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I grant approval to Gayle Forsht for her honors project entitled Sources of Stress of Mothers with Children Hospitalized.

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Sources of Stress of Mothers with Children Hospitalized

In Fulfillment of a Honors' Project

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Abstract

The purpose of this descriptive and comparative study is twofold: 1) to identify the sources of stress of mothers with children hospitalized in PICU, IU, or a general pediatric floor and 2) to compare the results of this study with results from a previous study identifying sources of stress of NICU mothers. The resultant research questions are "What are the sources of stress of mothers who have a child hospitalized in PICU, IU, CH2, or CH3 at a tertiary care hospital in north central Pennsylvania?" and "What are the similarities and differences between sources of stress of NICU mothers and sources of stress of mothers with a child hospitalized in PICU, IU, or a general pediatric floor at the same tertiary care hospital in north central Pennsylvania?" Seventeen mothers, conveniently chosen, who met the following criteria participated in the study: 1) had a child hospitalized in PICU, IU, CH2, or CH3 for at least 8 hours 2) had visited the child at least once prior to participating 3) the child was monitored and 4) could read and speak English. Once permission was obtained, through a letter of consent, the participants were asked to complete two questionnaires -- the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) and a demographic survey. The PSS: PICU is a 37 item questionnaire, divided into seven subscales: child's appearance, sights and sounds, procedures done to child, behaviors of the professional staff, parental role alteration, way the professional staff communicates with you, and behavioral and emotional responses. All data was analyzed using SPSS for Windows. Descriptive statistics were used to summarize the demographic data while the PSS:PICU was analyzed using descriptive and nonparametric inferential statistics -- Wilcoxon Rank, Kruskal-Wallis, and Mann-Whitney. A p-value of less than or equal to .05 was considered significant. Metric I and Metric II analysis was performed. In Metric I analysis, "NA" responses were coded as missing values. This metric measured the stress occurrence level of the mothers or the level of stress produces when a situation occurs. In Metric II analysis, "NA" responses were coded as "1", or not stressful. Metric II measured the overall stress level or the overall stress from the environment. All scores were on a scale from one to five. Procedures done to your child was the most stressful aspect for mothers in both Metric I ($m=2.40$ $s=.74$) and Metric II ($m=2.46$, $s=.82$). Statistically significant results were found when comparing procedures to parental role alteration in both Metric I ($p=.041$) and Metric II ($p=.032$). When comparing the PSS:PICU to the PSS:NICU statistically significant results were found for the parental role alteration in both Metric I ($p=.018$) and Metric II ($p=.022$) and also for child's appearance and behavior for Metric I ($p=.012$) and Metric II ($p=.008$). Further research needs to be conducted in order to expand on these findings and identify interventions to help expand on these findings and identify interventions to help reduce stress of mothers with children hospitalized.

Table of Contents

Abstract	i
Table of Contents	ii
Table of Graphs	v
Chapter I: Introduction	
Purpose	1
Definitions.....	1
Limitations	2
Assumptions	2
Significance	2
Chapter II: Background	
Review of the Literature	4
Theoretical Framework	8
Man	9
Health	9
Environment	10
Nursing	10
Levels of Prevention	10
Summary of Neuman's model	11
Chapter III: Methodology	
Participants	13

Setting	13
Instruments	14
Procedure	16
Treatment of Data	16

Chapter IV: Analysis and Discussion of Findings

Analysis of Findings	20
General Stress Response	21
Metric I Analysis	22
Metric II Analysis	23
Comparison of Metric I and Metric II Analysis	25
Comparison of PSS:NICU and PSS:PICU	25
Discussion of Findings	26
Threats to Validity	26
Serendipitous Findings	28

Chapter V: Conclusions and Implications for Nursing

Dissemination of Findings	31
---------------------------------	----

References32

Appendices

Appendix A

Demographic Graphs	33
--------------------------	----

Appendix B

Tools from PSS:NICU	45
---------------------------	----

Appendix C

Demographic Survey51
PSS:PICU52

Appendix D

Background on PSS:PICU57

Appendix E

Consent to Participate63

Appendix F

Script66

Appendix G

Letters68

Table of Graphs

page

Appendix A: Demographic Graphs

A.1. Age of Mothers	33
A.2. Ethnic Status	34
A.3. Marital Status	35
A.4. Educational Level	36
A.5. SES of Mothers	37
A.6. Miles from Geisinger	38
A.7. Child's Age	39
A.8. Length of Hospitalization	40
A.9. Primary Diagnosis	41
A.10. Floor Hospitalized On	42
A.11. Floor Admitted to	43

Chapter I

Introduction

It is well documented that hospitalization is a major source of stress for children.

However, the hospitalization is also very stressful for the parents of the child. In order to support parents during this difficult time, it is necessary for health care providers to know stressors that may be encountered throughout this difficult time. Research in the past has focused on both maternal and paternal sources of stress. However, little research has been done on maternal sources of stress. As a result, little is known about the sources of stress encountered specifically by mothers who have children hospitalized in either PICU or a regular pediatric floor.

Purpose

The purpose of this descriptive study is twofold. First the researcher will identify the sources of stress of mothers who have a child hospitalized in the Pediatric Intensive Care Unit (PICU), Intermediate Unit (IU) or a general pediatric floor, and the results will then be compared with a study by Forsht and Sheriff (1997) which looked at the sources of stress for mothers with infants in the Neonatal Intensive Care Unit (NICU). The research study will include sources of stress related to the following areas: child's behavior and emotions, child's appearance, sights and sounds, procedures, staff communication, behavior of the staff, and parental role alteration. The resultant research questions are "What are the sources of stress of mothers who have a child hospitalized in PICU, IU, or a general pediatric floor?" and "What are the similarities and differences between sources of stress of NICU mothers and sources of stress of mothers with a child hospitalized in PICU, IU, or a general pediatric floor?"

Definitions

In this study, the child will be defined as any person under the age of 18 hospitalized on a

pediatric unit. Stress is defined as "the body's nonspecific response to any demand made upon it" (Selye, 1974, p. 14). Stress will be measured using the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU). A mother will be defined as any female individual performing the behaviors and actions of the parental role.

Limitations

In order to correctly interpret the findings, limitations need to be recognized. Limitations of this study include the following:

- The author of this study has a limited time period in which to conduct the study. This limitation influences the number of subjects that could participate
- The author is limited to a convenience sample from only one hospital in one geographical area -- a tertiary care hospital in north central Pennsylvania. Therefore, the selected sample may not necessarily be representative of a larger population since generalizability of the findings is limited.

Assumptions

In this research study, there are assumptions that need to be considered. The researcher will assume that participants will respond honestly to the questions on the questionnaires. In addition, the researcher will assume that the mothers will answer the questionnaires independently without input from other family members.

Significance

Findings from the study may benefit many individuals. These include, but are not limited to, the following: children, mothers, and other family members; staff nurses; other health care providers; hospital administrators; nurse educators; and nurse researchers.

Staff nurses. The staff nurse will benefit from this study by becoming more aware of the stressors encountered by mothers. The staff nurse will then develop an understanding of the

support needed by mothers and implement stress-reducing interventions.

Mothers, children and other family members. Maternal stress reduction may be attained from the nursing staff who may be more conscious of the stress experienced by the mothers. The mothers and family members can then experience increased attachment because of the decreased stress levels.

Other health care -providers. Other health care professionals, such as physicians, social workers, and therapists, will also benefit from the study. Because of maternal stress reduction, these people will be able to communicate with the mothers more clearly. Increased communication with staff will enable mothers to participate more actively in the care of the child.

Nurse educators. In addition, nurse educators will be able to incorporate this study into teaching student nurses. Students may become more aware of stress encountered by mothers and will be able to anticipate the needs of the mothers.

Nurse researchers. Nurse researchers will also profit from this study because they will have an additional source on which to base further research. Future researchers will be able to utilize the study as a basis for comparing their findings relative to stress in mothers.

One must take into account the definitions, limitations, and assumptions in order to understand and interpret this research study. In addition, it is important for one to realize the various individuals that will benefit from the results of the study. The following chapter discusses the related research and the theoretical framework associated with this study.

Chapter II

Background

The purpose of this research study is twofold: to identify the sources of stress of mothers who have a child hospitalized in either PICU or a pediatric floor and to compare those stressors with results of a study looking at sources of stress for NICU mothers. The resultant research questions are "What are the sources of stress of mothers who have a child hospitalized in either PICU or a pediatric floor at a tertiary care hospital in north central Pennsylvania?" and "What are the similarities and differences between sources of stress of NICU mothers and sources of stress of mothers with a child hospitalized in PICU or a pediatric floor at a tertiary care hospital in north central Pennsylvania?"

The study by Forsht and Sheriff (1997) yielded many valuable results. In order to expand the results of that study, the author chose to sample pediatric mothers to see if the mothers of pediatric patients experienced significantly more or less stress associated with the child's hospitalization than the neonatal mothers experienced. This will enable nurses to see where the focus needs to be related to reducing the stress of parents.

Review of Literature

Overall, the articles reviewed identified either needs of parents or sources of stress encountered by parents who have a child hospitalized. Most of the articles focused on the intensive care unit. Many of the articles used varying tools to measure sources of stress and therefore have varied results.

According to Heuer (1993), the sights and sounds of the intensive care environment along with procedures associated with intensive care are areas of high stress for parents while staff communication, children's behaviors, staff behaviors, parental role, and child's appearance are areas of low stress. The study utilized the Parental Stressor Scale: Pediatric Intensive Care Unit

(PSS:PICU) which measures seven dimensions of parental perceptions of stressors related to the hospitalization of a child in a PICU. All items were measured on a six point Likert scale with 0 being not experienced and 5 being extremely stressful. Heuer (1993) revised the tool to include two additional areas which included social support and overall rating. The need for social support was not found in this study. However, Heuer (1993) discovered that fathers found the overall intensive care experience to be more stressful than the mothers (males, $M=3.30$ and females, $M=2.68$). Thirty-two parents participated in the study including 10 fathers and 22 mothers. Parental role was found to be the most stressful aspect for mothers ($M=2.29$, $s=1.48$) while the procedural aspect was the most stressful aspect for fathers- ($M=2.23$, $s=1.02$).

The PSS:PICU was also used by Miles and Mathes (1991) along with the Parent Preparation Questionnaire (PPQ), and a personal-situational questionnaire. This study studied the amount of preparation that was needed by parents prior to an intensive care unit experience for their child. Twenty-two mothers and six fathers of 22 children in a PICU were given questionnaires. The areas of PICU that were found to be most stressful were the child's behavior and emotional response ($M=3.09$) and parental role alterations ($M=3.06$). In contrast, least stressful areas of PICU included staff communications ($M=2.37$) and staff behaviors ($M=1.95$). Overall, the results showed that most of the participants felt adequately prepared by a health care provider for their child's hospitalization in PICU. According to Miles and Mathes (1991), these results are consistent with those of other research studies done in the past.

In a study performed by Forsht and Sheriff (1997), the sources of stress for NICU mothers were identified. the researchers used the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU) along with a demographic survey in order to identify the sources of stress and describe the population. The PSS:NICU is a 45-item questionnaire which is divided into four subscales: parental role alteration, infant appearance and behavior, staff communication, and

sights and sounds. The items used on the PSS:NICU uses a five-point Likert Scale. Metric I and Metric II analysis was performed on the data. In Metric I analysis, "NA" responses were coded as missing values. This metric measured the stress occurrence level of the mothers or the level of stress produced when a situation occurs. Metric II analysis measured the overall stress level or the overall stress from the environment and "NA" responses were coded as 1 or not stressful. Fifteen mothers participated in the study. Overall, parental role alteration was the most stressful aspect for the mothers in both Metric I ($m=3.38$, $s=1.2378$) and Metric II analysis ($m=2.6941$, $s=1.1519$). Staff behavior and communication were the least stressful aspect in Metric II ($m=1.51$, $s=.786$) while sights and sounds were the least stressful aspect in Metric I ($m=1.91$, $s=.6584$).

Seideman and associates (1997) compared different sources of stress between parents of children in NICU and PICU. Fifty-one parents who had children hospitalized in PICU or NICU for at least three days participated in the study. Overall, the NICU parents ($M=3.29$; $s=.9$) and the PICU parents ($M=3.49$, $s=1.18$) revealed that parental role alteration was most stressful. Within this area of concern, the most stressful aspects for NICU parents were "separation from their infant", "helplessness in regards to caring for their infant", and "helplessness related to the pain their infant is experiencing." In contrast, the PICU parents revealed that "not knowing how to help my child" and "not being with crying child" were most stressful (Seideman, et al, 1997).

