reliability of scoring of each trainee was evaluated by having each trainee administer the NNNS with the NNNS trainer observing and then scoring the examination independently. At the end of the six day training, the NICU team was cleared for NNNS certification. Periodically, some members teamed up to discuss agreement on scores on a given exam.

In addition to the procedures discussed in Chapter Two, once parents consented to the study, the NNNS team was notified and a member was assigned to complete the NNNS assessment on the infant within one week of admission.

Additional Measures

Child Outcome Measures

NICU Network Neurobehavioral Scale (NNNS; Lester & Tronick, 2004)

The NNNS examines the neurobehavioral organization, neurological reflexes, and 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. The exam takes 20-30 minutes to administer and consists of 45 items requiring specific manipulation of the infant and 70 items based on observation of the infant throughout the exam. Scores were based on different ranges per scales, however for all items scores 95-99 were used to describe why the item was not administered or why an item was discontinued. The 115 item scores can be totaled into 13 summary scales calculated by generating the mean of the scores of the 7-13 items that make up each scale. It has been

shown to exhibit adequate reliability and validity for clinical utility and research (Lester & Tronick, 2004). Inter-rater reliability in the sample was adequate (.98). Summary scales of the measure are detailed below:

Habituation: the capacity of the infant to protect his or her sleep environment by progressively tuning out a stimulus after an initial response. Stimuli (e.g., bell, rattle) are presented over 10 trials. Items were scored on a 1-9 scale, with scores 5-9 reserved for infants who shut out their responses successfully. Higher scores are indicative of better (more rapid) habituation. Sample item: Response to rattle. Hold the rattle 12 inches from the infant and shake it briskly two times in succession.

Attention: infant's response to the auditory and visual stimulation. Stimuli (e.g., ball, rattle noise, examiner) are presented. Items were scored on a 1-9 scale. Higher scores show good turning and following when examiner tries to orient the child as well as sustained alertness. Low scores may reflect a low threshold for stimulation and physiological instability. Sample item: Orientation to ball. This measures the infant's ability to fixate on and follow a red ball.

Handling: describes the number and type of maneuvers necessary to keep the infant in the appropriate state for the orientation procedures, including handling needed to arouse the infant from a drowsy state. Items were rated based on presence or absence of the maneuver during the exam in order to keep the infant aroused. Higher scores indicate infants who need substantial input from the examiner to elicit orientation. Sample item: Use of auditory stimulation (voice or rattle)?

Quality of movement: measures motor control, including smoothness, maturity, modulation of movement of the arms and legs, startles and tremors. Most items are

scored on a 1-9 point scale. High scores mean good quality of movement—smooth movement with little or no tremors and average amounts of elicited motor activity. Sample item: Motor Maturity. This is based on the quality or form of spontaneous and elicited arm movements assessed throughout the examination. It assesses smoothness versus jerkiness, reflecting the balance between flexors and extensors, and unrestricted versus restricted range of movement.

Self regulation: combines physiologic, motor, and attentional activation with the ease or difficulty on the part of the examiner of soothing the infant. It also incorporates the infant's ability to self sooth. Infants are scored on a 1-9 point scale. Higher scores indicate better regulation. Sample item: Response to being held by examiner. Give infant a chance to initiate cuddling.

Non-optimal reflexes: the count of nonoptimal scores in terms of eliciting reflexes in the child with an optimal response. Most items are rated on a 1-4 point scale with 3 being the optimal response. Items are then recoded to reflect an optimal response (0) or a non-optimal response (1). Higher scores mean worrisome performance. Sample item: Babinski reflex. A scratch from the toes to the heel is applied to each foot and extension of the big toe and spreading of the small toes is expected.

Stress abstinence: count for stress/abstinence signs infant presented during exam. It is calculated using the proportion of the stress signs endorsed by the examiner. Higher scores are more worrisome. Sample item: Fuss or crying during orientation. (yes = 1, no = 0).

Arousal: infant's overall arousal during the exam. Items were rated on a 1-3, 1-6, or 1-9 scale. Higher scores indicate an infant who is easily aroused to fuss and cry during

the exam, predominantly fussing and crying during the exam, and highly active while being handled and while left alone. Sample item: Irritability. Count the number of specific items to which the infant responded to audible fussing or crying for 3 seconds or more.

Hypertonicity: increased muscle tone in the arms, legs and trunk. Consists of the count of items in which a hypertonic response was recorded. Higher scores describe an infant whose overall tone is consistently hypertonic—has increased tone in the arms, legs, trunk, and shoulders. Sample item: Truncal tone. Examiner flexes infant's trunk muscles by bringing the infant's head forward from lying position all the way to sitting position. Rating of 5 = hypertonic response, not able to flex infant.

Hypotonicity: measures decreased or low muscle tone. Consists of the count of items in which a hypotonic response was recorded. High scores mean that the infant was consistently hypotonic in arms, legs, trunk, neck, and shoulders during motor activity and during active and passive assessment of tone. Sample item: Truncal tone. Examiner flexes infant's trunk muscles by bringing the infant's head forward from lying position all the way to sitting position. Rating of 1 = hypotonic response, little or no tone is felt as infant is flexed.

Asymmetrical reflexes: counts the number of times that the reflex on one side of the body is stronger or weaker than the other side. Multiple asymmetries that are consistently detected on one side may represent a clinically significant finding.

Excitability: measure of high levels of motor, state, and physiological reactivity. It includes signs of stress such as color changes, startles and tremors. Counts the number of times resistance or non-optimal movements are scored during an item. High scores

identify infants who become irritable during the examination, as well as those who remain irritable despite repeated examiner attempts to soothe them. Example: Resistance to being held by examiner during the cuddle in arm assessment.

Lethargy: measure of low levels of motor, state, and physiologic reactivity. Identifies infants who are underaroused. Count of number of low excitability items endorsed during examination. Higher score is reflective of the examiner's efforts to bring the infant to a stable alert state and suggest need for careful review of medications being administered as well as infant sleep schedule. Example: Does not focus or follow stimulus during orientation to ball task.

