Master's Research Project

Parental Stress and Coping

in the Neonatal Intensive Care Unit

By

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ABSTRACT

TITLE: Parental Stress and Coping in the Neonatal Intensive Care Unit

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This purpose of this study was to identify stressors experienced by parents of both hospitalized premature and critically ill newborn infants, as well as to identify the coping strategies employed in response to the identified stressors. This study employed an exploratory, descriptive, correlational design. A convenience sample of 28 parents from a Neonatal Intensive Care Unit in a Pacific Northwest medical center was used. The majority of subjects were upper middle class, Caucasian families. Quantitative data was collected using the Family Information Questionnaire, the Parental Stressor Scale: Neonatal Intensive Care Unit, the Revised Ways of Coping Questionnaire, and chart review of the infant's record. Additional qualitative data was derived from three open-ended questions.

Overall, parents of both genders reported the most stress from their altered parental role. Mothers reported more stress from parental role while fathers reported more stress from the infant's behavior and appearance and the sights and sounds of the NICU. Parents reported using positive reappraisal and seeking social support as their primary coping strategies. Differences were found between gender of parents with mothers using more seeking social support and positive reappraisal and fathers using more planful

problem solving, distancing and self controlling. Parent were also placed in high and low stress groups, and problem-focused and emotion-focused groups for comparison. Parents in the high stress group used emotion-focused and problem-focused coping equally, while the parents in the low stress group used more emotion-focused coping strategies. The qualitative data provided depth to the parents responses and supported the findings from the questionnaires. Interventions are described that can decrease the experience of separation and foster parenting behaviors, as well as promote attachment and involvement in the infant's daily care. Finally, implications for nursing practice and recommendations for further research are summarized.

Table of Contents

List of Tables

List of Figures

CHAPTER 1

Introduction

Today, neonatology is a highly sophisticated, technologically advanced specialty. Historically, the tertiary or Level III nursery was developed in the 1950's to provide care to premature and sick newborns requiring some level of life support. Over the past decade, there has been a dramatic improvement in infant survival rates and reduction in their long-term sequelae of prematurity and critical illness. In 1995, there were approximately four million births. Of these, approximately 200,000-250,000 infants required care in the neonatal intensive care unit from prematurity, low birth weight (LBW), congenital anomalies, complications of delivery, or neonatal sepsis or infections (Goldson, 1992; Guyer, Strobino, Ventura, MacDorman, & Martin, 1996). Several risk factors have been associated with the incidence of premature birth and low birth weight infants. These factors have been identifed as maternal age (less than 18 years and greater than 35 years), race (African American), marital status (unmarried), low socioeconomic status as well as low level of education. While these risk factors are not always contributing, a strong correlation has been made with low socioneconomic status due to high maternal risk factors (smoking, inadequate prenatal care, maternal undernutrition, illness, and past history of adverse pregnancy outcomes) (Behrman & Shiono, 1997). These factors often contribute to the families risk for inadequate family functions (physical, emotional, and economic support).

Traditional family functions have evolved and changed with modern times yet continue to support the family unit in it's physical, emotional, spiritual and economic development. Contemporary family functions of today delineate the following principle

functions of the family: (a) economic, (b) reproductive, (c) protective, (d) passing on religious faith, (e) education and socialization of it's members, (f) healthcare, and (g) the development of relationship (Hanson & Boyd, 1996). Additionally, families experience changes in both power and roles as they assume their responsibilities of reproduction and socialization of children (Martell & Imle, 1996).

The transition from a beginning family (a married couple or dyad) to a childbearing family may precipitate a crisis under normal circumstances (Freidman & Miller, 1992). With the birth of a child, families must incorporate new roles and ways of interacting with one another. Jeffcoate, Humphrey and Lloyd note that the birth of an infant is a crisis, irrevocably altering family relationships (1979).

Parents experience significant stress with the birth of a premature or critically ill infant. This experience precipitates a crisis for the family associated with feelings of guilt, fear, anxiety and depression. The experience of having a premature or critically ill infant is unique in that parents are expecting to deliver a healthy, full-term infant that can interact, engage and be held. What parents receive, in contrast, is the infant—either too small and frail, or too critically ill to be held. Parents may experience a compromised sense of importance and competence in caring for their infant as health care professionals assume sole responsibility in caring for their critically ill infant. The stress experienced by parents of these infants significantly affects their ability to cope and adapt; additionally, it may inhibit their ability to successfully form an attachment with their infant. Early parental separation from the infant may delay the formation of the attachment bond between parent and infant, and could lead to less than optimal parent infant interaction. (Field, 1987;

Goldson, 1992; Jeffcoate, Humphrey & Lloyd, 1979; Kaplan & Mason, 1960; Plunkett, Meisels, Stiefel, Pasick & Roloff, 1986; Sroufe & Fleeson, 1986).

Most of the current research on families has been completed in the Pediatric Intensive Care Unit (PICU). Families with children in the PICU have had the opportunity to develop their relationships with one another, having well-established routines and communication patterns. The family with a premature or critically ill newborn infant hospitalized in the Neonatal Intensive Care Unit (NICU) have not yet had the opportunity to interact and develop a relationship with one another. Most research carried out in the NICU is retrospective in nature and may not give an accurate, realistic perspective of the initial reaction and coping strategies employed by parents of hospitalized newborn infants. It is the opinion of these researchers that information from the PICU research cannot be generalized to the NICU population.

Further research is needed to expand existing knowledge and understanding about families' experiences in the NICU. It is critical for members of the health care team to understand the values and beliefs of the families they care for. Without this understanding, members of the healthcare team may become a barrier to families as they move through the family process, attempting to bond and attach with their new infant. Nurses are in a pivotal position to assist families as they attempt to incorporate their new infant into their family, facilitating parental coping, adjustment and adaptation to this stressful situation. The 24 hour presence of nurses in the NICU suggests they have the most contact with families at a time when they are very vulnerable. The stress parents experience may impact their communication with health care professionals as well as their participation in their infant's care (Goldson, 1992).

The purpose of this study is to identify stressors experienced by parents of both hospitalized premature infants and critically ill newborns, and the coping strategies they employ in response to the identified stressors. The delivery of a premature infant leaves a family in turmoil. Parents need both time and support to grieve for the loss of their "fantasy" infant as well at what they thought parenting would be. Plunkett et al. (1985) note that parental feelings of guilt, uncertainty and ambivalence concerning their high risk infant makes them emotionally unavailable. Sammons and Lewis (1985a) found that with the turmoil and stress surrounding premature birth , it is important to facilitate parental coping in order to generate feelings of hope within the family. They note that generating this feeling of hope opens the door to emotional attachment between parent and child. Parents must be assisted in overcoming their need to distance themselves and disengage emotionally from their infant (Plunkett et al., 1985).

The findings from this research can assist caregivers in understanding what parents experience as stressful in the NICU and how they are coping with this stress. This understanding can facilitate the development of interventions to promote secure attachment between parent and child. Additionally, this understanding may also help caregivers assist families as they perform their principle family functions of relationship, socialization and healthcare.

Research Questions

The following research questions are addressed:

I. **What do parents identify as stressors during the experience of having a hospitalized premature infant or critically ill newborn?**

II. **What strategies do parents utilize to cope with the identified stressors?**

III. **Are there differences in how mothers and fathers cope with the same stressors?**

IV. **Do parents employ specific coping strategies in response to specific identified stressors?**

CHAPTER 2

Conceptual Framework

The purpose of this study was to identify stressors experienced by parents of both hospitalized premature infants and critically ill newborns, and the coping strategies they use in response to the identified stressors. Chapter two will summarize Lazarus and Folkman's phenomenological model of stress and coping (1984), and Miles and Carter's framework on parental stressors in the intensive care unit (1983), which provides the conceptual framework for this study. The concepts of stress, cognitive appraisal, coping and resources will be defined and discussed.

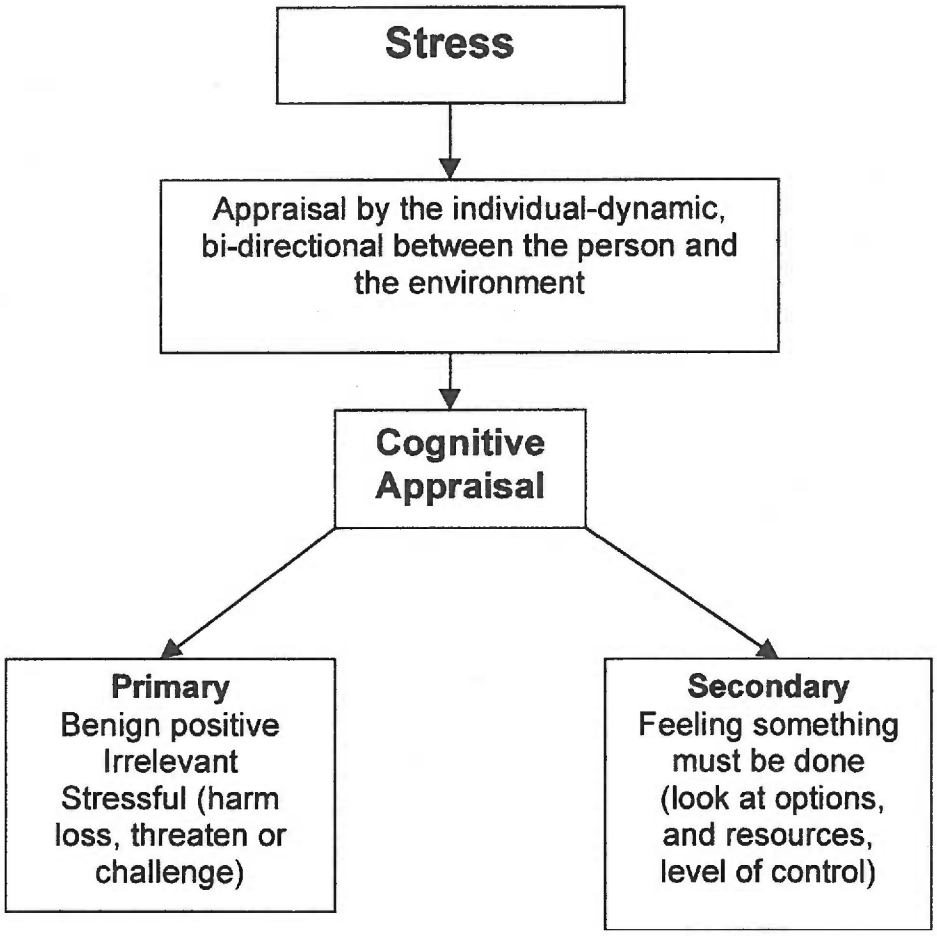
Lazarus and Folkman's Phenomenological Model of Stress and Coping

Psychological Stress

Lazarus and Folkman (1984) defined psychological stress as "a particular relationship between a person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being" (p. 19). This definition has two meanings in relation to the cognitive theory of stress: the first is that the person and the environment are in a constantly changing and dynamic relationship. The second is that this relationship is bi-directional with the person and the environment each acting on the other (Folkman, 1984). Recent developments in viewing this cognitive theory of stress have focused on stress as a subset of emotion. The stress emotions have been identified as the following: anger, anxiety, guilt, shame, sadness, envy, jealousy, and disgust, all of which arise out of conflict (Folkman & Lazarus, 1990; Lazarus, 1993). Stress is seen not merely as a response to environmental stressors but how those stressors

are construed by the individual. Personal meaning is an important aspect of psychological stress (Lazarus, 1993; See figure 1).

Figure 1: Cognitive Appraisal of Stress



Adapted from Lazarus R. S., and Folkman, S. (1984). Stress, Appraisal and Coping. (1 ed.). New York, New York: Springer Publishing Company.

Three major environmental stressors have been identified by Cohen and Lazarus (1979): (a) major changes effecting large numbers of people such as natural disasters or war, (b) major changes effecting small numbers of people such as the death of a loved one, being laid off, life threatening illness, or taking an exam, and (c) daily hassles which are

less traumatic and less stressful events of daily life, such as dealing with an inconsiderate smoker, having an argument with a spouse, or having too many responsibilities.

Cognitive Appraisal

In order for a stress response to be evoked in an individual, cognitive appraisal of the stressor must occur. Cognitive appraisal is based on an individual's subjective interpretation of the environmental event. It can occur continuously or discontinuously, either consciously or unconsciously. It is this evaluation of the environmental event that attaches both meaning and significance to it. Commitments and beliefs are personal factors that influence an individual's cognitive appraisal. Additionally, many situational factors also influence one's appraisal of the environmental event (for example, the predictability or uncertainty of the event, the imminence or duration of the event, timing, and ambiguity of the event). These differences in the personal and environmental variables may explain why an encounter may be appraised as a threat by one person and as neutral or a challenge by another (Folkman & Lazarus, 1990; Lazarus & Folkman,1984). The process of cognitive appraisal has been separated into two forms: primary appraisal and secondary appraisal (Lazarus & Folkman, 1984).