In addition, the infant's behavior and appearance were also found to be stressful ($M=3.15$; $s=.96$). For example, parents revealed that various aspects of seeing their infant were frightening such as "seeing their baby stop breathing", "seeing their baby suddenly change color", and "seeing their baby in pain" (Seideman, et al., 1997). Lastly, sights and sounds of NICU were also stressful ($M= 2.8$, $s=1.09$) for these parents. Within the sights and sounds subscale, parents revealed that "abrupt noises of the monitors" was most stressful.

As a result of the study, Seideman and associates (1997) found their research findings support findings reported by Miles, Funk, and Kasper (1991). Therefore, it is now known that both NICU and PICU parents experienced the greatest amount of stress related to alterations in their role as parents and from their child experiencing pain.

A qualitative study was conducted by Kasper and Nyamathi (1988) using semi-structured interviews and a demographic questionnaire to collect data. Using content analysis, needs of parents were classified as physical, psychosocial, or sociological in origin. In addition, subscales were determined for each classification. The sample used in this study consisted of nine mothers and six fathers. Through data analysis, 280 needs were identified. The parent reported a mean of 19 needs. Fifty-eight percent of the needs addressed were psychological needs, 76% of the needs were physical, and 15% of the needs were sociologic. The most significant need was to be with the child in PICU. In fact, 12 parents (80%) identified this need. Additional needs of high importance included: 1) to be given frequent, accurate, and truthful information (73%; n=11); 2) to have a place to sleep near the PICU (67%; n=10); and 3) to participate in my child's care in any way possible (67%; n=10).

According to Kasper and Nyamathi (1988), "Meeting parental needs for information about the child's condition, treatment, and prognosis is very important. Such information can increase parental understanding of the situation and enhance coping abilities, thereby decreasing the parents' anxiety and stress" (p. 579).

To identify needs of mothers Fisher (1994) used a demographic survey and a revised form of the Critical Care Family Needs Inventory (CCFNI). This form which was based on a original list of needs statements and one open ended question.

Fisher's (1994) sample included 15 mothers and 15 fathers of 30 children hospitalized in PICU at a large metropolitan hospital in northeastern United States. The CCFNI used a four

point Likert scale with responses ranging from not important (1) to very important (4). Average means ranged from 2.57 to 3.97 for individual items. The author found 15 of the 59 needs statements to be most important for the parents (M.3.80). These include the following: knowing the prognosis, feeling there is hope, knowing why things were done for the child, knowing that the child is comfortable, and knowing how the child is being treated medically. The author also found that the mean of 88% of the ranked needs of mothers were higher than the needs of fathers.

Theoretical Framework

In order to address the research questions "What are the sources of stress of mothers who have a child hospitalized in PICU, IU, or a general pediatric floor at a tertiary care hospital in north central Pennsylvania?" and "What are the similarities and differences between sources of stress of NICU mothers and sources of stress of mothers with a child hospitalized in PICU, IU, or a general pediatric floor at a tertiary care hospital in north central Pennsylvania?", Betty Neuman's Health Care Systems Model was used.

In Neuman's model, stressors are identified as any disrupting force within a system. Neuman (1982) describes homeostasis as "a state of balance requiring energy exchanges whereby man is able to adequately cope with his stressors and/or regain his optimal state of health following a reaction to a stressor and thus preserve his systems integrity" (p. 9).

Neuman's model focuses on "an individuals relationship to stress -- his reaction to stress and factors of reconstitution - and is thought of as dynamic in nature" (p. 14). In addition, the model encompasses several other health care models rather than conflicting with them. The following concepts are discussed related to Neuman's model: man, health, environment, and nursing. In addition, the researcher discuss Neuman's three levels of prevention.

Man

Neuman (1982) defines man as "an interacting open system in his total interface with his environment and is at all times either in a dynamic state of wellness or ill health in varying degrees" (p.9). In addition, man is constantly changing along with the environment.

Neuman (1982) relates stress to man in her model. According to Neuman (1982), "one must view the total person framework as an open systems model of two components -- stress and reaction to it" (P.14). Neuman (1982) states that a person can have multiple stressors at any one time. Stressors can be identified as intrapersonal, interpersonal, or extrapersonal. Intrapersonal stressors are "forces within the person," interpersonal stressors are "forces occurring between one or more individuals," and extrapersonal stressors are "forces occurring outside the person" (Neuman, 1982, p.37). Neuman's total person approach encompasses a holistic view of man, rather than one of separate entities. An individual is viewed as a whole whose parts are constantly interacting (Neuman, 1982).

In the current research study, man would be described as the mothers, most of whom are under some amount of stress related to their child's hospitalization. Many of these sources of stress probably are a result of the hospital environment and are unique to each person.

Health

Neuman (1982) defines health as "the condition in which all parts and subparts (variables) are in harmony with the whole of man" (p. 9). Health can be viewed as a measure of the level of wellness of an individual.

In the present study, the health of the parents is affected by their child's hospitalization. Parents, especially mothers, are faced with many stressors during this time. Many of the mothers have other children and family that they are responsible for in addition to employment responsibilities. In addition, many parents face lack of sleep, and lack of good nutrition during their child's hospitalization. These parents must be able to cope with the stressors encountered in

order to regain an optimal level of health.

Environment

According to Neuman (1982), environment consists of "the internal and external forces surrounding man at any point in time" (p. 9). In addition, Neuman believes that the surroundings or environment affects one's goals in life.

The hospital environment is an unfamiliar setting that can cause stress in parents. Areas of the hospital environment that could possibly produce stress in parents are as follows according to PSS:PICU (Carter & Miles, 1982): 1) child's behavior and emotions 2) child's appearance 3) sights and sounds 4) procedures 5) staff communication 6) behaviors of the staff and 7) parental role alteration. Neuman identified man and environment as the basic phenomena of her conceptual model. The stressors or sources of stress, a major feature in her model, make up the environment.

Nursing

According to Neuman (1982) "Nursing is seen as a unique profession in that it is concerned with all of the variables affecting an individual's response to stressors" (p. 14). Nurses are the professionals who have the most contact with parents during their child's hospitalization. Therefore, nurses must be aware of the sources of stress in mothers. In order to help reduce the stress levels, mothers should be encouraged to look to available resources, including nurses to help them deal with their sources of stress related to the hospitalization of their child.

In addition to describing man, health, and nursing, Neuman also focuses her theory on the three levels of prevention. The three levels are primary, secondary, and tertiary prevention.

Levels of Prevention

The three levels of prevention which can be applied to stress are primary, secondary, and tertiary. Neuman (1982) believes that "interventions can begin at any point at which a stressor is

either suspected or identified" (p. 15).

Primary. Primary prevention involves intervening before the reaction has occurred. In addition, this level of prevention deals with avoiding or minimizing the stressors (Neuman, 1982). Nurses can implement primary prevention for parents by allowing them to tour the floors and unit and explaining what to expect while their child is hospitalized. Unfortunately, primary prevention is not always possible in emergency situations.

Secondary. Secondary prevention occurs after the symptoms develop, and focus on returning to homeostasis (Neuman, 1982). This level is most useful for parents who have not anticipated having their child hospitalized. The role of the nurse is to help return mothers to homeostasis by assisting them to cope with their child's hospitalization. Nurses also need to provide parents with the vital information related to their child's condition.

Tertiary. Tertiary prevention, in contrast, involves maintaining adaptation after equilibrium has been reestablished (Neuman, 1982). Therefore, it is important for nurses to continually assess the needs of parents throughout their child's hospitalization as well as intervene to help reduce the stress of mothers. Implementing appropriate nursing interventions will permit the mothers to experience a stronger attachment with their child during and after the hospitalization.

Summary of Neuman's Model

Neuman's model utilizes multiple dimensions in order to unify the various relationships that occur in nursing care. By utilizing the concepts of Neuman's three levels of prevention, the researcher believes that nurses can help to reduce the stress found in mothers.

The researcher used Betty Neuman's Health Care Systems Model as a basis for conducting this research study because the model corresponds closely to the beliefs of the researcher as related to the needs of the mothers. The following chapter will describe the methodology of the study.

Chapter III

Methodology

The research study is descriptive and comparative in nature. The purpose of the study is twofold: 1) to describe the various sources of stress encountered by mothers who have a child hospitalized in a tertiary care hospital in north central Pennsylvania and 2) to compare the results with results from a previous study of sources of stress of NICU (Neonatal Intensive Care Unit) mothers. This section will describe the participants, setting, instruments, and procedure of the research study.

Participants

The researcher chose a convenience sample by approaching the mothers personally between March 1998 and April 1998. Three visits to a Pediatric Intensive Care Unit (PICU), Intermediate Unit (IU), Childrens' Hospital Floor 2 (CH2), and Childrens' Hospital Floor 3 (CH3) at the Geisinger campus of the Penn State Geisinger Health System to obtain participants were made by the researcher. Of the 17 mothers approached to participate in the study, all agreed. The criteria for participation in the study were the following: 1) they had a child hospitalized in PICU, IU, CH2, or CH3 for at least eight hours 2) they had visited that child at least once prior to participating 3) their child was monitored and 4) they were able to read and speak English. All 17 mothers met the criteria. The mean age of these mothers was 30 years old and the range of ages was from 20 to 49 (see Graph A.1 in Appendix).

Setting

The study was conducted in PICU, IU, and two pediatric floors at a tertiary care hospital in north central Pennsylvania. The rural hospital has approximately 40 beds dedicated to pediatrics. The IU was closed while the researcher was collecting data, therefore there were zero participants from IU.

Instruments

Instruments used for collecting data included a demographic survey and the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) (Appendix C). The tools used in this study are explained in detail in the following sections.

Demographic Survey. The demographic survey, developed by the researcher, includes 15 questions designed to provide specific information about the subjects being studied. The questions are divided into 11 short answer and four multiple-choice questions. The various aspects of the questionnaire include the following: age, ethnicity, occupation, socioeconomic status, marital status, number of other children, whether there was ever a child hospitalized before, whether they were prepared for the hospitalization, miles lived from Geisinger, child's age, date of hospitalization, diagnosis of child, unit originally admitted to, and time spent on other floors.

Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU). The PSS:PICU, developed by Carter and Miles (1982), consists of 37 items. According to Carter and Miles (1992), "The PSS:PICU is designed to measure parental perception of intensive care unit environmental stressors experienced during their child's hospitalization in a pediatric intensive care unit" (p. 21).

The questionnaire is divided into seven subscales that may represent causes of maternal stress. These include: a) child's appearance, b) sights and sounds, c) procedures done to your child, d) behaviors of the professional staff, e) parental role alteration, f) way the professional staff communicates with you, and g) behavioral and emotional responses. Internal consistency and construct validity have been proven for this tool. Alpha coefficients were computed for the seven different dimensions in addition to the whole instrument. The coefficients for the dimensions ranged from .72 to .99. The alpha coefficient for the total instrument was .95.

The first subscale relates to the child's appearance and includes items such as puffiness, color changes, and appearing cold. Seeing the heartbeat on the monitors, the sound of monitors and equipment, and the sudden sounds of monitor alarms relate to subscale two, sights and sounds. Individual items corresponding to procedures performed on the child include "injections/shots", "tubes in my child", "suctioning", "putting needles in my child for fluids, procedures or tests", "making my child cough and deep breath/pounding and clapping on my child's chest", and "bruises, cuts, incisions on my child." Individual items related to the behaviors of the professional staff include "joking, laughing, or talking loudly", "not talking to me enough", "too many different people (doctors, nurses, staff) talking to me", "not telling me their names or who they are." Related to parental role, items include "not taking care of my child myself", "not being able to visit my child when I wanted", "not being able to see my child when I wanted", "not being with my crying child", "not being able to hold my child", "how stressful, in general, has the total intensive care unit experience been for you." The individual items related to professional staff communication include "explaining things too fast", "using words I don't understand", "telling me different (conflicting) things about my child's condition", "not telling me what is definitely wrong," and "not talking to me enough." The individual items related to behavioral and emotional responses include "confusion", "rebellious or uncooperative behavior", "crying or whining", "demanding", "acting or looking as if in pain", "restlessness", "inability to talk or cry", "fright", "anger", and "sadness or depression" (Carter & Miles, 1982).

The mothers will rate the stressfulness of each item experienced by circling one of the following options:

- 1 = Not Stressful
- 2 = Minimally Stressful

3 = Moderately Stressful

4 = Very Stressful

5 = Extremely Stressful

Should the mother not experience any particular item, the response "NA", not applicable, is included.

The research instrument, PSS:PICU, was chosen for this study because of its correlation with the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU) which was used in the author's study on sources of stress of mothers with infants hospitalized in NICU. No other tools were found to correlate with the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU).

