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IDENTIFYING ENVIRONMENTAL STRESSORS AFFECTING PARENTS WITH AN INFANT IN THE NICU

by

Donna Mattson

A thesis submitted in partial fulfillment
of the requirements for the degree of

Master of Science

in

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Department of Nursing
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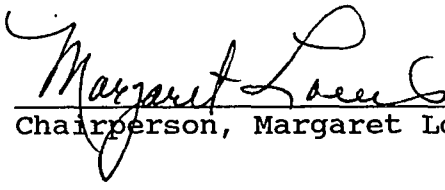
The thesis of Donna Mattson for the degree of Master of Science in Nursing is approved.



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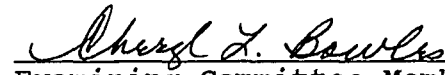

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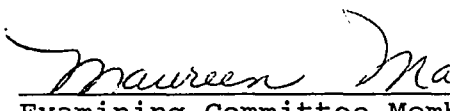

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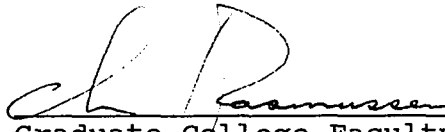

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ABSTRACT

Having a new baby who requires intensive care is a new experience for most parents and a source of great anxiety. Their concern for their infant's well-being, even survival, is influenced by many factors including the physical environment of the intensive care setting, the staff caring for the infant, the infant's condition and requirements for therapy, and their inability to be a parent to the infant as anticipated during pregnancy.

To discuss sources of stress for parents, a convenience sample of 47 parents of infants admitted to a NICU was obtained to complete questionnaires pertaining to different possible sources of stress. The questionnaires included the Parental Stressor Scale: Neonatal Intensive Care Unit, State-Trait Anxiety Inventory, and Parent/Child Uncertainty in Illness Scale.

The parents comprising the sample had elevated mean State and Trait Anxiety Inventory scores compared to reported normative scales of working adults. By t-test analysis, mothers had significantly higher mean State Anxiety scores than fathers and parents of preterm infants had significantly higher mean Trait Anxiety

scores than parents of full-term NICU infants.

Mothers also had higher mean scores than fathers on each of the sub-scales of the PSS:NICU (Sights/Sounds, Infant Appearance/Behavior, Staff Relations, and Role Alteration) with significant differences in mean scores for the total PSS:NICU instrument and the sub-scale Staff Relations.

The parents of preterm infants had higher mean scores for each of the PSS:NICU sub-scales than parents of full-term NICU infants with the difference significant for the sub-scale Role Alteration.

The Parent/Child Uncertainty in Illness Scale was utilized in conjunction with the PSS:NICU to further validate the later instrument. The PCUS closely correlated with the PSS:NICU sub-scale of Staff Relations.

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CHAPTER I

INTRODUCTION

The birth of a healthy infant can place new parents in a state of anxiety, or even maturational crisis, as they enter a period of adaptation to the role of parent. Although they may feel anxious, they frequently experience a sense of achievement and joy since their expectations for a healthy infant have been met. This positive reinforcement facilitates their adaptation to parenthood.

However, the birth of an infant requiring intensive care may not only precipitate a maturational crisis for the parents but a situational crisis as well. The deviant outcome of the pregnancy leaves parents disappointed, bewildered, and uncertain about the future. Parental reactions to the loss of the expected healthy baby often includes anger, grief, guilt, disbelief, and denial (Waechter, 1987; Oehler, 1981; Gardner & Merenstein, 1986; Brooten et al, 1988; and Garland, 1986).

STATEMENT OF THE PROBLEM

The primary concern of parents with an infant receiving care in the neonatal intensive care unit (NICU) is for the survival/well-being of the infant. Other stressors facing parents in the NICU experience have been identified objectively by health care givers and subjectively by parents but little research has been performed to clearly identify or quantitate these stressors.

PURPOSE OF THE STUDY

The purpose of the study is to identify NICU environmental stressors perceived by parents with an infant hospitalized in a NICU. The sources of the stressors in the environment include physical and psychosocial aspects of the NICU experience. If sources of stress can be identified by the sample group of participants, comparisons between groups can be made (i.e. between husbands and wives).

SIGNIFICANCE OF THE STUDY

The nurse is a vital member of the health care team caring for the high-risk infant and frequently has more

contact with the parents than other members of the team. Although the primary responsibility of the nurse is the provision of nursing care to the infant, there is an inherent two-fold responsibility to the parents. First, the nurse must assist parents to cope with the stressful experience of an ill infant. Second, the nurse must also assist parents in assuming their parenting role.

The parents' perceptions of the stressors may well be different from those of the nurse who is accustomed to the NICU environment and conditions of the patients. Some parents may be unwilling to freely express their concerns while other parents may be too overwhelmed to be able to identify their concerns. With greater awareness of the variety and severity of stressors confronting parents during their infant's stay in the NICU, nurses may more effectively intervene to assist parents in their coping and acceptance through the provision of appropriate information, guidance, and support.

THEORETICAL FRAMEWORK

The Roy adaptation model provides the theoretical framework for this study. Although the model is a comprehensive model for nursing practice, only aspects of

the model involved in identifying stressors are utilized for this study.

Adaptation is the positive response of the individual to environmental changes which promote the general goals of survival, growth, reproduction, and mastery. The individual possesses two major adaptive subsystems; the regulator and the cognator. The regulator consists of the autonomic and involuntary responses of the body when exposed to certain stimuli. The cognator refers to the cognitive-emotive responses of perception and information processing, learning, judgement, and emotions. Although stimuli affecting one subsystem frequently affects the other subsystem, this study will focus on stressors which elicit cognator responses.

The individual is constantly affected by stimuli from external and internal sources. The stimuli can become stressors if an adaptive response is necessitated. Stimuli can be focal, contextual, or residual in origin. The focal stimulus is the immediate stimulus with which an individual is confronted. The focal stimulus for parents with an infant in the NICU is usually the concern for the survival/well-being of the infant.

Contextual stimuli are the background or contributing stimuli to the focal stimulus. The contextual stimuli can be external (factors in the environment) or internal (thoughts or feelings the individual is experiencing).

Residual stimuli refers to the individual beliefs, attitudes, previous experiences, and other traits which might affect tolerance or perception of a situation.

The potential stressors for parents to be identified in this study are primarily contextual stimuli such as sights and sounds in the NICU, communications and behaviors of staff, appearance of their infant, and disruption of the parenting role. Some of these contextual stimuli have the potential of becoming focal stimuli. For instance, parental concern for the recovery of their infant may be the focal stimulus for a period of time. As the infant's condition improves, the focal stimulus may change to the parental concern for not being able to care for their infant themselves.

The nursing concern for the family as well as for the patient is consistent with the holistic approach of the adaptation model of nursing. The nursing assessment of the family is facilitated by the awareness of the

varied stimuli which can cause parents stress. The increased awareness of potential stressors stimulates anticipatory or early nursing interventions appropriate to the needs of the family (Roy, 1984; Roy & Roberts, 1981).

RESEARCH QUESTIONS

The research questions for this study include:

1. What are the sources of stress for parents in the NICU environment?

2. Are there differences in sources of stress between fathers and mothers in the NICU setting?

3. Are there differences in sources of stress between parents of pre-term infants and parents of term infants admitted to the NICU?

4. Since the PSS:NICU may relate overall to the differences in the sub-groups such as mother/father and parents of preterm/full-term, will these significant differences in the responses from the sub-groups remain after controlling for Trait Anxiety scores?

DEFINITIONS OF TERMS

Focal stimulus - The stimulus immediately

confronting the individual. For most parents, the infant's illness will be the focal stimulus.

Contextual stimuli - All other stimuli present in the environment or situation. Contextual stimuli for the study includes the physical environment of the NICU and the staff caring for the infant, for example.

Residual stimuli - Beliefs, attitudes, and traits which might have an effect on the perception on the situation. Parents religious beliefs, predisposition to stress, previous experiences with critically ill family members are examples of residual stimuli.

Stressor - A stimulus requiring an adaptive response. A parent receiving conflicting information from the staff about their infant's condition can be a stressor for the parent.

Adaptive response - A response which promotes the integrity of the individual in terms of the goals of survival, growth, reproduction, and mastery.

Cognator - Subsystem coping mechanism forming cognitive-emotive responses of perceptions, learning, judgement, and emotions (Roy, 1984).

ASSUMPTIONS

The assumptions for this study are reflective of the Roy adaptation model of nursing practice, a review of related literature, and the researcher's clinical experience.

1. The role of the nurse encompasses the needs of the family as those needs relate to the patient.

2. Stressors for parents with a critically ill infant are varied.

3. Some parental stressors generated by the NICU experience can be identified.

4. The effects of some environmental stressors on parents can potentially be prevented or minimized through nursing interventions.

SUMMARY

This chapter has presented an introduction to parent reactions when their infant is born ill, the statement of the problem, the purpose of the study, the significance of the study, research questions, definition of terms, and assumptions.

CHAPTER II

REVIEW OF RELATED LITERATURE

The literature review for the study includes narratives and research on the needs of family members of pediatric and adult intensive care patients. Since research pertaining to the needs of parents of infants hospitalized in neonatal intensive care units could not be found by computer search of nursing and related journals, the literature review includes narratives identifying sources of stress for parents of critically ill newborns. The literature review is divided into review of material related to parents of pediatric and neonatal intensive care patients, and material related to family members of adult intensive care patients.

PARENTS OF NEONATAL AND PEDIATRIC INTENSIVE CARE PATIENTS

Parents of infants hospitalized in neonatal intensive care units usually have little or no warning their infants will require intensive care. Often the

primary response of parents to this event is grief since they experience the loss of the expected healthy and perfect baby (Oehler, 1981; Waechter, 1987; Gardner & Merenstein, 1986; and McGovern, 1984).

While grieving for the loss, parents may also experience a sense of failure and, consequently, a loss of self-esteem. The infant is seen by parents, especially mothers, as an extension of themselves and if something is wrong with the baby then something is wrong with them (Oehler, 1981; Gardner & Merenstein, 1986).

Parents may also experience anticipatory grief if the infant is diagnosed, or perceived by the parents, as having a long-term or potentially fatal illness which could result in a lasting separation or loss of the infant (Waechter, 1987).

Parents not only experience anxiety from the infant's illness but also from the subsequent separation that interferes with the parenting role (Sameroff, 1981). Hawkins-Walsh (1980) stressed the need for caregivers to assist parents in managing their anxiety since stress often isolates parents from their infants. Further, if parents are to be helped to cope and positively adapt to the situation, they must be assessed on an individual

basis for their immediate concerns. Parental knowledge or feelings cannot be taken for granted since "The world of sick babies, oxygen requirements, and intravenous needs is usually alien to parents" (Hawkins-Walsh, 1980, p. 33).

Any ICU environment is foreign to most lay persons. A pediatric intensive care unit (PICU) shares many similarities to a neonatal intensive care unit (NICU). Both units have open ward arrangements, highly technical equipment, an increased number and variety of caregivers, and increased unit activity. Parfit (1975) described a pediatric intensive care unit as experienced by parents:

> The monitoring machines and their zig-zag tracings, the comings and goings of white-coated doctors and technicians, while in one sense reassuring parents that everything possible is being done, nevertheless are frightening to parents who are already under stress. Bleeps, tubes, flashing red lights, and alarm bells increase their sense of awe and fear. (p. 1512)

Upon interviewing parents of children in PICU's, Lewandowski (1980) found parents frequently felt unprepared for the shock they experience when first

seeing their child with all the equipment and tubes. The parents felt a sense of loss due to their inability to help and protect their child who had come under the care of machines and hospital staff.

Rothstein (1980) states the initial grief stage of shock and disbelief can be intensified by the physical appearance of the child as a result of "...trauma, dermatologic manifestations of the disease, bandages, endotracheal tubes, chest tubes, monitoring lines, and urinary catheters" (p. 614).

With so much emphasis on the pathophysiology and technology in today's NICU's, medical and nursing personnel focus their care on the infant and the needs of the parents may not be recognized (McGovern, 1984). Green (1979) noted that the higher the intensity of care for infants and children in ICU's, the less evident the caregivers concerns with families. Stevens (1981) was also aware of the need to "humanize" the PICU experience by identifying the psychosocial needs and problems not only of the child but also of the family. Nursing interventions should be planned and performed based on knowledge of the child's level of growth and development, the family system, and the stressors present in the PICU

environment; "...the nurse's ability to render effective psychosocial care is enhanced by an understanding of potential stressors existing in the PICU setting" (Stevens, 1981, p. 613).

Broome (1985) stated family anxiety, even crisis, can occur when a child is admitted to an intensive care unit. The sources of anxiety were attributed largely to unfamiliarity with the equipment, the environment, and the professionals providing care to the child.

Miles and Carter (1983) described the PICU setting as "...strange and overwhelming, filled with a sense of urgency" (p. 354). According to their conceptual framework, potential parental stressors arise from personal/family background factors, situational conditions, and environmental stimuli. The responses of parents are dependent upon the interaction between these stressors as mediated by the parents' cognitive appraisals, coping responses, and resources available to help them cope. Environmental stressors include physical and psychosocial aspects of the intensive care unit. Miles and Carter further suggested nurses should assess not only the situational conditions but also the parents' perceptions of the environmental stimuli.

Eberly et al (1985) studied the effects of expected versus unexpected admissions of children to PICU's on parental stress. The Parental Stressor Scale: Pediatric Intensive Care (PSS:PICU) was used to assess physical and psychosocial stimuli arising from the intensive care environment. The State-Trait Anxiety Inventory (Spielberger et al, 1983) was also completed by participants to assess overall anxiety response and anxiety tendency. The researchers concluded parents of children admitted unexpectantly to PICU's had a slightly high mean state anxiety score compared to the parents of children whose admissions were expected. The "unexpected" parents also had higher mean scores in all ICU environmental dimensions of the scale including significantly higher scores in the four dimensions of sights and sounds, child's appearance, changes in the child's behavior and emotions, and parental role alterations. The significance of this study relates to the effectiveness of the PSS:PICU instrument in identifying stressors and also in comparisons between two groups. The data for this study was from a large sampling, 233 parents who experienced planned admissions of their children to a PICU and 262 parents whose

children were admitted to the PICU unexpectedly.