Primary Appraisal

Primary appraisal of a stressor can be either benign-positive (something that preserves well-being), irrelevant, or stressful. Stressful appraisals are further categorized as either harmful or pertaining to loss (some damage has already been sustained), threatening (harm or loss is anticipated), or challenging (involving feelings of anticipation, excitement and eagerness). The primary appraisal of harm/loss, threat and challenge are not necessarily mutually exclusive (Folkman, 1984; Lazarus & Folkman, 1984).

Secondary Appraisal

Secondary appraisal involves a feeling that something must be done about the situation, taking into account the coping options available and the likelihood that they can be accomplished (Folkman & Lazarus, 1990; Lazarus & Folkman, 1984). Secondary appraisal also includes the situational appraisal of control that changes as an encounter unfolds (Folkman, 1984).

Lazarus and Folkman (1984) note that primary and secondary appraisal are interdependent and influential on one another, together determining the degree of stress and emotional reaction that is perceived by the individual.

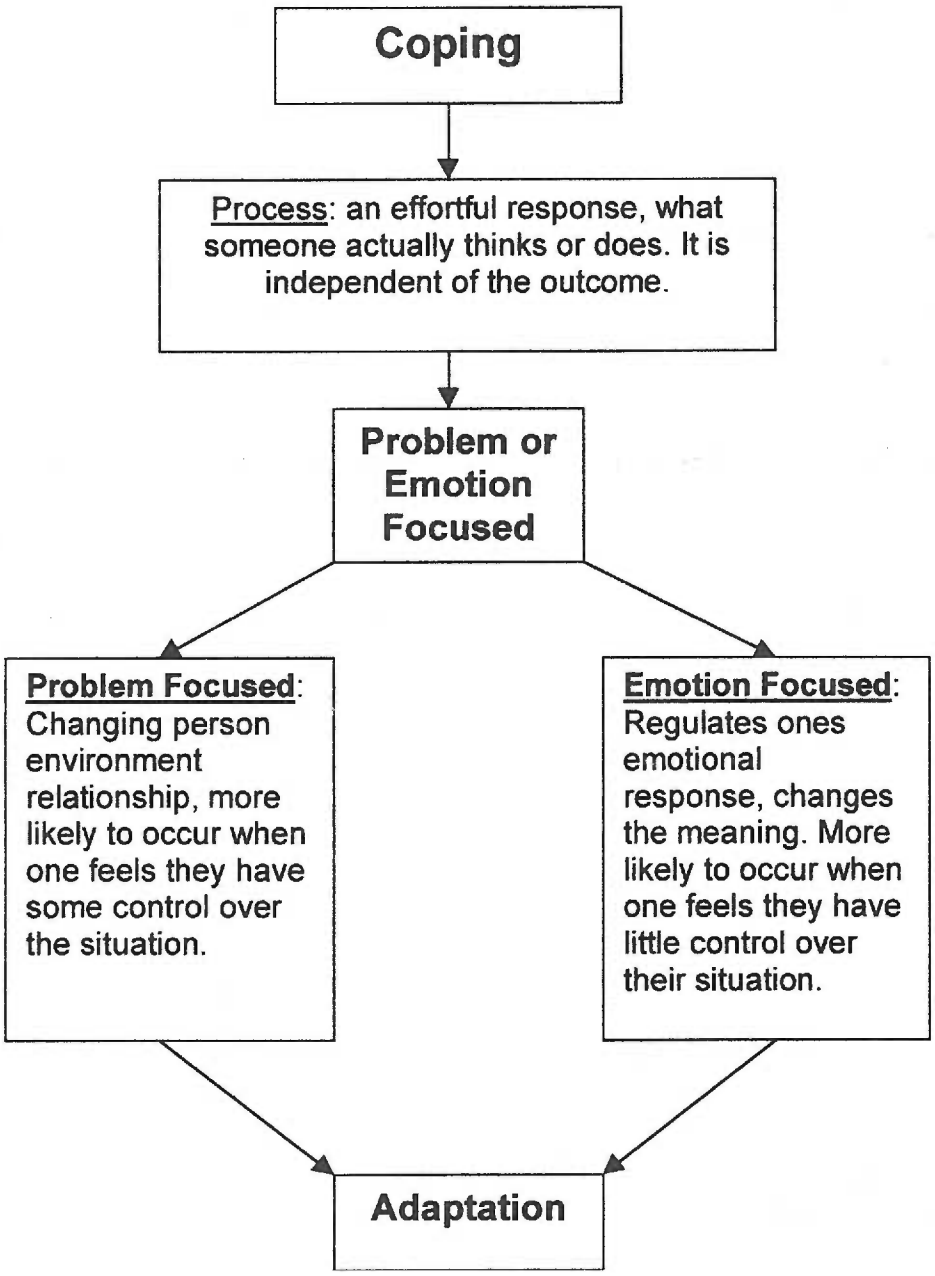
Coping

Coping is defined by Lazarus and Folkman (1984) as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person"(p. 141). Lazarus and Folkman further delineate that coping is a dynamic process, involving what a person actually thinks and does in response to their appraisal of the situation/stress, and that as a stressful encounter unfolds, there will be a change in how one copes with the situation. Coping is defined independent of the outcome of the stressful encounter (Folkman, 1984).

Coping is a process that involves an effortful response and is a subset of adaptational activities that involves effort and does not include everything that a person does to relate to the environment. Many behaviors are originally effortful and reflect coping, but become automatized and adaptive through the learning process. Adaptation is thus the return to a state of equilibrium and an incorporation of the coping behaviors into one's daily life (Lazarus & Folkman, 1984).

The process of coping encompasses the following three features: (a) observation and assessment of the coping strategies involved in what the person actually thinks and does, (b) what the person thinks or does is examined in a specific context, and (c) coping is a dynamic process. Furthermore, coping is a function of continuous appraisals and reappraisals of the person/environment relationship (Folkman, 1992; Folkman & Lazarus, 1990; Lazarus, 1993; and Lazarus & Folkman, 1984). Lazarus and Folkman (1984) identify two different types of coping: problem-focused coping and emotion-focused coping (See figure 2).

Figure 2: Problem-Focused and Emotion-Focused Coping



Adapted from Lazarus R. S., and Folkman, S. (1984). Stress, Appraisal and Coping. (1 ed.). New York, New York: Springer Publishing Company.

Problem-Focused Coping

Problem-focused coping is aimed at managing or altering the perceived problem. This type of coping usually involves changing the troubled person/environment relationship by acting on the environment or oneself (Lazarus, 1993). Problem-focused coping is most likely to occur when the situation is appraised as being amenable to change (Folkman, 1992; Folkman & Lazarus, 1990; Lazarus & Folkman, 1984). Problem-focused coping strategies are similar to problem-solving strategies, often directed at defining the problem, generating alternative solutions, weighing the alternatives, choosing among them and acting on them. Examples of problem-focused coping strategies are the following: information seeking, direct action, inhibition of action, defensive coping, magical thinking, and palliation (Lazarus & Folkman, 1984).

Emotion-Focused Coping

Emotion-focused coping is aimed at regulating ones emotional response to the problem. This type of coping usually involves either changing the way a stressful encounter with the environment is attended to or by changing the relational meaning of what is happening with the encounter (Folkman, 1984, 1992; Folkman & Lazarus, 1990; Lazarus, 1993). Emotion-focused coping is more likely to occur when the situation is appraised as being unchangeable, with little personal control over the situation (Folkman & Lazarus, 1990). Emotion-focused coping strategies can be used to maintain hope and optimism, deny fact and implication, to refuse to acknowledge the worst, and to act as if what happened didn't matter. Emotion-focused coping strategies diminish the threat that an individual perceives by changing the meaning of the event (this change in meaning is also known as cognitive reappraisal). Examples of emotion-focused coping are the

following: avoidance, minimization, distancing, selective attention, positive comparisons, and wresting positive value from negative events (Lazarus & Folkman, 1984).

Resources

Lastly, how an individual copes depends on the resources available to them. Major categories of resources available for use in times of stress are the following: physical resources (health and energy), psychological resources (positive beliefs), problem solving skills, social skills, social support and material resources (money, goods, and services). These resources are either readily available for use or attainable by the individual in times of stress. Lazarus and Folkman (1984) note that a resourceful person either has a multitude of resources available to them or is clever in finding ways of using them to counter demands.

Parental Stress in the Intensive Care Unit

Miles and Carter (1983) developed a conceptual framework for assessing parental stress in the intensive care unit. Their framework is based on their research and Selye's Stress Theory, Lazarus' Coping Theory, Roy's Nursing Theory, and Moos' Theory of Coping with Illness. They identified three areas as sources of stress for parents: personal and family background factors, situational considerations, and environmental stimuli. The parents life experiences, coping strategies, and self-esteem are examples of family and background factors. Situational considerations include the severity of the infant's illness and the amount of parental uncertainty associated with the illness and outcome. The environmental stimuli are sorted into categories which include the appearance of the infant, the sights and sounds in the unit, changes in parental roles, and staff communication and behavior patterns (Miles, Funk, & Carlson, 1993).

Response to Stressors

Miles and Carter (1983) describe responses to stressors as falling into three categories: cognitive appraisal of the situation, coping responses, and resources available. Parent's cognitive appraisals may be both positive or negative depending on their perception of the stressor. Coping behaviors are also affected by parent's perception of the meaning and power of the stressors.

Summary

In summary, coping is a dynamic process revolving around an individual's cognitive appraisal of an environmental event or stressor, and how they actually think or respond to that interpretation of the event or stressor. This chapter examined the conceptual framework of stress and coping developed by Lazarus and Folkman (1984). Additionally, Miles and Carter's (1983) conceptual framework of parental stress in the intensive care unit was summarized. The following concepts were described: psychological stress, cognitive appraisal, coping, both problem-focused and emotion-focused, and individual resources.

CHAPTER 3

Literature Review

A comprehensive review of the literature was done to assess the current and past research on parental stress and coping in the PICU and the NICU. Chapter three summarizes the key literature.

The critical care environment is recognized as being highly stressful for parents (Blackburn, 1982), as well as a barrier to the attachment process (Hummel & Eastman, 1991). It is also well documented and recognized that the experience of having a premature infant in the NICU is stressful for parents (Brooten et al., 1988; Hummel & Eastman, 1991; Miles, 1989). The following will summarize parental stress in both the PICU and the NICU.

Parental Stress

Pediatric Intensive Care

Miles and Carter developed the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) to assess the impact of specific environmental stressors on both the child and the family. Variables found to be stressful for parents revolve around six dimensions: (a) sights and sounds, (b) child's appearance, (c) child's behavior and emotional reaction, (d) procedures, (e) staff communication and behaviors, and (f) parental role revision. The child's behavior and emotional reaction was found to evoke the highest level of stress, followed by the child's appearance and parental role revision. Parents also report higher levels of stress from procedures when the admission was unplanned as opposed to a scheduled surgery or relapse from chronic illness (Carter, Miles, Buford & Hassanein, 1985).

Neonatal Intensive Care

Miles, Funk and Carlson (1983) developed the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU) to assess parental perceptions of stressors encountered during hospitalization in the NICU. Within the NICU experience, four dimensions were identified as stressful for parents: (a) child's appearance and behavior, (b) parental role alteration, (c) staff communication, and (d) sights and sounds of the NICU (Miles & Funk, 1991). Miles (1989) found that the appearance of the infant contributed the most significant degree of stress for parents followed by the altered parental role. Perhudoff (1990) found in her research with the PSS:NICU that mothers identified the altered parental role as most stressful whereas fathers identified the sights and sounds of the nursery as most stressful. In Shields-Poe and Pinelli's (1997) research on variables associated with parental stressors in the NICU, mothers again reported the altered parental role as most stressful and fathers reported equal stress from both the altered parental role and sights and sounds of the NICU. Additionally, there is evidence from Miles, Funk and Kasper's (1992) research with administering the PSS:NICU on two separate occasions, two weeks apart, that parent's level of stress decreased over time. With regard to the environment, both mothers and fathers reported more stress at T1 (first assessment) than at T2 (second assessment), they also reported more stress from the infant's appearance at T1 than at T2. Mothers notably reported more stress from the altered parental role than fathers. The findings from their research illustrates that what parents perceive as stressful changes over time and that there are differences between what mothers and fathers perceive as being most stressful. This has implications for all healthcare practitioners when individualizing a family's care.