Data Analysis Plan for Aim 3

Descriptive statistics on the NNNS summary scores were analyzed in order to gain a better understanding of the infant characteristics of LLU Medical Center's NICU. These scores were compared to the NNNS norms taken from a sample of healthy infants as well as a sample of prenatally exposed infants. Means and standard deviations taken from the healthy sample and drug exposed infant sample were used to calculate z-scores based on the means and standard deviations of the study sample. The normed healthy sample was used to compare the infants in the study sample to those who are performing age-appropriately. In addition, the cocaine exposed infant sample was also used as a comparison group as drug exposure alters fetal brain development and subsequent functioning and therefore provides a model for understanding multiple risk factors (e.g., prematurity, intrauterine growth retardation, poverty, lack of prenatal care, biological complications) that may affect infant functioning. As the NICU population is not

composed of an entirely homogenous sample (e.g., only preterm, only with a specific diagnosis) it was important for the study to characterize functioning in a broad way. Many of the infants in the NICU are at-risk for similar developmental deficits as those resulting from altered fetal brain development, and as such comparison to the cocaine-exposed sample was made in order to investigate how they differ.

Partial correlations were run in order to investigate the relationships between parental mental health variables and the summary scales of the NNNS controlling for the infant's health severity as measured by the NTISS.

At the end of data collection, 43 families of the larger sample had complete parent and infant data at time 1 and as such, only 43 families were included in the above analyses. Power calculations with regard to the use of correlations indicated that given the sample, the study had 9.86% power to detect a small effect size (.10), 52.15% for medium (.30), and 95.87% for large (.50).

Results

Infant Descriptive Statistics

Infants in the sample had a mean gestational age of 33 weeks (*SD* = 4.2), with 41.4% being female, a majority being classified as Caucasian (43.3%) and 30% Hispanic. Moreover, the average length of stay was 30 days (*SD* = 23) and 69% of infants were from the non-surgical population. Descriptive statistics of the infant sample's NNNS summary scores were analyzed (Table 36 and 37) and compared to the normative healthy infant and cocaine-exposed at-risk samples using z-scores.

Results indicated that overall compared to both the normative sample and cocaine-exposed sample, infants in this population did not score more than +/-1.96 standard deviations than either sample. When investigating scores further, results showed that infants in the study sample exhibited similar patterns of habituation, handling, arousal, regulation, excitability, lethargy, non-optimal reflexes, hypotonicity, and hypertonicity compared to healthy infants, all -1 < z-scores > 1. Compared to the at-risk sample, infants in this population exhibited similar patterns of habituation, regulation, quality of movement, excitability, non-optimal reflexes, asymmetric reflexes, hypotonicity, and hypertonicity, all -1 < z-scores > 1.

In contrast, there were several subscales on the NNNS where infants in the sample performed differently (+/- 1 standard deviations) compared to the normative healthy infant population. More specifically, this infant sample showed lower attention (z = -1.53), stress/abstinence (z = -1.6), and asymmetric reflexes (z = -1.12) scores. In other words, infants in this sample were less responsive to visual and auditory stimuli (i.e., scored better than only 6.3% of the healthy sample with regard to attending to stimuli presented), showed less stress signs (lower scores mean better functioning; i.e., these infants scored in the top 5.5% compared to the healthy sample with regard to exhibiting distress during the exam), and less asymmetry with regard to reflexes compared to health infants (lower scores mean better functioning; i.e., infants scored in the top 6.3% of the healthy sample with regard to symmetry of reflexes). In addition, infants in the sample showed higher scores than the normative sample with regard to quality of movement (z = 1.19). The infants in the sample had better motor control (e.g. smoothness, maturity,

modulation of movement of the arms and legs, startles and tremors), scoring in the top 88.3% of infants in the healthy sample.

Infants in this sample also performed differently (+/- 1 standard deviations) compared to the at-risk sample on several subscales of the NNNS. Infants in the sample were less responsive to visual and auditory stimuli (attention z = -1.19), less active during the exam (arousal z = -1.32), needed less handling by the examiner to be calmed (handling z = -1.10), and showed less stress signs (stress/abstinences z = -1.22) than prenatally exposed, at-risk infants. More specifically, infants in this sample were less responsive to visual and auditory stimuli (i.e., scored better than only 12% of the at-risk sample with regard to attending to stimuli presented), less aroused to fuss and cry during the exam (lower scores mean better functioning; i.e., infants scored better than 90.7% of the at-risk sample with regard to arousal), needed less handling (lower scores mean better functioning; i.e., scored better than 86.4% of the at-risk sample), and showed less distress (lower scores mean better functioning; i.e., scored better than 88.9% of the at-risk sample). In contrast, the infants in the sample were more underaroused (lethargy z = 1.86) than the prenatally exposed sample (i.e., scored in the 96.9^{th} percentile compared to the at-risk sample with regard to being underaroused during the examination).

Table 38. *Descriptive Statistics for NNNS in Sample Compared to Normed Sample*

Variable	Sample					Normative Healthy Sample						
	N	M	SD	Min	Max	N	M	SD	Min	Max	z-score	%
Habituation	36	8.23	1.26	4	9	68	7.91	1.14	4	9	.28	61
Attention	43	3.71	1.28	1.14	7.29	66	5.3	1.04	2.75	7.57	-1.53	6.3
Arousal	43	3.48	.66	2.14	4.86	125	4.16	.81	2.17	5.86	-.84	20
Regulation	43	5.21	.76	3.86	7.08	97	5	.82	3.1	6.5	.26	60
Handling	36	.22	.16	0	.63	125	.27	.27	0	1	-.19	42.5
Quality of Movement	43	4.74	.55	2.5	5.5	125	3.81	.78	1.6	5.83	1.19	88.3
Excitability	43	2.16	2.17	0	10	125	4.23	2.43	0	10	-.85	19.8
Lethargy	43	6.91	2.72	0	12	125	6.32	3.24	0	12	.18	57.1
Non-Optimal Reflexes	43	5.51	2.33	1	10	125	4.32	1.73	0	9	.69	75.5
Asymmetric Reflexes	43	.44	.91	0	3	125	1.93	1.33	0	7	-1.12	13.1
Hypertonicity	43	.12	.45	0	2	125	.07	.26	0	1	.19	57.5
Hypotonicity	43	.7	1.1	0	5	125	.55	.76	0	3	.20	57.9
Stress/Abstinence	39	.07	.04	.02	.18	125	.15	.05	.02	.25	-1.6	5.5.