A semistructured interview guide and demographic questionnaire was developed by Kasper and Nyamathi (1988) and was administered to 15 parents of children hospitalized in a pediatric intensive care unit. The parental needs expressed in the interviews were identified and classified as physical, psychologic, or sociologic in origin. The single most identified need expressed by the parents was to be with the child in the PICU (80%). The need for frequent, truthful, and accurate information was the second most identified need (73%). The need to have a place to sleep near the PICU and to participate in their child's care in any way possible were identified by 67% of the parents. In relation to the adult ICU family studies, the need for the PICU patient to receive the best possible care was the most clearly stated similar need. The differences in findings between the parents needs and family needs of adult patients were attributed to the disruption of the parenting role. The authors defined the parental role as "The function that a person assumes as a result of the birth or adoption of children. It includes the behaviors and actions organized around the physical, psychologic,

and sociologic responsibility for those children until they attain adulthood" (p. 575). The needs to visit, stay nearby, care for the patient, and to know about the patient's condition clearly relate to the dependent relationship between parent and child and the assumed responsibilities of the parental role. The authors further state the disruption of the parental role produces considerable stress for the parent. In relation to this interruption of the parental role Parfit (1975) states "Almost everyone rises to an emergency and can cope if they feel there is something they can do....It is far too easy for professionals in a hurry to deny parents the right to something for their sick child" (p. 1512).

In a retrospective descriptive study, mothers of prematures recalled feeling less anxiety surrounding the infant's hospitalization when they had more physical contact with their infant and more frequent visits to the intensive care nursery (Philipp, 1983). The imposed separation of parent from sick child was also identified by Stevens (1981) as a source of stress for parents.

FAMILY MEMBERS OF ADULT INTENSIVE CARE PATIENTS

Although there may be differences in family members

needs or sources of stress when the patient is an adult versus and infant or child, inferences may be made since families share the commonalities of role strain, concern for a love object, and frequently, an unfamiliarity with the ICU setting.

The identification of needs of family members of intensive care patients (mostly adults) has been published in several studies. Molter (1979) performed a descriptive study to identify physical and psychosocial needs of family members in order to enable caregivers to provide more appropriate nursing interventions with the goal of assisting families in coping with the patient's illness. It is Molter's opinion interventions for families are mostly generalized and frequently based on needs of the family as perceived by the staff. A 45-item Likert-type scale was given to 40 adult relatives of critically ill adult patients. The need for hope was rated as very important by all of the respondents. Needs rated as very important by at least 50% of the respondents include the needs for: information about the patient's condition; to have explanations given in terms that are understandable; to know exactly what is being done for the patient and why; to feel hospital personnel

care about the patient; to have explanations given about the ICU environment prior to visiting for the first time; to have the pastor visit; to feel accepted by hospital staff; to be assured the best possible care is being given; to have questions answered honestly; to be called about changes in the patient's condition; to have a waiting room with comfortable furniture; to have a bathroom near the waiting room; and to see the patient frequently. The majority of these needs were identified by the respondents as being met by nurses most of the time.

Leske (1986) administered Molter's questionnaire to family groups of patients who were critically ill. In this study the family answered the questionnaire collectively after a consensus was reached. The sampling consisted of family members (55 participants) of twenty critically ill patients. The overall scores were higher compared to Molter's study but the items rated important to very important were much the same.

In comparing selected psychosocial needs of family members of critically ill adult patients and perceived family member needs by intensive care nurses, Norris and Grove (1986) administered a revised Molter questionnaire

(shortened from 45 items to 30 items and application of Q sort methodology to generate median scores for the items) to twenty members of each group. The needs for hope, honest information, a caring attitude from the staff, and to be assured the patient is receiving the best possible care were of the greatest importance to the family members. The nurses rated highest the needs of families to receive accurate information and to feel the hospital personnel cared about the patient. The needs identified as most important for family members by nurses were also rated high by family members but the nurses rated informational needs slightly higher than the family members. The nurses rated less high than the family group the need to feel the patient is receiving the best possible care and the need to feel there is hope. The authors also concluded the nurses did not appear to be aware of their importance to the family and the family's needs to feel accepted by them. Nor did the nurses rate as high as the family members the need to be called at home with changes in the patient's condition and the need to know the prognosis. Items also rated higher by family members included the need to know the types of staff caring for the patient.

An analysis of variance yielded a pvalue of 0.012 indicating a significant difference between the two groups at the .05 level. However, this was a small, convenience sampling from one ICU setting, and the revised questionnaire had limited content validity assessment and no reliability assessment prior to the study. The authors emphasize the needs of the family are important in order to provide comprehensive nursing care to the patient but too often nurses lack adequate knowledge or background due to a lack of research on the psychosocial needs of family members.

Daley (1984) recognizes hospitalization for serious illness can precipitate a crisis for even the most organized family structures but the needs of family members are too often ignored or forgotten by staff members. The author states the dilemma is primarily due to lack of time for the nurse to assess or intervene with the family, lack of knowledge on dealing with family members, or a lack of understanding of family members' needs. The author developed a structured interview tool consisting of a 46 need statements which were categorized into six areas of need: the need for relief of anxiety; the need for information; the need to be

helpful to the patient; the need for support and ventilation; and personal needs. The sampling consisted of 40 family members of critically ill patients ages 5-80 years. The findings from the study revealed the need for relief from anxiety rated the highest among the respondents. Within this category were the needs to know the expected outcome; to know the treatments and equipment in use, to be called of changes in condition, and to be told there is hope. The second highest rated category was the need for information. The needs in this category included the needs to have questions answered honestly, to receive information in understandable terms, to be able to talk with the physician, to be able to talk with a nurse, to be informed of changes in condition, and to be able to call the unit any time.

Of the remaining categories, the items with the highest ratings (3.4 on a 4.0 scale) included the need to be with the patient, the need to be reassured the patient is doing alright, and to have other family members nearby. The concern for personal needs and the needs for ventilation and support were not as important as the aforementioned needs. The family members perceived the physicians and nurses to be the most likely persons to

meet their needs. Although there was little validity testing and no reliability testing reported for the instrument, and the sampling was small and limited to one hospital setting, the identified needs and their relative significance to the family members were similar to the other studies already cited. Of particular interest in this study is the identification of the family members' needs to call the unit any time and the need to be with the patient.

Stillwell (1984) notes there have been limited or conflicting data on the effects of family visits on patients in the ICU. There has been even less research on the importance of visitation for the family members. Borrowing eight visitation needs for family members from Molter's instrument and adding a ninth statement concerned with the concept of privacy, the author administered the instrument to a convenience sampling of 30 family members of patients admitted to the ICU. The importance of visiting needs was the dependent variable and the following were the independent variables: the family member's age, the socioeconomic level, the ethnic background, past experience in an ICU setting, religion, attendance at church, relationship to the patient, major

source of social support, perceived condition of the patient, and the diagnosis of the patient. The findings revealed a significant correlation existed between the family's perceived condition of the patient and the ranked importance of the need to see the relative frequently. The family's need to see the patient frequently increased in importance as the perceived severity of the patient's condition increased (utilizing Kendal's tau b, $r=0.63$; $p \leq 0.05$). There was no statistical significance between the ranked importance of the visiting needs and the other variables. The author states the need of family members to visit frequently may be an effective coping mechanism since seeing the patient can foster acceptance of the patient's condition and foster crisis resolution within the family.

SUMMARY

A review of the literature revealed numerous sources of stress for family members of patients of all ages requiring intensive care. Similarities in the review included the needs for family members to receive accurate information, to visit the patient, to feel there is hope, to feel the best possible care is being given, and to

feel hospital personnel care about the patient. As mentioned when reviewing the literature pertaining to parents' needs, the disruption in the parenting role is unique to the pediatric, and likely the neonatal patient's family.

CHAPTER III

METHODOLOGY

The parents of an ill newborn are affected by numerous stimuli during their infant's acute illness and hospitalization. The focal and contextual stimuli may be sources of stress for parents. The purpose of the study was to identify NICU environmental (contextual) stressors perceived by parents with an infant hospitalized in a NICU.

This chapter presents the research design, sample, setting, resources, cost/benefit, instrumentation, and data analysis.

DESIGN

To identify sources of stress for parents in the NICU environment, an exploratory research design was proposed. The primary instrument was the Parental Stressor Scale: Neonatal Intensive Care (PSS:NICU) developed by Margaret S. Miles, R.N., Ph.D., circa 1987. The instrument encompasses common contextual stimuli

experienced by parents of infants hospitalized in neonatal intensive care units. These stimuli include sights and sounds present in the environment, the appearance and behaviors of the infant, the behaviors and communications of the staff, and aspects of the parenting role.

Although data has not been published about the application of the PSS:NICU instrument, Dr. Miles and her associates have administered the instrument to parents and the outcome data information is available in an abstract format. In her study, Dr. Miles and her associates also administered the Spielberger et al (1983) State-Trait Anxiety Inventory (STAI) and the Parent/Child Perception Uncertainty Scale (PCUS) (Mishel, 1983). These instruments were incorporated by Miles for validation for the PSS:NICU instrument.

The present research was not an exact replication of Dr. Miles' study since there were differences in sampling and in data collection. Dr. Miles' study included parents of prematures while this study included parents of all infants who were admitted to the NICU with a serious illness but not known to be permanently handicapped or to be terminally ill. The testing was not

performed when parents were in the hospital but, rather, the parents were given the questionnaires in a packet to take home and answer.

SAMPLE

The sample included parents: 1) Whose infant had been admitted to a regional NICU; 2) Who were at least 18 years of age and were not known or suspected to be mentally ill (determined from the mother's chart and on interview); 3) Who could speak, read, and write English (determined on interview); 4) Whose infant had been hospitalized between 24 hours to one week at the time of the survey (determined from infant's medical chart); 5) Who had the opportunity to visit their infant at least once (determined from infant's medical chart); 6) Whose infant was diagnosed to be seriously ill but not known to be permanently handicapped or to be terminally ill at the time of the survey (determined from infant's medical chart); 7) Whose infant was a singleton birth since multiple births may be an added source of stress for parents; 8) Whose infant had an expected stay in NICU of a minimum of one week.

During a three month period, all parents meeting the above criteria were approached by the researcher to explain the study and seek their participation. All parents were approached by the infant's sixth hospital day. The parents who agreed to participate in the study (Appendix A), were given a personal data questionnaire (Appendix B) and the three instruments (Appendices D, E, F). The participants were asked to complete the questionnaire at home independently of the other parent, and mail the data forms to the researcher in the stamped envelope provided.

The NICU utilized for the study had an average admission rate of forty patients per month. Over the three month period there were a maximum of 129 individual parents from which to take the sampling.

SETTING

The 37-bed NICU within a 670-bed private hospital is located in Clark County, Nevada, which has a population of approximately 660,000 (Bureau of Business and Economics Research, 1989). The NICU also serves smaller, outlying communities within approximately a 300 mile radius. Approximately one-half of the admissions to

the unit were from referring hospitals within this catchment area. Although the hospital is designated as private, all referrals to the NICU were accepted by the neonatologists based on the infant's condition and, therefore, the sampling included families from a broad spectrum of socioeconomic status, including the medically indigent.

Visitation: The visitation policy allows parents and grandparents to visit the unit any time of day except during nursing change-of-shift. Rarely are durations of visits limited. Sibling visitation is available once a week by appointment. Parents are able to telephone the unit at any time for information about their infant. The parents can identify a "significant other" to visit in cases of a single parent or when grandparents are not available.

RESOURCES

Background information for this study was obtained from a literature review which included the Roy adaptation model of nursing, parent experiences with stress and coping, concepts of stress and adaptation, development of the instruments and the available

credentialling data for the instruments. Written agreements were obtained from the developers of the PSS:NICU and PCUS instruments (Appendices D and F).

Ancillary departments within the hospital where the NICU is located were of assistance. The social service department, nursing department, medical library, and the nursing education department were helpful in providing information and direction for the study. Approval to implement the study was obtained from the hospital's administration (Appendix C).

Resources were also available from the Department of Nursing, University of Nevada, Las Vegas. Nursing instructors with expertise in the field of nursing research and the availability of data processing assistance provided further input into the research project. Approval was obtained from the Department of Nursing-UNLV Human Subjects Rights Committee before data collection began (Appendix C).

COST/BENEFIT

The three questionnaires include a total of 137 items which required fixed choices and two optional brief answers. The personal data questionnaire consisted

of 19 items requiring selections or brief answers (Appendix B). To provide more insight into the amount of time required for the participant to complete the questionnaires, a pilot study consisting of three participants was performed. A pilot study was helpful in providing information on time required to complete the questionnaire (30-45 minutes), but no revisions in content or length was made. Due to the sensitivity of some of the questions, participants were instructed to leave a question blank if answering it caused them undue anxiety. Since the PSS:NICU required parents to explore their feelings about stressors, some participants may have experienced emotional discomfort. Debriefing by the researcher who had extensive experience in the NICU or the NICU social worker was available to the participants. Two parents shared thoughts and feelings stimulated by the questionnaires with these two individuals. Their concerns primarily centered on conflicting information being received from the NICU staff and feeling depressed.

The developers of the PSS:PICU questionnaire reported parents expressed a feeling of contribution to helping others when they participated in their study

(Eberly et al, 1985). This occurred with this sampling of parents as well. The informed consent letter clearly identified the positive rationale for the purpose of the study. The benefit to the participants of improved nursing awareness of their concerns and fears cannot be measured until interventions are developed, implemented, and studied for effectiveness. However, identification of these concerns and fears may be a beginning.

INSTRUMENTS

The Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU) was developed during the mid 1980's by Margaret S. Miles, R.N., Ph.D. to measure parental perceptions of stressors while their infants were hospitalized in a neonatal intensive care unit (Miles, 1987). Environmental stressors are defined by Miles as those stressors arising from the physical and psychosocial aspects of the ICU environment.

The PSS:NICU was adapted from the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) developed by Melba Carter, R.N., Ph.D. and Margaret Miles in the early 1980's. Substantial support for the content validity of the PSS:PICU instrument has been reported.

The NICU instrument was modified to better reflect the differences between the NICU and PICU patients' appearances and behaviors, changes in the parental roles that differ for parents of sick newborns, and differences in the environments of NICU's. These changes arose from observations made in the NICU, interviews with parents, and extensive literature search.

The first draft of the PSS:NICU instrument was given to 10 NICU professionals (neonatal nurses and physicians) and to 20 parents of recently discharged infants from the NICU. These respondents evaluated the instrument for redundancy, clarity, and comprehensiveness of the content and further revisions were made.