Parental Coping

The following summarizes parental coping in both the PICU and the NICU. Helping parents to cope with the stressful experiences associated with hospitalization in the NICU is essential to their adjustment.

Parental Coping in the Pediatric Intensive Care

There is abundant research looking specifically at how parents cope with the experience of having a child in the PICU. LaMontagne, Hepworth, Johnson, and Deshpande (1992), using Lazarus and Folkman's Revised Ways of Coping Questionnaire, interviewed parents first at 24 to 48 hours post-admission, and again at 72 hours post-admission, and found that parents used problem-focused coping (seeking social support, planful problem solving, confrontation) and emotion-focused coping (positive reappraisal, self control, escape-avoidance, accepting responsibility, distancing) strategies almost equally. They did however, identify some differences in coping with regard to parental age, with older parents using more problem-focused coping strategies than younger parents, and younger parents using more emotion-focused strategies. Additionally, parents with higher anxiety levels, as measured by the State-Trait Anxiety Inventory, used more escape-avoidance and less problem solving strategies. Parents who used more emotional support activities were found to employ less distancing and escape-avoidance strategies (LaMontagne et al., 1992). LaMontagne and Pawlak (1990) found similar results in their study looking at stress and coping of parents in the PICU. They found the most frequently used coping strategies to be seeking social support (problem-focused) and positive reappraisal (emotion-focused). Overall, parents were found to use more emotion-focused strategies than problem-focused strategies.

Parental Coping in the Neonatal Intensive Care

Affleck, Tennen and Rowe (1991) conducted a longitudinal study attempting to predict parents psychological well being at six and eighteen months following discharge from the NICU. Using Lazarus and Folkman's (1984) stress and coping framework, they asked parents at discharge from the NICU what coping strategies they had used during their infants hospitalization. They found that parents reported using a combination of problem-focused and emotion-focused strategies: positive reappraisal, seeking social support, escape-avoidance, planful problem solving and distancing. When comparing mothers and fathers coping strategies, mothers used more escape avoidance and seeking social support than fathers. Fathers used more distancing and planful problem solving than mothers. They also found that when one spouse scored high on the relative use of distancing, seeking social support or positive reappraisal, the other spouse tended to score higher on the same coping strategy as well. Only one coping strategy predicted outcome six months after discharge. Mothers who used escape-avoidance coping strategies were more depressed and had less positive mood. Mothers who used positive reappraisal experienced fewer symptoms of psychological distress eighteen months after discharge. Positive reappraisal and seeking social support predicted more positive mood for mothers whose child had a subsequent developmental disability (Affleck &Tennen, 1991; Affleck, Tennen & Rowe, 1991).

Hughes, McCollum, Sheftel, and Sanchez (1994) conducted a study looking at how parents cope within their first three weeks in the NICU. They conducted their study in a large metropolitan level three NICU. Data were collected using a combination of open ended interview questions and the Revised Ways of Coping Questionnaire. Sixty-seven

families met eligibility criteria for the study with 52 percent agreeing to participate. Thirty-two mothers and 25 fathers (n = 57) completed interviews and questionnaires. Interviews were conducted within three weeks of admission, questionnaires were self reported. Parental coping strategies were first identified from the data with differences then separated out between mothers and fathers. Their findings identified the following coping strategies were used most frequently by parents: seeking social support and positive reappraisal. When parents were asked what additional strategies they had used, mothers identified "focusing on the infant" as an additional strategy. This strategy served to manage parental anxiety, reassuring themselves of their infant's health (p.11) Additionally, they found that mothers reported a larger variety of coping strategies (135) than fathers (70) (Hughes et al., 1994). Both mothers and fathers reported using positive reappraisal and seeking social support as coping strategies; however, their strategies diverged at that point with mothers using escape-avoidance more than fathers, and fathers using planful problem solving more than mothers.

Attachment

The birth of a premature or high risk infant leaves a family in turmoil. The parents expectations for the delivery of their child are shattered and the infant born to them is far from their expectations. The premature infant is oversensitive and tends to overreact to even small amounts of stimulation. Additionally, they are less alert and responsive than the full term infant (Sammons & Lewis, 1985a; Macey, Harmon & Easterbrooks, 1987). Many parents have concerns that due to the circumstances following their premature or high risk infants birth that they are missing out on the opportunity to attach and bond with their child. Klaus and Kennel (1982) note that while there is a sensitive period of

attachment immediately following birth, it is not a critical time and that all is not lost to the attachment and bonding process if this first contact is not made. In fact, attachment has overall been found to take longer with a premature infant. Because of the very characteristics of the premature infant (less responsive and alert, does not suck or interact positively) it takes more time for parent and child to be both readable and predictable to one another. This readability and predictability are precursors for the attachment process. However, before premature infants can begin to display the recognizable and pleasing social behaviors parents are seeking, such as smiles, gazing and alerting to their face, they must first recover from severe, often catastrophic illness (Sammons & Lewis, 1985b).

Attachment Disorder

Attachment is the end result of relationship building. It is an "enduring relationship between parent and child within which they can interact, positively and negatively, secure in the knowledge that their love will remain intact" (Sammons & Lewis, 1985b, p. 55). Infants who lack a consistent caring adult in their lives have the potential to develop attachment disorders, characterized by behavior problems (e.g. irritability), feeding problems (e.g. failure to thrive) and sometimes failure to progress medically or exacerbation's of current medical problems (Goodfriend, 1992). Field (1987) found that attachment disorders have been found to be more prevalent in premature infants. Her findings are further supported by a study done by Plunkett et al. (1988), where premature infants hospitalized for a period of greater than one month and who had some degree of respiratory illness, were found to display less than optimal attachment behaviors at two years of age. These infants demonstrated anxious-resistant attachments with the Ainsworth Strange Situation, suggestive that in the first year of life, their primary

caregiver had difficulty being consistent, sensitive and responsive to their needs. Infants need closeness, i.e. attachment, for reasons above and beyond the fulfillment of their physical needs (Plunkett et al., 1988). Premature infants must have consistent, caring adults, preferably their parents, to hold them, touch them and talk to them (Goodfriend, 1993).

Summary

From the review of the literature it is evident that the experience of having a premature or high risk infant is a stressful one for parents. The circumstances surrounding their delivery as well as the very characteristics of their premature infant place them at risk for attachment disorders. It is important for caregivers to facilitate parental coping with the stresses surrounding the intensive care experience to allow families to grieve for what will never be and to generate hope for what lies in the future.

However, there are limitations in the available research in understanding how parents cope with their infant's NICU hospitalization. The majority of the literature consists of retrospective studies looking at how parents coped with the hospitalization. When looking at data retrospectively, there may be a tendency to either under report or over intensify situations or responses. Additionally, there can be memory bias or information may have been selectively or inaccurately recalled. Hughes et al. (1994) was the only prospective study available looking at how parents coped with the NICU hospitalization. This research builds on the findings of Hughes et al. (1994) not only with regard to parental coping but with an additional correlation to the parental stressors experienced.

CHAPTER 4

Method

Chapter four provides a description of the methods used in this study. In order to indentify the stressors experienced by parents of both hospitalized premature infants and critically ill newborns, and the coping strategies they utilize in response to the identified stressors, a sample of parents with infants hospitalized in the neonatal intensive care unit were asked to participate in this study. Following consent, they completed the Parental Stressor Scale: Neonatal Intensive Care Unit, the Revised Ways of Coping questionnaire, and a family information questionnaire.

Design

An exploratory, descriptive, correlational design was used for this study. A descriptive study design allows for the observation, description, and documentation of aspects of situations as they naturally occur (Polit & Hungler, 1995). Thus, this design allows for identification of parental stressors and coping strategies employed during their infant's NICU hospitalization. Furthermore, a descriptive correlational design allows for the description of relationships between variables, which for this study is the relationship between stressors experienced and coping responses (Polit & Hungler, 1995).

Setting

This study was conducted in a 32-bed level III Neonatal Intensive Care Unit in a major medical center located in the Pacific Northwest. Neonatologists and neonatal nurse practitioners provide medical management of the infants within the NICU, with nursing care provided under a primary nursing model by an all RN staff. Parental visitation is

available 24-hours a day. The investigators of this study were employed as staff nurses at the medical center and gained access to the study population through that association.

Sample

A convenience sample was used for the study. The average admission rate for the NICU is 30-40 full term or premature infants per month allowing for ample sample size during a finite period of time. Study subjects were enrolled from October 24, 1997 through December 24, 1997. Parents of infants admitted to the NICU for a period of time greater than 24 hours and who met the following inclusion criteria were approached to participate: (a) infant admitted to the neonatology medical service, (b) parents 18 years of age or older, (c) parents spoke English, (d) parents could be married or single, and (e) parents signed informed consent to participate.

Parents were not excluded from participation on the basis of their infant's gestational age or severity of illness due to the fact that all parents with infants admitted to the NICU experience grief and loss for their healthy or full term infant. It is believed that all parents experience many of the same stressors, and therefore must employ coping strategies to deal with those stressors. Parents were not excluded if one member of the parental dyad declined or was unavailable to participate. The family defined its own members, anyone who provided support to the infant and/or the parents (Hanson & Boyd, 1996; McGrath & Conliffe-Torres, 1996). Non-English speaking parents were excluded due to language and cultural barriers.

Instrumentation

Data collection was accomplished using four instruments: (1) Family Information Questionnaire, (2) Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU), and

(3) The Revised Ways of Coping Questionnaire (Revised Ways of Coping), and (4) the Infant Subject Record. The variables measured by these instruments are presented in Table 1.

Family Information Questionnaire

The Family Information Questionnaire (FIQ) was developed by the investigators. This questionnaire collected information about subject age, marital status, education, socioeconomic level, previous experience in the NICU, number of children, and ethnicity. In addition to the above information, three open-ended questions were presented for self-report: (a) what has been the most stressful thing for you during this experience, (b) what are you doing to handle this stress, and (c) what has been most helpful to you (See Appendix A).

Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU)

The PSS:NICU (Miles & Carter, 1991) is a 46-item scale asking parents whether they have experienced a particular stressor or situation. The PSS:NICU addresses stress along three dimensions: infant behavior and appearance, parental role alteration, and sights and sounds of the NICU environment. Questions are concise statements regarding the appearance of the baby (presence of needles and wires, being on a ventilator, size of the premature infant), the nursery environment (monitor alarms, noise, bright lights), and the altered parent role (not being able to feed, hold their infant). A fourth dimension regarding staff communication was optional and not included in data analysis. Each item utilizes a five-point likert-like response scale ranging from one (not at all stressful) to five (extremely stressful).

Table 1: Measurement of Variables

Variables	Tools	Collected from whom
Demographics: Age Marital Status Education Income Number of Children Previous NICU experience Infant weight Infant gestational age	Family Information Questionnaire Infant Subject Record	Parents who consent to participate Chart Review
Parental Stressors: Infant Behavior and Appearance (13 items in scale) Parental Role Alteration (7 items in scale) Sights and Sounds (6 (items) Optional: Staff communications	Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU) (Miles, 1989)	Parents who consent to participate
Parental Coping Strategies: Problem Focused *Seeking Social Support (6 items) *Planful Problem Solving (6 items) *Confrontive (6 items) Emotion Focused *Positive Reappraisal (7 items) *Self Controlling (7 items) *Escape Avoidance (8 items) *Accepting Responsibility (4 items) *Distancing (6 items)	Revised Ways of Coping Questionnaire (Lazarus and Folkman, 1988)	Parents who consent to participate

Content validity of the PSS:NICU was established through a pilot study and expert review. Construct validity of the scale is evident with r = .44 and .41 for infant appearance, and r = .44 and .40 for parental role alterations. Factor analysis accounted for 57.5% of the variance. The PSS:NICU demonstrates strong internal consistency with Cronbach's alpha coefficients of .94 and .89 for the entire scale and .73 to .92 for the three individual scales (Miles & Funk, 1991; See Appendix B). The PSS:NICU was selected because it is the only established tool for assessing what parents perceive as stressful in the NICU.

Revised Ways of Coping Questionnaire (Revised Ways of Coping)

The Revised Ways of Coping Questionnaire (Lazarus & Folkman, 1988) is a 66 item self report instrument asking the participants to identify how often they use a particular coping strategy. There are 66 coping strategies elicited from the questionnaire representing eight different types of coping: confrontive coping (aggression, hostility), distancing (detachment, minimization), self-controlling (regulating feelings and actions), seeking social support, accepting responsibility, escape-avoidance (wishful thinking, behavioral efforts to escape/avoid), planful problem solving and positive reappraisal (seeking meaning from situation, religious dimension) (See Table 2).