Table 39. *Descriptive Statistics for NNNS in Sample Compared to Cocaine Exposed Sample*

	Sample					Cocaine Exposed Sample						
Variable	N	M	SD	Min	Max	N	M	SD	Min	Max	z-score	%
Habituation	36	8.23	1.26	4	9	298	7.23	1.89	1	9	.53	70
Attention	43	3.71	1.28	1.14	7.29	1213	5.36	1.39	1.29	8.43	-1.19	12
Arousal	43	3.48	.66	2.14	4.86	1213	4.39	.69	2.43	6.67	-1.32	9.3
Regulation	43	5.21	.76	3.86	7.08	1213	5.05	.87	2.220	7.50	.18	57.1
Handling	36	.22	.16	0	.63	1213	.54	.29	0	1	-1.10	13.6
Quality of Movement	43	4.74	.55	2.5	5.5	1213	4.41	.77	1.20	6.20	.43	66.6
Excitability	43	2.16	2.17	0	10	1213	3.87	2.30	0	11	-.74	23
Lethargy	43	6.91	2.72	0	12	1213	3.24	1.97	0	11	1.86	96.9
Non-Optimal Reflexes	43	5.51	2.33	1	10	1213	4.62	2.14	0	12	.42	66.3
Asymmetric Reflexes	43	.44	.91	0	3	1213	.88	1.15	0	7	-.38	35.2
Hypertonicity	43	.12	.45	0	2	1213	.57	.95	0	8	-.47	31.9
Hypotonicity	43	.7	1.1	0	5	1213	.24	.57	0	5	.81	79.1
Stress/Abstinence	39	.07	.04	.02	.18	1213	.18	.09	0	.57	-1.22	11.1

Relationship to Parental Mental Health

Each of the summary scale scores on the NNNS was investigated in relation to negative aspects of parental mental health variables (e.g., stress, depression, acute stress) using partial correlations, which controlled for infant health severity as measured by the NTISS (Table 38 and 39). Results indicated that parent rating of total stress was significantly correlated with infant habituation ($r = .77$, $p < .01$), such that parents with higher endorsement of stress had infants who exhibited more rapid habituation. In addition, number of ASD symptoms endorsed and self-regulation were significantly correlated ($r = -.61$, $p < .05$), such that more symptoms of ASD were associated with more difficulty for the infants to self-regulate. All other relationships were not clinically significant ($p > .05$).

Relationships between parental positive well-being and NNNS summary scales were also investigated. The results revealed some significant relationships. More specifically, problem-focused coping was significantly related to habituation ($r = .72$, $p < .05$), such that higher parental use of problem-focused coping was associated with better ability of infants to habituate to novel stimuli. Emotion-focused coping was associated with lower number of non-optimal reflexes ($r = -.63$, $p < 0.05$) meaning that parents with higher endorsement of healthy coping strategies had infants who showed expected reflexes (e.g., expected Babinski reflex is that the infant's big toe will move upward and other toes fan out when the sole of the foot is stroked). Additionally, the positive relations subscale of the parental well-being measure was significantly correlated with handling ($r = -.67$, $p < .05$), such that higher parental endorsement of positive relations was related

to less need for the examiner to hold, calm, or make noise in order to get the infant ready to participate in a task. All other relationships were not significant ($p > .05$)

Table 40. *Correlations Between NNNS Subscales and Parent Variables*

Variables	Stress	Depression	ASD	COPE-Problem	COPE-Emotion	COPE-Less Useful	QOLI
1. Habituation	.77**	.45	.55	.72**	.33	.39	-.19
2. Attention	-.49	-.36	-.07	-.05	.09	-.23	.08
3. Arousal	.03	-.25	.18	.14	-.04	-.25	.06
4. Regulation	-.34	-.34	-.61*	.20	.19	-.23	.13
5. Handling	.21	-.17	-.02	.40	.09	.01	-.17
6. Quality of Movement	-.4	-.20	-.05	-.05	.07	-.06	.12
7. Excitability	.27	.03	.44	.14	-.20	-.03	-.13
8. Lethargy	.28	.40	-.12	-.10	-.05	.42	-.22
9. Non-Optimal Reflexes	-.41	.003	-.006	-.17	-.63*	.42	-.50
10. Asymmetric Reflexes	-.10	.00	.00	.05	-.30	.23	-.17
11. Hypertonicity	.22	.16	.09	-.53	-.34	.05	-.16
12. Hypotonicity	-.10	.18	.01	-.04	-.05	.46	-.10
13. Stress/Abstinence	.05	-.08	.10	-.53	-.34	.09	-.10