A pilot study was performed by administering the instrument to 58 parents of infants hospitalized in a NICU. After data analysis and obtaining input from content experts (NICU nurses, maternal-child nursing educator, and a psychometrician) the content of the instrument was again revised. Items with a high number of zeroes ("not experienced"), or low means, or poor spread of scores were eliminated or combined with other items based on conceptual similarity and high inter-item correlations.

The internal consistency reliability coefficients for each of the conceptualized dimensions were examined. The items which tended to lower the coefficient alpha were removed or combined with other items. Parental answers to open-ended questions to identify other stressors were coded, categorized, and evaluated for relevancy. Items considered important by NICU professional staff were also evaluated for relevancy. From the open-ended questions and items identified from the staff, five new items were added resulting in a 47-item scale.

The final version was conceptually categorized into four dimensions. The Cronbach's alpha was computed for the revised instrument prior to the addition of the five items mentioned earlier. The reliability coefficients for the dimensions were: Sights and sounds - .67; Child's appearance and behavior - .85; Staff relations - .92; Parental role alteration - .89. The alphas computed after the addition of the five items were not included in Miles' abstract.

In evaluation of the construct validity of the scale, Pearson Product-Moment Correlation Coefficients were computed between each of the parental stressor scale

dimension scores and state anxiety scores. Correlation coefficients were significant at p=.01 for the dimensions of sights and sounds (r=.48), infant's appearance and behavior (r=.43), and parental role alteration (r=.43). There was no significant correlation between state anxiety scores and staff relations scores. The correlation between total PSS:NICU scores and state anxiety scores was r=.42.

The psychometric properties of the instrument were again tested when the instrument was given to 122 parents of prematures with the first three days of the infant's hospitalizations in NICU. Cronbach's alpha coefficients for each of the dimensions and for the total instrument were all above .70. Factor analysis supported the priority structure of the PSS:NICU with the exception of the dimension of staff relations. Few parents in this sampling reported experiencing items in this category and the dimension was, therefore, eliminated from analysis.

The State-Trait Anxiety Inventory scale was administered along with the PSS:NICU (Appendix E) to validate state anxiety among the respondents and their propensity to stress. This 40-item Likert-type scale requires 10-20 minutes to complete. In the construction

and standardization of Form Y of the STAI (the form to be used for this study) more than 5,000 subjects were tested and factor structure yielded clear-cut distinctions between state and trait anxiety. Extensive reliability and validity testing has been performed on the STAI and the instrument is the most widely used tool for the measurement of anxiety (Spielberger, Lushene, Vagg, and Jacobs, 1983).

The Parental/Child Uncertainty Scale (PCUS) developed by Mishel (1983) was also administered with the PSS:NICU instrument. The PCUS was administered by Miles with the PSS:NICU and the STAI to validate situational variables including parental perception of severity of infant's illness. Mishel developed the scale to measure the perceptual variable of uncertainty since this variable may influence parents' responses to their child's illness and hospitalization. The scale was an adaptation of the Measurement of Uncertainty in Illness (MUIS) developed also by Mishel (1981). The PCUS (Appendix F) is a 31-item Likert-type scale measuring four subscale characteristics of uncertainty (ambiguity, complexity, lack of information, and unpredictability). The instrument received reliability and construct

validity testing including item analysis, coefficient alpha, coefficient theta, factor analysis, and one-way analysis of variance of uncertainty scores by treatment groups. The alpha for the total scale was .91 and the alphas for each of the sub-scales were as follows: Ambiguity .87, Complexity .81, Lack of Information .73, and Unpredictability .72. Coefficient theta was estimated for the total scale and for each of the sub-scales. When the theta values were compared to the alpha values, no difference was found among the reliability estimates. Classical factor analysis and an othogonal rotation resulted in four factors of uncertainty as predicted with the following eigenvalues: Ambiguity 8.40, Complexity 1.8, Lack of Information 1.7, and Unpredictability 1.12. Ninety-nine percent of the items loaded at .40 or higher. Mishel concluded the construct validity needed further study, but the tool provided a means for evaluating the perception of uncertainty in one person concerning a significant other.

Although the number of items comprising the total of the instruments have been cumbersome for the respondents, the instruments shared the same questionnaire format (Likert-type scales) which may have provided ease in

administering the test. Also the respondents may have found responding to the questionnaires less confusing since there was less opportunity to misinterpret how to complete the instruments.

DATA ANALYSIS

The data analysis includes a description of the population sampled (age, race, education, economic status, marital status, etc.).

The mean scores for the four dimensions of the PSS:NICU, and the state anxiety mean scores, are included in tables for comparisons of experienced stress by the parents. Since the dimension of staff behaviors and overall perception of uncertainty conceptually appear the most related, the mean scores of these items were assessed for correlation using the Pearson Product-Moment measure. This comparison was not reported in Miles' research. Since the PCUS scale may be related to this PSS:NICU, a correlation matrix is presented.

The Cronbach's alpha coefficient measure was applied to each of the four dimensions of the PSS:NICU to further validate internal consistency and construct validity. The results were compared to Miles' research. Alpha coefficients were also computed on the PCUS scale

and the results were compared to Mishel.

To further test for construct validity, the Pearson Product-Moment measure was applied to note the correlations between the four dimensions of the PSS:NICU, the overall scores of the PSS:NICU, and the state anxiety scores obtained from the STAI. Miles' research revealed weakly positive correlations of the total scores and the dimensions scores of the PSS:NICU with the state anxiety scores. The correlation values accounted for 18-24% explanation of the variance. The lower correlations may have been due to sample size or the smaller variance of the PSS:NICU and/or STAI.

The responses to the open-ended questions were tabulated. As anticipated, some of the responses were repetitive of items included in the PSS:NICU and do not require new categories. Some of the responses suggest new categories should be considered for future application of the instrument.

Analysis of covariance was implemented to compare the groups of husbands and wives, and parents of preterm infants with parents of term infants. This measurement compares group differences in overall stress response

measured by the PSS:NICU scale. The trait anxiety score was the covariate.

SUMMARY

This chapter has presented the methodology of the research including research design, sample, setting, available resources, cost/benefit to the participants and the researcher, descriptions of the instruments, and a summary of data analysis.

CHAPTER IV

RESULTS

The research questions proposed for this study included the identification of sources of stress for parents with an infant hospitalized in a NICU. The Parent Stressor Scale: Neonatal Intensive Care Unit Scale was used to measure the sources of stress for parents. The State-Trait Inventory and Parent/Child Uncertainty Scale were also utilized to further validate parents' perceptions of stress from the NICU experience. Further, parent sub-groups were compared (mothers and fathers, parents of full-term infants and parents of premature infants) to determine differences in perceptions of stress.

Demographic data, reliability/validity testing for PSS:NICU and PCUS instruments, results from STAI measurement, comparisons of mothers to fathers by PSS:NICU and STAI instruments, comparisons of parents of full-term infants and parents of premature infants by PSS:NICU and STAI instruments, and analysis of covariance

for comparisons between parent sub-groups are also presented in this chapter.

DEMOGRAPHIC DATA

The subjects for the study were drawn from parents of infants admitted to the NICU during the period June 1, 1989 to August 31, 1989, who met the study criteria.

During the three months of data collection, one hundred twenty-nine parents who met the sampling criteria were approached in person by the researcher, asking them to participate in the study. These parents were informed of the general research purpose and what they would be required to do if they agreed to participate. The parents were, of course, reassured of the confidential nature of the study and that their anonymity would be maintained. Those who agreed to participate were reminded to complete the questionnaires within one week of their infant's admission date and to do so independently from their spouses/partners. Due to various complications, including mothers' prolonged hospitalizations in referring hospitals, criteria for response times were changed to within three weeks of admission if the infant was still hospitalized in the

NICU and discharge was not imminent. The mean subject response time was 6.5 days of admission with a range of 2 to 16 days. The parents, when necessary, received up to two reminders to return the materials.

The final sample size was 47 of 129 (a 36.4 percent return rate), of whom 29 were mothers. Of the infants represented by parents in the study, 19 were full-term (at least 37 weeks gestational age) and 28 were premature. Gestational age was determined by modified Ballard examinations (Klaus & Fanaroff, 1986) performed by a staff physician or nurse practitioner in the NICU.

Table 1 presents data on age and sex among the 47 sample members. Note, the average ages for mothers and fathers are virtually identical. The range is greater for fathers, and one mother (at age 42) tended to skew the female age distribution.

Table 1

Sex and Age of Respondents

	N	%	$\bar{X}$	Range
Mothers	28	59.6	29.1	19-42
Fathers	19	40.4	29.9	19-55
Total	47	100.0		

Table 2

Marital Status and Ethnic Identification of Respondents

	N	%
Single	4	8.5
Married	41	87.2
Divorced	2	4.3
Total	47	100.0
Caucasian	40	85.0
Hispanic	2	4.3
Black	2	4.3
Asiatic	3	6.4
Total	47	100.00

Table 2 represents two additional demographic characteristics of the sample. First, 41 of the 47 sample members were married at the time of the interview, an additional 4 were single, and remainder divorced. Of the six unmarried, five had partners at the time of interviewing. The remainder of Table 2 includes ethnic identification. In this case, 40 of 47 sample members

call themselves "Caucasian" or "White American," with the remainder spread pretty evenly among Hispanic (2), Black (2), and Asiatic (3). In comparing these ethnicity findings with the distribution of ethnic option in the Clark County, Nevada population as a whole, both Black Americans and Hispanic Americans are under-represented (Blacks represent about 11 percent of Clark County households, Hispanics about 5 percent) (D. E. Carns, personal communication, October 1, 1988). This is not a surprising finding considering the research setting was a large, privately-owned hospital. One would suppose that similar research conducted at the large, county-run, not-for-profit hospital which contains a level II NICU, would uncover much higher percentages of Hispanic and Black parents of neonates.

Table 3

Educational Attainment, Employment Status, Occupation, and Annual Household Income of Respondents

Education	N	%
Less Than HS Graduate	4	8.7
High School Graduate	15	32.6
Some College/Trade School	20	43.5
College Graduate or More	7	15.2
Total	46*	100.0
Employment Status		
Full-time	28	59.6
Part-time	4	8.5
Not Employed/Homemaker	15	31.9
Total	47	100.0
Occupation		
Homemaker	11	24.4
Blue Collar	20	44.4
White Collar	11	24.4
Military	3	6.8
Total	47	100.0

Table 3 (continued)

Annual Household Income	N	%
Less than $15,000	4	10.8
$15,000-$24,999	9	24.3
$25,000-$34,999	12	32.4
$35,000-$44,999	4	10.8
$45,000 or More	8	21.6
Total	47	100.0

*Variation from N=47 due to non-responses

From Table 3, one can see the distribution of completed education is similar to all Clark County households; the majority of subjects fall into the high school graduate and some college/trade school categories with relatively few below or above these levels of education (D. E. Carns, personal communication, October 1, 1988). Among males in the sample, about three out of four reported more than high school training compared to 46 percent of females. Data on employment status reveal the majority of the sample were employed full-time (28 of 47), while the unemployed/homemaker category comprises another 15 respondents, the bulk of whom were homemakers.

The sample respondents who were not homemakers, 20 were coded in blue-collar occupations (bartenders, maids, carpenters, etc.) and 11 in white-collar occupations (casino manager, physician, engineer), with the remaining three in the military (one of whom was the mother). Of the 28 mothers in the sample, 17 worked outside the home (60.7 percent); of these, 14 worked full-time and 3 part-time. In terms of annual household income, 13 of 37 respondents who answered this question reported household incomes below $25,000 per year, another 12 fell into the $25,000 to $34,999 range, and 12 earned $35,000 or more per year. The mean annual household income, computed from the income response categories was $31,058 with a range of $9,600 to $70,000.

Table 4

Number of Children at Home, Health Insurance Status, Previous Experience with ICU's, and Previous NICU Experience of Respondents

		N	%
Number of Children at Home			
None		17	36.2
One to Two		17	36.2
Three to Four		13	27.6
Total		47	100.0
Health Insurance Status			
Has Health Insurance		39	83.0
No Health Insurance		8	17.0
Total		47	100.0
Previous ICU Experience			
Yes		22	46.8
Outcome:			
Good	14		
Poor	3		
Death	5		
No		25	53.2
Total		47	100.00

Table 4 (continued)

		N	%
Previous NICU Experience			
Yes		9	19.1
Outcome:			
Good	5		
Poor	2		
Death	2		
No		38	80.9
Total		47	100.0

For 17 of the 47 respondents, the infant in the NICU was their first child; another 17 had one or two children at home; and the remainder (13) had more than two children at home. No parent in the sample had more than four children. Thirty-nine respondents reported having health insurance to cover some or all of their infant's hospitalization. Those lacking health insurance, or whose insurance was inadequate to cover the charges resulting from NICU care, received referrals for public financial assistance. Twenty-two of the participants reported having family members or themselves with

previous experience in ICU's (of any kind). Fourteen of the twenty-two reported a positive outcome from the experience. Nine of the 47 reported previous NICU experience (themselves or close family members). Of those nine, five reported a good outcome from the experience.

Table 5

Respondents Perceived Severity of Infant's Illness, Perceived Support Structure, Where Infant was Born, Religious Preference, and Importance of Religious Faith

	N	%
Perceived Severity of Illness		
Critically Ill	8	17.0
Severely Ill	14	29.8
Moderately Ill	17	36.2
Slightly Ill	7	14.9
Not Ill	1	2.1
Total	47	100.0
Perceived Support Structure		
Yes	40	85.1
Yes, but not always avail.	6	12.8
No	1	2.1
Total	47	100.0
Where Infant was Born		
Inborn	26	55.3
Outborn	16	34.0
Admission from Home/MD	5	10.7
Total	47	100.0

Table 5 (continued)

	N	%
Religious Preference		
Catholic	13	28.4
Protestant	26	56.5
Jewish	2	4.3
Other	2	4.3
None	3	6.5
Total	46*	100.0
Importance of Religious Faith		
Very Important	33	71.7
Somewhat Important	12	26.1
Not Important	1	2.2
Total	46*	100.0

*Variation from N=47 due to non-responses.

Twenty-two subjects perceived their infant's illness to be severe or critical in nature, while the remainder felt that the illness was less severe. Forty of the 47 respondents reported having a full-time working support structure, six more said their support structure was "not always available when it was needed," and only one

reported no support structure at all. Twenty-six of the 47 birth episodes occurred within the hospital containing the NICU when this research was conducted. Another 16 birth episodes involved children who were transported into the unit from another hospital. The remaining five birth episodes were either readmissions from home or from a physician's office.