Table 2: Description of the Coping Scales

Confrontive Coping	Describes aggressive efforts to alter the situation and suggests some degree of hostility and risk-taking.
Distancing	Describes cognitive efforts to detach oneself and to minimize the significance of the situation.
Self-Controlling	Describes efforts to regulate ones feelings and actions.
Seeking Social Support	Describes efforts to seek informational support, tangible support, and emotional support.
Accepting Responsibility	Acknowledges ones own role in the problem with a concomitant theme of trying to put things right.
Escape-Avoidance	Describes wishful thinking and behavioral efforts to escape or avoid the problem. Items on this scale contrast with those on the distancing scale, which suggest detachment.
Planful Problem Solving	Describes deliberate problem focused efforts to alter the situation, coupled with an analytic approach to solving the problem.
Positive Reappraisal	Describes efforts to create positive meaning by focusing on personal growth. It also has a religious dimension.

Folkman, S., & Lazarus, R. S. (1988). Revised Ways of Coping Questionnaire sampler set (p. 11). Palo Alto, CA: Mind Garden Press.

Each item uses a four-point likert-like response scale ranging from zero (not used) to three (used a great deal). Construct validity for the tool has been established using repeated factor analysis deriving very similar factor loading patterns. Factor analysis was done with eight scales accounting for 46.2 percent of the variance. The eight scales represent the eight different types of coping: (a) confrontive coping, r = 0.30-0.70, b) distancing, r = 0.25-0.55, c) self-controlling, r = 0.28-0.55, d) seeking social support, r = 0.45-0.73, e) accepting responsibility, r = 0.39-0.71, f) escape-avoidance, r = 0.36-0.66, g) planful problem solving, r = 0.38-0.71, and h) positive reappraisal, r = 0.43-0.79. Internal consistency for the eight scales ranges from 0.61 to 0.79 (Folkman, Lazarus, Dunkel-Schetter, Delongis, & Gruen, 1986). The Revised Ways of Coping questionnaire is a classic for identifying coping strategies employed by individuals during times of stress (See Appendix C).

Infant Subject Record

After obtaining informed consent and distribution of the questionnaires, the investigators collected data from the infant's chart. Information was collected on the infant's weight and gestational age, as well as maternal gravity and parity from the medical record (See Appendix D).

Procedures

The investigators checked the NICU admission log book daily for new admissions and determined if the infants met inclusion criteria for the study. Those parents of infants that met the inclusion criteria for the study were approached either in the NICU or in their patient room to participate in the study. This was done within 48 hours of their infant's admission to the NICU. After 48 hours, those parents not approached were excluded from

participating. All subjects who agreed to participate signed a consent form and were assured of their anonymity and confidentiality. Upon receipt of informed consent, the subjects were given the three data collection tools: (a) Family Information Questionnaire, (b) PSS:NICU, and (c) Revised Ways of Coping Questionnaire. Parents were asked to complete the questionnaires and return them in the sealed manila envelop provided. Parents who did not complete and return the questionnaires within one weeks time received one telephone call as a reminder. Parents were offered the opportunity to receive a copy of the study results upon its completion.

Protection of Human Subjects

Approval for this study was granted from Institutional Review Boards at both Oregon Health Sciences University and the medical center involved. Human subject protection was provided through participants informed consent. Subjects received a written explanation of the study as well as an explanation of risks and benefits of participation in the study. The signed informed consents were kept separate from the questionnaires to assure confidentiality. Anonymity was maintained by assigning an identification number to questionnaires. Participants were allowed to review questionnaires prior to committing to participate. Participation did not effect the care their infant received.

Data Management and Statistical Analysis

Following the process of data collection, sample characteristics were summarized inclusive of number of participants, participants' age, number of men, number of women, and gravity/parity. The findings of the PSS:NICU are presented using descriptive statistics and measures of central tendency. Mean scores, standard deviations and adjusted means

for the three dimensions of the PSS:NICU were computed and reported. Upon advisement of a consulting statistician, investigators used a median split to separate individuals into high stress and low stress grouping. Individuals whose scores fell above the mean were placed in the high stress group and individuals whose scores fell below the mean were placed in the low stress group. A T-test was on the three dimensions of the PSS:NICU to test for the significance in differences between mothers and fathers.

For the Revised Ways of Coping questionnaire, frequencies and percentage reporting were computed for the individual coping strategies identified in the scale. For each participant a relative score for the Revised Ways of Coping was computed indicating which of the eight types of coping strategies was used most often by the individual. The most prevalent coping style for the individual was then identified. Individuals were then grouped by their most prevalent coping style into either a problem-focused or emotion-focused coping category. Cross tabulation was then used to explore relationships between the low stress groups and the high stress groups on the three PSS:NICU dimensions and the coping category (problem-focused or emotion-focused).

Qualitative data was analyzed using content analysis. Content analysis allows for quantitative reporting of qualitative data in a systematic and objective manner (Polit & Hungler, 1995). Content was organized around central themes that emerged during analysis with frequencies reported. Additionally, statements reported by mothers and fathers are included.

CHAPTER 5

Results and Discussion

Chapter five summarizes the study sample characteristics for the parent population and their infants as well as quantitative data from the PSS: NICU, Revised Ways of Coping questionnaire, the infant subject record, and qualitative data from the Family Information Questionnaire. The findings of this study are organized around the four research questions presented in Chapter one: **I. What do parents identify as stressors during the experience of having a hospitalized premature infant or critically ill newborn ?, II. What strategies do parents utilize to cope with the identified stressors ?, III. Are there differences between how mothers and fathers cope with the same stressors ?, and IV. Do parents employ specific coping strategies in response to specific identified stressors ?.**

Study Sample

During data collection for the study, 95 infants were admitted to the NICU at a major medical center in the Pacific Northwest. Of those 95 infants admitted, 47 met study criteria. Parents of these infants were approached to participate in the study within the infant's first 48 hours of admission. Overall acceptance to participate was high with only one family refusing to participate. This family had an infant born with undiagnosed congenital anomalies and did not feel they could put the effort into filling out the questionnaires completely and adequately. Fifty parents of the 47 infants consented to participate in the study and were given study questionnaires to complete and return within one week. Data collection was carried out for 60 days with 29 of the 50 questionnaires being completed and turned in (58 percent). Of the 29 questionnaires returned, two

individuals had omitted the Revised Ways of Coping questionnaire and were excluded from the coping analysis. On examination of the FIQ responses for these individuals, it was noted that they were from low socioeconomic levels (less than $20,000/year) and may be classified as high risk. Additionally, one questionnaire was excluded from data analysis due to all responses being marked not applicable on both the PSS:NICU and the Revised Ways of Coping. On examination of his FIQ responses, he was noted to be a single, African American male. Investigators felt that this subject may have felt it was easier to consent than refuse, not wanting to be confrontative with his infant's caregivers. It is also possible that the questionnaires may not have captured his areas of stress or coping styles. Although missing data was excluded from analysis, these findings should serve as a signal to caregivers that these individuals are potentially at higher risk for inadequate coping and may need further assessment. A total of 28 questionnaires were analyzed for the PSS:NICU and 26 questionnaires were analyzed for the Revised Ways of Coping.

Sample Characteristics

Characteristics of the study sample are described using descriptive statistics. Information was collected using the family information questionnaire developed by the investigators. Included are sample characteristics of the parents and infants enrolled in the study.

Parent Sample

The sample recruited for the study was a convenience sample consisting of 17 women (61 %), ranging from 21 to 43 years in age (mean 29 years), and 11 men (39 %), ranging from 23 to 43 years in age (mean 31 years). The majority of subjects were Caucasian (n = 21, 75%), college educated (n = 21, 75%) and married (n = 25, 89 %) with

a household income of greater than $30,000 a year (n = 18, 69 %). Of the 29 questionnaires returned, seven mother and father dyads completed the questionnaires, ten mothers participated without their partners and four fathers participated without their partners. Seventy-five percent (n = 19) reported that this was not their first child; however, few reported having had previous NICU experience (n = 3, 11 %) (See Table 3).

While the characteristics of this sample are very different from the national demographics associated with premature birth and low birth weight infant's, it is an accurate representation of the population in the unit where this study was conducted.

Table 3: Demographic Data of Parent Sample

Demographic Variable	N = 28	Percent
Gender		
Men	11	39 %
Women	17	61 %
Total	28	100 %
Ethnicity		
Caucasian	21	75 %
Hispanic/Asian/African	4	14 %
Other	3	11 %
Total	28	100 %
Education		
High School	7	25 %
Some College	8	29 %
College/Grad. Degree	13	46 %
Total	28	100 %
Income		
$30,000 or less	8	29 %
$30,000 to $60,000	12	43 %
$60,000 or more	6	21 %
Missing data	2	7 %
Total	28	100 %
Marital Status		
Married	25	89 %
Single/Significant Other	3	11 %
Total	28	100 %
Age (in years)		
Men	range: 23-43	mean: 31
Women	range: 21-43	mean: 29
Previous NICU Experience		
Yes	3	11 %
No	25	89 %
Total	28	100 %
First Child		
Yes	7	25 %
No	19	68 %
Missing data	2	7 %
Total	28	100 %

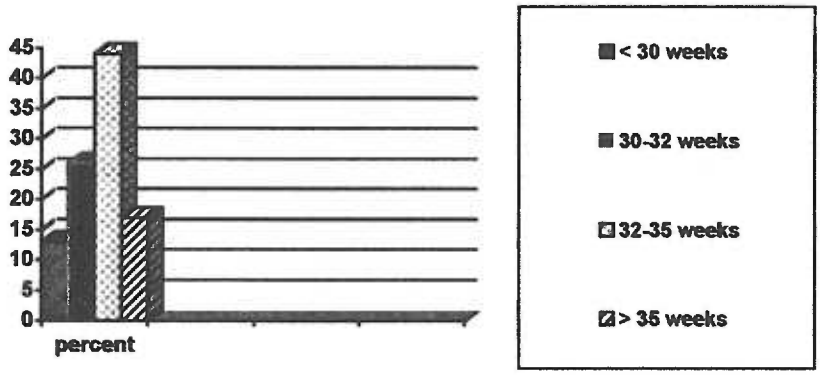
Infant Characteristics

There were 23 infants associated with the study sample of 29 parents. Seventeen of the infants were single birth infants, and six of the infants were from twin births (three sets of twins). Each set of twins contributed one set of parents to the study population. Most of the infants weighed less than 2500 grams (n = 18, 78 %), with a gestational age of less than 35 weeks (n = 19, 83 %) (See Table 4, Figure 3).

Table 4: Infant Characteristics

Birthweight	N= 23	Percent
< 1000 grams (less than 2 lbs.)	2	8 %
1000-1500 grams (2-3 lbs.)	5	22 %
1500-2500 grams (3-5.5 lbs.)	11	48 %
> 2500 grams (greater than 5.5 lbs.)	5	22 %
Total	23	100 %
Gestational Age	N= 23	Percent
< 30 weeks	3	13 %
30-32 weeks	6	26 %
32-35 weeks	10	44 %
> 35 weeks	4	17 %
Total	23	100 %

Figure 3: Infant Gestational Age



Major Findings and Discussion

The major findings from this study are addressed and discussed in order of the research questions posed in Chapter one. Descriptive data are presented from the PSS:NICU questionnaire and the Revised Ways of Coping questionnaire as well as qualitative data collected from the Family Information Questionnaire (FIQ).

Parental Stress

In order to address research question **I. What do parents identify as stressors during the experience of having a hospitalized premature infant or critically ill newborn?** quantitative data from the PSS:NICU will be presented. Additionally, qualitative data from the following open-ended question from the FIQ will be presented: "what has been most stressful for you during this experience".

Quantitative Data

Parents were asked to report on three of the four dimensions of stress on the PSS:NICU: 1) sights and sounds, 2) infant behavior and appearance, and 3) parental role alteration. The fourth dimension, staff communication, was optional and analysis was not done on the data received.

Descriptive statistics for the three dimensions analyzed on the PSS:NICU are presented. Additionally, since the number of items on the individual scales differed, an adjusted mean for the scale is presented (scale mean score) with a possible range of one to five, one signifying low stress and five signifying high stress. Scale mean scores on the sights and sounds scale were 1.99 (raw mean 11.96, range of 6 to 18, Standard Deviation (SD) 3.32). For infant behavior and appearance scale mean scores were 2.08 (raw mean

27.04, range 14 to 56, SD 9.18). Lastly, on parental role alteration scale mean scores were 2.98, (raw mean 20.89, range 10 to 35, SD 6.90).