Procedure

All data within this study was collected by the researcher. Approval of protocol and consent was obtained from both the Geisinger Medical Center Institutional Review Board and the Nursing Research Committee prior to beginning the study. The researcher followed a script when recruiting possible participants (see Appendix F), and each participant was given a letter of consent outlining the study (see Appendix E). The letter of consent explained to the participants that completing the two questionnaires gave the researcher consent to use the findings in the research study.

Each participant was asked to complete the two questionnaires while visiting her child in PICU, IU, CH2, or CH3. The researcher was present while the questionnaires were being completed. In addition, the PICU social worker, Kathy Herman, was available to the participants if any untoward effects develop as a result of participation in the study.

Treatment of Data

Once the mothers complete the questionnaires, the researcher analyzed the data.

Descriptive statistics were used to summarize the demographic data. The PSS:PICU, using the Likert scale, yielded ordinal data from two different metrics. As a result, the researchers used descriptive and nonparametric inferential statistics to analyze the data. The nonparametric tests that were used include the following: Wilcoxon, Mann-Whitney, and Kruskal-Wallis. All data was analyzed using SPSS for Windows. A p-value of less than or equal to .05 was considered significant. The Wilcoxon rank test was used when comparing the means within the metrics for the seven different subscales and when comparing individual questions within the subscales. The Mann-Whitney was used when comparing the means of the subscales between the PSS:PICU and the PSS:NICU. Mann-Whitney and Kruskal-Wallis were used when comparing qualitative demographic information with items on the PSS:PICU. Additionally, Spearman rank correlation were found in order to relate ordinal demographic information with items on the PSS:PICU.

The PSS:PICU was scored using two scaling metrics -- Metric I and Metric II. The data was coded for each item on the PSS:PICU with the integers 1 to 5, where 1 represents not stressful (1), 2 represents a little stressful (2), 3 represents moderately stressful (3), 4 represents very stressful (4), and 5 represents extremely stressful (5). The not applicable (NA) responses were coded differently depending on what metric was being analyzed. In Metric I, the NA responses were coded as missing values. In Metric II, the NA responses were coded as one (1) indicating that the experience was not stressful for the mothers.

Metric I determines the amount of stress associated with each aspect of the environment. This metric yielded information about the frequency of occurrence of stressors in PICU, IU, or general pediatric floor or the percentage of mothers experiencing each item. In Metric I, only those who reported having the experience receive a score on the item. The Metric I score was

calculated by averaging stress responses for the applicable items on each scale and for the total scale (Miles & Funk, 1991).

Metric II was used to describe the levels of stress that the mothers have experienced related to having a child in the PICU, IU, or general pediatric floor. This metric measured the overall stress from the environment. This method of analysis assumed that if the mother did not experience an item then she did not experience any stress related to that item. The Metric II score was calculated by averaging the stress responses for the items on each scale and for the total scale (Miles & Funk, 1991).

All qualitative data contained within the demographic questionnaire was coded using a standard procedure such as 1= yes and 2=no, or 1=single, 2=married, 3=divorced, and 4=widowed. The numerical values from the demographic questionnaire, such as age, number of miles, and child's age, were entered as they were recorded on the questionnaire.

Missing data was coded with an asterisk on both the demographic questionnaire and the PSS:PICU. This information is left blank in the SPSS data file and was not included in the data analysis.

PSS:PICU analysis shows that a high item score indicated a high level of stress for the mothers. In contrast, low scores show that the item was not related to high stress levels for the mothers. The lowest score possible was one while the highest value reported was five.

In order to compare the PSS:PICU results with the results of the previous study using the PSS: NICU, the researcher combined several of the categories of the PSS:PICU to make it more comparable to the PSS:NICU. The categories of behavior and emotional responses and appearance of the child were combined and a new mean was calculated. In addition, the categories of behaviors of the professional staff and communication with the professional staff were combined and a new mean was calculated also. The category procedures on the PSS:PICU

was not used for the comparison because it did not directly correlate with any of the categories on the PSS:NICU.

After considerable manipulation of data related to the demographic survey and the PSS:PICU, the researcher determined significant and nonsignificant results related to the sources of stress encountered by pediatric mothers. In the following chapter, the researcher discusses the results of the analysis and discussion of the findings.

Chapter IV

Analysis and Discussion of Findings

The purpose of this research study is to identify the sources of stress of pediatric mothers in a tertiary care hospital in north central Pennsylvania and to compare the results of this study with results from a similar study of NICU mothers. In this chapter, the results of descriptive and inferential statistical manipulation are presented.

Analysis of Findings

As indicated in Chapter III, all of the scores and subscores to measure stress were based on a scale of one (not stressful) to five (extremely stressful). The data for the PSS:PICU (Parental Stressor Scale: Pediatric Intensive Care Unit) was analyzed in two different ways with Metric I and Metric II. Using Metric I, the mean stress score was calculated only for items the subject experienced. Not experienced items were coded as missing values in the data file. Using Metric II, an overall stress score was calculated with not experienced items being coded as one (1), indicating that the experience was not at all stressful. This scoring technique was recommended by Miles & Funk (1991). In addition to the questions related to each of the subscales, the tool asked the mothers to identify, how stressful, in general, the experience has been. General stress along with the seven subscales of the PSS:PICU were analyzed to answer the research questions: "What are the sources of stress of mothers who have a child hospitalized in PICU, IU, or general pediatric floor at a tertiary care hospital in the north central Pennsylvania?" and "What are the similarities and differences between sources of stress of NICU mothers and sources of stress of mothers with a child hospitalized in PICU, IU, or general pediatric floor at a tertiary care hospital in north central Pennsylvania?"

Demographical Information

Ninety-four percent of the mothers were Caucasian and 6% were Hispanic (see Graph A.2 in Appendix). Fifty-three percent of the mothers were married and 47% were single (see Graph A.3 in Appendix). Forty-one percent of the mothers were high school graduates and 30% of the mothers were college graduates (see Graph A.4 in Appendix). Fifty-four percent of the mothers had a gross annual income of less than \$30,000 (see Graph A.5 in Appendix). The average number of miles lived from Geisinger was 58 miles while the range of distances was from 4 miles to 125 miles (see Graph A.6 in Appendix).

The mothers whom the researcher interviewed had children who ranged from four months to 20 years old with a mean age of five years old (see Graph A.7 in Appendix). The mean number of days spent in the hospital was 5 days with a range from 2 to 30 days (see Graph A.8 in Appendix). The primary diagnoses of the children varied with 47% of the children being diagnosed with respiratory conditions -- primarily RSV. Other diagnoses included trauma, diabetes, tetralogy of fallot, and various GI conditions (see Graph A.9 in Appendix).

Thirty-six percent of the mothers had children who were in PICU while 47% of the mothers had children in CH2 and 17 % of the mothers had children in CH3 (see Graph A.10 in Appendix). Forty-one percent of the children were originally admitted to another floor -- primarily PICU (see Graph A.11 in Appendix).

General Stress Response

The mothers were asked to indicate how stressful, in general, the experience of having a child hospitalized has been for them. Overall, the mothers reported that the general stress elicited was moderately stressful to very stressful in both metric I (M=3.64) and metric II (M=3.18) analysis.

Metric I Analysis

Procedures done to your child. The child having procedures done was the most stressful aspect of hospitalization for the parents ($m=2.46$, $s=.82$). Statistically significant results were found when compared with parental role ($p=.041$). This indicates that the procedures performed elicited a significantly greater amount of stress for the mothers than the parental role alterations did. Overall, the items related to the child having procedures done were a little to moderately stressful.

The individual items found to be most stressful for the mothers related to the procedures performed include tubes in the child and bruises, cuts, or incisions on the child. On the other hand, some items related to parental role were not found to be highly stressful. These include suctioning and making child cough and deep breathe or clapping on child's chest.

Sights and Sounds. The sights and sounds of the hospital was the second stressful aspect of the hospitalization for the mothers. There were no statistically significant results when compared with the other subscales. The items ranged from being a little stressful to moderately stressful ($m=2.31$, $s=1.24$). Overall, the items that were most stressful for the mothers included the sudden sounds of monitor alarms, while items that were not as stressful included seeing the heart beat on the monitors.

Behaviors and Emotional Responses. Overall, the behaviors and emotional responses of the children was a little stressful for the mothers ($m=2.06$, $s=.91$). There were no statistically significant results when compared to other subscales. This was the third stressful aspect for the mothers. Individual items that were highly stressful in this category include the child acting looking as if in pain, fright, and anger. Items that were not stressful in this category include rebellious or uncooperative behavior and demanding behavior.

Child's Appearance. Overall, the child's appearance was found to be not stressful to a little stressful for the mothers ($m=1.52, s=1.41$). No statistically significant results were found when compared with the other six dimensions of the scale.

Parental Roles. The parental role alterations was identified as the fifth most stressful aspect for mothers. Consequently no statistically significant results were found when compared with the other subscales. Overall, the items related to parental role alterations were not stressful to a little stressful ($m=1.80, s=1.31$). However, mothers reported that most stressful aspects related to parental roles include not being able to see child when I wanted, not being with the crying child, and not being able to hold the child. The least stressful aspects include not taking care of the child myself and not being able to visit the child when I wanted.

Behaviors of Professional Staff. Overall, behaviors of the professional staff were not stressful or only a little stressful for mothers ($m=1.61, s=1.26$). Although no statistically significant results were found, the behaviors of the professional staff was the sixth stressful area for the mothers. Highest areas of stress occurred when the staff did not talk to the mother enough. Lowest stress occurred when the staff joked, laughed, or talked loudly.

Professional Staff Communication. The communication of the professional staff was the least stressful aspect for the mothers ($m=1.31, s=.98$). Overall, item analysis shows the items related to this subscale were not stressful to a little stressful. There were no significant results found when compared to other subscales. The item that was most stressful included telling me conflicting things about the child while the item that was least stressful includes using words I don't understand.

Metric II Analysis

Procedures done to your child. The procedures done to the child was the most stressful aspect of the hospitalization for the mothers. Overall, the mothers rated this aspect as a little to

moderately stressful ($m=2.40$, $s=.74$). The procedures that were most stressful were injections, shots, and putting needles in the child for fluids, procedures, and tests. Statistically significant results were found when compared with parental role ($p=.037$). This indicates that procedures was associated with significantly greater stress than parental role alterations.

Sights and Sounds. Overall, sights and sounds was the second most stressful aspect of the hospitalization for the mothers. The mothers rated the items in this subscale as a little to moderately stressful ($m=2.12$, $s=1.04$). No statistically significant results were found when comparing this subscale to the other subscales. The item that was most stressful was the sudden sounds of monitor alarms while the least stressful aspect was seeing the heart beat and the sound of the equipment.

Behaviors and Emotional Responses. The behaviors and emotional responses of the child was the third stressful aspect for the mothers. Overall, they rated this subscale as a little stressful ($m=1.99$, $s=.95$). There were no statistically significant results related to this category. Individual items that were rated as being highly stressful include the child acting or looking as if in pain. Individual items that were not found to be stressful include the child's demanding behaviors.

Child's Appearance. Overall, the child's appearance was found to be not stressful to a little stressful ($m=1.76$, $s=.93$). There were no statistically significant results when comparing child's appearance to other subscales. The individual items that were the most stressful included color changes in the child. The individual items that were not stressful included the child appearing cold or puffy.

Parental Roles. The changes in parental role were found to be not stressful to a little stressful ($m=1.71$, $s=1.23$). Overall, this subscale was the fifth stressful aspect for mothers. The individual items that were highly stressful in this area include not holding or taking care of the child. The areas that were not stressful for the mothers included not being able to see or visit the

child when I wanted.

Behaviors of Professional Staff. The behaviors of the professional staff were not found to be highly stressful for mothers. Overall, the mothers rated this subscale as not stressful to a little stressful ($m=1.57$, $s=1.24$). There were no statistically significant results when compared with other subscales. The individual questions which were highly stressful in this category were not talking to me enough and too many different people talking to me, while those that were not at all stressful were joking, laughing, or talking loudly and telling me who they are.

Professional Staff Communication. Overall, the communication of the professional staff was not found to be stressful for mothers ($m=1.40$, $s=1.06$). The mothers rated this category as the least stressful aspect of the hospitalization. There were no statistically significant results related to this subscale. Individual items that were highly stressful include telling me different things about the child's condition and not telling me what is definitely wrong, while the items that were not highly stressful include explaining things too fast and using words that I don't understand.

Comparison of Metric I and Metric II Analysis

Overall, the results of both Metric I and Metric II show that procedures done to the child was the most stressful aspect for the mothers in both metrics. In fact, the communication of the professional staff was the least stressful in both metrics, and both metrics yielded statistically significant results when comparing procedures with parental role alterations. Additionally, the ranking of the subscales from most stressful to least stressful for the mothers was the same in both metrics.