In terms of religion, the 28 percent who report Catholicism and the 56 Protestant correspond closely with reported estimates from the University of Nevada State Poll, Clark County data segment. The two people who reported "other" were Jehovah's Witnesses. The importance of respondents' religious faiths presented an interesting pattern: 71.7 percent of all subjects said religion was "very important" in their lives; this broke down to 86 percent of the females answering religion was very important versus 50 percent of male respondents. Note only one respondent said that religion was not important.

RELIABILITY-VALIDITY TESTING

To assess the reliability of the Parent Stressors Scale: Neonatal Intensive Care Unit (PSS:NICU) and its

four sub-scales (Sights and Sounds, Infant's Appearance and Behavior, Role Alteration, and Staff Relations), Cronbach's alpha coefficient of internal consistency was computed for the five scales. Alpha measures the extent to which the outcome on any item on an instrument is an accurate indicator of the outcome on any other item; that is, it is the mean of all possible split-half coefficients derived from any particular set of subjects. Table 6 presents the results from this analysis along with alpha coefficients reported by Miles (1987) when she developed the tool.

Table 6

Alpha Coefficients for PSS:NICU and Four Sub-scales for Present Study (n=47) and Study by Miles (1987) (n=206)

	Mattson n=47	Miles n=206
PSS:NICU	.91	.88
Sights/Sounds (5)*	.75	.74
Infant Appearance/Behavior (19)	.83	.87
Role Alteration (11)	.83	.80
Staff Relations (11)	.89	.81

*Number of items within sub-scale contained in parentheses.

The coefficients for the sub-scales and the total PSS:NICU are comparable with Miles' findings even though the sample size for the present study was much smaller than Miles' sample of 206 (Table 6). Note the coefficients in the total scale and the subscale exceed .70 for the present sampling as well as the coefficients reported by Miles (1987).

To test external validity of the PSS:NICU and the sub-scales, each was correlated with "state anxiety" scores obtained from the State-Trait Anxiety Inventory (Spielberger et al, 1983). Pearson Product-Moment

Correlation Coefficients were computed and are presented in Table 7 along with equivalent findings from Miles (1987).

Table 7

Pearson Product-Moment Correlation Coefficients Between PSS:NICU and Sub-Scales with State Anxiety Scores, Two Samples

	Mattson n=47	p	Miles n=206
PSS:NICU	.64	.001	.42
Sights/Sounds	.29	.024	.48
Infant Behavior/Appear	.48	.001	.43
Role Alteration	.39	.003	.43
Staff Relations	.63	.001	*

*Not reported

Miles (1987) was not precise in reporting the significance of the correlation coefficients between the PSS:NICU scales and State Anxiety Scores but reported all were significant at or below p = .01 (the probability that chance alone could reproduce these findings is one in one hundred or less). She did not report a correlation coefficient between the Staff Relations sub-

scale and State Anxiety Scores due to a relatively low number of parents in her study who had experienced the items contained in the Staff Relations sub-scale.

For the present sampling of sub-scale responses (n=47), the correlation between Staff Relations and State Anxiety was the largest found r=.63, and this in turn created an impact on the overall correlation coefficient between PSS:NICU and State Anxiety: r=.64, much higher than the same correlation reported by Miles (minus Staff Relations) of r=.42.

The sub-scale of Infant Behavior/Appearance and Role Alteration produced correlation coefficients similar to those of Miles' study. In contrast, the Sights/Sounds sub-scale in the present study revealed a much lower correlation (r=.29) with State Anxiety than found in Miles' study (r=.48). This difference could be due to the unstable sampling of items (k=5 for this sub-scale), sampling error in the present sample, physical differences in the NICU's where the respective samples were selected and measured, mode of administration of questionnaires, inclusion of parents of infants who were full-term, and one NICU versus five different units in Miles' study. Much of this must remain speculative since

demographic profiles of Miles' sample are not available in the abstract.

Miles and her associates did not report correlation coefficients between the PSS:NICU plus sub-scales and the Parent/Child Uncertainty Scale (PCUS) plus four sub-scales. Correlations between these scales and sub-scales for the present study (n = 47) are presented in Table 8.

Table 8

Pearson Product-Moment Correlation Coefficients
Between PSS:NICU/Sub-Scales and
PCUS/Sub-Scales

	Sub-Scales				
	PCUS	Ambig	Complex	Lack	Unpred
PSS:NICU	.35*	.26*	.40*	.30*	.22
Subscales					
Sights/Sounds	.10	.02	.12	.17	.15
Infant Behav	.22	.22	.10	.24	.19
Role					
Alteration	.23	.62*	.11	.01	.23
Staff					
Relations	.40*	.35*	.36*	.30*	.26*

*p < .05

The total scales PSS:NICU and PCUS were correlated ($r=.35$, $p=.007$). The sub-scale Staff Relations of the PSS:NICU scale was significantly correlated with all four sub-scales of the PCUS as well as the overall PCUS scale. Since the items of the sub-scale focus on the parent gaining comprehensible information from staff members, it is not surprising these significant correlations resulted. Mishel's PCUS measures uncertainty from four sources: (1) Ambiguity: the inability to place an event within a comprehensible Gestalt, vagueness, inconsistencies; (2) Complexity: the inability to understand due to incomplete explanations, explanations too technical to comprehend; (3) Lack of Information: insufficient information due to lack of sharing and/or lack of information available; (4) Unpredictability: inability to determine or imagine the outcome of the illness (Mishel, 1983). These sources of stress are closely related or integrated into the Staff Relations items on the PSS:NICU as for example "staff using words I don't understand" and "staff telling me different (conflicting) things about my baby" and "difficulty in getting information or help when I visit or telephone the unit" (see Appendix D for more detail).

The significant correlations between the PCUS scales and the Staff Relations scale adds to the validity of the latter. Further, the correlation between PCUS and the PSS:NICU scales (overall) is probably due primarily to the strength of the correlations between Staff Relations and the components of the PCUS scale.

The significant correlation between Role Alteration and Ambiguity ($r=.62$, $p=.001$) may be due to conceptual overlap between these two dimensions since the more ill the infant appears to be to the parent, the less the person can "parent" the infant and thus, the more confused they will be about multiple disease entities, treatment modalities, and the personnel involved. The lack of comprehension on behalf of the parent would likely affect the parents' perceptions of their roles as parents. The Ambiguity sub-scale contains items such as "the results of my child's tests are inconsistent" and "the effectiveness of treatment is undetermined" and "it's difficult to determine how long it will be before I can care for my child myself" (Appendix F). All these items are related to elements of the sub-scale Role Alteration of the PSS:NICU ("feeling hopeless about how to help my baby during this time"; "being unable to

protect my baby from pain and painful procedures"; "being afraid of touching or holding my baby" (Appendix D). Further, the Ambiguity sub-scale items total 13 and it is the largest sub-scale of the PCUS.

Since the Parent/Child Uncertainty Scale (PCUS) is a relatively new scale with little reliability or validity testing reported, Cronbach alpha coefficients were computed for the overall PCUS and four component scales, and the results were compared with the same data reported by Mishel (1987). This information is contained in Table 9.

Table 9

Comparisons of Reported PCUS Mean Scores, Standard Deviations, and Alpha Coefficients Between the Present Study (n=47) and Mishel (1987) (n=42)

	Mattson n=47			Mishel n=42		
	$\bar{X}$	SD	A	$\bar{X}$	SD	A
PCUS	79.1	20.9	.93	79.6	20.4	.93
Ambiguity (13)*	32.8	11.2	.91	35.4	11.3	.90
Complexity (9)	20.7	6.3	.80	19.2	6.5	.83
Lack of Info. (5)	12.1	4.1	.75	11.3	4.0	.79
Unpredict-ability (4)	13.4	3.3	.71	13.8	3.4	.79

*Number of items within sub-scale contained in parentheses.

The two sample sizes are quite similar with comparable means and standard deviations for the scale and sub-scales. The only comparison between two alpha coefficients that yields a noteworthy difference is the Unpredictability sub-scale; the overall scales and sub-scales do not differ by more than .04 between the two studies. Since information is lacking about Mishel's research techniques including instructions on the use of

the PCUS instrument, one cannot use such comparisons to account for the slight discrepancies noted. The present replication of Mishel's scales suggests that the reliability of the scales (as measured by internal consistency) has been reconfirmed.

FINDINGS RELATED TO RESEARCH QUESTIONS

Research Question 1: What are the sources of stress for parents in the NICU environment?

Recall the PSS:NICU was selected as the most appropriate existing instrument to measure overall stress and specific aspects of stress in the NICU environment from the point of view of parents. The PSS:NICU contains 46 separate items which break into four separate sub-scales of 19, 11, 11, and 5 items respectively for Infant Appearances/Behaviors, Role Alteration, Staff Relations, and Sights/Sounds. Table 10 presents results of the administrations of these scales from the sample of 47 parents and includes mean scores, standard deviations, and the mean percentage of the total possible score on the overall scale and sub-scales.

Table 10

PSS:NICU Overall and Sub-scale Mean Scores, Standard Deviations, and Percentage of Total Possible Score (n=47)

	$\bar{X}$	SD	% of total possible score
PSS:NICU	86.88	31.41	38
Sights/Sounds (5)*	11.55	3.90	46
Infant Appearance/Behav.(19)	35.43	15.46	37
Role Alteration (11)	10.26	9.32	19
Staff Relations (11)	29.45	12.87	54

*Number of items within the sub-scale contained in parentheses.

First, Staff Relations emerge as the single most stressful dimension of the PSS:NICU as measured by the percent of total possible response (higher the score, more the stress). Sights and Sounds was second highest in stressfulness using the same indicator. Role Alteration, judging by the very high standard deviation and relatively low mean value, does not adequately discriminate stress in this sample (n=47) due to the high

percentage of zero ("not experienced" = 51.6%) responses.

Research Question 2: Are there differences in source of stress between mothers and fathers of infants in the NICU setting?

Of the 47 respondents in the present study, 18 were fathers and 29 mothers. Since the PSS:NICU and its sub-scales can be treated as interval measures, t-tests were computed on sub-groups of mothers and fathers. Table 11 presents t-test findings for mother/father sub-groups in relation to the five scales.

Table 11

PSS:NICU and Sub-scale Mean Scores and t-test Results for Sub-groups of Mothers and Fathers of Infants in the NICU setting (n=47)

	$\bar{X}$	SD	t	p
PSS:NICU				
Mothers	96.1	32.7	2.80	.008*
Fathers	71.5	22.8		
Sights/Sounds				
Mothers	12.2	4.2	1.56	.126
Fathers	10.4	3.3		
Infant Appear/Behav				
Mothers	38.7	16.7	1.89	.066
Fathers	30.2	11.9		
Role Alteration				
Mothers	10.9	9.5	0.63	.534
Fathers	9.2	9.1		
Staff Relations				
Mothers	34.2	11.6	3.64	.001*
Fathers	21.7	11.2		

The significance of the difference in mean scores between mothers and fathers on the overall PSS:NICU scale (p=.008) was influenced to a large degree by the significance of the gender difference on the sub-scale Staff Relations (p=.001). Further, the difference in mean scores between mothers and fathers on the Infant Appearance/Behavior sub-scale (p=.066) approaches the pre-determined alpha error criterion of .05.

Research Question 3: Are there differences in sources of stress among parents of preterm infants and term infants admitted to the NICU?

In the final sample of 47, there were 19 parents of full-term infants and 28 parents of premature infants. These two sub-groups were compared in a t-test model similar to the one used to answer research question number two. These findings are presented in Table 12.

Table 12

PSS:NICU and Sub-scale Mean Scores and t-Test Results for Sub-groups of Parents of Preterm and Full-Term Infants (n=47)

	$\bar{X}$	SD	t	p
PSS:NICU				
Preterm	94.0	33.7	1.99	.053
Full-Term	76.0	24.9		
Sights/Sounds				
Preterm	11.8	4.5	0.57	.573
Full-Term	11.2	2.9		
Infant Appear/Behav				
Preterm	37.8	15.2	1.26	.215
Full-Term	32.0	15.7		
Role Alteration				
Preterm	12.9	10.4	2.80	.008*
Full-Term	6.3	5.7		
Staff Relations				
Preterm	31.5	13.3	1.31	.195
Full-Term	26.5	11.9		

Sources of stress for parents -- mothers and fathers alike -- are compared in Figure 1. Score means are presented in the bar graph and, since there are differing numbers of items in the sub-scales, a percentage of total possible score is given. In Figure 2, sources of stress for parents of preterm and full-term infants are presented in the same fashion as in Figure 1.