Overall, parents reported having more stress from parental role alteration than either the infant's appearance or the sights and sounds of the NICU environment, as evidenced by the scale mean of 2.98. A possible explanation for this may be that with premature birth and the NICU experience, families experience separation and an alteration in their expectations about the birth experience. The infant often requires immediate medical care possibly delaying that first parental contact and involvement in the infant's care. Parents may have experienced less stress from the sights and sounds of the nursery due to the family centered approach in today's NICU experience. In the NICU where this study was conducted, nursery staff seem to be adept at orienting families to the equipment in the nursery as well as providing an aesthetically pleasing environment similar to that of a nursery at home. Additionally, parents often have the opportunity to experience a prenatal tour of the unit prior to delivery to become accustomed to the sights and sounds of the nursery. An alternative explanation as to why parents may have experienced less stress from infant behavior and appearance is due to the increased media attention to both hospital settings in general and exposure to premature infants; an example of this is the extensive media coverage of the septuplets recently born in Iowa.

When comparing mothers to fathers, mothers returned higher raw mean scores on parental role alteration (raw mean 21.47) than fathers (raw mean 20.00). Alternately, fathers scored higher raw mean scores than mothers on both sights and sounds (raw mean 12.73) and infant behavior and appearance (raw mean 27.91) (See Table 5).

Table 5: Descriptive Statistics/PSS: NICU Subscales

	Overall (n = 29)			Fathers (n = 11)		Mothers (n = 17)	
	Scale Mean	Raw Mean	SD	Raw Mean	SD	Raw Mean	SD
Sights and Sounds	1.99	11.96	3.32	12.27	3.29	11.76	3.42
Infant Behavior/Appearance	2.08	27.04	9.18	27.91	10.90	26.47	8.12
Parental Role Alteration	2.98	20.89	6.90	20.00	7.63	21.47	6.57

An independent sample t-test was done to examine differences between mothers and fathers along the three dimensions. For sights and sounds the t-value was .700, for infant behavior and appearance the t-value was .693, and for parental role alteration the t-value was .592. Based on these t-values investigators were unable to demonstrate statistically significant differences between men and women. This may be due to the small sample size of this study.

The literature supports these findings in that Miles, Funk and Kasper (1992), Perhudoff (1990), and Shield-Poe and Pinelli (1997) also reported that women experienced higher stress from parental role alteration than men. However, there is much variation in the literature surrounding differences between men and women. In contrast to our findings with men scoring higher than women on infant behavior and appearance and sights and sounds, Shield-Poe and Pinelli (1997) and Perhudoff (1990) reported that women scored higher than men on all dimensions. The findings from this study may differ possibly due to fathers being present immediately following delivery, often times during resuscitation and medical procedures. Mothers are usually unable to be present at that time due to recovery from labor and delivery. Before mothers make contact with their infant, sufficient time has usually passed to clean and stabilize the infant improving the infant's appearance. It is possible that women experience more stress from the altered parental role

due to their expectation for assuming total care and nurturing for their infant. Although fathers participate in these activities, it is central to the mother's role.

Individual items on the PSS:NICU questionnaire most frequently identified by parents to be very stressful or extremely stressful were the following: "being separated from my baby" (mean 4.04), "feeling helpless about how to help my baby during this time" (mean 3.32), "feeling helpless and unable to protect my baby from pain and painful procedures" (mean 3.14), and "sudden noises of monitor alarms"(mean 2.89). In the initial work done by Miles (1989), similar items were also reported as being most stressful for parents, specifically, separation for long periods, not knowing how to help, and unable to protect infant from pain (item wording was modified in 1991 by Miles and Funk; This modified tool was used in this study).

Qualitative Data

In addition to the PSS:NICU questionnaire to answer the research question: **I. What do parents identify as stressors during the experience of having a hospitalized premature infant or critically ill newborn?**, parents were asked to answer the following open ended question from the FIQ: "What has been most stressful for you during this experience." This question allowed parents to identify additional stressors that may not have been covered by the items on the PSS:NICU.

Twenty-five of the 28 subjects responded to this question. Content analysis was completed by investigators to determine recurrent themes, with more than one theme being present in some of the statements. When this occurred, statements were coded for both of the identified themes. Five themes emerged encompassing separation from the

infant (6 responses), infant's appearance (5 responses), uncertainty/the unknown (7 responses), travel (5 responses), and helplessness (5 responses).

Statements involving the theme of separation from the infant were "not having my baby with me", "being kept away from the baby", and "not being able to take the babies home with us". Statements involving the infants appearance were "how small he was when he was born", "hoses and tubing's being connected to infants body", and "seeing the baby medically reconfigured". Themes of uncertainty/the unknown emerged from the statements of "the unknown/having to wait and see what is wrong with the baby", "the unknown and not being able to take care of my baby", and "not knowing how he is progressing or what to expect". The theme of travel came from responses involving "going back and forth to the hospital everyday", "traveling to and from the hospital at 7 to 8 o'clock p.m." and "traveling back and forth 70 miles round trip". The final theme of helplessness came from statements of " feeling helpless, not being able to do anything to help his progress along", "not understanding or knowing what is normal, feeling useless", and "being in the hospital on bedrest".

After content analysis, the comprehensiveness of the PSS:NICU was evident with four of the five themes being represented by items on the PSS:NICU subscales. However, the additional information regarding travel is significant in that it seems to contribute highly to parental stress. Perhudoff (1990) also collected additional stressor information from parents. Similarly, she reported that living out of town and having uncertainty about the infants survival and future development were common themes.

Parental Coping

In order to address research question **II. What strategies do parents utilize to cope with the identified stressors?** quantitative data from the Revised Ways of Coping will be presented. The Revised Ways of Coping questionnaire assessed parental coping mechanisms used in response to the stress of having an infant hospitalized in the NICU. In addition qualitative data from an open-ended question from the FIQ will be presented: "what are you doing to handle this stress".

Quantitative Data

Descriptive statistics for the Revised Ways of Coping are now presented. Analysis of the data revealed a relative score for each of the eight types of coping represented on the questionnaire. The relative score is representative of how often the individual uses that particular type of coping (range 0 to 100 percent). On analysis, three subjects were found to have their primary coping strategy equally split between two of the eight individual coping strategies. When this occurred, the subject was given half representation (0.5) in both coping strategies. It was found that most parents reported using positive reappraisal (n = 10.5, 40.5 %) and seeking social support (n = 6.5, 25.0 %) as their primary coping strategy, followed by planful problem solving (n = 3.5, 13.5 %), distancing (n = 2, 7.7 %), self controlling (n = 1.5, 5.8 %), escape avoidance (n = 1.5, 5.8 %), and accepting responsibility (n = 0.5, 2 %).

It is substantially supported in the literature that parents used positive reappraisal and seeking social support as their top strategies. Affleck, Tennen and Rowe (1991) , Crnic et al. (1984) , Hughes et al. (1994), LaMontagne and Pawlak (1990) and Pederson, Bento, Chance, Evans, and Fox (1987) similarly reported that seeking social support and

positive reappraisal were parents top coping strategies. However, one should be cautious in generalizing this. The study samples were very homogenous comprised of individuals who based on their demographics have many resources available to them (married/significant other, income greater than $30,000/year, high school or college education). If the study were done on a more heterogeneous sample with both married and single families, high and low socioeconomic status and varying education levels, the findings may be different.

On the Revised Ways of Coping questionnaire, there are six items that represent confrontive coping. In this study, none of these items were reported as being used as a coping mechanism. Confrontive coping may imply that an individual feels they can aggressively change their current situation through their actions. It appears that confrontive coping is not commonly used in the healthcare setting as it involves some degree of control over one's situation. Confrontive coping may not be used in the healthcare setting due to the individual feeling vulnerable and powerless at the time, unable to take an aggressive approach with caregivers. Because of this Hughes et al. (1994) excluded confrontive coping from their analysis.

Qualitative Data

In addition to the Revised Ways of Coping questionnaire to answer research question **II. What strategies do parents utilize to cope with the identified stressors?**, parents were asked to respond to the following open-ended question from the FIQ: " What are you doing to handle this stress". This question was asked to allow subjects to identify coping strategies not represented by items on the Revised Ways of Coping questionnaire.

Twenty-five of the 28 subjects responded to this question. Content analysis was done to identify recurrent themes, however, more than one theme was present in some of the statements. When this occurred, statements were coded for both of the identified themes. Five themes emerged encompassing: spiritual strength (6 responses), positive thinking (6 responses), talking to family (3 responses), talking to nurses (3 responses), and being involved in the infant's care (8 responses).

Statements that involved the theme of spiritual strength were "trying to relax", "praying to God", and "trusting the Lord to get me through". Some statements regarding the theme of positive thinking were "trying to be as positive as possible", "thinking about eventually bringing my son home and that in the scheme of things a couple of weeks is not that bad", and "looking towards the future when this tough experience will be over". Statements that represented the theme of talking to family were "talking to my wife and relatives about this situation", "I talked to family and friends about the baby and how he is doing", and "talking to anyone who will listen or has opinions". The theme of talking to nurses was represented by statements such as " talking to nurses assures me everything will be okay", "asking the nurses questions", and "talking to the nurses makes everything seem okay". Lastly, the theme of being involved in the infants care was represented with statements regarding "doing what I can to make him more comfortable during his stay", "learning all about what needs to be done and following through with it", "visiting him often" and "trying to read information on premature babies".

Following content analysis, the identified themes closely correlated to the Revised Ways of Coping questionnaire with no new themes being identified. This supports the comprehensiveness of the Revised Ways of Coping Questionnaire.

Additionally, these qualitative themes supported the findings of positive reappraisal and seeking social support as being top strategies used by parents. Positive reappraisal according to Lazarus and Folkman (1988) describes "efforts to create positive meaning by focusing on personal growth including a religious dimension", supported by the themes of internal measures (prayer, relaxation, and trust in God) and positive thinking. Seeking social support describes efforts to "seek information, tangible support and emotional support" supported by the themes of talking to family/friends and nurses. Planful problem solving as defined by Lazarus and Folkman (1988) describes "deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem" supported by the theme of being involved in the infants care. Hughes et al. (1994) also reported that parents coped by "focusing on the infant" (p. 11), similar to these findings of planful problem solving being a top coping strategy. However, "focusing on the infant" involved active involvement with the infant as well as the development of an emotional bond.

Differences between mothers and fathers

In order to address the research question **III. "Are there differences in how mothers and fathers cope with the same stressors?"** a comparison was done between the relative coping scores of mothers and fathers from the Revised Ways of Coping Questionnaire.

It is evident in the literature that mothers and fathers use different coping strategies to handle the same stress. Differences between how mothers and fathers cope with having an infant in the NICU are now presented.

When looking at differences between mothers and fathers, mothers used seeking social support more often than fathers (mothers, n = 4.5, 69 %, fathers, n = 2, 31 %). Mothers also used positive reappraisal more often than fathers (mothers, n = 8, 76 %, fathers, n = 2.5, 24 %). Alternately, fathers used planful problem solving more often than mothers (fathers, n = 2, 57 %, mothers, n = 1.5, 43 %). Distancing and self-controlling were reported as being used only by fathers, consistent with the findings of Affleck, Tennen and Rowe (1991). Mothers were the only ones who reported using escape avoidance and accepting responsibility. These findings are supported by the work done by Affleck, Tennen and Rowe (1991), and Hughes et al. (1994) where mothers were reported as using more escape avoidance than fathers (See Table 6). For descriptions of the coping styles please refer to Table 2 (page 27).

Table 6: Summary of Coping Styles

	Overall		Fathers		Mothers	
	n=26	%	n=10	%	n=16	%
Confrontive	-	-	-	-	-	-
Distancing	2.0	8 %	2.0	100%	-	-
Self-controlling	1.5	5 %	1.5	100%	-	-
Seeking Social Support	6.5	25%	2.0	31 %	4.5	69 %
Accepting Responsibility	0.5	2 %	-	-	0.5	100%
Escape Avoidance	1.5	5 %	-	-	1.5	100%
Planful Problem Solving	3.5	14 %	2.0	57 %	1.5	43 %
Positive reappraisal	10.5	41 %	2.5	24 %	8.0	76 %

One of the sixteen mothers reported that accepting responsibility as her primary coping style. This may be representative of the mother's feelings of responsibility and acceptance of her own role with having an infant in the NICU. Two of 10 fathers reported that distancing was a coping style used to handle stress. This may represent the father's

differing role and perspective on the labor and delivery of their infant. From this study, it is evident that mothers and fathers cope in both similar and different ways with a stressful situation.

Coping in response to specific stressors

To address research question IV. **"Do parents employ specific coping in response to specific identified stressors?"** data from both the PSS:NICU and the Revised Ways of Coping Questionnaire were used to group parents by high stress or low stress and coping style (problem-focused or emotion-focused).