Comparison of PSS:NICU and PSS:PICU

Overall, both parental role alteration and child's appearance and behavior were the most stressful aspects when comparing sources of stress of NICU mothers with sources of stress for

mothers of pediatric patients. Statistically significant results were found when comparing child's appearance on the PSS:NICU to child's appearance and behavior and emotional responses of child on the PSS:PICU in both metric I ($p=.012$) and metric II ($p=.008$). The neonatal mothers reported a significant greater stress level associated with the appearance and behavior of the child than the pediatric mothers did. In addition, statistically significant results were found when comparing parental role alteration on the PSS:NICU with parental role alteration on the PSS:PICU in both metric I ($p=.018$) and metric II ($p=.022$). Once again the neonatal mothers reported a significantly greater stress level associated with parental role alterations than the pediatric mothers.

Discussion of Findings

The analysis of this data yielded many insightful results. In general, the results of this research support previous research. Heuer (1993) found that procedures along with sights and sounds were the most stressful aspects of the hospitalization. Miles and Mathes (1991) found that the child's behavior and emotional response were the most stressful aspects while staff communication and staff behavior were the least stressful aspects. The article by Seidman and associates (1997) comparing sources of stress of parent with children in NICU and PICU had results similar to the present study. Overall, they found that the most stressful aspect for NICU mothers and PICU mothers was parental role alteration. The current study found that parental role alteration along with child's appearance were the most stressful aspects for mothers.

Threats to Validity

Within this research study, many threats to validity were noted by the researcher. The primary threat to validity was the small sample size used in the study.

Internal Validity. Internal validity deals with the extent to which the effects of the study are a true reflection of reality (D. Parrish, Lecture Notes, October 1, 1997). There are many

internal threats to validity in this research study.

A primary threat to internal validity was instrumentation. The fact that the tool was not used on the population on which it was normed is a possible threat. The tool was normed on parents who had children hospitalized in PICU. In the current research, the study was conducted on mothers who had children in PICU along with the general pediatric floors.

The fact that the researcher used a convenience sample in this study could also be a threat to the internal validity because the results of the study cannot be generalized to a larger population. The results can only be generalized to the 17 mothers who participated in the study.

External Validity. External validity deals with the extent to which the findings can be generalized beyond the sample (D. Parrish, Lecture Notes, October 1, 1997). In addition to the internal threats discussed, external threats to validity also could exist within the present study.

Three primary threats to external validity may have existed – the Hawthorne Effect, the Rosenthal Effect, and the Novelty Effect. The Hawthorne Effect refers to mothers who may have changed their responses just by virtue of being in a research study. There is no way to know whether this occurred; however, researchers must consider its potential impact. The Rosenthal Effect suggests that the way the mothers responded was influenced by the way that the researcher approached them. The researcher may have influenced the participants because of nonverbal cues and also by the tone of the researcher's voice when reading the script. The Novelty Effect may also be a threat to external validity. This effect is related to the newness of the experience of participating in a study, which could alter the responses of the mothers. Many of the mothers stated that they had never participated in a research study before. An additional threat to the validity is the fact that the findings cannot be generalized to a larger population as a result of the convenience sampling design.

There are many possible explanations as to why some of the results were not statistically significant, but one primary explanation is important. The small sample size (17 mothers) may have affected the potential for significance in the study. A larger sample size is needed to detect other potentially significant results.

Serendipitous Findings

In addition to the results related to the main purpose of the research study, many additional findings were discovered. Several of the demographic variables were correlated with the subscales within the different metrics using Spearman-Rank correlations. Using Metric I analysis, there were significant positive correlation between age of the mothers and parental role alterations ($r=.596$, $p=.012$) and between the number of miles traveled to the hospital and the child's appearance ($r=.552$, $p=.022$). As the number of miles the mothers lived from the hospital increased, the amount of stress experienced related to the child's appearance also increased. Additionally, as the age of the mothers increased so did the stress related to the parental role alteration.

Metric II analysis also shows significant positive correlations were also found between number of miles mothers had to travel and their child's appearance ($r=.804$, $p=.00$), age of the mothers and the parental role alteration ($r=.596$, $p=.012$), and whether or not the child was admitted to a different floor and behaviors of the professional staff ($r=.552$, $p=.022$). As the number of miles the mother lives from the hospital increased, the amount of stress experienced related to the child's appearance also increased. Similarly, as the age of the mothers increased, the amount of stress related to the parental role alteration also increased. In addition, as the number of floors the child spent time on increased, the amount of stress related to behaviors of the professional staff also increased.

Mann-Whitney and Kruskal-Wallis tests show several of the qualitative demographic variables are related to the seven subscales for the different metrics. Using Metric I analysis, the only statistically significant relationship was found between job status and parental role alteration ($p=.041$). Therefore, employed mothers have significantly higher stress than unemployed mothers. Metric II analysis revealed a significant relationship between educational level and the behaviors and emotional responses of the child ($p=.033$). Mothers with less than a high school diploma of education have more stress related to the behavior and emotional responses of the child.

Perhaps, if a larger sample size was used, more significant results may be found relative to the other demographic variables. The results relating job status and educational level item results have not been reported in any other studies.

Overall, many interesting and potentially useful results were found in this study. Nurses, along with other health care professionals, can apply this information to help reduce the stress of mothers with children hospitalized. In the final chapter of this paper, the researchers discuss possible implications for nursing, additional research areas, and ways to disseminate information about the study.

Chapter V

Conclusions and Implications for Nursing

The research questions addressed in this study are “What are the sources of stress of mothers who have a child hospitalized in PICU, IU, or a general pediatric floor?” and “What are the similarities and differences between sources of stress of NICU mothers and sources of stress of mothers with a child hospitalized in PICU, IU, or a general pediatric floor?” Overall, the results of this study indicate that the major sources of stress for mothers of pediatric patients include procedures done to the child and the sights and sounds in the unit.

In addition, the other five subscales also were found to cause some stress for the mothers. These include behaviors and emotional responses, the child’s appearance, parental role alterations, behaviors of the professional staff, and the communication with the professional staff. Based on the results of this study, interventions need to be focused on reducing the stress of pediatric mothers in all areas. Nurses need to focus interventions on helping mothers understand and cope with various aspects of their child’s illness, such as explaining the necessity of procedures and the typical appearance of a hospitalized child. In addition, professionals need to be sensitive to the various parental responses to observing their child.

Two aspects which were not stressful for mothers were behaviors of the professional staff and communication with the professional staff. This may be the result of high quality care and effective communication between staff and mothers. However, an additional explanation for a low source of stress associated with staff communication may be that mothers are not able to express concerns with staff immediately because they are focused on their child’s well-being. In addition, mothers may be hesitant to say anything negative about the staff because they are dependent on them.

Further research on this topic needs to be conducted with a larger sample size which could possibly yield more significant results. In addition, expanding the study to include different ethnic classes, different geographical areas, and different socioeconomic classes may provide significantly different results and would make the findings applicable to parents in general. Performing the study at more than one institution will also enable researchers to expand the generalizability of the results. Conducting a longitudinal study may show how the mother's stress changes during and after the hospitalization. In addition, the use of additional tools such as the State-Trait Anxiety Inventory (STAI) or the Parent preparation Questionnaire (PPQ) may help find additional information related to increasing need for preparing parents.

Dissemination of Findings

The findings of this research study were reported to nurse educators, nurse researchers, and nurse managers, along with hospital personnel at the institution approving the study. In addition, the results of this study could be disseminated through publications. The results of the study were sent to the University of Kansas, to assist in increasing the reliability and validity of the tool. Additional presentations could be made at professional meetings upon request.

In conclusion, the researcher answered the questions, "what are the sources of stress of mothers who have a child hospitalized in PICU, IU, or a general pediatric floor?" and "what are the similarities and differences between sources of stress of NICU mothers and sources of stress of mothers with a child hospitalized in PICU, IU, or a general pediatric floor?" The results of this study were similar to the results of Heuer (1993) in that procedures done to the child and sights and sounds were the most stressful aspects. Through dissemination of the findings and further research in this area, health care professionals, especially nurses, may be able to implement strategies to hopefully reduce the stress experienced by mothers when their child is hospitalized.

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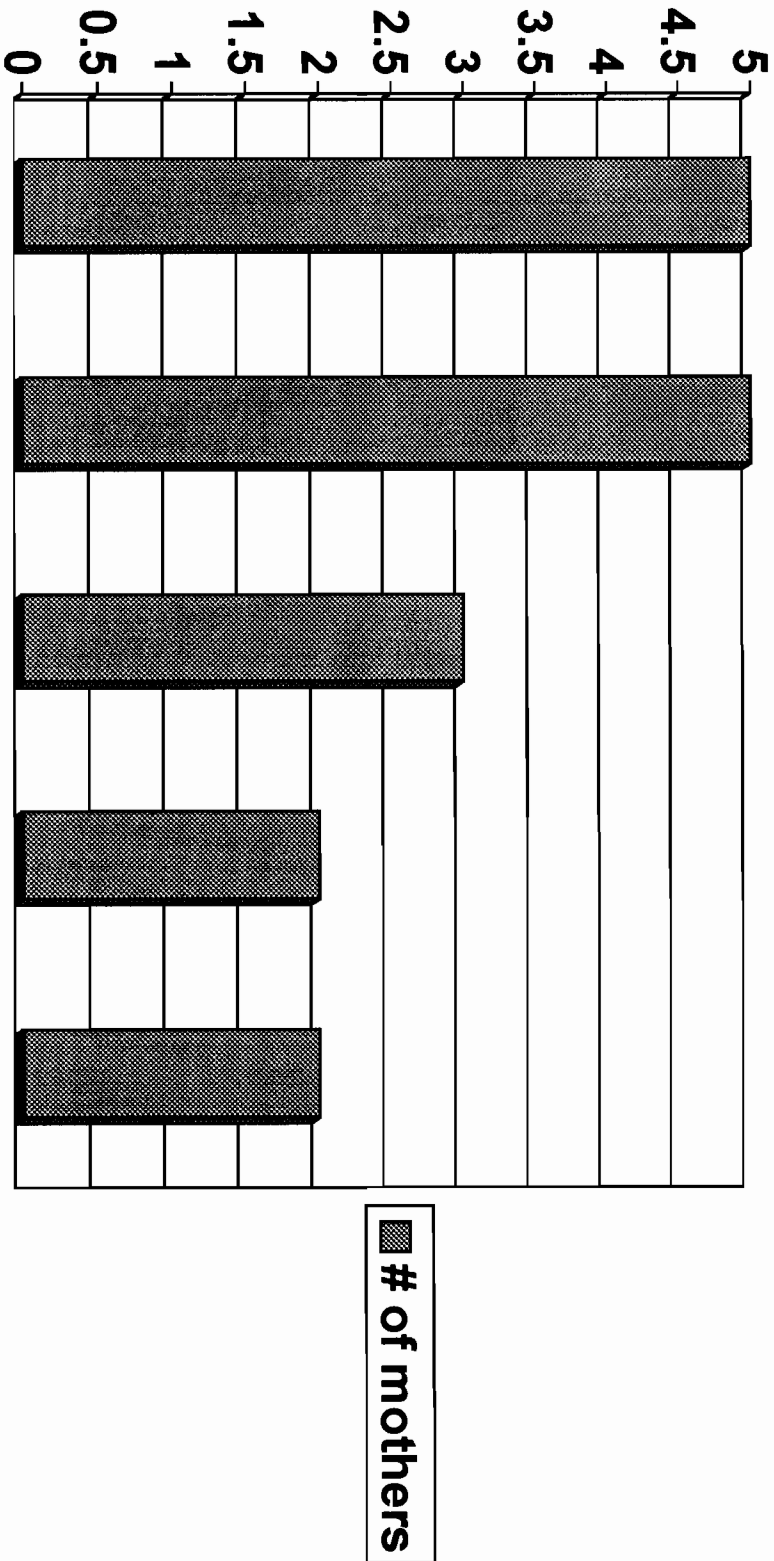
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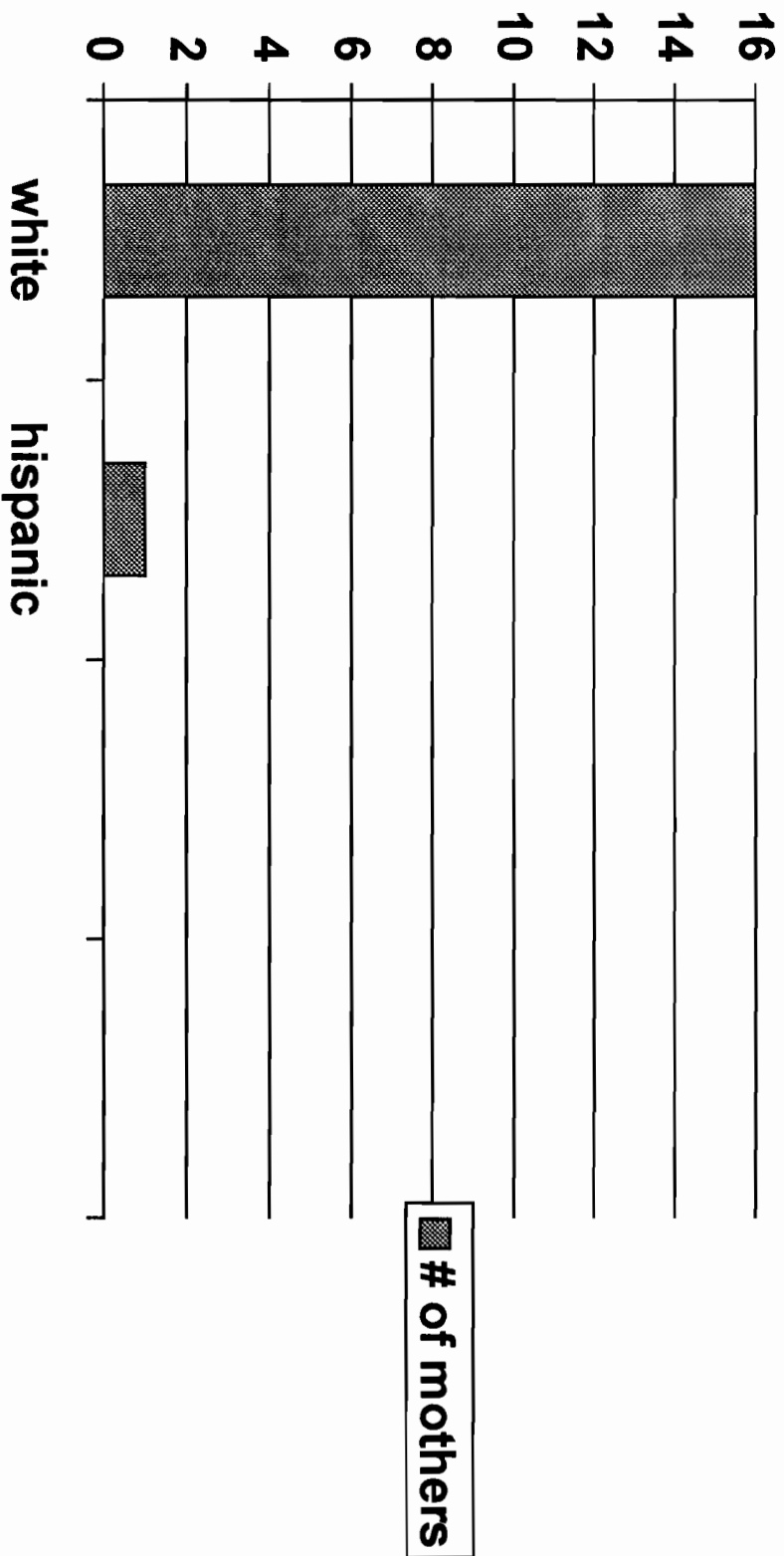
Appendices