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

Table 41. *Correlations Between NNNS Subscales and Parent PWB Variables*

Variables	Self Acceptance	Positive Relations	Autonomy	Environmental Mastery	Purpose in Life	Personal Growth
1. Habituation	-.46	-.63	-.30	-.52	-.49	-.36
2. Attention	.22	.21	.42	.12	.30	-.07
3. Arousal	-.15	-.32	.36	-.15	.11	-.52
4. Regulation	.50	.16	.44	.33	.51	.55
5. Handling	-.24	-.67*	.13	-.43	-.05	-.56
6. Quality of Movement	.34	.03	.03	.13	.29	.24
7. Excitability	-.48	-.50	.04	-.43	-.29	-.65
8. Lethargy	-.26	-.16	-.43	.18	-.33	.31
9. Non-Optimal Reflexes	-.18	-.18	-.35	-.29	-.34	-.12
10. Asymmetric Reflexes	-.26	.08	.00	-.16	-.30	.03
11. Hypertonicity	-.51	-.04	-.24	-.23	-.35	-.43
12. Hypotonicity	-.10	.04	-.39	-.08	-.25	.20
13. Stress/Abstinence	-.57	-.07	-.33	-.34	-.45	-.53

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

Discussion

The present study lends valuable information about the demographic characteristics of infants specific to the LLU NICU. Not only does the study replicate similar findings in the literature examining the performance of infants in at-risk populations (Lester & Tronick, 2004; Miller-Loncar et al., 2005; Pineda et al., 2013), but it also reveals valuable information about the resilience of infants in the LLU population as well as areas of functioning that could be targeted for early intervention. Moreover, results of the study are more generalizable as the LLU population is comprised of surgery and non-surgery children with a variety of diagnoses, which is more inclusive compared to the full-term and drug exposed normative samples. The current study showed that infants in this sample exhibited less attention than the normative sample, as predicted. This has implications to become problematic with regard to future ability to learn and retain information if not addressed early on. On the alternative side, infants in the study exhibited less stress, less asymmetry in reflexes and movements, and better quality of movement compared to the normative sample, which has positive implications for later fine motor and gross motor development. These findings suggest that while this at-risk population of infants has areas of difficulty compared to healthy infants, they also exhibit areas of resilience in that they are performing on par with the healthy population in several areas related to regulatory behaviors, alertness, and motor function (e.g., habituation, handling, self-regulation, lethargy, hypotonicity, and hypertonicity).

While infants in the sample performed poorer than healthy-term infants, as expected, comparison with a cocaine exposed sample was also made in order to better understand the strengths and weaknesses of the sample infants. Cocaine exposure alters

the development of an infant brain and later functioning, which provides a framework for understanding multiple risk factors that NICU infants may also exhibit. Many infants in the NICU may be admitted due to prematurity, intrauterine growth retardation, lack of prenatal care, and biological complications that affect brain functioning and later development. Comparison of the performance of infants in this sample to infants in a cocaine-exposed sample indicated that while infants in the NICU are at-risk for cognitive deficits and developmental delays, they exhibit better self-regulatory abilities (e.g., attention to new stimuli, able to be calmed quickly, less distressed), which are precursors to the development of executive functioning. Ability to self-regulate is linked to higher order executive skills needed for behavior regulation, planning, organizing, self-initiation, and self-monitoring. Lower attention, regulation, and higher distress scores in infants, especially those who have been prenatally exposed, have been linked to behavior problems, deficits in school readiness, and lower cognitive abilities in toddlers (Brown et al., 2006; Miller-Loncar et al., 2005). Future research should aim to investigate more in depth correlates of the NNNS scales with later performance on the Bayley scales of development as well as performance on measures of cognitive intelligence and executive functioning skills. This would require a longitudinal study tracking performance of infants on the NNNS while in the NICU and at discharge, in addition to follow-up evaluations every 2 years in order to track the trajectory of cognitive development as well as implications of NNNS findings on cognitive performance throughout life.

Information from the NNNS not only provides information about the infant's early cognitive development, but it also informs medical treatment. NNNS scores can be used by medical professionals to enhance quality of care by targeting specific areas (e.g.,

muscle tone, control of movement) that are found to be difficult or problematic for each infant with the use of physical therapy. In addition, areas of weakness in an infant can be used to inform parents of ways to help their infant function. For example, if an infant is less able to habituate or fussy, a parent can create a space that has little noise and few stimulating objects. Moreover, the NNNS scales can be used by professionals to inform parents about an infant's cognitive development as well as provide recommendations in order to optimize functioning at a much earlier age/stage, much like how the Wechsler Scales of Intelligence or other neuropsychological measures are used to inform functioning.

Limitations of the study likely had an impact on explaining the resulting outcomes. Many parent variables were correlated with the 13 subscales of the NNNS, resulting in 169 total correlations being run. The low number of cases and multiple analyses decreases the power and increases the Type I error such it would be expected 8 findings to be significant just by chance. Results of the correlations indicated that only 5 correlations were found to be significant. Due to the high likelihood of Type I error, it is very likely that the 5 significant relationships found in the present study were due to chance. It was important to run all the correlation analyses because the researcher wanted to investigate which mental health factors (both positive and negative) were related to infant neurobehavioral status. Given that the NICU population has not been as widely investigated as other populations, and knowing this is one of the first studies to investigate neurobehavioral status (as measured by the NNNS) in relation to both parental mental health and well-being, the researcher did not want to limit the investigation to specific variables. While the limitations of the study increase the likelihood that some of

the results can be due to chance, it is still important to know about possible relationships between parent and infant health variables in an effort to gain a better understanding of this population.

Despite the limitations of the statistical analyses, the findings of this study lend valuable information about the relationship between parental mental health and infant neurobehavioral status. More specifically, parental acute stress may impact regulatory behaviors early in life, such as infant ability to attend to information. This study also had some interesting findings that a higher level of perceived stress in parents related to the NICU was associated with better infant ability to habituate. Habituation is indicative of learning from the environment and filtering out which information is important to attend to, which becomes increasingly important as a child grows and needs to pay attention in school. Research has found that impaired habituation abilities in children with attention deficit hyperactivity disorder contribute to off-task behavior and resulting behavior and learning difficulties (Barkley, 1997; Jansiewicz, Newschaffer, Denckla, & Mostofsky, 2004). Previous research would lead one to predict that the opposite results of the present study would be found, parental stress would be related to less habituation (de Weerth, Buitelaar, & Beijers, 2013) as prenatal stress and cortisol are related to altered infant cortisol responses to a stressor (O'Connor, Bergman, Sarkar, & Glover, 2013; Tollenaar, et al., 2011; Velders et al., 2012). The different results of this study could be explained by the ways that habituation was measured (e.g., response to light, response to rattle, response to bell). In addition, there are many constant sights and sounds in the NICU and it is possible that these infants have already been habituated to such stimuli. A future investigation should use different stimuli for habituation that are not similar to the

environment of a NICU, such as repeated exposure to a card with specific designs, in order to investigate if this study's results are replicated and infants with more stressed parents are in fact able to habituate faster.