High stress versus low stress

After the findings from the PSS:NICU were analyzed, parents were placed in either a high stress or low stress group. This was determined using a median split placing those parents whose scores fell above the mean in the high stress group and those parents whose scores fell below the mean in the low stress group. A limitation of using the median split is that it is an artificial determination in which approximately half of the subjects will fall into each group. On the sights and sounds dimension, fourteen parents fell in the high stress group (54%) and twelve parents fell in the low stress (46 %) group. On infant behavior and appearance, fifteen parents fell in the high stress group (58%) and eleven parents fell in the low stress group (42%). Lastly, on parental role alteration, fourteen parents fell in the high stress group (54%) and twelve parents fell in the low stress group (46%).

Problem-focused versus emotion-focused coping

After analysis of the subjects relative coping styles, subjects were grouped by their primary coping strategy into one of two categories: 1) emotion-focused or 2) problem-

focused. Sixteen subjects were in the emotion-focused category (fathers, n = 6, mothers, n = 10, total n = 16, 61.5%) and ten subjects were in the problem-focused category (fathers, n = 4, mothers, n = 6, total n = 10, 38.5%). Three subjects reported that their primary coping strategy was equally split between two individual coping strategies. These two coping strategies were found to be in the same category, either emotion-focused or problem-focused and they were thus placed in their respective group.

Comparison of stress and coping

The comparison between high stress and low stress groups with the problem-focused or emotion-focused coping categories was carried out with cross tabulation. From this analysis, parents who experienced high stress on the sights and sounds dimension used problem-focused (n = 7) and emotion-focused (n = 7) coping equally. However, those parents in the low stress group used more emotion-focused (n = 9) coping than problem-focused (n = 3) coping. Parents who experienced high stress on infant behavior and appearance used slightly more emotion-focused (n = 8) coping than problem-focused (n = 7) coping. Parents who experienced low stress on infant behavior and appearance used more emotion-focused (n = 8) coping than problem-focused (n = 3) coping. Parents who experienced high stress on parental role alteration used more emotion-focused (n = 8) coping than problem-focused (n = 6) coping. Parents who experienced low stress on parental role alteration used more emotion-focused (n = 8) coping than problem-focused (n = 4) coping (See Table 7: Cross Tabulation).

Table 7: Cross Tabulation Table for PSS:NICU and Coping Style

	Coping Style	
PSS:NICU Dimension	Emotion-Focused	Problem-Focused
Sights and Sounds		
High	7	7
Low	9	3
Infant Behavior and Appearance		
High	8	7
Low	8	3
Parental Role Alteration		
High	8	6
Low	8	4

Parent with high stress were found to use problem-focused and emotion-focused coping almost equally, as Folkman and Lazarus (1985) noted that positive reappraisal (an emotion-focused coping strategy) facilitates the use of problem-focused coping strategies. It was also found that parents with low stress used more emotion-focused coping than problem-focused coping, possibly due to their appraisal of the situation as less stressful, and a subsequent decreased need to problem solve.

Another explanation for this may be that parents with low stress could have more personal energy for the use of emotion-focused coping strategies (positive reappraisal, accepting responsibility, distancing, escape avoidance, and self controlling). Conversely, parents with high stress may be so consumed by the sights and sounds of the nursery, their infant's appearance and their altered parental role that they must use active problem-focused coping strategies (seeking social support, planful problem solving, and confrontive coping).

A comparison was then done for items on the PSS:NICU that parents reported as being highly stressful and the two coping categories. With this analysis, some differences were found. Parents who scored high (greater than or equal to 4) in response to sudden noises, feeling helpless about helping their baby, and being separated reported using emotion-focused coping strategies. Conversely, parents who scored high (greater than or equal to 4) on the statement "feeling helpless and unable to protect my baby from pain and painful procedures", reported using problem-focused coping strategies.

Additional qualitative data

In addition to data collected on parental stress and coping, parents were asked to respond to a third open-ended question from the FIQ regarding "what has been most helpful to you". Twenty-five of the 28 subjects responded to this question. Content analysis was done by investigators to identify recurrent themes, however, more than one theme was present in some of the statements. When this occurred, statements were coded for both of the identified themes. Six themes emerged encompassing 1) understanding medical information and the plan of care (6 responses), 2) positive outlook (4 responses), 3) family support (5 responses), 4) support from staff (13 responses), 5) trust in God (2 responses), and 6) comfortable environment (3 responses).

The first theme of understanding medical information and the plan of care involved statements such as "knowing the technological knowledge", "knowing what would be going on all the time" and "the doctors and nurses answering my questions". Statements regarding the theme of positive outlook included "visualizing a positive outcome", "seeing baby grow and get better", and "knowing my husband was there for me in an emergency and that my family was so solid". The theme of family support involved statements of

"talking to each other", "gaining reassurance from my husband and my mother" and "family, friends and hospital staff". The theme of staff support was prominent with statements of " doctors and nurses have been great about answering my questions", "the nurses, they become part of your life and your babies", and "the nurses have all been exceptional and all so helpful". Trust in God was evident from statements of " the Lords peace" and "prayer". The final theme of a comfortable environment evolved from statements of " the parenting room being available", "guest housing" and "the NICU is a warm place".

Summary

In summary, the findings from this study support the current literature with regard to parental stress and coping in the NICU. Overall, parents reported the most stress from the altered parental role. When looking at gender, mothers were found to be more stessed by the altered parental role, and fathers were found to be more stressed by the sights and sounds of the NICU, as well as the infant's appearance and behavior. Parents most frequently used seeking social support and positive reappraisal as their primary coping strategy. Differences between how mothers and fathers cope is also supported in the current literature with mothers using seeking social support and positive reappraisal more than fathers, and fathers using planful problem solving more than mothers. Parents who fell in the high stress group used both problem-focused coping and emotion-focused coping equally, while those parents in the low stress group used more emotion-focused coping than problem-focused coping.

CHAPTER 6

Conclusions, Implications, Recommendations and Summary

Chapter six describes the major conclusions for this study, implications for practice, limitations of the study, and recommendations for further research. The major conclusions are organized around the four research questions presented in Chapter 1.

Major Conclusions

Despite technological advances in today's neonatal medicine, families continue to be impacted by the experience of having a premature or critically ill infant. Families experience stress from the NICU environment, their infant's appearance and most of all from their altered parental role. Additionally, mothers and fathers experience and cope with this stress in different ways. Nine conclusions were derived from the findings of this study and are presented.

Parental Stress

The findings from research question **I. What do parents identify as stressors during the experience of having a hospitalized premature or critically ill newborn?** contributed three major conclusions. First, families with a premature or critically ill infant in the NICU experienced stress from the NICU environment, the infant's appearance, and their altered parental role. Overall, parents experienced the most significant amount of stress from their altered parental role. During the course of the pregnancy, the mother and father have begun the transition from the beginning family to a childbearing family, incorporating their new role identities as parents. With the birth of a premature or critically ill infant, parents are not able to assume their new roles. During the hospitalization, healthcare practitioners assume the care of the infant creating an

environment in which parents can feel incompetent and unimportant. When parents are able to begin assuming the care of their infant, they often continue to feel inadequate in their caregiving role as they view the healthcare practitioner as the expert.

Second, parents also experienced stress from the NICU environment and the infant's behavior and appearance although at levels less than that of the parental role alteration. These findings are supported in the literature with overall less stress being reported from the environment and infant's appearance. It is possible that healthcare providers have overestimated the stress parents experience from these stressors. Stress from the environment was lower than expected possibly due to the increased visibility of the NICU environment in the media and the visually pleasing decor in today's family centered nurseries. Additionally, many families take a tour of the NICU prior to delivery gaining exposure to the appearance of a premature infant and the equipment and noises commonly present in the NICU.

Third, many pregnancies are complicated by infertility, advanced maternal age, and maternal medical complications (pregnancy induced hypertension, incompetent cervix, premature rupture of membranes, preterm labor). Because of these problems, many families may experience relief at birthing a viable infant irregardless of the potential medical complications associated with prematurity.

Parental Coping

The findings from research question **II. What strategies do parents utilize to cope with the identified stressors?** contributed two major conclusions. First, in response to having an infant in the NICU, families must cope with the experience in order to successfully adapt and allow the incorporation of their new infant into their family.

Overall, the two most prevalent coping styles reported were seeking social support and positive reappraisal.

Although the information derived from the quantitative questionnaire, The Revised Ways of Coping, was useful in understanding how parents cope with this experience, coping strategies more specific to the NICU experience came from qualitative data. When parents were asked what they were doing to cope with the NICU experience, parents most frequently reported that they were involved in their infant's care. This finding closely correlates to the primary source of stress being the altered parental role. Parents are involved with their infant's care at varying degrees during the hospitalization. Initially, parents gather general information about their infant and begin the process of knowing their infant's cues, behavior and personality. Mothers learn about breastfeeding and expression of breastmilk very early as this is central to their nurturing and caretaking role. As infants improve, parents begin to have a more direct role in their infant's care with diaper changes, feeding, skin to skin holding, providing clothes and blankets and giving baths.

Second, parents also reported that talking to extended family and nurses was central to their ability to cope, gaining the emotional support and nurturing that they need at this time. Additionally, family and friends often assumed the birthing family's basic functions by maintaining the home environment (cooking, cleaning, childcare for siblings). Talking with nurses also provides parents with the knowledge and understanding they need in order to better understand their infant's behaviors. Additionally, this informal education provides the basis for parents being able to read their infants cues and to respond predictably, thus promoting successful attachment. The communication also

facilitates the continuous reappraisal of the current situation (for example, how concerned they need to be about their infant).

Differences Between Mothers and Fathers

The findings from research question **III. Are there differences in how mothers and fathers cope with the same stressors?** contributed to one major conclusion regarding differences in how mothers and fathers cope with the same stressors. Mothers used seeking social support and positive reappraisal more often than fathers and fathers used planful problem solving more than mothers. These differences may be derived from the traditional family functions and sex roles. Mothers traditionally take on the primary caregiver role for the new infant with the father assuming the primary family provider role. As primary caregiver for the infant, mothers use seeking social support to locate tangible information and emotional support as they learn to care for their new infants within the NICU. This is done by learning about expression and storage of breastmilk, feeding their infant, and daily activity schedules (feeding times, baths, temperature taking, diapering). As primary provider, fathers use planful problem solving as they assume their role as provider for their infant and new family. They incorporate specific problem-focused activities such as bringing the mother to the NICU to see their infant, bringing breastmilk from home during the night for feeding, and taking information to the mother and family members immediately following delivery.

Coping in Response to Specific Stressors

Findings from research question **IV. Do parents employ specific coping strategies in response to specific identified stressors?** contributed one major conclusion. Parents overall used positive reappraisal as their primary coping strategy.

Interestingly, parents who had high stress used both problem-focused and emotion-focused coping almost equally for all three areas of stress. Conversely, it was found that those parents with low stress used more emotion-focused coping than problem-focused coping. This may be due to parents having the ability to use both problem-focused and emotion-focused coping as it is recognized in the literature that using positive reappraisal facilitates the use of problem-focused coping strategies. Those parents with low stress may have appraised their situation as less stressful, and subsequently had a decreased need to problem solve.

Additional Conclusions

Additionally there were three other conclusions from this study regarding participation, the instruments used in this study, and the conceptual framework on which it was based.

First, consideration should be given to those families who declined to participate and or failed to return the questionnaires. These families may have been so stressed by their experiences that they did not have the ability to respond to the questions or responded generically (not applicable) to all questions merely to participate. These families may actually be at higher risk for inadequate coping and should not be overlooked by healthcare providers.

Second, when both the quantitative and qualitative data were analyzed and compared with one another, there was strong support for both the validity and reliability of the established tools (PSS:NICU and Revised Ways of Coping). No new information was gained regarding stressors from the qualitative data as the PSS:NICU was specifically designed to target parental stressors in the NICU. However, while the Revised Ways of

Coping provided an overall general description of parental coping, it lacked specificity for the NICU. The information from the open ended question on coping elicited a more refined portrayal of how parents coped specifically with the stressors of the NICU.

Third, the findings from this study directly support and defend Lazarus and Folkman's stress and coping theory. The information gained from the research tools (PSS:NICU and Revised Ways of Coping) was internally consistent with the conceptual framework on which it was based.

Implications for Practice

This section summarizes three major implications for practice that evolved from the findings of this study. These implications involve incorporating the family as a whole into the infant's care, incorporation of the parental role and lastly the nursing role in facilitating parental coping.