Appendix A

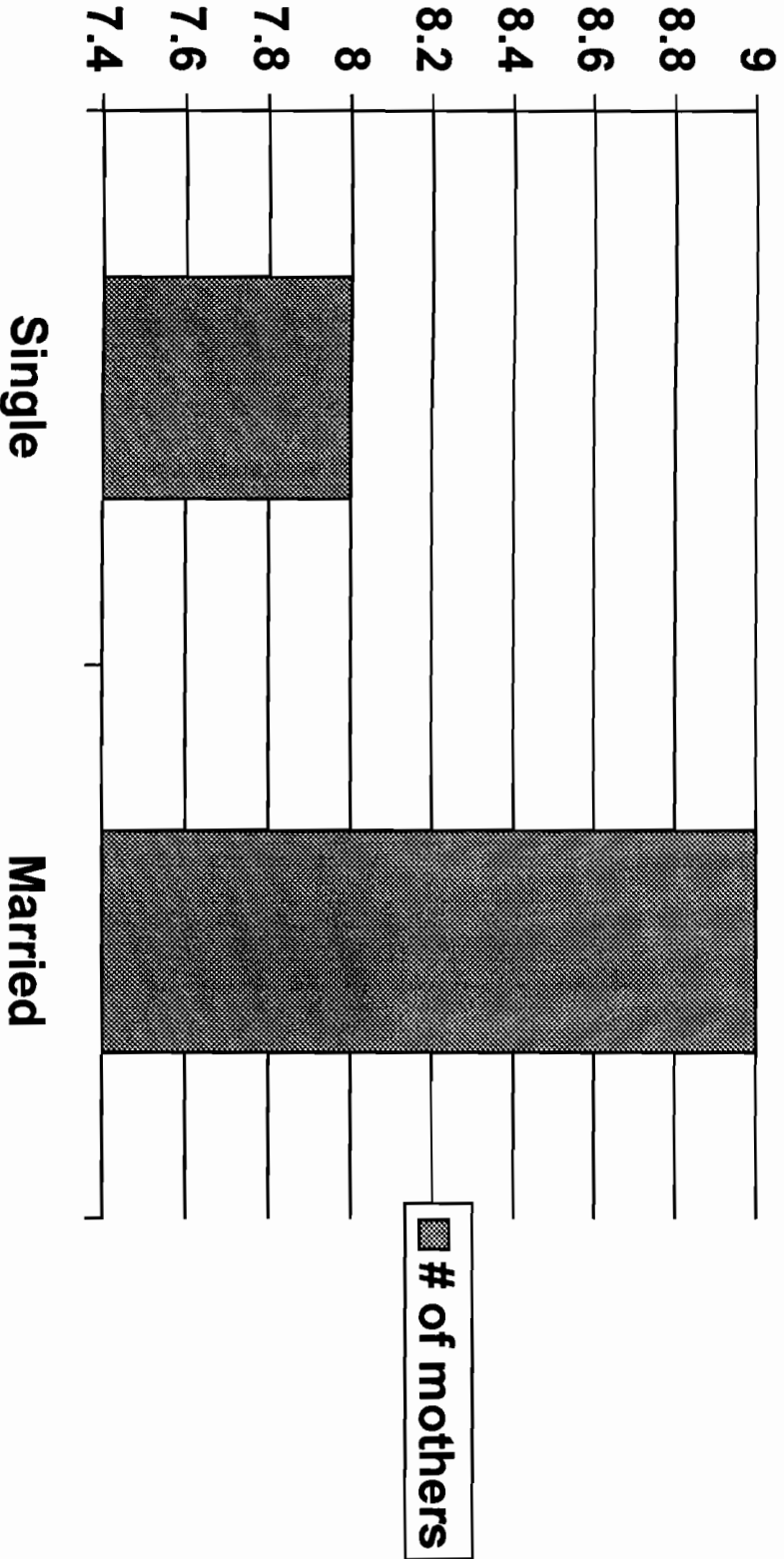
Graph A.1 Age of Mothers



Graph A.2 Ethnicity of Mothers

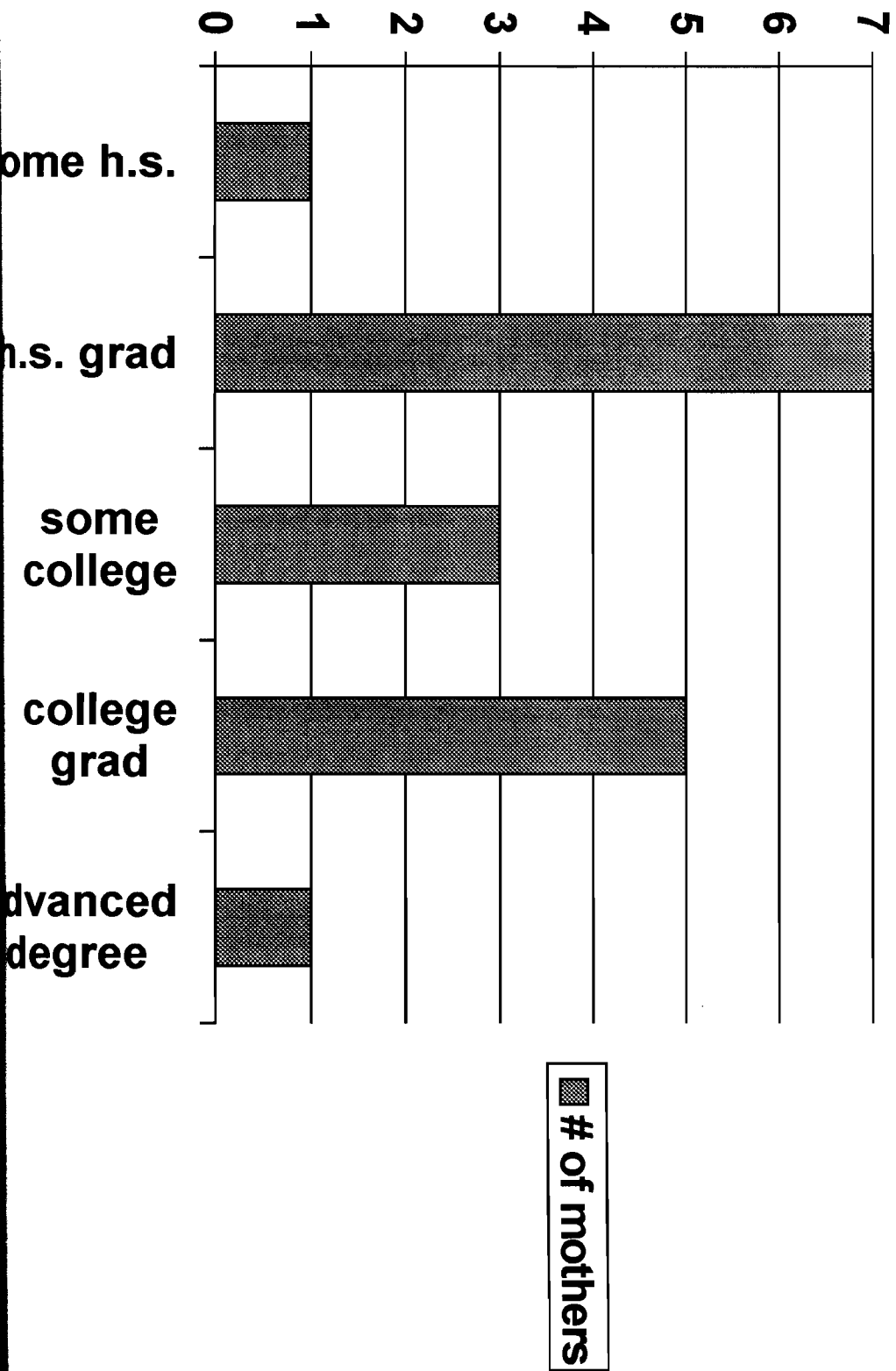


Graph A.3 Marital Status

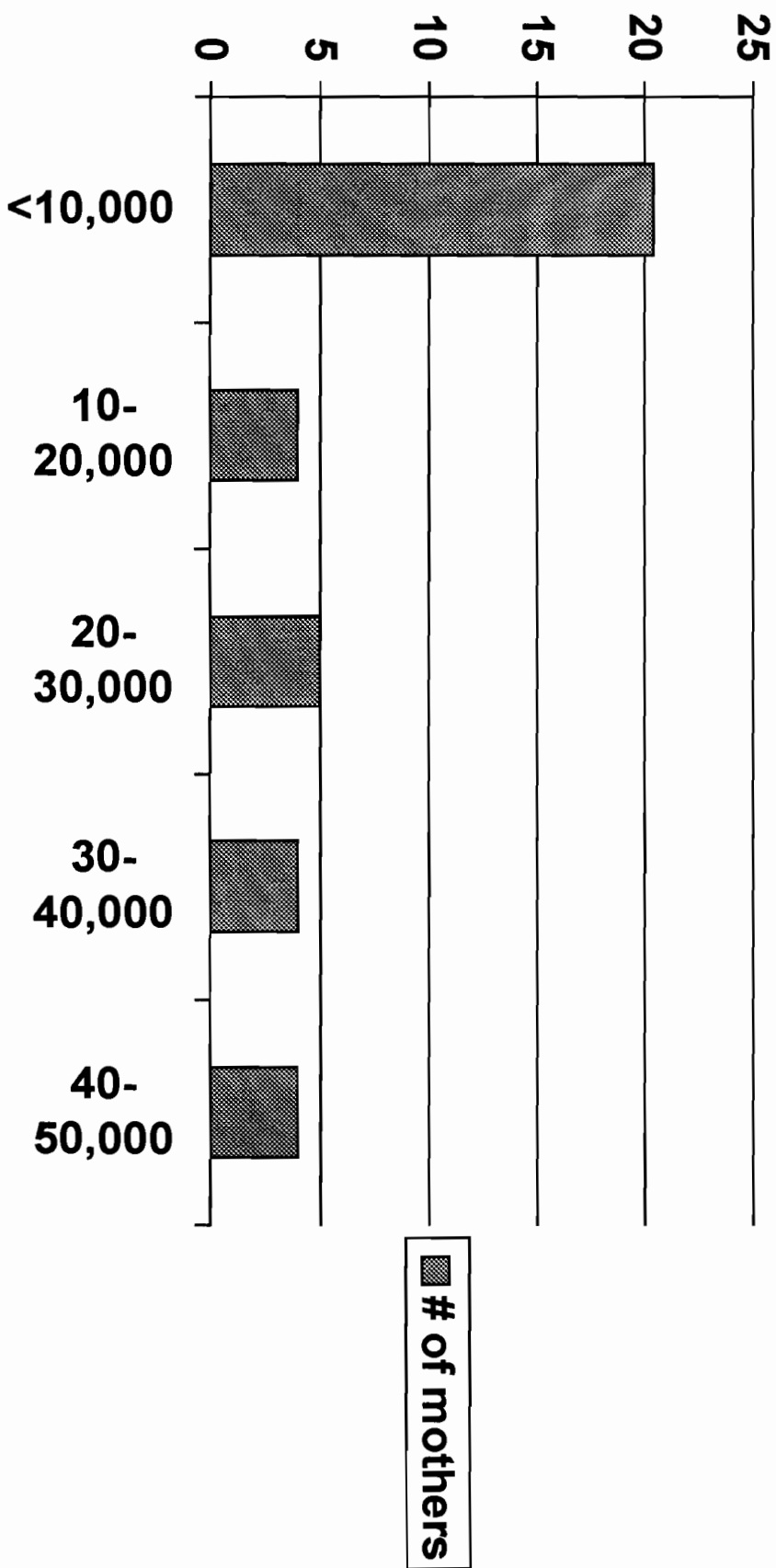


Graph A.4

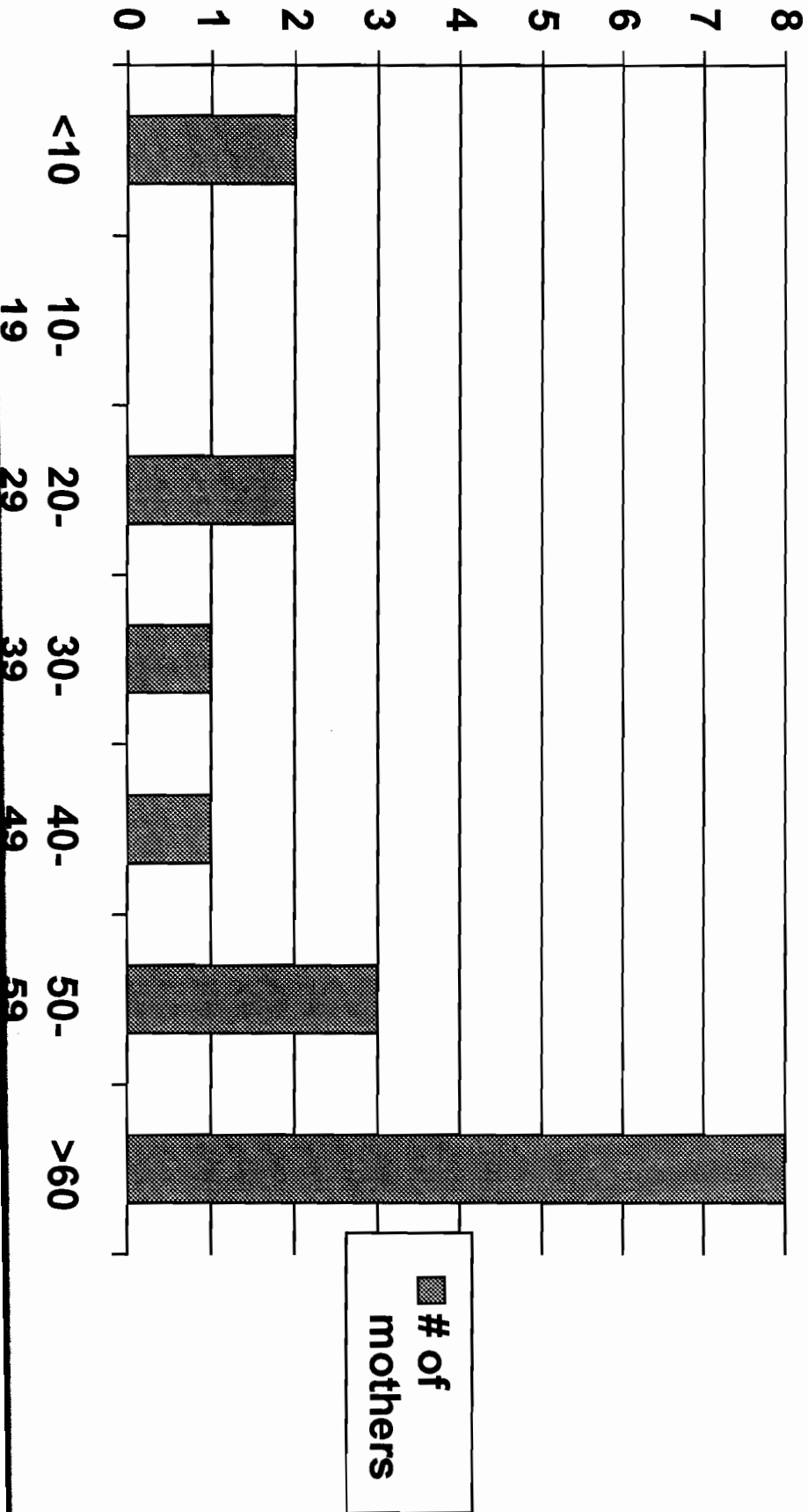
Educational Level of Mothers



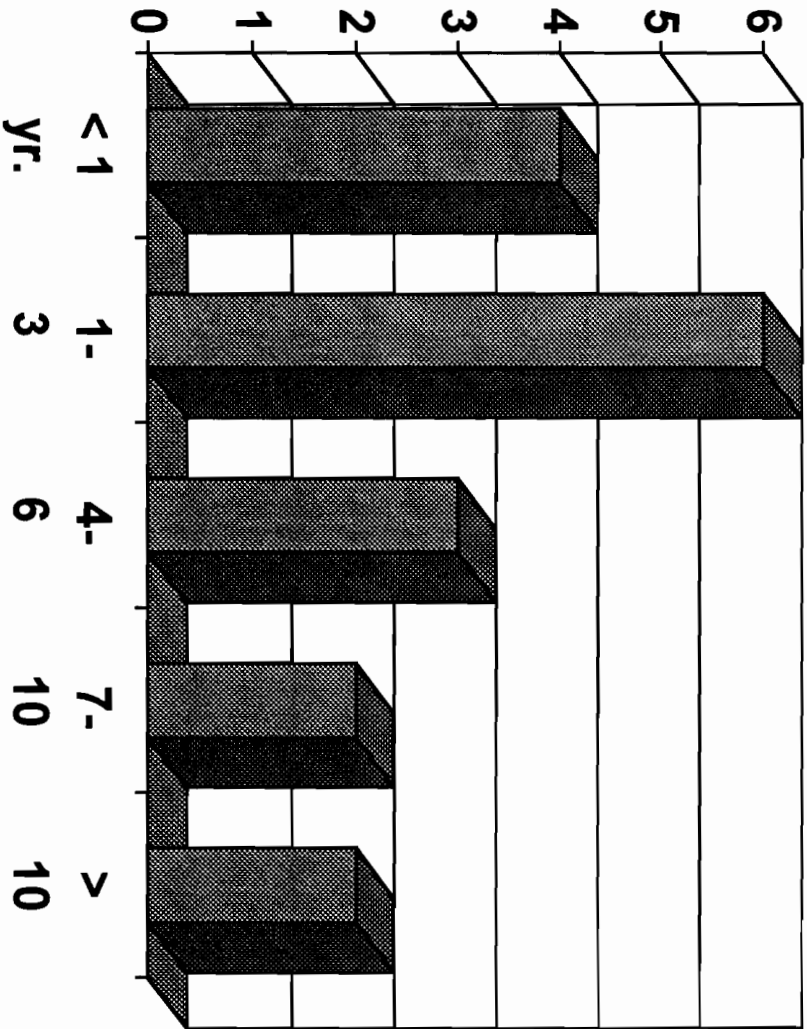
Graph A.5 SES of families



Graph A.6 Miles from Geisinger

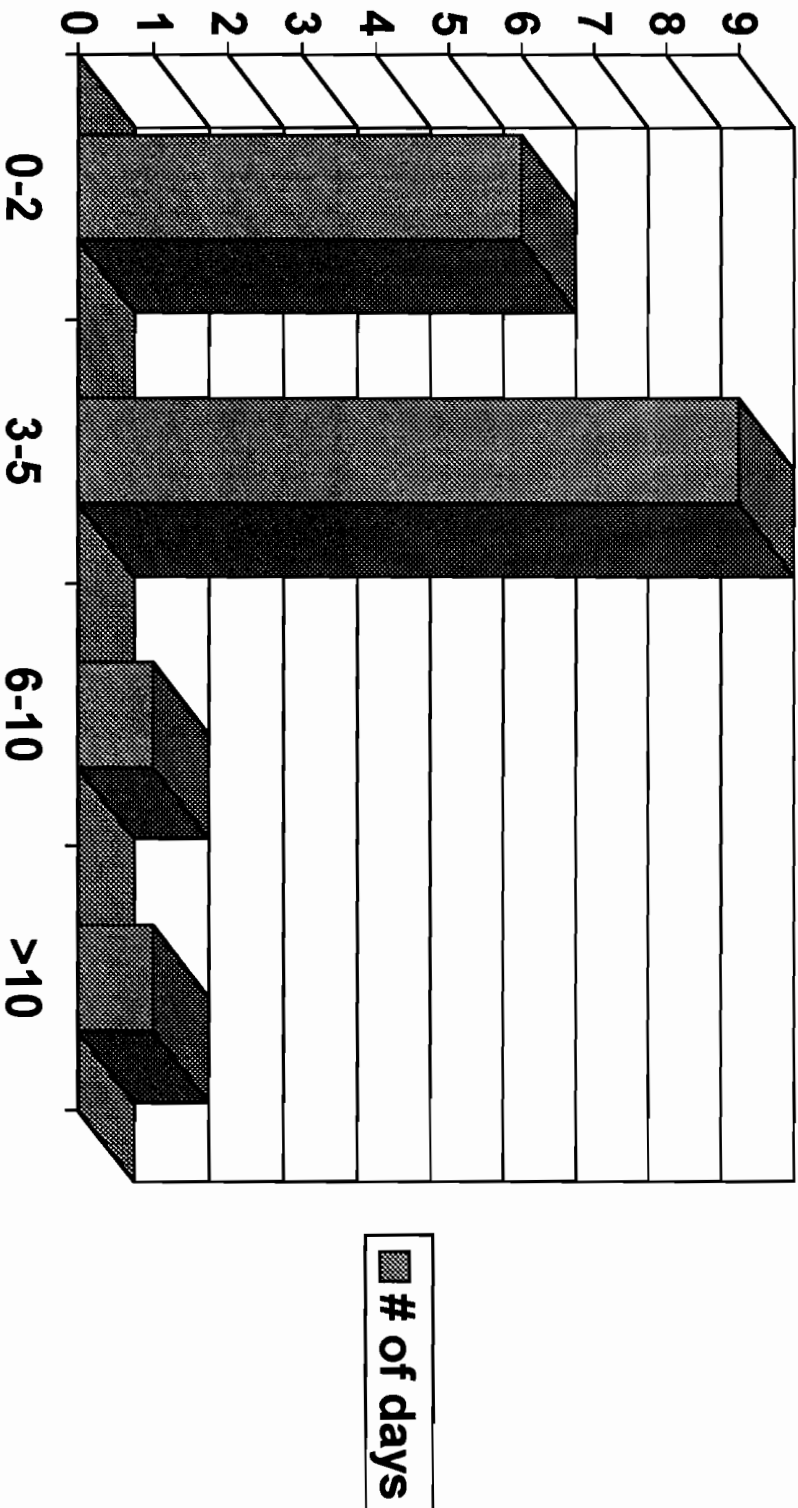


Graph A.7 Child's Age

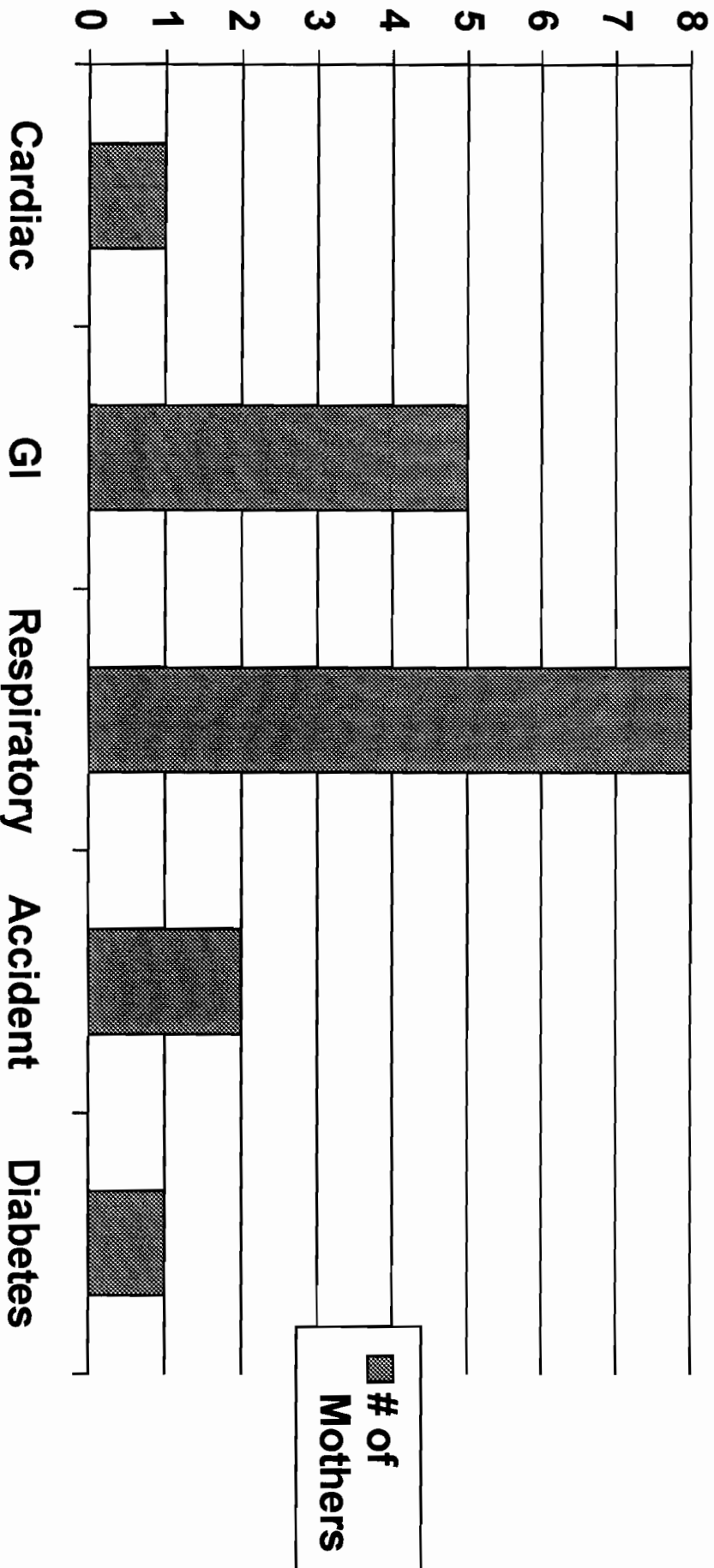


■ # of children

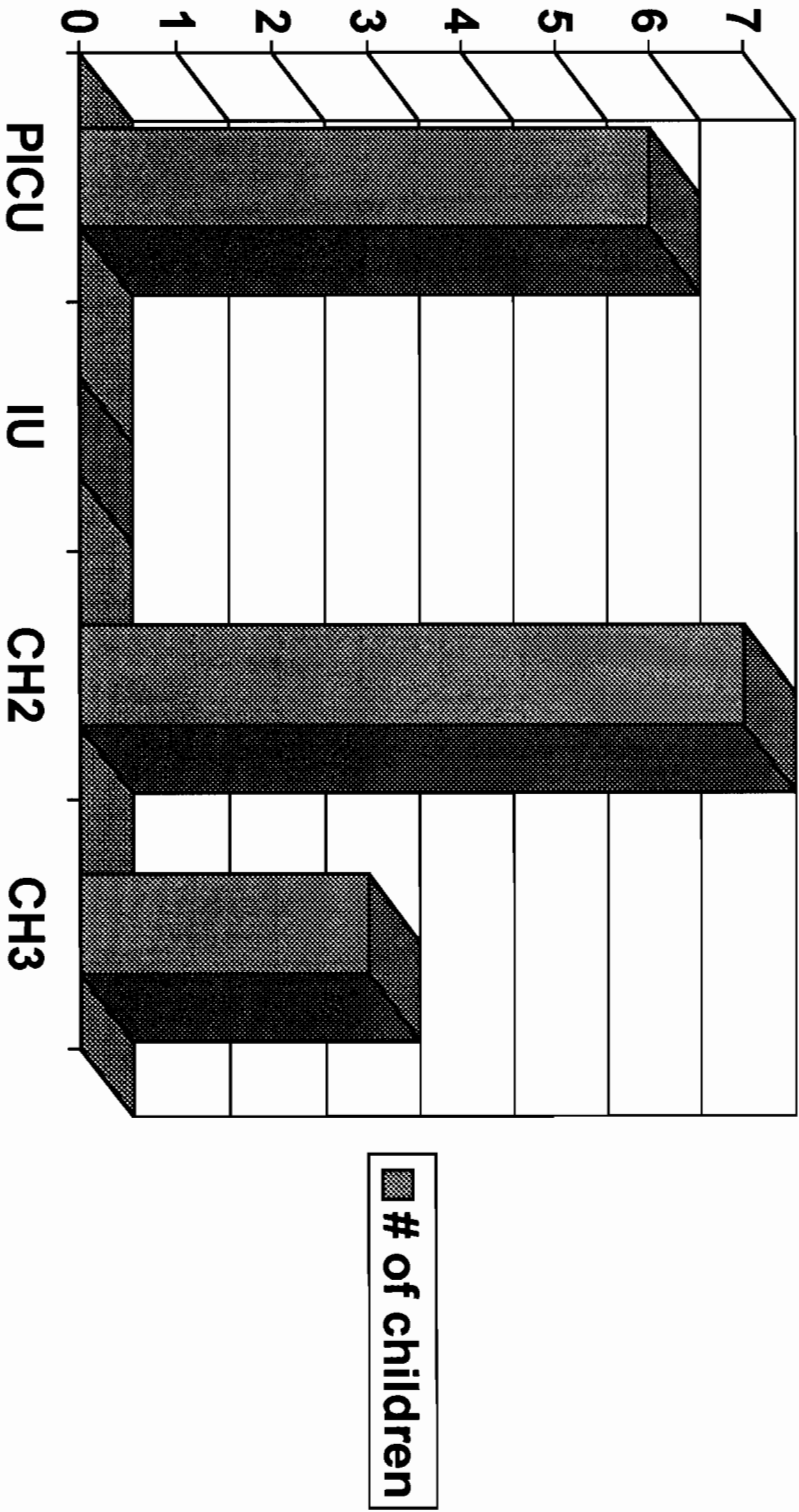