On the alternative side, despite the fact that parental mental health may negatively impact infant neurobehavioral development, there is also evidence to show that positive psychology factors may also contribute to positive outcomes in their children. More specifically, inherent protective factors that these parents possess are related to better regulatory behaviors in infants such as habituation, lower non-optimal reflexes, and need for less handling in order to orient to the environment. Longitudinal research is warranted in order to investigate if these early relationships translate into child functioning later in life. A longitudinal study should follow neurobehavioral and neuropsychological performance of infants in the NICU throughout childhood in order to understand if parent well-being factors early in life that are related to better infant self-regulation and learning are still related as the child is older.

Results from this study are important because they shed light on an area of research that is still in its infancy and warrants further replication and generalization of results to other NICU populations. Information from the study is useful as it can inform parents about how their functioning can impact their infant's early development (e.g., behavior and cognitive regulatory activities), which impacts later cognitive functioning. Additionally, findings provide rationale for the importance of intervention in this population as parent mental health has implications for infant neurobehavior, which is indicative of cognitive functioning later in life. Future longitudinal research using the

NNNS is needed in order to further investigate the impacts of parental positive and negative mental health factors on long-term neurobehavioral functioning.

CHAPTER SIX

CONCLUSION

The results of this dissertation provide valuable information about a population that has not been extensively studied in the past. Numerous amounts of research have indicated that parents of NICU infants are highly distressed. However, less research has investigated positive psychological factors that may buffer the development of psychopathology from the related distress. The first investigation showed that specific well-being variables (i.e., personal growth, purpose in life, and environmental mastery) predicted change in depression and ASD symptoms over time. While studies have shown that parental mental health has implications for later child development, less is known about the more immediate impacts of parental mental health on earlier stages of life. The second investigation revealed that negative mental health variables were strongly related to the course of infant health compared to well-being factors and the third study provided information about parent factors that influence early stages of cognitive development.

The results of the investigations discussed above shed light on protective factors that mental health and healthcare professionals can utilize in order to improve the NICU experience and related impacts on these parents. More specifically, increasing parental sense of personal growth, purpose in life, and environmental mastery may decrease distress and the development of psychopathology in this population. In addition, information about more short-term (while in the NICU) impacts of parental mental health on childhood outcomes on infants in this population will further enrich our knowledge of the transactional relationships between parents and children. This investigation indicated that parental distress (e.g., ASD symptoms and depression) as well as negative coping

strategies have the strongest relationship to infant severity in the NICU. Moreover, parental distress and ASD symptoms are also strongly related to negative performance in neurobehavioral tasks. On the contrary, positive coping skills and positive relations were related to better neurobehavioral performance in infants. These findings can be used to help tailor interventions in order to better suit both parent and infant needs in the NICU. Targeting interventions towards diminishing experienced distress and psychopathology can positively impact the course of infant illness. In addition, interventions used to enhance positive psychological factors can positively impact infant neurobehavior performance in the NICU, which not only has positive implications for cognitive development but also for quicker discharge. Lastly, the findings of this research provide a stronger rationale for the importance of continued investigation into the mental health of parents in this population.

While this study provided significant contributions to the literature, there are also a number of limitations to the project's design. Currently, the study measures are only available in English, which means that the study was not able to include individuals from the larger Spanish speaking community to which Loma Linda University caters. In addition, many of the parents in the NICU did not live in the area and had multiple children at home, which made it difficult to follow the strict time constraints set for the project in order to collect valid data. Moreover, because the study had a limited number of staff as well as trained nurses on the NNNS, all of who have various other commitments, it was difficult to contact and enroll every child whose parents consented to participating in the project.

With regard to the study design, the researcher realizes that in choosing the data analyses one concern was elevated Type 1 error given the small sample size and number of statistical tests run. While it was planned to only investigate the PWB variables found to significantly impact psychopathology in the literature, it was decided that given a model of resilience is yet to be suggested in the NICU population, it would be important to investigate the effects of all PWB variables. Findings shed light on PWB variables that can be used for targeted intervention in this population to alleviate the distress related to the NICU experience. It is also recognized that the last proposed analyses likely required a larger sample size than the one analyzed, and as such this analysis may be underpowered. However, given the exploratory nature of the question about infant neurobehavior being related to variables of parental mental health and well-being, the effect size of this relationship is not clear and, thus, the anticipated power was difficult to estimate. Nevertheless, given the risk involved and likely impact of parental mental health factors on infant neurodevelopment, it was felt that this was important to investigate even with a limited sample size. This dissertation is the first investigation examining both parental psychopathology, well-being, and infant health and neurobehavior variables in conjunction and thus, this preliminary investigation, although underpowered still provided a multitude of contributions to the literature.

This study also contributes to the literature by using more in-depth measures than previous studies. In the past, infant illness has been investigated using singular measures of outcome such as length of stay, birth-weight, or gestational age (Gray et al., 1992). The NTISS measure used in this study combines various therapies that a child may receive in the NICU, thereby providing a more specific way of categorizing infant illness

severity. Additionally, the use of the NNNS measure provides important information about neurobehavioral status, which has not been investigated in relation to parental mental health and psychological well-being. Further longitudinal investigations can be used to investigate the direction of the relationship between parent and infant variables, in addition to studying the impact of targeted interventions on parents and their infants in the NICU.