Figure 1

Percent of Total Possible Scores for PSS:NICU for Mothers, Fathers, and Total Sample

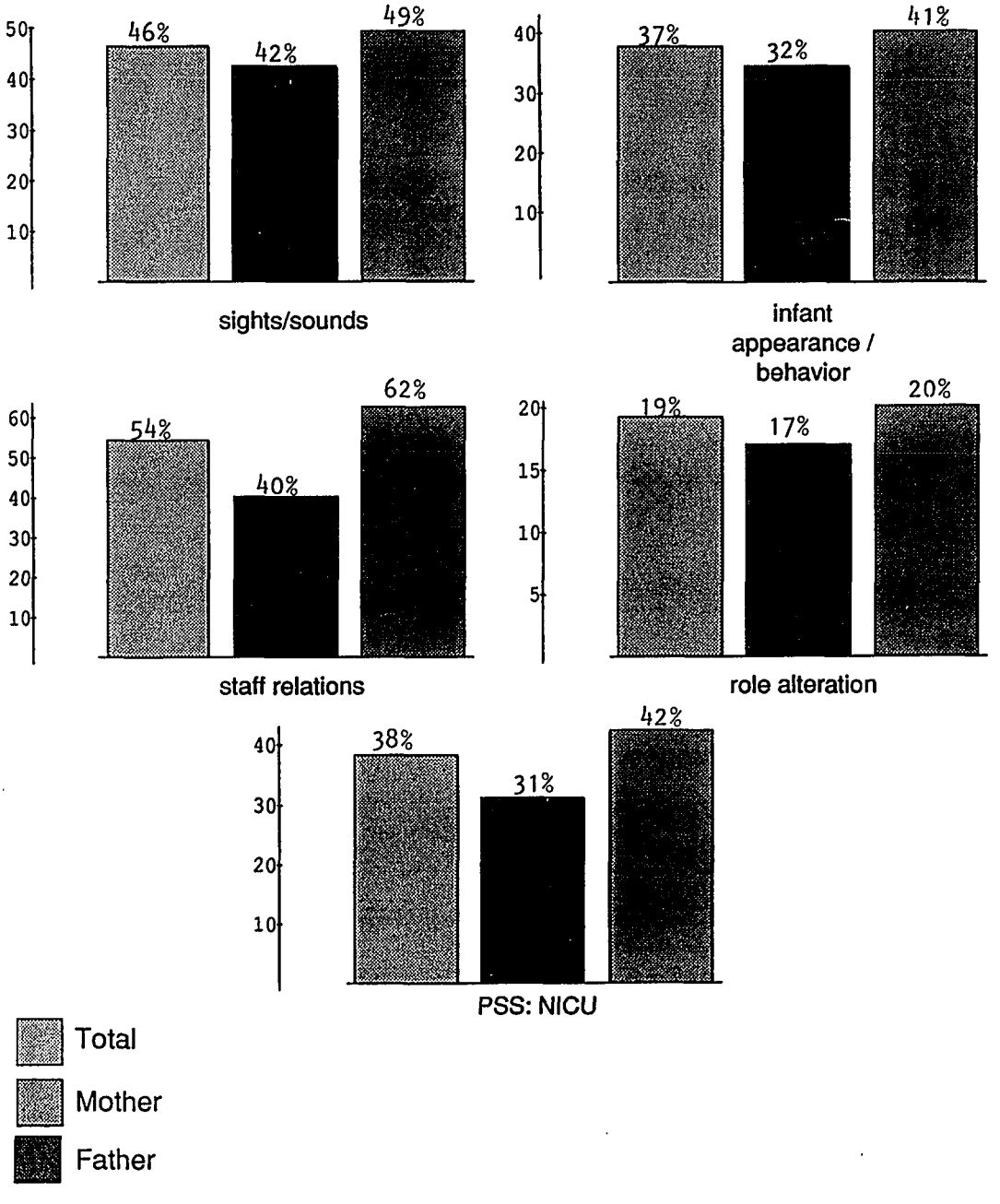
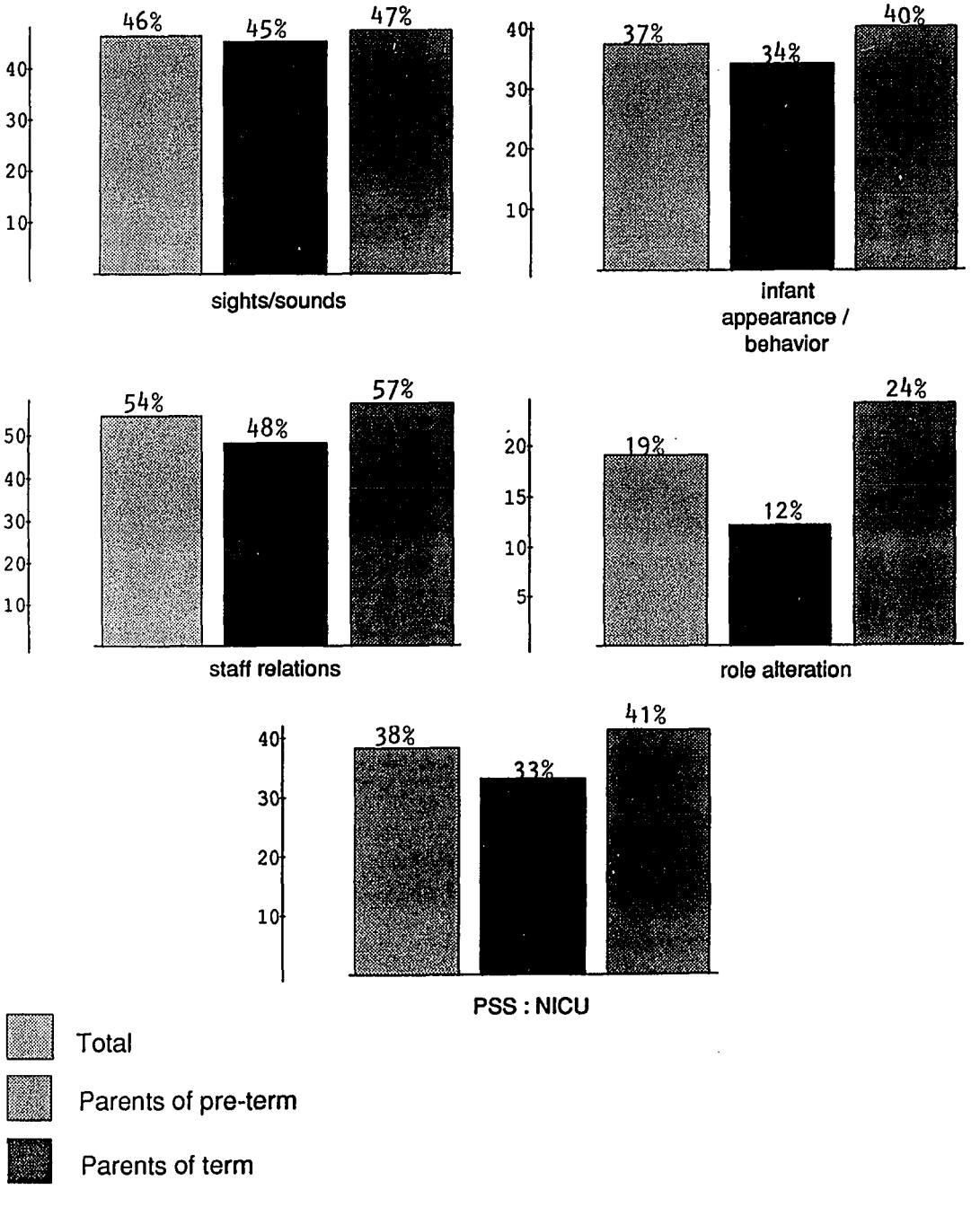


Figure 2

Percent of Total Possible Scores for PSS:NICU for Parents of Preterm Infants, Full-term Infants, and Total Sample



The t-test results revealed the sub-scale Role Alteration to be significantly different in value for the two groups of parents (parents of preterm and parents of full-term infants) (p=.008). The total PSS:NICU approached significance at .053.

Research Question 4: Since the PSS:NICU may relate overall to the differences in sub-groups such as mother/father and parents of preterm/full-term infants, will these significant differences in the responses from the sub-groups remain after controlling for Trait Anxiety scores?

Trait Anxiety Scales were designed to measure background (individualized) states of anxiety in respondents, presumably prior to their experiencing situations causing stress. Table 13 presents an Analysis of Covariance in which the PSS:NICU scale (overall) is the criterion variable (measure of stress), parental gender and preterm/full-term of infant are predictors, and Trait Anxiety is the covariate (control). If significant differences remain between sub-groups of mothers vs. fathers and parents of preterm vs. full-term infants after removing effects of background sources of

anxiety, the findings in Research Questions 2 and 3 will have more validity.

Table 13

ANCOVA Results of PSS:NICU by Respondent Sex and Infant Gestational Age Category with Trait Anxiety Scale as Covariate (n=47)

Source of Variation	MS	F	p
Covariate (Trait)	8516.2	11.6	.001
Main Effects	3014.5	4.1	.023
Sex (Mothers/Fathers)	4830.8	6.6	.014
Preterm/Full-term	1073.9	1.5	.233
Two-Way Interaction	43.5	0.1	.809

The gender groups (mother/father) differ significantly on the PSS:NICU measure of stress even when the effects of Trait Anxiety are removed (p=.014). There was no significant preterm/full-term difference remaining after removing the effects of trait anxiety, nor was there any two-way interaction effect between sex and gestational age on the PSS:NICU.

OTHER FINDINGS

The State-Trait Anxiety Index is a standardized measurement tool; thus further validity and reliability testing was not done. The mean Trait Anxiety score for the sample of parents (n=47) was in the 76th percentile range for working adults in the age range 19-39 years (which covers the majority of the present study's participants). The mean State Anxiety score for the sample was in the 85-86th percentile range (Spielberger et al, 1983). This would suggest the parents in the sample were experiencing anxiety at the time of completing the questionnaires and that they may have a susceptibility to stress as evidenced by the elevated mean Trait Anxiety score. Spielberger et al (1983) does not report significant differences between the sexes for working adults. Table 14 tabulates mean scores for the total sample and each of the four sub-groups.

Table 14

State and Trait Mean Anxiety Scores for Total Sample (n=47) and Four Sub-groups

	State $\bar{X}$	Trait $\bar{X}$
Mothers (n=28)	52.07	43.14
Fathers (n=19)	42.17	40.06
Parents/Full-Term (n=19)	43.21	37.95
Parents/Pre-Term (n=28)	51.71	44.68
Total Sample (n=47)	48.28	41.96

To compare mean scores between these group pairings from Table 14, t-test statistics were computed. Mothers had higher mean scores than fathers on both State and Trait Anxiety Scales, but only the State Scale difference (52.07 versus 43.14) was statistically significant (p=.04). Parents of premature infants had higher mean anxiety scores on both State and Trait Scales, but only the Trait Scale difference in means (44.68 versus 37.95) was significant (p=.04).

In addition to the PSS:NICU, data from the PCUS was also analyzed. The PCUS mean scores, standard deviations, and alpha coefficients for this sample were

very comparable to findings reported by Mishel (1987). The PCUS overall mean score of this study sample (n=47) was 79.1 compared to Mishel's sample (n=42) of 79.6 (Table 9). The percentage of total possible score values for the PCUS scale in this study (n=47) was 48 percent (that is, of the entire possible score, the average person attained 48 percent; this controls for number of items in the sub-scales). The total possible percent scores for each of the sub-scales are given in Table 15.

Table 15

PCUS Sub-scales; Average Percent of Total Possible Scores; (n=47)

	% of total possible score
Ambiguity (13)*	42%
Complexity (9)	46%
Lack of Information (5)	48%
Unpredictability (4)	67%

*Number of items within sub-scale contained in parentheses.

Nineteen of the subjects reported experiencing concerns not included in the scales at the time of participation in the study. Some of these subjects reported their concerns by answering the open-ended question on the demographic data form. The concerns and the number of subjects identifying the concern were as follows: Ten subjects reported financial concerns; three subjects listed concerns about their ability to parent well; two subjects identified concerns about illnesses in family members other than the NICU infant; two subjects were concerned about new jobs/positions for themselves or spouse; and two subjects were concerned about a planned move to a new location. The concerns which directly related to the NICU experience were financial concerns and the concern about the ability to parent well.

The open-ended question included in the PSS:NICU, "Was there anything else that was stressful for you during the time that your baby has been in the neonatal intensive care unit?" resulted in the following responses: Six subjects felt stress about the uncertainty surrounding their infants' diagnoses, tests, procedures, and anticipated length of stay; five subjects felt stress from the questionable quality of

medical/nursing care; three subjects were experiencing stress related to the possible side effects from their infant's therapies; two subjects were also concerned about other family members who were ill. Isolated concerns included the infant being transported from the hospital where the mother was a patient, the NICU visitation policy considered too strict, concern for other parents in the unit, and the congestion in the unit (crowding).

Most of the concerns written in the PSS:NICU open-ended question related to parents' lack of knowledge about their infants' condition, treatments, and test results. Lack of confidence in the caregivers as well as the responses concerning lack of information conceptually related to the Staff Relations sub-scale (the highest scoring source of stress for the sample subjects). The concern about separation from the infant is a reiteration from an item in the Role Alteration sub-scale. The concern about other parents, the visitation policy, and the unit congestion are not items included in the PSS:NICU.

The PSS:NICU also contained a broad question asking the parents how stressful in general the total intensive

care unit had been for them. The answers to the overall stress question from the PSS:NICU instrument resulted in a mean response of 3.5 (3=moderately stressful and 4=very stressful).

In addition to the variables introduced in the four research questions, a number of additional variables, thought to possibly create an impact on stress levels of parents, were measured in the present study (n=47). These included:

1. Whether this child was the first for the parents.
2. Previous NICU experience within the family.
3. Previous ICU experience within the family.
4. Whether the child's hospitalization was covered by insurance.
5. Family annual income (35,000 or less; more than $35,000).
6. Educational attainment of the parent (high school or less; more formal education).
7. Parent's perception of support systems or not.
8. Whether the child was born in the research site hospital or not.
9. Number of visits made by parents to the NICU (8

or less; more than 8 visits).

10. Severity of child's illness as perceived by parents: critically or severely ill vs. moderately to mildly ill.
11. Perceived importance of religion in the life of the respondent: very important vs. somewhat or not important.

Of these potential predictors of NICU stress, only the last two proved to be significantly related using the t-test distribution as a criterion. For example, severity of illness of the child discriminates the Staff Relations sub-scale such that those whose child was more ill scored a mean of 33.6 while parents with children who were less ill had a mean value of 25.8 ($p=.037$). And those parents who considered religion to be very important in their lives scored a mean value of 32.2 on the Staff Relations sub-scale as compared to a mean of 22.9 for parents whose religious feelings were not so strong ($p=.027$).

SUMMARY

This chapter presented the demographic data to describe the subjects and findings in relation to the

research questions. Parents who were the subjects of the study rated the PSS:NICU sub-scale Staff Relations as the most stressful aspects of the NICU experience addressed within the PSS:NICU tool. Mothers had higher mean scores on each of the PSS:NICU sub-scales than fathers with significant differences from fathers for the PSS:NICU overall scale and the Staff Relations sub-scale.

Parents of preterm infants had higher mean scores than parents of full-term NICU infants on each of the PSS:NICU sub-scales, with the mean score of the sub-scale, Role Alteration, significantly higher for parents of preterm infants.

As further indicators of experienced stress, mothers had higher mean scores for State and Trait Anxiety inventories with State Anxiety significantly higher. Parents of preterm infants had higher mean scores for both Anxiety inventory scales with Trait Anxiety significantly higher.

CHAPTER V

DISCUSSION

The purpose of this study was to identify sources of stress in the NICU environment for parents. Research questions included identifying the sources of stress and then comparing sub-groups (mothers and fathers; parents of full-term infants and preterm infants). A review of related literature included numerous sources of stress for family members of patients of all ages requiring intensive care. Frequently cited sources of stress included the needs of family members to receive accurate information, to visit the patient, to feel there is hope, to believe the patient is receiving the best possible care, and to feel staff care about the patient. For parents, the disruption in the parenting role was a major concern.