Graph A.8 Length of Hospitalization



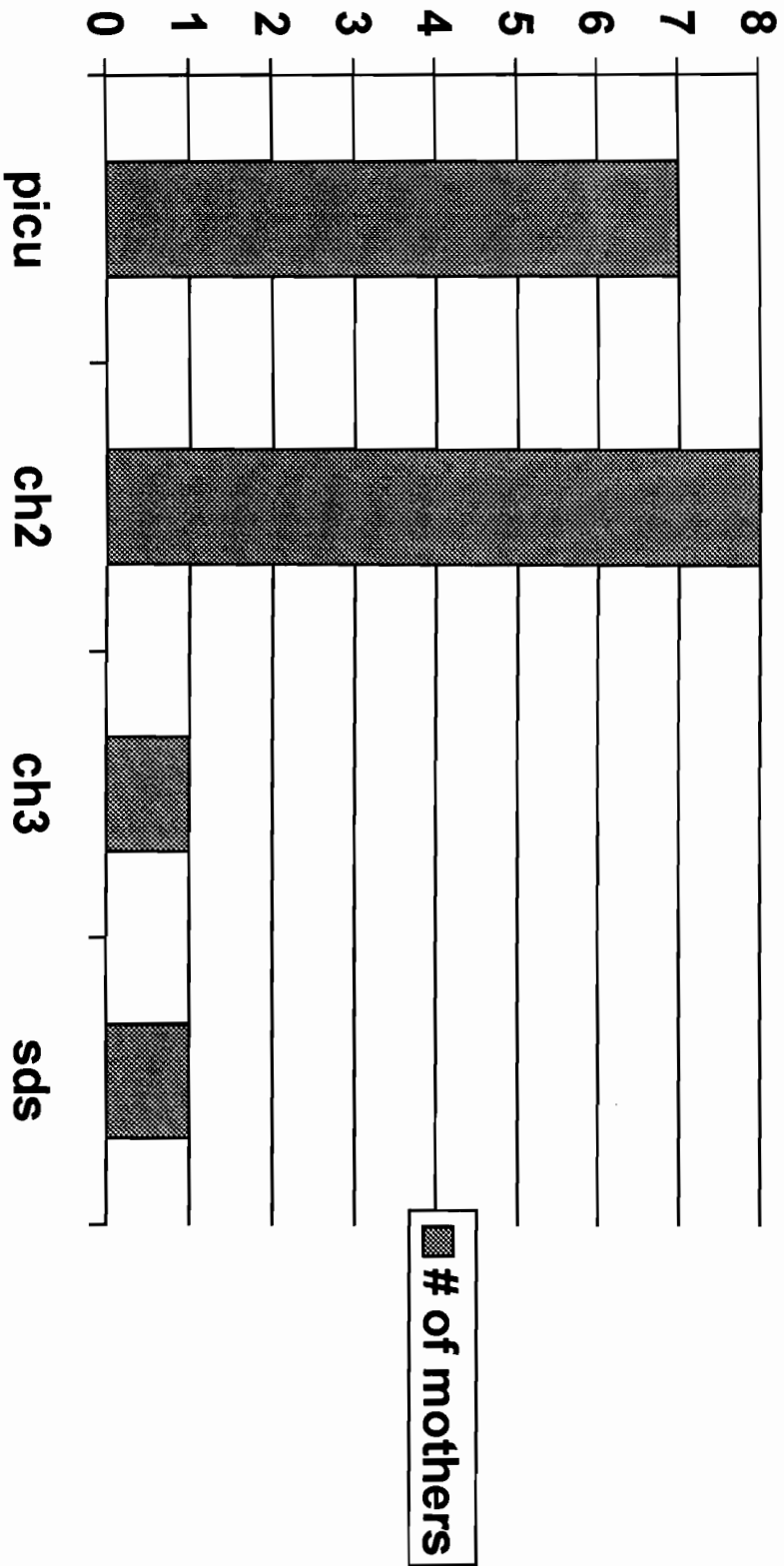
Graph A.9 Primary Diagnosis



Graph A. 10 Floor Hospitalized On



Graph A.11 Original floor admitted to



Appendix B

PARENTAL STRESS SCALE: NEONATAL INTENSIVE CARE UNIT

Self Report Format

c Margaret S. Miles, RN, PhD 1987

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

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

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

On the questionnaire, circle the single number that best expresses how stressful each experience has been for you _____.* The numbers indicate the following levels of stress:

- | | |
|--------------------------|---|
| 1 = Not at all stressful | the experience did not cause you to feel upset, tense, or anxious |
| 2 = A little stressful | |
| 3 = Moderately stressful | |
| 4 = Very stressful | |
| 5 = Extremely stressful | the experience upset you and caused a lot of anxiety or tension |

Remember, if you have not experienced the item, please circle NA "not applicable"

Example

Now let's take an item for an example: The bright lights in the NICU.