Incorporation of the Family

Implications for incorporating the family as a whole into the infant's care are now described. Mothers and fathers should be viewed separately since no two parents experience stress or cope in the same way. However, the family as a whole needs to be considered as the parental dyad is only a small piece of the extended family unit that provides for the way that families function. Visitation in the NICU could be liberalized to allow for parents to surround themselves with their extended family and friends. This would allow for family and friends to gain insight into the stresses that parents are experiencing, possibly improving their ability to both empathize and provide support. Patient care conferences should also be structured to allow for the inclusion of extended family and friends to provide parents with a support system during the delivery of

oftentimes distressing news. While this may be more costly and time consuming for care providers, it does allow for families to support one another during times of stress.

Incorporation of the Parental Role

Implications for incorporation of the parental role are now described. From the findings of this study, it is evident that both mothers and fathers experience great stress from their altered parental role due to their inability to perform their family functions as parents (healthcare, socialization, economic, protective, relationship). Thus, it is imperative that nurses assist both mothers and fathers in finding ways to better "parent" in the NICU. This can be accomplished in many ways. First, a care philosophy can be adopted within the NICU that recognizes parents as very important people in the lives of their infants. Nurses traditionally control many aspects of the infant's daily care placing parents in a secondary role. Nurses can release part of this control, allowing parents to participate in many more aspects of their infant's care (change diapers, hold feedings, bring blankets and toys from home, pick out their infant's clothes). Second, parents can be involved in determining the schedule the infant feeds on and the timing of baths and rest periods. Third, parents can also be assisted in taking the role of advocate/protector for their infant, decreasing their feelings of helplessness and uselessness. This can be done by encouraging parents to urge caregivers to respect their infant's rest periods, encouraging handwashing before touching of their infant, and by requesting a primary nurse or consistent caregiver.

Beyond the daily care needs of their infant, parents should be encouraged and allowed to fulfill the loving and nurturing role they will continue to play in their infant's life. This can be accomplished by encouraging skin-to-skin holding, therapeutic touch and

infant massage, providing breast milk, and reading stories to the infant on tape to be played in the parents absence.

Lastly, nurses can be instrumental in facilitating feelings of mutual respect between parents and caregivers for the expertise of the other. While nurses are experts at giving technical care to the infant, parents are experts at loving and being a "parent" to their infant. Many parents can alert nurses to subtle differences in their infant's behavior (more apnea spells, poor feeding, more sleepy, not as interactive) allowing early detection of problems.

Mothers and fathers may have different expectations of their parental role. Traditionally, mothers have taken a more expressive role with direct provision of care (diapering, feeding) for their infant, while fathers have traditionally taken a more instrumental role, assuming responsibility for the care and well being of both mothers and infants. Based on these differences, mothers and fathers may need to be offered different ways to parent in the NICU. For example, both mothers and fathers can be encouraged to be involved in direct care activities (feeding, soothing, calming, skin-to-skin contact). Fathers who are more hesitant for hands on direct care can be encouraged to bring items from home (blankets, toys, pictures, breastmilk) allowing them to fulfill their role as provider.

Central to parental stress is the separation experienced while their infant is hospitalized. Parents need to have the opportunity to practice parenting their infant in a more homelike environment providing both comfort and privacy, yet with support from nursing staff. Nurseries should have adequate numbers of parenting (rooming-in) rooms as well as central family rooms where extended family and friends may visit, and siblings may

play and be active without disturbing the nursery. This promotes family unity, supporting and encouraging one another in their new role. To decrease the stress of long travel, hospitals could also provide housing facilities within close proximity (apartments, Ronald McDonald House, etc.) and at reasonable cost.

Through these interventions, nurses can help parents meet their physical and emotional needs, facilitating their successful coping and adaptation to a stressful situation and the development of an optimal attachment with their infant.

Nursing Role in Facilitating Parental Coping

Nurses play a valuable role in parental coping and adaptation to the NICU experience through their everyday communications. Nurses may underestimate the power of their conversations with families, and may view this interaction as purely social and friendly, rather than as a direct intervention. Through this therapeutic communication, nurses help families to redefine and reappraise their situation, allowing for the definition and attachment of both meaning and significance. Continuity of care is also central to this process, promoting the establishment of a trusting relationship between parents and caregivers, and allowing for an open exchange of information. Parents may feel more comfortable with disclosing personal information in such a relationship. Parents specifically need to be asked on a regular basis what they are finding as stressful, what they are having difficulty with, and what they are doing to handle their stress, since situations and needs change over time.

Limitations of the Study

There were five limitations of the study which are now presented. The first limitation addresses the small size of the sample. The small sample size limited

investigator's ability to demonstrate statistical significance and could be overcome by recruitment of a larger sample. The second limitation was the homogeneity of the sample. This study used a convenience sample collected from a private hospital in an urban area of the Pacific Northwest. The study sample was primarily comprised of individuals that were married, well educated and of an upper-middle socioeconomic status. The sample appeared to have more than average resources readily available to manage stress and to cope with the experience of having an infant in the NICU. This limitation impacts the generalizability of the study in that it would not be representative of a more diverse population, such as one found in an NICU in a rural or inner city hospital (i.e. low socioeconomic, single, teen parents, limited education, more diverse ethnic representation).

A third limitation was the infant sample in that data on infant morbidity was not collected. This was a limitation in that variations in parental stress level could not be accounted for based on varying degrees of infant morbidity. Additionally, it is possible that parents of more premature or critically ill infants may not have completed the questionnaires due to extreme stress levels. This finding should not be dismissed, but serve as an indicator for caregivers that these parents may need additional support.

The fourth limitation involved the fact that data was collected only during the infants initial hospitalization (within the first week). The literature documents that stress and coping with the NICU experience changes over time (LaMontagne et el. 1992; Miles, Funk & Kasper, 1992) and longitudinal data would be desirable.

A final limitation of this study is that it focused on mothers and fathers only, with other members of the extended family being excluded from data collection. This is a

limitation in that it discounts the impact this stressful situation has on the entire family unit, as the relationships within the family are so intricately woven that a change with one member inevitably effects all other members of the family. By narrowly focusing on mothers and fathers alone, the true impact on the family unit is lost.

Recommendations for Further Research

There were six recommendations for further research. The first four recommendations related to the study sample. First, further research would need to recruit a more diverse study sample possibly by using a multi-center approach capturing both rural and urban populations with mixed socioeconomic and culturally diverse populations. Second, teen parents are one subset of the population that has yet to be examined and could provide an enriching contrast to current information. Third, collecting data on infant morbidity would allow for the grouping of parents based on either high or low morbidity, possibly accounting for differences in stress levels and coping strategies of these parents. And fourth, if data collection was conducted at various times during the hospitalization, differences in coping in response to specific situational stressors (relapse, need for surgery, preparation for discharge) could be illustrated.

The fifth recommendation involves examining the family as a whole, as the unit-of-study. By doing so, the existing information on parental stress and coping would be enriched, allowing for the understanding of the family's changing role structure and the changing family functions in response to the current situation. This would also provide a more refined view of the role of the extended family in supporting parental attachment to the new infant (the assumption of basic family functions).

Sixth and finally, a comparison study assessing parental stress and coping could be conducted between families with a newborn infant requiring intensive care and families with a healthy newborn infant newly discharged to home. Inherent in the NICU is an assumption that the environment of the intensive care unit contributes significantly to stress experienced by new parents. However, the environment alone may not be the major contributing factor to this stress, but rather the individual's appraisal of their situation that has the most impact. The question arises as to whether new parents, whether at home or in the NICU, experience the same level of stress over the assumption of the parenting role.

Summary

The purpose of this study was to identify stressors experienced by parents of both hospitalized premature and critically ill newborn infants, as well as to identify the coping strategies employed in response to the identified stressors. This study employed an exploratory, descriptive, correlational design. A convenience sample of 28 parents from a Neonatal Intensive Care Unit in a Pacific Northwest medical center was used. The majority of subjects were upper middle class, Caucasian families. Quantitative data was collected using the Family Information Questionnaire, the Parental Stressor Scale: Neonatal Intensive Care Unit, the Revised Ways of Coping Questionnaire, and chart review of the infant's record. Additional qualitative data was derived from three open-ended questions.

Overall, parents of both genders reported the most stress from their altered parental role. Mothers reported more stress from parental role while fathers reported more stress from the infant's behavior and appearance and the sights and sounds of the NICU. Both mothers and fathers reported using positive reappraisal and seeking social support as

their primary coping strategies. Some differences were found between gender of parents with mothers using more seeking social support and positive reappraisal and fathers using more planful problem solving, distancing and self controlling. Parent were also placed in high and low stress groups, and problem-focused and emotion-focused groups for comparison. Parents in the high stress group used emotion-focused and problem-focused coping equally, while the parents in the low stress group used more emotion-focused coping strategies. The qualitative data provided depth to the parent's responses and supported the findings from the questionnaires.

Implications for practice are described that may decrease parent's experience of separation as well as foster involvement in their infant's care. By encouraging parental involvement, parents can begin to overcome their feelings of uselessness and incompetence in caring for their infant, facilitating the development of a healthy parent-infant relationship. Additionally, nurses play an instrumental role in helping families to redefine and reappraise their current situation through their everyday communications. Finally, liberal visitation of extended family members should be encouraged as they provide the emotional and supportive care the parents needs most.

Limitations for the study are described that limit the generalizability of the study. The study sample was small and very homogenous and thus not representative of a more diverse population. Information on infant mortality was not collected and could not be correlated with parental stress levels. Data was collected at only one point in time preventing the assessment of how parental stress and coping changes over time. Lastly, the family as a whole was not incorporated into the study with the true impact on the family unit being lost.

Lastly, recommendations for further research are described. The recruitment of a more diverse population from both rural and urban communities would enhance the generalizability of the study. Furthermore, the inclusion of teen parents would provide an enriching contrast to current information. Additionally, information collected on infant morbidity could account for possible differences in parental stress levels based on the severity of the infant's illness. Longitudinal data collection would allow for the assessment of changing parental stress and coping over time. Assessment of the family as a whole would allow for a deeper understanding of the families changing role structure and family functions during times of stress. Finally, a comparison study between families with healthy newborn infants and families with premature or critically ill infants could allow for the differentiation of stress experienced during a normal family transition and stress experienced from the NICU hospitalization.

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Appendix A

Family Information Questionnaire

Identification Number: _____

Gender:
☐ Male ☐ Female

Marital Status:
☐ Single ☐ Married ☐ Divorced ☐ Significant Other

Age: _____

Ethnicity:
☐ Caucasian ☐ African Amer. ☐ Hispanic ☐ Asian/Pacific ☐ Other

Education: Highest level of education completed:
☐ Some High School ☐ Some College ☐ Technical Education/Training
☐ High School diploma ☐ College Degree ☐ Graduate Degree

Household Income:
☐ $10,000-$19,999 ☐ $30,000-$39,999 ☐ $60,000-$79,999
☐ $ 20,000-$29,999 ☐ $40,000-$59,999 ☐ $80,000 +

Number of Children: _____

Previous Experience with a child/relative in the NICU. If Yes, please summarize:
☐ Yes ☐ No

What has been most stressful for you during this experience?

What are you doing to handle this stress?

What has been most helpful to you?

Appendix B

Parental Stressor Scale: Neonatal Intensive Care Unit

Nurses and others who work in neonatal intensive care units are interested in how this environment and experience affects parents. The neonatal intensive care unit is the room where your baby is receiving care. Sometimes we call this room the NICU for short. We would like to know about your experience as a parent with a child that is presently in the NICU.

This questionnaire lists various experiences other parents have reported as stressful when their baby was in the NICU. We would like you to indicate how stressful each item listed below has been for you. If you have not had the experience, we would like for you to indicate this by circling N/A (meaning that you have "not experienced" this aspect of the NICU).

By stressful, we mean that the experience has caused you to feel anxious, upset, or tense.

For example:

The bright lights of the NICU.

If this was extremely stressful to you, you would circle 5. If the lights were not stressful to you, you would circle 1. If the lights were not on when you visited, you would circle NA.

Please try to answer all questions.

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

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

Please continue to the next page…

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

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

Please continue to the next page...

The last area we want to ask about is how you feel about your own **RELATIONSHIP** with your baby and your parental role. If you have experienced the following situations or feelings, indicate how stressful they have been for you by circling the appropriate number. Again circle NA if you did not experience the item.

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

Using the same rating scale, indicate how stressful in general, this experience of having your baby hospitalized in the NICU has been for you.

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

Please continue to the next page...