The exploratory research design incorporated a convenience sampling of parents whose infants were admitted to a NICU. The PSS:NICU was the primary instrument applied to measure sources of stress. The

PCUS and the STAI were also administered for reliability and validity testing purposes.

DISCUSSION

The data identified and clarified sources of stress for parents of an infant in the NICU. The PSS:NICU instrument provided the sub-scales and items which identified specific sources of stress for parents. The PCUS and the STAI were helpful in further validation of the PSS:NICU instrument while also providing additional insight into the subjects of the study.

The mean scores of State and Trait anxiety were found to be in the 76th to 86th percentile range when compared to normal working adults used to provide norms for these scales (Spielberger et al., 1983). This finding supports the literature review that parents are anxious when their children receive NICU care. Daley (1984) reported family members of critically ill patients stated their need for relief of anxiety was their primary concern. Parental anxiety in the NICU may increase with the perceived severity of illness of their infant. In the present study, parents who felt their infant was critically or severely ill (compared to those who

perceived severity as moderately or slightly ill) had significantly higher state anxiety scores (p=.034). The comparison of mean Trait Anxiety Scores revealed an elevated mean score for parents who perceived their infant more ill but not a significant difference level.

The elevated trait anxiety scores for the parents in the sample may be a reflection of a higher predilection to stress, or it may be a product of a changed perception of their normal feelings due to the stress they were experiencing at the time of completing the research forms. Thus, the latter point of view supports a higher intercorrelation between State and Trait anxiety scales. Spielberger et al. (1983) reported a .75 correlation between the two scales for working men (age 19-35) and a .70 correlation for working women (age 19-35). This study revealed comparable correlation of .82 for fathers and .69 for mothers.

Although the sub-scale of Unpredictability received the highest mean percentage of total score of the PCUS instrument, the sub-scale consists of only four items (the smallest of the four sub-scales under PCUS), thus rendering it rather unstable in this regard (Table 15). However, Miles (1987) also reported the sub-scale of

Unpredictability received the highest scores in her findings (n=206). The lack of prior experience with the NICU setting leaves parents with little or no experience resources for coping with the situation. The day-to-day events confuse parents since the infant's progress is often not consistent. Caregivers may attempt to simplify information they give to parents in order to avoid overwhelming them with too much information, often of a technical nature, at one time. The result may be that the parent receives additional and sometimes conflicting information with each visit. Parents become confused about what to anticipate next in their infant's condition. In critical care settings, especially neonatal intensive care units, setbacks are common for the patient. Parents, therefore, may find few evidences of their infant's improvement. To further compound the problem, caregivers may view the infant's condition differently from one another as well as express themselves differently to the parent.

The significant difference on the Staff Relations sub-scale of the PSS:NICU (p=.037) between the parent groups who considered their infants critically or severely ill versus parents who considered their infants

moderately to mildly ill may well be explained by the consideration that the more ill a parent perceives the infant, the more emotional demands he/she may make on visible and important staff members who are the caregivers responsible for the infant.

The significant difference on the Staff Relations sub-scale (p=.027) between parents who identified religion as very important versus parents who identified religion as somewhat important or not important may be a spurious finding due to the gender variable since mothers identified themselves as more religious than fathers as mentioned earlier.

RESEARCH QUESTION 1: What are the sources of stress for parents in the NICU environment?

The PSS:NICU scale and it's four sub-scales' scores from this sampling of subjects revealed the sub-scale Staff Relations to be the highest source of stress for the parents (Table 10). The mean score for this sub-scale was 29.5 for the total subjects (n=47) which was 54% of the total possible score for the sub-scale (Figure 1). Miles (1987) reported her sample subjects (n=206) rated the Staff Relations sub-scale less stressful than the sub-scales of Role Alteration and

Infant Appearance/Behavior. The items in the Staff Relations sub-scale focus on parental perceptions of receiving understandable information and staff appearing not competent or caring enough. The sub-scale correlated with the total PCUS score and each of the PCUS sub-scales at $p<.05$ ($r=.40-.26$) (Table 8). These correlations are not surprising since the PCUS is conceptually related to the parent's understanding of the infant's condition and a need for confidence in the staff to keep the parent informed (the major themes to the items within the Staff Relations sub-scale).

The staff with whom the present study's subjects had primary contact was nurses. Most of the nurses were registered nurses (91%) as opposed to licensed practical nurses, and the majority of the nurses worked twelve-hour shifts. The nurses were usually assigned to the same patients during their work-week (usually three days) but were frequently assigned to different patients after returning to work after off days. The result was a variety of nurses cared for the same infant over the hospital length of stay.

The parents included in the study usually visited their infant every day according to self-reporting on the

study's demographic data form. The parents also telephoned the NICU often and spoke with the nurse caring for their infant (this data was obtained from the infant's medical chart). Although physicians were available in the NICU twenty-four hours a day, they were not as accessible at the infants' bedsides as the nurses. During the three month sampling period, the NICU was very busy (full capacity) and the nursing shortage frequently required the nurses to be assigned to more patients than the unit's nurse/patient ratio standard recommends.

Therefore, the results from the Staff Relations sub-scale may be a reflection of the variety of caregivers to whom the parents were exposed, the increased nursing responsibilities which may have caused hurried or no explanations to the parents, and little time by the staff to provide parents with emotional support. Since the sub-scale did not differentiate caregivers (i.e., nurses or physicians) some parents may have considered the lack of or confusing information as coming from physicians and not nurses.

Further, the parents were under stress as determined from the State Anxiety scale and this may have affected their comprehension of the information given to them.

Even though the equipment and treatments may have been explained to parents, the parents may not have asked for further clarification in order to avoid appearing unintelligent, inattentive, uncaring or a bother to such a busy staff. Waechter (1987) stated this is a time of crisis and great anxiety for parents which may distort their perceptions resulting in greater vulnerability and sensitivity to people around them. Kasper and Nyamathi (1986) identified parents need to receive frequent information about the child's condition which is truthful and accurate. This sharing of information from the staff builds trust between parents and caregivers and provides the parents with assurance the infant is receiving quality care. Through the sense of assurance parents may find hope, a prevalent need for family members of the critically ill patient (Molter, 1979; Daley, 1984; Norris & Grove, 1986). Further, some parents may search for more and more information about their infant in order to cope with the situation on an intellectual level rather than on an emotional level (Lewandowski, 1980).

The Staff Relations sub-scale consisted of eleven items. Item analysis revealed only one item had more than 50% of the sample responding "not experienced" with

an average response for the sub-scale of "not experienced" of 23.2%. The fact that more parents had experience with most of the items brought the mean score higher. The awareness that some of the items on the PSS:NICU scale had a high incidence of "not experienced" responses must be tempered with the awareness a parent cannot experience stress unless he/she is exposed to the source of the stress. Therefore, the PSS:NICU results require item analysis in order for the researcher to discover whether low scores are a reflection of the subjects not experiencing stress or not being exposed to the stressors.

The second highest rated sub-scale as a source of stress for the subjects was Sights/Sounds with a mean score of 11.6 accounting for 46% of the total possible score for the sub-scale. This sub-scale identified physical sources of stress for the parent in the NICU environment. The NICU from which the sample subjects were drawn was an open ward with bright fluorescent lighting, many pieces of equipment (each with lights and audible alarms), and patients located in close proximity to one another. The unit was often noisy due to the monitoring equipment, telephones, and many staff members

on duty. Oehler (1981) stated parents are often awed and intimidated by the equipment and level of activity in the NICU.

The Sights/Sounds sub-scale was the smallest sub-scale of the PSS:NICU and contained only five items. There were no items with more than 50% of the subjects responding "not experienced" and an overall mean response of "not experienced" of 19.6%. The low "not experienced" response rate reflected the commonality of the experiences contained in the items of the sub-scale for the sample subjects. This is also true of the Staff Relations sub-scale.

The sub-scale Infant Appearance/Behavior mean score for the total sample was 35.4 which accounted for 37% of the total possible score for the sub-scale. This sub-scale contained items pertaining to the parent's perceptions of how the infant looks and behaves while in the NICU setting. Waechter (1987) reported parents feel deeply about how their ill child looks. The parents often feel helpless and powerless in their ability to reduce the perceived or actual pain and suffering of their infant yet feel a strong need to protect their child (Lewandowski, 1980).

The Infant Appearance/Behavior sub-scale contained nineteen items (much larger than the other sub-scales of the PSS:NICU). There were nine items in the sub-scale to which 50% or more of the subjects responded "not experienced." For instance, 91.5% of the subjects responded they had not experienced seeing their infant stop breathing. The average "no experience" responses for the sub-scale was 41.8%. The higher percent of "no experience" responses, of course, lowered the mean scores considerably.

The sub-scale of Role Alteration contained eleven items with a mean score for the total sample of 10.3. The percent of total possible scores was only 19%, the lowest score in the PSS:NICU for these sample subjects. After item analysis of the sub-scale, it was discovered eight of the eleven items had 50% or more responses of "not experienced." The average percent of "not experienced" for the sub-scale was 51.6%, accounting for the low mean score.

Disruption in the parenting role due to the illness of the infant or child was cited in the literature as stressful for parents (Lewandowski, 1980; Stevens, 1981; McGovern, 1984). The mean scores from the sample

subjects for the present study may not have reflected their anxiety from their inability to "parent" their infant as they would have preferred, but, rather, the confusing or inadequate wording of the sub-scale's items may have had an effect. For example, 57.4% answered "not experienced" to the item "Being separated from my baby." Of course, the parents in the sample were separated from their infant but they may have felt the proper answer was "not experienced" since they were able to visit their infant or they understood and accepted the reasons necessitating the separation. The item "Not being alone with my baby" received 51.1% responses as "not experienced." Again, the parents did not have the opportunity to be alone with their infants. But some parents may have considered being alone with their baby as time when the nurse was not at the bedside. Further refinement of the items may be in order before future research is conducted with the instrument.

RESEARCH QUESTION 2: Are there differences in sources of stress between mothers and fathers in the NICU setting?

In comparing the sub-groups of mothers and fathers of the sample, t-test results revealed mothers had higher mean scores on the total PSS:NICU instruments as well as

on each of the PSS:NICU sub-scales (Table 11, Figure 1). The differences between the two groups was significant for the total instrument (p=.008) and for the sub-scale Staff Relations (p=.001). Miles (1987) reported no significant differences between mothers and fathers on the PSS:NICU instrument.

The differences between mothers and fathers scores on the Staff Relations sub-scale may, in part, be attributed to the researcher's impression mothers visit their infant more often and have longer visits than fathers (although this data was not collected for this study). Therefore, mothers may have more contact with the staff than fathers.

There are many differences between mothers and fathers which may also account for these differences. The mother has experienced the psychological and physiological changes of pregnancy and childbirth. Her own health and sense of well-being may have affected her responses on the PSS:NICU instrument. Further, feelings of guilt at not delivering a healthy baby is a pervasive response from parents, especially mothers whose sense of self-esteem is partially related to successful reproduction. One mother wrote, "What did I do wrong to

cause this? Why am I such a failure as a childbearer? Will I ever be able to have a normal pregnancy?" (Cohen, 1982, p. 17). Oehler (1981) reported grief is a common response when parents are confronted with an infant who does not match their fantasies prior to the birth with a resulting sense of failure rather than pride.

A mother may feel the staff have taken over the care of the infant and she is left with little "mothering" to perform. Some jealousy or resentment could incur. Cohen (1982) wrote, "As caring as the nurses are to the babies, a parent may view this as threatening and resent the bond" (p. 24).

Further, mothers express more feelings of grief (crying, sadness, guilt, anger) than fathers (Gardner & Merenstien, 1986). Fathers, however, may experience the same feelings as mothers but be less expressive. The decreased expression on behalf of fathers may have attributed to some of the differences between mothers and fathers on the PSS:NICU instrument.

In comparing mothers and fathers, the mother's family role is drastically changed with the birth of a sick infant. She was expecting to be primary caregiver to her baby but, instead, feels a void while the infant

remains hospitalized. On the other hand, the status of the father remains unchanged, he continues to go to work, etc. This is not to dispel the effects on the father. However, societal expectations for fathers includes his being strong and avoiding the show of emotion. The results can be an increased sensitivity to the NICU experience for mothers than fathers. Further, the mothers had higher mean scores on both State and Trait anxiety scales than fathers with the differences in the State scale significant (p=.04) (Table 14).

In addition to the previously mentioned differences between mothers and fathers comprising the sample subjects, the wording of the PSS:NICU items often included the terms "my baby" which may be more biased to mothers than to fathers. Fathers often use the terms "our baby" or the infant's given name when referring to the infant. If the wording was more sensitive to mothers, the fathers may have related less to the items due to perceiving them as more pertinent to mothers.

RESEARCH QUESTION 3: Are there differences in the sources of stress for parents of preterm infants and full-term infants admitted to the NICU?

The study sample consisted of nineteen parents of

term infants and twenty-eight parents of preterm infants. The mean scores for the PSS:NICU and it's sub-scales revealed parents of preterm infants had higher mean scores than parents of term infants for the total PSS:NICU scale as well as for each of the instrument's sub-scales. The sub-scale Role Alteration was the only scale in which the difference between the sub-groups was significant (p=.008) although the total PSS:NICU scores neared significance (p=.053). The differences in the sub-scale Role Alteration may be due to the differences in the premature infant as compared to the term infant. The premature infant is smaller, usually more ill, more likely to require ventilatory support and a neutral-thermal environment (incubator) causing the parent to participate less in the infant's care than parents of the term infants who usually are larger and more stable. The technology required for the support of the very small or very ill infant often serves as a barrier between the parent and the infant (Philipp, 1983). The parents of preterm infants also had higher mean scores on both the State and Trait Anxiety scales (Table 14). Only the differences between the Trait anxiety scores were significant (p=.04). The cause for the higher mean Trait

score for the preterm parent group is uncertain but could be related to the higher State Anxiety Score.

However, due to the large mean percentage of "not experienced" (51.6%) for the sub-scale and the small number of subjects, more research would be necessary before further generalizations could be made. The gender of the parents for the parents of the preterm and the term parent groups was dispersed sufficiently to not have an effect on the results (mothers of preterm infants, 18, mothers of term infants, 11; fathers of preterm infants, 10; and fathers of term infants, 8).