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APPENDIX A

Q-Q PLOTS FOR NORMALITY OF NTISS MEASUREMENTS

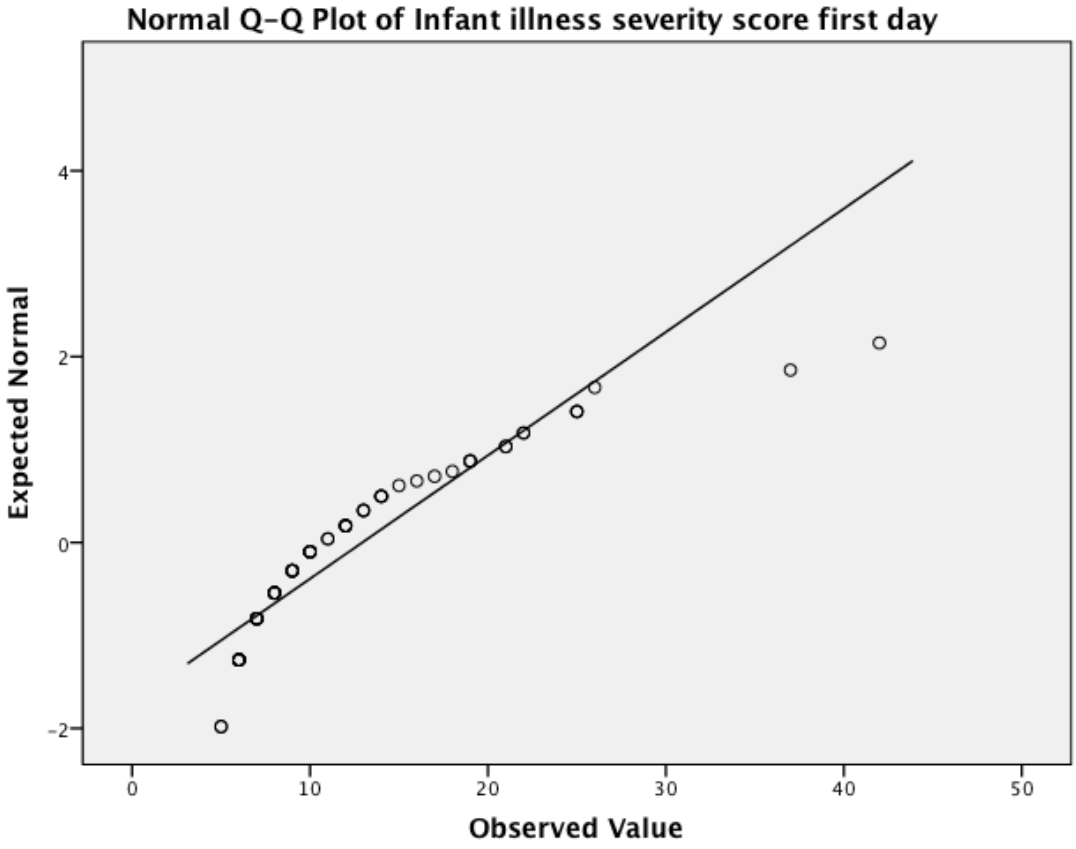

Figure 2. Q-Q Plot for Normality Test of Infant Illness Severity Score for Day 1

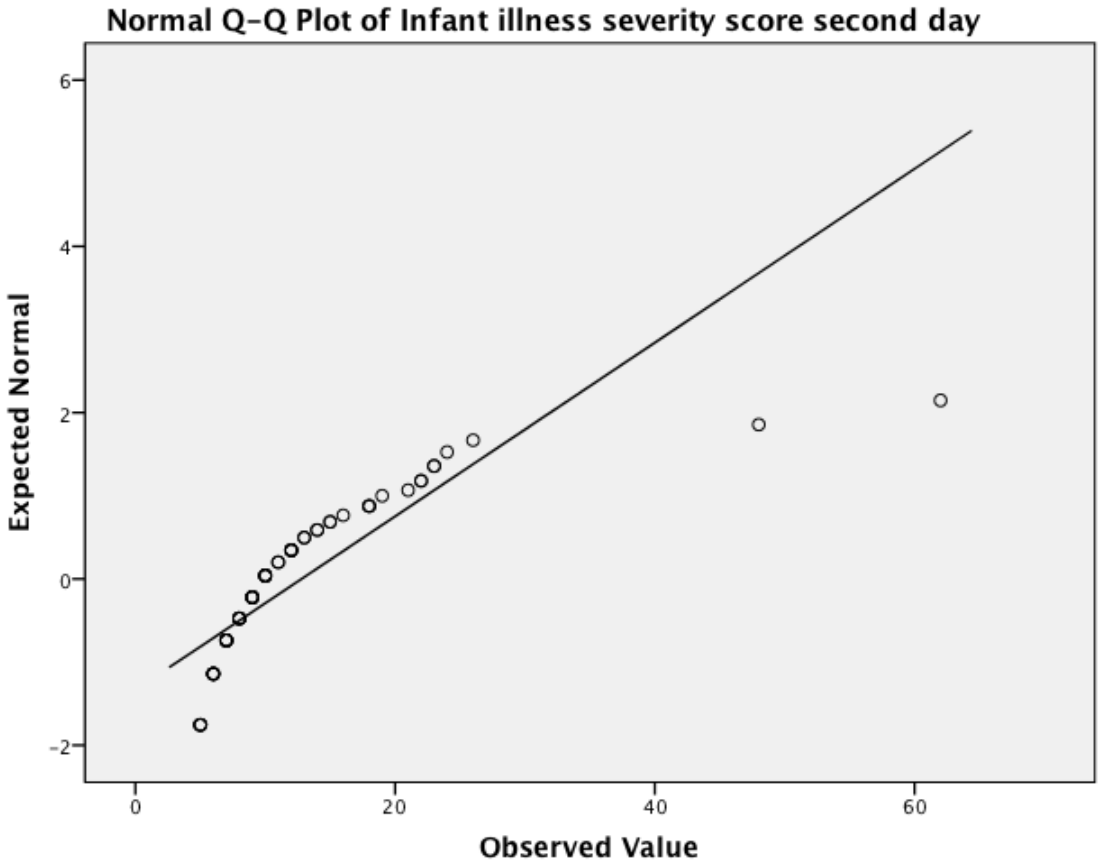

Figure 3. Q-Q Plot for Normality Test of Infant Illness Severity Score for Day 2

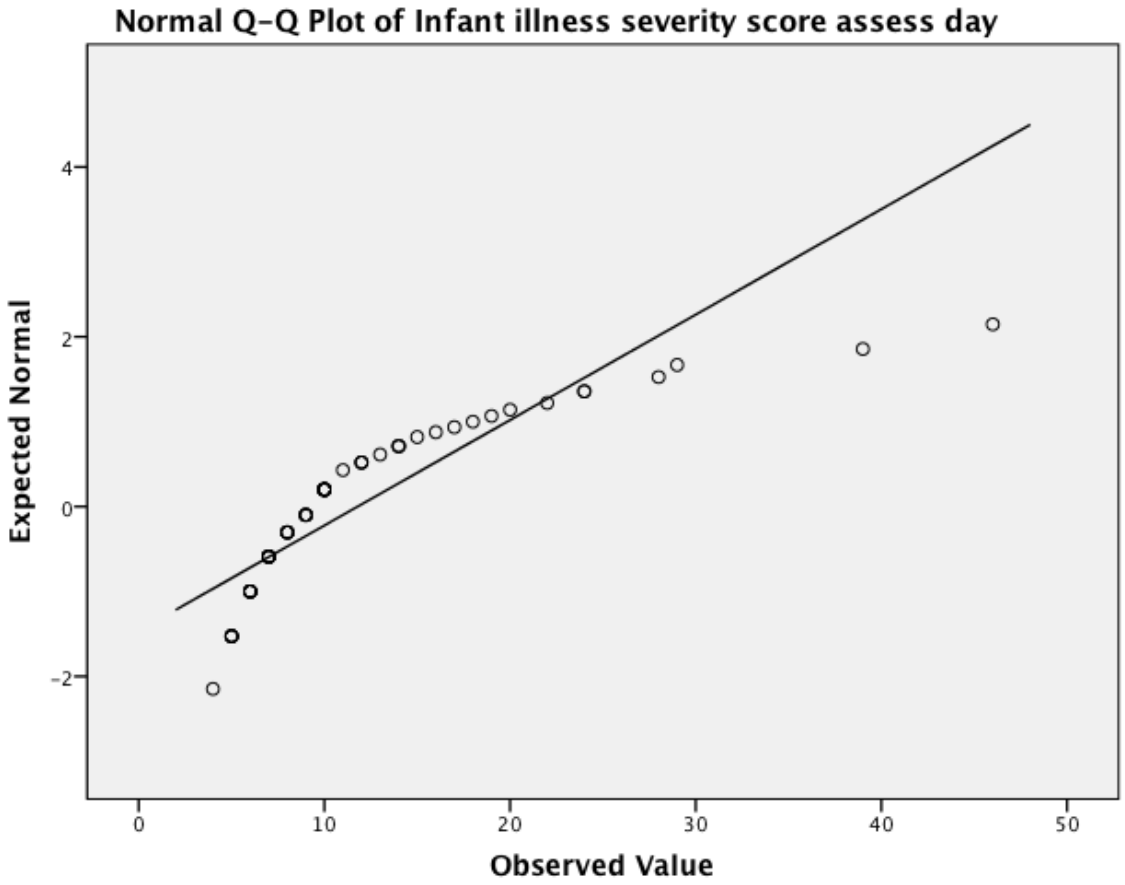

Figure 4. Q-Q Plot for Normality Test of Infant Illness Severity Score for Day 3

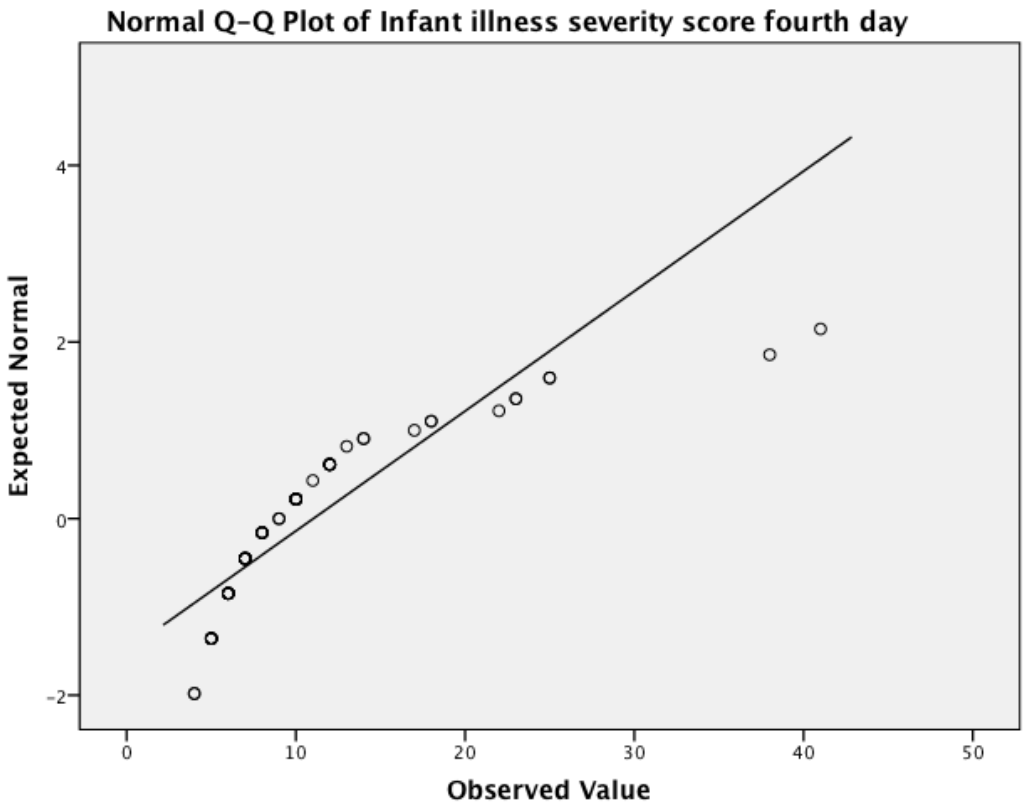

Figure 5. Q-Q Plot for Normality Test of Infant Illness Severity Score for Day 4

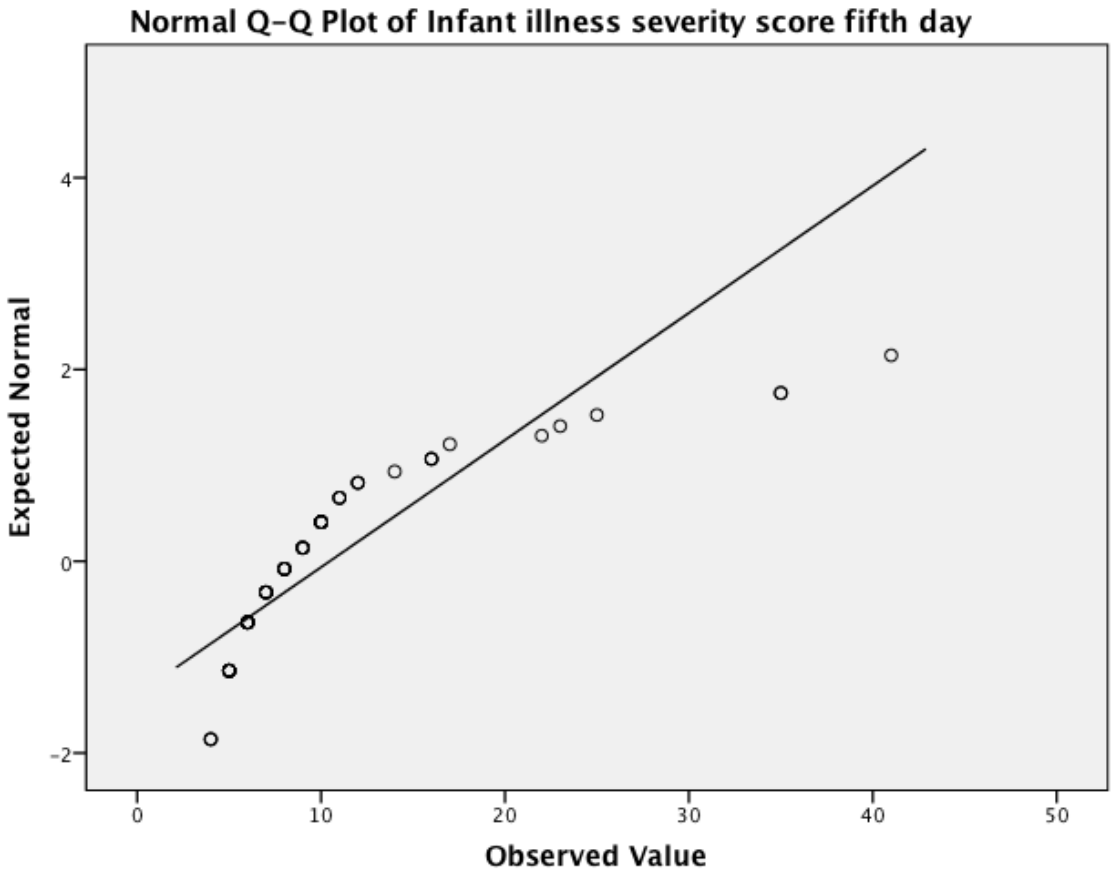

Figure 6. Q-Q Plot for Normality Test of Infant Illness Severity Score for Day 5

APPENDIX B

PARENT MEASURES

1. COPE
2. CES-D
3. SASQ
4. Psychological Well-Being Scales