Optional Scale

We are also interested in whether you experienced any stress related to **STAFF BEHAVIORS AND COMMUNICATION**. This scale is optional and you do not have to complete it. Information gained will help us to improve our communication with you. Again, if you experienced the item indicate how stressful it was by circling the appropriate number. If you did not experience the item, circle the NA meaning "not applicable". Remember, your individual answers are confidential and will not be shared or discussed with any staff member. A summary of the information will be provided to the staff following the completion of the study.

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
1. Staff explaining things too fast.	NA	1	2	3	4	5
2. Staff using words I don't understand.	NA	1	2	3	4	5
3. Telling be different (conflicting) things about my babies condition.	NA	1	2	3	4	5
4. Not telling me enough about tests and treatments being done to my baby.	NA	1	2	3	4	5
5. Not talking to me enough.	NA	1	2	3	4	5
6. Too many different people (doctors, nurses, others) talking to me.	NA	1	2	3	4	5
7. Difficulty in getting information or help when I visit or telephone the unit.	NA	1	2	3	4	5
8. Not feeling sure that I will be called about changes in my baby's condition.	NA	1	2	3	4	5
9. Staff looking worried about my baby.	NA	1	2	3	4	5
10. Staff acting as if they did not want parents around.	NA	1	2	3	4	5
11. Staff acting as if they did not understand my baby's behavior or special needs.	NA	1	2	3	4	5

Please continue to the next page...

Appendix C

Revised Ways of Coping Questionnaire

When answering the following questions, think about how you feel about your baby being here in the NICU, and how you are handling this stressful situation. Each question identifies a way (coping strategy) that a stressful situation can be handled. Please circle the number that corresponds to how often you used/or are using the coping strategy in the question asked during this stressful time here in the NICU. Please try to answer each question.

Example: #1. concentrated on what I had to do next.

If you used this strategy a great deal, you would circle **3**, if you did not use it you would circle **0**.

	Not used	Used somewhat	Used Quite a bit	Used a great deal
1. Just concentrated on what I had to do next--- the next step.	0	1	2	3
2. I tried to analyze the problem in order to understand it better.	0	1	2	3
3. Turned to work or substitute activity to take my mind off things.	0	1	2	3
4. I felt that time would make a difference--- the only thing to do was wait.	0	1	2	3
5. Bargained or compromised to get something positive from the situation	0	1	2	3
6. I did something which I didn't think would work, but at least I was doing something.	0	1	2	3
7. Tried to get the person responsible to change his or her mind.	0	1	2	3
8. Talked to someone to find out more about the situation.	0	1	2	3
9. Criticized or lectured myself.	0	1	2	3
10. Tried not to burn my bridges, but leave things open somewhat.	0	1	2	3
11. Hoped a miracle would happen.	0	1	2	3
12. Went along with fate; sometimes I just have bad luck.	0	1	2	3
13. Went on as if nothing had happened	0	1	2	3
14. I tried to keep my feelings to myself.	0	1	2	3
15. Looked for the silver lining, so to speak; tried to look on the bright side of things.	0	1	2	3

Please continue to the next page…

Folkman, S., & Lazarus, R. S. (1988)

	Not used	Used somewhat	Used Quite a bit	Used a great deal
16. Slept more than usual.	0	1	2	3
17. I expressed anger to the person(s) who caused the problem.	0	1	2	3
18. Accepted sympathy and understanding from someone.	0	1	2	3
19. I told myself things that helped me feel better.	0	1	2	3
20. I was inspired to do something creative.	0	1	2	3
21. Tried to forget the whole thing.	0	1	2	3
22. I got professional help.	0	1	2	3
23. Changed or grew as a person in a good way.	0	1	2	3
24. I waited to see what would happen before doing anything.	0	1	2	3
25. I apologized or did something to make up.	0	1	2	3
26. I made a plan of action and followed it.	0	1	2	3
27. I accepted the next best thing to what I wanted.	0	1	2	3
28. I let my feelings out somehow.	0	1	2	3
29. Realized I brought the problem on myself.	0	1	2	3
30. I came out of the experience better than when I went in.	0	1	2	3
31. Talked to someone who could do something concrete about the problem.	0	1	2	3
32. Got away from it for a while; tried to rest or take a vacation.	0	1	2	3
33. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc.	0	1	2	3
34. Took a big chance or did something very risky.	0	1	2	3
35. I tried not to act too hastily or follow my first hunch.	0	1	2	3

Please continue to the next page…

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	Not used	Used somewhat	Used Quite a bit	Used a great deal
36. Found new faith.	0	1	2	3
37. Maintained my pride and kept a stiff upper lip.	0	1	2	3
38. Rediscovered what is important in life.	0	1	2	3
39. Changed something so things would turn out all right.	0	1	2	3
40. Avoided being with people in general.	0	1	2	3
41. Didn't let it get to me; refused to think too much about it.	0	1	2	3
42. I asked a relative or friend for advice.	0	1	2	3
43. Kept others from knowing how bad things were.	0	1	2	3
44. Made light of the situation; refused to get too serious about it.	0	1	2	3
45.Talked to someone about how I was feeling.	0	1	2	3
46. Stood my ground and fought for what I wanted.	0	1	2	3
47. Took it out on other people.	0	1	2	3
48. Drew on my past experiences; I was in a similar situation before.	0	1	2	3
49. I knew what had to be done, so I doubled by efforts to make things work	0	1	2	3
50. Refused to believe that it had happened.	0	1	2	3
51. I made a promise to myself that things would be different next time.	0	1	2	3
52. Came up with a couple of different solutions to the problem.	0	1	2	3
53. Accepted it, since nothing could be done.	0	1	2	3
54. I tried to keep my feelings from interfering with other things too much.	0	1	2	3
55. Wished that I could change what had happened or how I felt.	0	1	2	3

Please continue to the next page…

Folkman, S., & Lazarus, R. S. (1988)

	Not used	Used somewhat	Used Quite a bit	Used a great deal
56. I changed something about myself.	0	1	2	3
57. I daydreamed or imagined a better time or place than the one I was in.	0	1	2	3
58. Wished that the situation would go away or somehow be over with.	0	1	2	3
59. Had fantasies or wishes about how things might turn out.	0	1	2	3
60. I prayed.	0	1	2	3
61. I prepared myself for the worst.	0	1	2	3
62. I went over in my mind what I would say or do.	0	1	2	3
63. I thought about how a person I admire would handle this situation and used that as a model.	0	1	2	3
64. I tried to see things from the other person's point of view.	0	1	2	3
65. I reminded myself how much worse things could be.	0	1	2	3
66. I jogged or exercised.	0	1	2	3

Thank you for your time in completing these questions.

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Appendix D

Infant Subject Record

Parent ID Number	G/P	Infant Weight	Gestational Age

Appendix E

Glossary

Family:

Conceptual definition: "Two or more individuals who depend on one another for emotional, physical and/or economic support. The members of the family are self-defined" (Hanson & Boyd, 1996, p. 6).

Operational definition: the family is defined by its members, anyone who provides support to the infant and/or the parents.

Psychological Stress:

Conceptual definition: " A particular relationship between a person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being" (Lazarus & Folkman, 1984, p. 19).

Operational definition: A person's feelings of not being able to handle a situation, it can be positive or negative depending on the situation, the event and the individual's perception of the situation.

Cognitive Appraisal:

Conceptual definition: "An evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment are stressful" (Lazarus & Folkman, 1984, p. 20).

Operational definition: Individual's subjective interpretation of the environmental event or situation.

Adaptation:

An individuals response to stressors in an attempt to return to a steady, balanced state. It is the outcome of a stressful encounter and like coping can be either positive or negative. (Lazarus and Folkman, 1984).

Coping:

Conceptual definition: "Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141).

Operational definition: What a person actually thinks and does in order to manage a situation that the person feels is stressful.

Stressor: An experience that has caused one to feel stress.

Attachment:

Conceptual definition: "An enduring relationship between parent and child within which they can interact, positively and negatively, secure in the knowledge that their love will remain intact, and that each other's well-being is of prime importance" (Sammons & Lewis, 1985b ,p. 56).

Attachment Disorder:

Conceptual Definition: Infants with this disorder have "markedly disturbed social relatedness", at two months of age there may be lack of attention, interest and gaze reciprocity. May be predisposed to disorder by "lack of affectionate body-to-body contact during the first weeks of life" (Goodfriend, 1993, p. 139).

Premature Infant: Infant born before 37 completed weeks of gestation.

High Risk/Critically Ill Infant: An infant requiring intensive medical care following birth (oxygen therapy, intravenous fluids, tube feedings, mechanical ventilation, surgical intervention).

Level III/Tertiary Care Nursery: Nursery providing specialized medical care to high risk and premature infants. A level III nursery is capable of caring for premature infants born after completing 24 weeks of pregnancy, infants requiring mechanical ventilation (short and long term), and infants requiring surgical intervention.

Appendix F

OREGON HEALTH SCIENCES UNIVERSITY
and
PROVIDENCE ST. VINCENT MEDICAL CENTER
Informed Consent

TITLE.

Parental Stress and Coping in the Neonatal Intensive Care Unit.

INVESTIGATORS.

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Kim Dimino, RN, BSN. OHSU Graduate Student, Telephone: (503) 494-3869

RESEARCH COMMITTEE.

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PURPOSE.

You have been invited to participate in this research study because you are the parent of an infant who has been admitted to the Neonatal Intensive Care Unit. The purpose of this study is to find out which aspects of the Neonatal Intensive Care Unit experience are stressful for parents and what parents are doing to cope with this stressful situation. We believe this study will provide information that will help nurses and other health professionals better understand and care for parents when their infants are patients in the neonatal intensive care unit. The study is being conducted by investigators from Oregon Health Sciences University and patients at Providence St. Vincent Medical Center are being asked to participate.

PROCEDURES.

The study involves filling out three questionnaires during the first week of your infant's hospitalization. The questionnaires will take approximately 30 to 45 minutes to complete. The first questionnaire contains general questions about yourself. The second questionnaire is made up of groups of statements about the stress you may have experienced since your infant was admitted to the Neonatal Intensive Care Unit. You will be asked to rate statements related to the sights and sounds in the unit, your infant's appearance, alterations in your parental role, and staff communication and behavior on whether you have experienced the situation, and if so how stressful was the experience for you. The third questionnaire contains phrases about actions you may have used in response to any stress you have felt. You will be asked whether you have used any of the actions or not, and if so how often did you use the particular action. Investigators will collect data from your infants chart about gestational age and weight, as well as number of pregnancies and previous births.

If you agree to participate in this study, the investigator will give you an envelope with the three questionnaires to fill out. Once you have filled out the questionnaires, you will return them to a secure box in the unit in the sealed envelope. The questionnaires will not be reviewed by any of the staff except the investigators. You will also be asked if you would like a copy of the study findings after completion of the study. Parents who do not complete and return the questionnaires in 1 week will receive one telephone call at home as a reminder.

BENEFITS.

You will not personally benefit from participating in this study. However, by

serving as a subject, you may contribute new information which may benefit parents in the future as we seek ways to decrease the stress of having a baby in the Neonatal Intensive Care Unit.

RISKS AND DISCOMFORTS.

A potential risk of participating in this study is that the questionnaires may make you recall unpleasant events or feelings. If some of the questions make you upset or uneasy, you may skip them or stop filling out the questionnaires.

CONFIDENTIALITY.

Information you provide to the investigators will be kept strictly confidential. Collected data will be kept in a locked file. We will keep coded data indefinitely and may use it in future related research. The Providence Health System Institutional Review Board and the Health Care Finance Administration will have access to the coded study information. Participation in this study will by no means influence or interfere with the care your infant receives. Neither the name nor the identity of the participants will be used for publication or publicity purposes. According to Oregon law, suspected child or elder abuse must be reported to appropriate authorities.

COST.

There will be no charge to you for participating in this study.

LIABILITY.

The Oregon Health Sciences University, as a public institution, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from this research project, compensation would be available to you only if you establish

that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call the Medical Services Director at (503) 494-8014. Providence Health System is not the sponsoring agency of this research project and will not assume financial responsibility for such treatment, or provide financial compensation for such injury. By signing this consent form and agreeing to participate in this study you are not waiving any of your legal rights.

PARTICIPATION.

Robin Barnes, RN, (503) 494-3869 and Kim Dimino, RN, (503) 494-3869 have offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887 or the Providence Health System Institutional Review Board at (503) 215-6512. Your participation in this research is voluntary. You may refuse to participate, or may withdraw from this study at any time. Neither you nor your infant will receive different treatment from Providence St. Vincent Medical Center if you withdraw from the study. You will receive a copy of the consent form. Your signature indicates that you have read this form and agree to participate.

_____

Participant's Signature Date

_____

Investigator's Signature Date

_____

Witness's Signature Date