Since the appearances and severity of illnesses between preterm and term infants in the NICU can be very diverse, the outcome of so little difference between mean scores for the PSS:NICU and the sub-scales may reflect the intensive care experience for both of the sub-groups of parents may be much the same. The sample subjects for the preterm parent sub-group included parents of infants who were twenty-seven to thirty-six weeks gestation (mean thirty-three weeks) while the parents of the term infants included infants thirty-seven to forty weeks gestation (mean 38.3 weeks). There was a greater disparity for parents of the preterm infants since there was a nine

week range of gestational ages but only a three week difference in the gestational ages of the term infants. The twenty-seven week premature infant is usually considerably more ill and one whose appearance is quite different from the thirty-five week premature infant. On the other hand, the disparity between infants of thirty-five weeks gestational age and infants of thirty-seven weeks gestational age may be negligible, especially to parents. A better research design for future research would be to categorize the infants differently such as term, moderately premature, and very premature or categorize by illness acuity.

RESEARCH QUESTION 4: Since the PSS:NICU may relate overall to the differences in the sub-groups such as mother/father and parents of preterm/full-term infants, will these significant differences in the responses from the sub-groups remain after controlling for the Trait Anxiety Scores?

Traits that one brings to stressful situations may accentuate stressful reactions (the very significant relationship between Trait Anxiety and PSS:NICU documents this). The significance of the differences between mothers and fathers ($p=.014$) determined from analysis of

covariance (Table 13) accounted for much of the significance in the main effects (p=.023). Therefore, the differences in the mean PSS:NICU scores of the mothers and fathers in the sample are more valid and may reflect true and reproducible differences between these sub-groups.

However, the differences between parents of preterm and full-term infants were not significant (p=.233). The t-test results for these sub-groups approached significance on the total PSS:NICU instrument (p=.053) while the mean score for the sub-scale Role Alteration was significant (p=.008) (Table 12). This sub-scale was considered less reliable than the other sub-scales due to the fact eight of the eleven items had responses with 50% or more of the subjects answering "not experienced." Since the sample size of the sub-groups was small (n=19, n=28) and there was a high response rate of "not experienced" for the sub-scale Role Alteration, generalizable findings for the PSS:NICU were not possible for the sub-groups of parents of preterm and full-term infants. Further research comparing these sub-groups of parents is recommended.

LIMITATIONS OF THE STUDY AND RECOMMENDATIONS FOR FUTURE RESEARCH

Although the non-experimental design of the study is by definition of a weaker design than experimental studies, the data to be obtained can imply causality if the tool can demonstrate similarities among the participants in replicated studies. Although the study was not a true replication of Dr. Miles' research, the addition of parents of term infants hospitalized in a NICU may make the study findings more generalizable. This change in the sampling and the change in administering the questionnaires (take home rather than answering the questionnaire on the hospital premises with a research assistant present) made comparisons of data between this study and Dr. Miles' research more difficult. The change in administering the questionnaires may have resulted in a decreased return rate. This may have been partially counteracted by the researcher's employment and visibility in the NICU setting.

The generalizations from the findings of this study must be made with caution due to the small sample size and the convenience sampling from one NICU. Research

using a similar design and methodology is recommended with a larger sample and with multi-center locations. On this latter point, a complex (multivariate) characterization of the physical environment and staffing characteristics associated with each unit could be used as an important predictor or covariate in future research.

Refinement of the PSS:NICU instrument should be considered since some items could be made more clear for respondents' choices and a number of the items did not discriminate especially well in the present study. For instance, "Being separated from my baby" may be better worded as "Not having the baby at home." The latter clarifies for this subject the term "separation." Also, "Not having privacy when I visit the baby" may be a better choice than "Not being alone with my baby" since the former does not ask the parent about the impossible, i.e., time alone with the baby. Also, replacing "my baby" with "the baby" or "our baby" may make differences in the responses from mothers and fathers. Input from parents and caregivers would be appropriate before refinements are made and further validation of the instrument performed. Also, concerns identified by the

parents in the open-ended questions are likely to be common to other parents of NICU infants and should be considered as possible sources of stress in future research.

Further, low salience rates (high percentages of zero responses: "never experienced") for items in some of the scales suggest that refinement and paring are required to increase internal consistency and thus validity of these sub-scales. For example, the Role Alterations sub-scale of the PSS:NICU revealed an average of 51.6 percent of items in the 11-item scale as being "not experienced." In other scales, certain items did not discriminate at all. For future research consideration, these scales must be pruned of non-working items and/or alternative items substituted which will provide more adequate discrimination.

As mentioned, the comparison of parents of full-term and preterm infants needs to be more clearly delineated. The group of preterm infants in this study was probably too broadly defined (27 to 36 weeks gestation) to reveal significant differences between the parent groups. It may also be helpful to categorize the NICU patients by acuity and then compare parents' perceptions as well as

their responses on the PSS:NICU.

Parents in the present study completed the questionnaires at two to sixteen days after their infants' admissions. This variance in timing may well have contributed to differences in perceptions of stress emanating from the NICU experience. And, lurking in all such studies is the question: To what extent did self-administration of the scales affect responses in contrast to other modes of questionnaire administration such as face-to-face, researcher as interviewer, professional interviewer, or other methods.

CONCLUSIONS

The results of this study indicate there are many sources of stress for parents in the NICU environment and the experienced stress is related to the parents perception and their exposure to the stressors. The sub-scale Staff Relations was the major source of stress for this sample group (Table 10). Further, the NICU experience was stressful for parents as measured by the STAI (Table 14).

The sub-group of mothers (n=28) had higher mean scores for the STAI (State and Trait scales) than fathers

(Table 14) with the difference between the sub-group mean scores significant at p=.04 for the State Anxiety scores. Mothers also had higher mean scores than fathers for the PSS:NICU total instrument as well as for each of the four sub-scales (Table 11, Figure 1) with significant differences for the total PSS:NICU mean scores (p=.08) and the sub-scale Staff Relations (p=.001).

Parents of preterm infants also rated higher mean scores than parents of term infants for the State and Trait Anxiety scales but only the differences in Trait Anxiety was significant (p=.04). Parents of preterm infants also rated higher mean scores for the total PSS:NICU instrument as well as for each of the sub-scales. Only the mean scores for the sub-scale Role Alteration was significantly different between the two sub-groups of parents (p=.008) while the difference in the total PSS:NICU instrument neared significance (p=.053) but should be considered when future research designs are developed.

The outcomes of the study identified focal stimuli for parents; the infant's illness conceptually related to the infant's appearance/behavior and accounts for the elevated State Anxiety score. Contextual stimuli (also

potential sources of stress) conceptually include the sights and sounds in the NICU environment, the relations with staff, and alterations in the parent role. Trait anxiety conceptually relates to the residual stimuli. The comparatively high scores for the State Anxiety scale suggested a need for adaptation for this parent sampling. The specific areas of the NICU experience which revealed foci for interventions to promote adaptation related primarily to the Staff Relations sub-scale, then the Sights/Sounds sub-scale, followed by the Infant Appearance/Behavior sub-scale, and lastly the Role Alteration sub-scale.

Roy (1981) proposed how an individual will adapt to a change depends on the degree of environmental change perceived necessary and the individual's pattern of coping. The environment includes internal (changes within the self, i.e., illness) or external stimuli which can be physical or psychosocial in focus. The individual's level of adaptation determines whether a response to the environment will be positive (avoid disequilibrium) (Miles & Carter, 1983).

Parents respond to the NICU experience by using coping mechanisms already developed by past experiences

(residual stimuli) or by developing new coping skills through their cognitive-emotive ability. The coping can be adaptive if adequate resources from the environment are made available and are used by the parent (Miles & Carter, 1983). The parents comprising this study's sample group identified the major source of stress to be related to the need for information. The provision of the information and emotional support to enhance the cognator coping mechanism of the parent depends largely on nursing personnel, the caregiver with whom the parent has the most contact.

IMPLICATIONS FOR NURSING

With the identification of potential sources of stress for parents with an infant in the NICU, nurses may be able to intervene to alleviate or reduce the sources of stress. When a source of stress cannot be altered, the nurse can provide the parent with emotional support.

The outcomes from this study revealed Staff Relations as a significant source of stress for the sample subjects, especially the sub-group of mothers. The improvement in providing parents with information through use of understandable terms, speaking more

slowly, allowing the parent time to ask questions, and asking the parent for feedback may reduce the levels of stress perceived by parents. The sharing of the study's findings with the nurses could promote improved communication with the parents. Nurses may need to listen more to parents in order to identify their needs. Also, more effort needs to be made to limit the number of nurses involved with each patient. Primary nursing (where one or two nurses direct the patient's nursing care) has been successfully instituted in hospitals even though nurses work twelve-hour shifts. The NICU could move in this direction by reassigning nurses to the same patients after their days off, at least during the time the infant is most unstable. The concept of primary physicians for each patient would also be helpful in providing consistency of care while promoting a trusting relationship with the parent.

The shortage of nurses is a country-wide, multi-factorial dilemma which will not be discussed further except to note the impact of the shortage may affect the parents gaining information and support from nurses. The incorporation of additional support personnel to further assist with providing the parent with information might

include the social worker and the discharge planning nurse. The NICU from which the sampling was taken, had a parent support group but the attendance was usually poor. Perhaps, a more functional support group could reduce parents' stress.

The responses to items concerning potential stress in the Sights/Sounds sub-scale are more difficult to alter since the items relate to the physical environment of the NICU. However, insight into unit design may be helpful for future NICU parents (and staff). Ward structure with fewer patients would reduce the noise and appearance of crowding. Just as the trend for adult ICU's has been away from open wards to private and semi-private rooms, so might the same trend be considered for the newborn infant. In the meantime, nurses need to answer all alarms as quickly as possible and to offer reassurance to the parent, if appropriate, after the alarm is silenced. Also, nurses need to be cognizant of their own contribution to noise levels and clutter at the bedside.

The responses to the Infant Appearance/Behavior sub-scale revealed the parents in the sample were mostly anxious about invasive procedures or equipment (breathing

machines, tubes, intravenous lines), signs of trauma (cuts and bruises), unusual skin color (pale or jaundiced), unusual breathing patterns, and signs from the infant of discomfort (expressions of pain, sadness, or being afraid). Nursing interventions for these parental concerns should include providing, as mentioned, accurate and clear information about the parents' observations, provide as much comfort measures for the infant as possible while relating these measures to the parent so they, too, can perform them. It would be helpful to give the parent some idea of how long an invasive procedure may be necessary which would require the nurse to collaborate with the physician(s). Some of the items in the sub-scale reflect barriers to normal parenting behavior (i.e. tubes, lines, respirator). This could account for some of the decreased responses on the Role Alteration sub-scale since the parent may have accepted he/she cannot, nor may want to, perform parenting duties until the infant is more stable.

The Role Alteration sub-scale received the lowest mean score of the PSS:NICU's four sub-scales. There was a large percent of "not experienced" responses (eight of the 11 items had 50% or more "not experienced"

responses). Of interest, Miles (1987) reported the Role Alteration to rate the highest of the four sub-scales in her research. Without more demographic information about Miles' sample group or actual score means, further comparisons between the studies are not possible. Again, the present study consisted of a small sample (n=47) and inferences must be made with caution.

Nurses need to be aware mothers may be experiencing more stress than fathers as evidenced from this study, especially in the area of receiving information. Also, parents of full-term infants in the NICU may experience less stress than parents of preterm infants but the findings were not significant. Therefore, nurses need to give both groups of parents the same consideration.

As medical and technological advances have provided for the survival of premature and other critically ill newborn infants, the awareness of the psychological impact of the critical illness of the infant on the parents continues to be under investigation (Rothstein, 1980). Waechter (1987) provided excellent insight into the needs of parents when she wrote parents can be our (nurses) teachers and our students but we must observe and listen to their needs. Only through assisting the

parents can we feel we are providing the critically ill infant comprehensive nursing care. Through research about the needs of the parents, observations can be made and nursing practice improved to meet those needs. The recommendations for nursing practice resulting from this study could only be considered effective if further measurements were made to support that conclusion.

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APPENDIX A: INFORMED CONSENT

Dear NICU Parent:

As a graduate student at the University of Nevada, Las Vegas, I am conducting a study concerning potential sources of stress for parents whose infants are hospitalized in a neonatal intensive care unit. Your participation in this study to identify parental stressors and related factors would be helpful in providing nurses with greater insight into parents' concerns and feelings. The knowledge gained from the study may help nurses to better understand and assist parents during their infant's hospitalization.

You are not required to participate in the study and can change your mind after beginning to complete the questionnaires. Participant identity will remain confidential and information obtained will be reported as aggregate data in relation to the study.

There are no expected risks to the participants in the study. Should the questionnaires stimulate concerns which you would like to discuss, an appointment can be made with me (the researcher) or with the NICU medical social worker.

Your completion of the enclosed questionnaires indicates your consent to participate in the study. If you are interested in obtaining a summary of the results of the study, or if you wish additional information, please contact me at 731-8240.

Thank You,

Donna G. Mattson

Donna G. Mattson, R.N., B.S.N.
Principal Researcher
Department of Nursing
University of Nevada, Las Vegas
4505 S. Maryland Parkway
Las Vegas, NV 89154

APPENDIX B: DEMOGRAPHIC AND SITUATIONAL DATA

INSTRUCTIONS TO PARENTS: Please complete all of the questionnaires. Answer each question with the answer choice that best describes your experience or feelings. Read the instructions carefully at the beginning of each questionnaire. Do not compare answers with your spouse.

DEMOGRAPHIC AND SITUATIONAL DATA

Instructions: Check the item or fill in the blank with the correct answer.