5. 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 experienced	very rarely experienced	rarely experienced	sometimes experienced	often experienced	very often 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

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 more

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. _____oz.
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	
Mechanical ventilation[a]	3	yes		Volume expansion (>15 mL/kg)[c]	3	yes	no
Mechanical ventilation with muscle relaxation[a]	4	yes	no	Vasopressor administration (1 agent)[d]	2	yes	
Hight-frequency ventilation[a]	4	yes		Vasopressor administration (>1 agent)[d]	3	yes	no
Surfactant administration	1	yes	no	Cardiopulmonary resuscitation	4	yes	no
Endotracheal intubation	2	yes	no	Pacemaker on standby[e]	3	yes	
Tracheostomy care[b]	1	yes		Pacemaker used[e]	4	yes	no
Tracheostomy placement[b]	1	yes	no				
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	3	yes	no	Urinary catheter	1	yes	no
Treatment of metabolic acidosis	3	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	
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		Central venous line	2	yes	no
Multiple chest tubes in place[j]	3	yes	no				
Thoracentesis	3	yes	no				
Pericardial tube in place[l]	4	yes					
Pericardiocentesis[l]	4	yes	no				
Minor operation [k]	2	yes					
Major operation [k]	4	yes	no				

Clear

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

Superscript letters represent mutually exclusive variables.

Reference

Gray JE, Richardson DK et al. Neonatal Therapeutic Intervention Scoring System : a therapy-based severity-of-illness index. *Pediatrics*. 1992;90:561-7.