1. AGE____ TODAY'S DATE_____

2. SEX_____

3. MARITAL STATUS: Single____ Married____
Separated____ Divorced____ Widowed____

4. RACE OR ETHNIC IDENTIFICATION (Check the item(s) to which you most identify):
Caucasian (white)____ Black____ Hispanic____

Oriental or South Pacific____ American Indian____

Other (specify)_____

5. HIGHEST LEVEL OF EDUCATION OBTAINED (include number of years of college or trade school, if applicable):_____

_____

6. EMPLOYMENT: Full-time____ Part-time____

Unemployed____ Disabled____

7. OCCUPATION:_____

8. APPROXIMATE HOUSEHOLD ANNUAL INCOME:_____

9. NUMBER OF CHILDREN AT HOME:_____ Ages_____

10. DO YOU HAVE HEALTH INSURANCE TO COVER YOUR BABY'S HOSPITALIZATION: Yes____ No____

11. HAVE YOU EXPERIENCED A CLOSE FAMILY MEMBER HOSPITALIZED IN AN INTENSIVE CARE UNIT BEFORE? Yes_____ No_____

If yes, what was the outcome?_____

_____

12. HAVE YOU EXPERIENCED HAVING AN INFANT IN A NEONATAL INTENSIVE CARE UNIT BEFORE? Yes____ No_____

If yes, what was the outcome?_____

_____

13. HOW ILL DO YOU CONSIDER YOUR BABY? 124
Critically ill____ Severely ill____ Moderately ill____
Slightly ill____ Not ill____

14. DO YOU HAVE RELATIVES OR CLOSE FRIENDS WITH WHOM YOU CAN SHARE YOUR FEELINGS OR CONCERNS ABOUT YOUR BABY'S ILLNESS?
a. Yes____
b. Yes, but they are not always available when I need them_____
c. No_____

15. HOW MANY TIMES HAVE YOU BEEN ABLE TO VISIT YOUR BABY?____
DO YOU HAVE ANY PROBLEMS WHICH PREVENT YOU FROM VISITING YOUR BABY (e.g. lack of transportation, health problems)?
Yes___ No____

16. MOTHERS, DID YOU RECEIVE PRENATAL CARE (seen by a doctor during your pregnancy)? Yes____ No____
If yes, approximately how many visits did you make to the doctor?_____

17. RELIGION: Catholic____ Protestant____ Jewish____.
None____ Other (specify)_____

18. HOW IMPORTANT IS IT TO YOU TO HAVE A FAITH IN GOD OR A "HIGHER BEING"? Very important____ Somewhat important____
Not important____

19. ARE THERE OTHER MAJOR CONCERNS IN YOUR LIFE AT THIS TIME? Yes____ No____

If yes, would you share these concerns in the space provided?_____

_____

_____

APPENDIX C: HUMAN SUBJECT RIGHTS COMMITTEE APPROVAL, FACILITY APPROVAL

SUBMIT TO OFFICE OF THE GRADUATE DEAN: Original and 11 copies of the Protocol Form (pp. 1-3) plus one copy of the entire research proposal.

APPENDIX C

DATE RECEIVED: _____

LOG # _____

TYPE OF REVIEW
( ) Expedited
( ) Regular

FUNDING SOURCE:
( ) University
( ) State
( ) Federal
( ) Other/None

UNIVERSITY OF NEVADA, LAS VEGAS

PROTOCOL FORM

FOR RESEARCH INVOLVING HUMAN SUBJECTS

INVESTIGATORS: List person principally responsible for the investigation on line a). If principal investigator is a student, list faculty advisor on line b).

	Investigator	Department	Phone
a)	Donna Mattson	Nursing	361-6768
b)			
c)			
d)			

UNLV status of Principal Investigator (circle): Faculty/Post-doctoral/Graduate /Undergraduate/Other _____

TITLE OF PROJECT Identifying Environmental Stressors Affecting Parents With An Infant In The NICU

NAME AND ADDRESS of sponsoring agency or foundation (if other than UNLV) _____

CONTRACT OR GRANT NUMBER (if known) _____

DURATION OF STUDY (Protocols must be renewed annually) 6/1/89 Start 9/1/89 Conclude

TYPE OF SUBMISSION
x New
___ Continuation
___ Renewal (attach progress report)
___ Modification
___ Previous Log # (if any) _____

LOCATION(S) OR FACILITIES where study will take place Humana Hospital-Sunrise 3186 Maryland Parkway, Las Vegas, Nevada, 89109

April 27, 1989
Date

Donna M. Mattson
Principal Investigator's Signature

April 27, 1989
Date

Rosemary Wist
Department Chair or Unit Head's Signature

4-27-89
Date

Margaret Lamb
Faculty Advisor's Signature (if warranted)

BE SURE TO COMPLETE PAGES 2 & 3

SUBJECTS: (Please estimate numbers)

____	Patients as experimental subjects	____	Prisoners, incarcerated subjects
____	Patients as controls	_X_	Normal adult volunteers
____	Minors (under 18)	____	Persons whose first language is not English.
____	UNLV students	____	Other (please specify)
____	Pregnant women or fetuses		_____
____	Mentally disabled	____	TOTAL ANTICIPATED SUBJECTS

PROCEDURES: (ATTACH relevant materials, such as questionnaires, interview schedules, written test instruments, etc.)

_X_	Survey, questionnaire(s)	____	Investigational Drug*
____	Interview: phone/in-person	____	Approved Drug, New Use*
____	Medical or other personal records	____	Investigational Device (attach relevant info)
____	Filming, taping, recording	____	Placebo
____	Observation	____	Ionizing Radiation (attach CURRENT approval)
____	Participant observation	____	Surgery
____	Anthropological fieldwork	____	In vitro fertilization
____	Psychological intervention	____	Venipuncture
____	Incomplete disclosure of purpose	____	Other body fluids, excreta
____	Payment of subjects	____	Abortus, placenta, excess tissue
____	Costs to subject/third parties	____	Other (please specify)
____	Brief Explanation of Procedures:		

_____ _____

_____ _____

_____ _____

_____ _____

_____ _____

UNIVERSITY OF NEVADA, LAS VEGAS

PROTOCOL FORM APPROVAL SHEET

FOR RESEARCH INVOLVING HUMAN SUBJECTS

Log Number: _____

Title of Project: Identifying Environmental Stressors Affecting Parents With An Infant in the NICU

Investigator: Donna Mattson

After reviewing this proposal, the members of the Nursing Department Review Committee have indicated below their approval/disapproval of this proposal.

Signature of Committee Members	Approve	Disapprove
Susan Rush Michael	✓	
Myrlene S. LaMonaca	✓	

The above named project is hereby approved/disapproved (circle one)

Date: May 1, 1989

Cheryl Bowles
Committee Chairman's Signature

RESEARCH ABSTRACT

1. SUBJECTS: The subject population will be parents of infants who are hospitalized in a neonatal intensive care unit. The parents will be asked to participate in the study during the first week of their infant's hospitalization if the parent is at least 18 years of age; can read, write, and speak English; is not known or suspected to be mentally ill; whose infant has been hospitalized in the neonatal intensive care unit for at least 24 hours up to one week at the time of the survey; who have had the opportunity to visit their infant at least once; and whose infant is not known to be permanently handicapped or to be terminally ill.
2. PURPOSE, METHODS, PROCEDURES: The purpose of the study is to identify stressors experienced by parents when their newborn requires intensive care. With greater awareness of the variety of stressors confronting parents during the NICU experience, nurses may be more able to intervene to assist parents in their coping and acceptance through the provision of information, guidance, and support.

Three questionnaires will be given to both parents of infants admitted to the NICU located at Humana Hospital-Sunrise, Las Vegas, Nevada. These questionnaires include the Parental Stressor Scale: Neonatal Intensive Care Unit, the State-Trait Anxiety Inventory scale, and the Parents'

Perception of Uncertainty Scale. All three of these scales are based on a Likert-type format. Also included with the questionnaires will be a personal data questionnaire. After reading the informed consent cover letter, the participants will be given a packet containing the questionnaires to complete at home. The questionnaires must be completed within seven days of the infant's admission to the NICU.

3. RISKS: The completion of the questionnaires should incur no or minimal risks to the participants. Since the tools require the participant to scale frequently identified stressors found in the NICU experience, some of the participants may experience some emotional discomfort as their perceptions and feelings are explored. The parents will be afforded the opportunity to discuss their feelings or concerns with the researcher or with the NICU medical social worker. Should the participant find the questionnaires too overwhelming and/or emotionally disturbing, the participant may withdraw from the study. These aspects are covered in the informed consent cover letter.

Names of participants will not be included on the data collection forms to protect participant confidentiality. Information obtained will not be made available to others or to the public except in the form of pooled data. Only the principal researcher will have access to the raw data which will be kept in a locked file.

4. BENEFITS: There is little benefit to the participant from participation in this study. The questionnaires may be helpful to some participants to identify more clearly their concerns or fears. Some participants may find the experience rewarding since they will be aware the study may provide new insights for nurses. Since nurses have close contact with parents in the NICU setting, improved knowledge and sensitivity to the needs of these parents will further assist nurses in planning and intervening to promote parental coping ability and the transition to the parenting role.

5. RISK-BENEFIT RATIO: There are minimal risks to the participants as mentioned in #3. There may be some benefit as mentioned in #4. The risks and benefits are too minimal to project a ratio.

6. COSTS TO SUBJECTS: There are no anticipated costs to participants.

7. INFORMED CONSENT: Potential participants will be identified by the researcher and they will be given an informed consent cover letter explaining the purposes and procedure of the study. The potential participants will be approached by the researcher, or another representative, within the first week of their infant's admission to the NICU. The researcher will be available to participants to answer questions.

April 27, 1989

Ms. Ann Lynch
Risk Manager
Humana Hospital - Sunrise
3186 Maryland Parkway
Las Vegas, NV 89109

Dear Ms. Lynch:

To fulfill requirements for a Master of Science in Nursing degree from the University of Nevada Las Vegas, a research proposal has been submitted and approved by the university's Nursing Department.

Attached are copies of the research abstract, approval from the Human Subjects Rights Committee (UNLV), informed consent letter, and questionnaires to be utilized for the study. The complete research proposal is available upon request.

Contingent upon facility approval, the proposed research will begin June 1, 1989 and end September 1, 1989. Please indicate below the facility's approval decision.

X Approval is granted for the proposed research.

____ Approval is granted for the proposed research with the following exception(s):_____

_____

_____

Signature/Title Ann Lynch Dir Marketing and Community

Date May 23, 1989

Thank you,
Donna G. Mattson

Donna G. Mattson, R.N., B.S.N.
Principal Researcher
M.S.N. Student, University of Nevada Las Vegas

APPENDIX D: PARENTAL STRESSOR SCALE: NEONATAL INTENSIVE CARE UNIT, AND AGREEMENT

TO: Donna Mattson
Name of Student and/or Faculty

FROM: Margaret S. Miles, R.N., Ph.D., F.A.A.N.
Professor, School of Nursing
University of North Carolina at Chapel Hill
(919) 966-5499

RE: Use of instrument: Parental Stressor Scale: Neonatal Intensive Care Unit
Name of instrument

Name of study: Identifying Environmental Stressors Affecting Parents With An Infant In The NICU

✓ I hereby give my permission for you to copy and use the above named instrument for use in your study. This permission is valid only for the study named above.

✓ I would like to have the results of the study for use in further establishment of the reliability and validity of the instrument. The data sent to me would not be used for any other purpose than instrument development.

____ I do not give my permission for you to copy the above instrument as it is published and may be obtained at the following address:

_____

____ You may use the instrument for your study but it must be purchased from me at the following cost:

_____

____ You may not use my instrument for your study as it is not ready for release for research purposes at this time.

Margaret S Miles — Signature of author — 1/21/88 — Date

Donna J. Mattson — Signature of student/faculty — May 1, 1989 — Date

3660 Citadel Circle — Address — 702-361-6768 — Phone

Las Vegas, NV 89118

APPENDIX E: STATE-TRAIT ANXIETY INVENTORY SCALE

SELF-EVALUATION QUESTIONNAIRE

Developed by Charles D. Spielberger
in collaboration with
R. L. Gorsuch, R. Lushene, P. R. Vagg, and G. A. Jacobs

STAI Form Y-1

Name _____ Date _____ S ____

Age _____ Sex: M ____ F ____ T ____

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

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	①	②	③	④
2. I feel secure	①	②	③	④
3. I am tense	①	②	③	④
4. I feel strained	①	②	③	④
5. I feel at ease	①	②	③	④
6. I feel upset	①	②	③	④
7. I am presently worrying over possible misfortunes	①	②	③	④
8. I feel satisfied	①	②	③	④
9. I feel frightened	①	②	③	④
10. I feel comfortable	①	②	③	④
11. I feel self-confident	①	②	③	④
12. I feel nervous	①	②	③	④
13. I am jittery	①	②	③	④
14. I feel indecisive	①	②	③	④
15. I am relaxed	①	②	③	④
16. I feel content	①	②	③	④
17. I am worried	①	②	③	④
18. I feel confused	①	②	③	④
19. I feel steady	①	②	③	④
20. I feel pleasant	①	②	③	④

Consulting Psychologists Press
577 College Avenue, Palo Alto, California 94306

SELF-EVALUATION QUESTIONNAIRE

STAI Form Y-2

Name _____ Date _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	①	②	③	④
22. I feel nervous and restless	①	②	③	④
23. I feel satisfied with myself	①	②	③	④
24. I wish I could be as happy as others seem to be	①	②	③	④
25. I feel like a failure	①	②	③	④
26. I feel rested	①	②	③	④
27. I am "calm, cool, and collected"	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them	①	②	③	④
29. I worry too much over something that really doesn't matter	①	②	③	④
30. I am happy	①	②	③	④
31. I have disturbing thoughts	①	②	③	④
32. I lack self-confidence	①	②	③	④
33. I feel secure	①	②	③	④
34. I make decisions easily	①	②	③	④
35. I feel inadequate	①	②	③	④
36. I am content	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind	①	②	③	④
39. I am a steady person	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	①	②	③	④

APPENDIX F: PARENT/CHILD UNCERTAINTY IN WELLNESS SCALE AND AGREEMENT

No._____

MISHEL UNCERTAINTY IN ILLNESS SCALE--PARENT/CHILD FORM

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

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

2. I have a lot of questions without answers.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
_____	_____	_____	_____	_____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

9. I understand everything explained to me.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

21. The effectiveness of the treatment is undetermined.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

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

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

Request Form

I request permission to copy the Parent/Child Uncertainty in Illness Scale for use in my research entitled,

Identifying Environmental Stressors Affecting Parents With An Infant In The NICU

In exchange for this permission, I agree to submit to Dr. Mishel a copy of the one-page scoring sheet for each subject tested or a printout of the data, with a data dicticnary. This data will be used to establish a normative data base for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses. I also agree to send Dr. Mishel a copy of my findings. I understand that my report will be used to compile information on the theory of uncertainty in illness. Credit will be given to me in any reports referring to my findings.

Joanna A. Mattson
(Signature)

10-31-88
(Date)

MSN Student, UNLV
3660 Citadel Circle
Las Vegas, Nev. 89118

Position and full address of investigator

Permission is hereby granted to copy the PCUS for use in the research described above.

Merle H. Mishel
Merle H. Mishel

11/5/88
(Date)

Please send two signed copies of this form to:

Merle H. Mishel, Ph.D.
College of Nursing
University of Arizona
Tucson, Arizona, 85721.

MHM:gb