If for example you feel that the bright lights in the neonatal intensive care unit were extremely stressful to you, you would circle the number 5 below:

NA 1 2 3 4 5

If you feel that the lights were not stressful at all, you would circle the number 1 below:

NA 1 2 3 4 5

If the bright lights were not on when you visited (not likely), you would circle NA indicating "Not Applicable" below:

NA 1 2 3 4 5

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

- | | |
|--|--------------|
| 1. The presence of monitors and equipment | NA 1 2 3 4 5 |
| 2. The constant noises of monitors and equipment | NA 1 2 3 4 5 |

- | | | | | | | | |
|-----|---|----|---|---|---|---|---|
| 16. | The limp and weak appearance of my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 17. | Jerky or restless movements of my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 18. | My baby not being able to cry like other babies | NA | 1 | 2 | 3 | 4 | 5 |
| 19. | Clapping on baby's chest for chest drainage | NA | 1 | 2 | 3 | 4 | 5 |

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

- | | | | | | | | |
|-----|---|----|---|---|---|---|---|
| 1. | Being separated from my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 2. | Not feeding my baby myself | NA | 1 | 2 | 3 | 4 | 5 |
| 3. | Not being able to care for my baby myself (for example, diapering, bathing) | NA | 1 | 2 | 3 | 4 | 5 |
| 4. | Not being able to hold my baby when I want | NA | 1 | 2 | 3 | 4 | 5 |
| 5. | Sometimes forgetting what my baby looks like | NA | 1 | 2 | 3 | 4 | 5 |
| 7. | Not being able to share my baby with other family members | NA | 1 | 2 | 3 | 4 | 5 |
| 8. | Feeling helpless and unable to protect my baby from pain and painful procedures | NA | 1 | 2 | 3 | 4 | 5 |
| 9. | Being afraid of touching or holding my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 10. | Feeling staff is closer to my baby than I am | NA | 1 | 2 | 3 | 4 | 5 |
| 11. | Feeling helpless about how to help my baby during this time | NA | 1 | 2 | 3 | 4 | 5 |

- | | | | | | | | | |
|----|--|----|----|---|---|---|---|---|
| 3. | The sudden noises of monitor alarms | NA | 1 | 2 | 3 | 4 | 5 | |
| 4. | The other sick babies in the room | | NA | 1 | 2 | 3 | 4 | 5 |
| 5. | The large number of people working in the unit | | NA | 1 | 2 | 3 | 4 | 5 |

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

- | | | | | | | | |
|-----|--|----|---|---|---|---|---|
| 1. | Tubes and equipment on or near my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 2. | Bruises, cuts or incisions on my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 3. | The unusual color of my baby
(for example looking pale or yellow jaundiced) | NA | 1 | 2 | 3 | 4 | 5 |
| 4. | My baby's unusual or abnormal breathing patterns | NA | 1 | 2 | 3 | 4 | 5 |
| 5. | Seeing my baby suddenly change color
(for example, becoming pale or blue) | NA | 1 | 2 | 3 | 4 | 5 |
| 6. | Seeing my baby stop breathing | NA | 1 | 2 | 3 | 4 | 5 |
| 7. | The small size of my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 8. | The wrinkled appearance of my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 9. | Having a machine (respirator) breathe for my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 10. | Seeing needles and tubes put in my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 11. | My baby being fed by an intravenous line or tube | NA | 1 | 2 | 3 | 4 | 5 |
| 12. | When my baby seemed to be in pain | NA | 1 | 2 | 3 | 4 | 5 |
| 13. | My baby crying for long periods | NA | 1 | 2 | 3 | 4 | 5 |
| 14. | When my baby looked afraid | NA | 1 | 2 | 3 | 4 | 5 |
| 15. | When my baby looked sad | NA | 1 | 2 | 3 | 4 | 5 |

We are also interested in whether you experienced any stress related STAFF BEHAVIORS and COMMUNICATION. Again, if you experienced the item indicate how stressful it was by circling the appropriate number. If you did not experience the item, circle the NA meaning "Not applicable." Remember, your answers are confidential and will not be shared or discussed with any staff member.

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

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

1 2 3 4 5

Thank you for your help. Now, was there anything else that was stressful for you during the time that your baby has been in the neonatal intensive care unit? Please discuss below:

Demographic Survey

Age

Ethnicity

Marital Status

Single

Married

Divorced

Widowed

Occupation

Socioeconomic Status (Total Household Income per Year)

<\$10,000

\$10,000-\$20,000

\$20,000-\$30,000

\$30,000-\$40,000

\$40,000-\$50,000

\$50,000-\$75,000

>\$75,000

Highest Educational Level Completed

Number of Other Children

Have you ever had a Child Hospitalized before?

Yes No

Were you prepared for your child's hospitalization?

Yes No

How many miles do you live from Geisinger?

Child's date of birth

Date of child's hospitalization

Primary Diagnosis of Child

What unit or floor was your child originally admitted to?

Has your child spent any time during this admission on another floor or unit? If yes,

where?

Yes No Where

PARENTAL STRESSOR SCALE: PEDIATRIC ICU

Sources of 52

Melba C. Carter and Margaret S. Miles, C 1982
University of Kansas, School of Nursing

(This instrument is not to be duplicated or used
without written permission of the authors.)

OF GREAT CONCERN TO NURSES AND OTHERS WHO WORK IN A PEDIATRIC INTENSIVE CARE UNIT IS THE EFFECT OF THIS ENVIRONMENT AND EXPERIENCE ON PARENTS. THIS QUESTIONNAIRE CONTAINS A NUMBER OF ITEMS THAT MAY BE STRESSFUL TO PARENTS WHILE THEIR CHILD IS IN AN I.C.U. WE ARE INTERESTED IN YOUR VIEW OF THESE STRESSORS. BY STRESSFUL, WE MEAN AN EXPERIENCE THAT CAUSE YOU TO FEEL ANXIOUS, UPSET, OR TENSE.

ON THE QUESTIONNAIRE, YOU ARE ASKED TO CIRCLE THE NUMBER THAT BEST EXPRESSES HOW STRESSFUL EACH ITEM WAS FOR YOU. ON THE SCALE, THE NUMBER 1 REPRESENTS "NOT STRESSFUL," AND THE NUMBER 5 REPRESENTS "EXTREMELY STRESSFUL." PLEASE READ EACH OF THE FOLLOWING ITEMS CAREFULLY. IF YOU DID NOT EXPERIENCE THE ITEM, PLEASE CIRCLE ZERO (0) UNDER THE COLUMN "NOT EXPERIENCED."

EXAMPLES

If, for example, you feel that an item was extremely stressful to you, you would circle the number 5

	<u>NOT EXPERIENCED</u>	<u>NOT STRESSFUL</u>	<u>MINIMALLY STRESSFUL</u>	<u>MODERATELY STRESSFUL</u>	<u>VERY STRESSFUL</u>	<u>EXTREMELY STRESSFUL</u>
	0	1	2	3	4	5
	0	1	2	3	4	5

If you feel that an item was not stressful at all, you would circle the number 1

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

LET ME REMIND YOU TO CIRCLE ZERO (0)
FOR THOSE ITEMS YOU DID NOT EXPERIENCE

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

Below is a list of items that might describe your CHILD'S APPEARANCE. Using the rating scale on the right, circle the number that best expresses how stressful these things have been for you.

NOT EXPERIENCED
NOT STRESSFUL
MINIMALLY STRESSFUL
MODERATELY STRESSFUL
VERY STRESSFUL
EXTREMELY STRESSFUL

	0	1	2	3	4	5
1. Puffiness of my child	0	1	2	3	4	5
2. Color changes in my child (pale, blue or yellow)	0	1	2	3	4	5
3. Child appearing cold	0	1	2	3	4	5

Below is a list of SIGHTS AND SOUNDS in an intensive care unit (I.C.U.). Circle the number that best expresses how stressful each of these items has been for you.

	0	1	2	3	4	5
1. Seeing the heart beat on the monitors	0	1	2	3	4	5
2. The sound of monitors and equipment	0	1	2	3	4	5
3. The sudden sounds of monitor alarms	0	1	2	3	4	5

Below is a list of PROCEDURES that may have been done to your child. Circle the number that best expresses how stressful these procedures have been for you.

	0	1	2	3	4	5
1. Injections/shots	0	1	2	3	4	5
2. Tubes in my child	0	1	2	3	4	5
3. Suctioning	0	1	2	3	4	5
4. Putting needles in my child for fluids, procedures or tests	0	1	2	3	4	5
5. Making my child cough and deep breath/pounding and clapping on my child's chest	0	1	2	3	4	5
6. Bruises, cuts, incisions on my child	0	1	2	3	4	5

Below is a list of BEHAVIORS of the PROFESSIONAL STAFF (doctors and nurses) that you may have observed. Circle the number that best expresses how stressful these items have been for you.

NOT EXPERIENCED
NOT STRESSFUL
MINIMALLY STRESSFUL
MODERATELY STRESSFUL
VERY STRESSFUL
EXTREMELY STRESSFUL

	0	1	2	3	4	5
1. Joking, laughing or talking loudly	0	1	2	3	4	5
2. Not talking to me enough	0	1	2	3	4	5
3. Too many different people (doctors, nurses, staff) talking to me	0	1	2	3	4	5
4. Not telling me their names or who they are	0	1	2	3	4	5

These items relate to PARENTAL ROLES. How stressful have the following been for you?

	0	1	2	3	4	5
1. Not taking care of my child myself	0	1	2	3	4	5
2. Not being able to visit my child when I wanted	0	1	2	3	4	5
3. Not being able to <u>see</u> my child when I wanted	0	1	2	3	4	5
4. Not being able to be with my crying child	0	1	2	3	4	5
5. Not being able to hold my child	0	1	2	3	4	5
6. Using the same rating scale, how stressful, in general, has the total intensive care unit experience been for you?	0	1	2	3	4	5

Below is a list of items that relate to how the professional staff (doctors and nurses) may COMMUNICATE with you about your child's illness. Please indicate the stress level of these items.

	0	1	2	3	4	5
1. Explaining things too fast	0	1	2	3	4	5
2. Using words I don't understand	0	1	2	3	4	5
3. Telling me different (conflicting) things about my child's condition	0	1	2	3	4	5
4. Not telling me what is definitely wrong with my child	0	1	2	3	4	5
5. Not talking to me enough	0	1	2	3	4	5

Below is a list of BEHAVIORS AND EMOTIONAL RESPONSES that your child may have exhibited while in the intensive care unit. Using the same rating scale as above, how stressful were these things for you?

	0	1	2	3	4	5
1. Confusion	0	1	2	3	4	5
2. Rebellious or uncooperative behavior	0	1	2	3	4	5
3. Crying or whining	0	1	2	3	4	5
4. Demanding	0	1	2	3	4	5
5. Acting or looking as if in pain	0	1	2	3	4	5
6. Restlessness	0	1	2	3	4	5
7. Inability to talk or cry	0	1	2	3	4	5
8. Fright	0	1	2	3	4	5
9. Anger	0	1	2	3	4	5
10. Sadness or depression	0	1	2	3	4	5

Appendix D

The Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) is designed to measure parental perception of intensive care unit environmental stressors experienced during their child's hospitalization in a pediatric intensive care unit.

Conceptual Framework

Selye's theory of stress (1956) and Roy's model of nursing practice (Riehl & Roy, 1980) provided the conceptual framework for development of the instrument. Common to the theories of both Selye and Roy are the premises that measured stress is affected by the individual's perception of the power of the stressors and that stressors arise from factors within the individual, the situation, and from the environment. In the conceptual framework developed for the instrument, stressors experienced by parents when their child is in an intensive care unit were identified as personal, situational, and environmental. Personal stressors, which correspond with Selye's conditioning factors and Roy's residual stimuli, included stress factors which parents bring into the intensive care unit experience, along with their propensity for anxiety. Situational stressors, which can be equated with Selye's stressors arising from the physical and psychosocial environment and Roy's contextual stimuli, included parental perception of the stressors experienced from the intensive care unit environment (Miles & Carter, 1983). The instrument, PSS:PICU, measures the concept of environment (Miles & Carter, 1983). The instrument, PSS:PICU, measures the concept of environmental stressors, while the personal-experiential questionnaire collects selected data on personal and situational variables. Environmental stressors were defined as stressors arising from the physical and psychosocial aspects of the ICU environment.

Instrument Development

The process used for development of the pediatric ICU stressor scale utilized a successive interplay between inductive and deductive methods to develop, validate, and modify concepts and theories.

Establishing the Content Domain

Observational data were collected on sources of parental stress experienced by parents during their child's admission to a pediatric intensive care unit (PICU). Parents of children recently discharged from a PICU were then asked informally to validate these stressors and to identify other aspects of their experience which were particularly difficult for them. These responses were recorded and examined in an attempt to categorize the data into a meaningful pattern.

Fifty-six process items defining the concept of ICU environmental stress were identified from these observations and interviews and from the literature. These items were evaluated and expanded in a small pilot study in which ten parents whose children were recently discharged from an ICU and eleven nurses with extensive

experience in these units were asked to add to the list and to comment on the appropriateness and clarity of the items. As a result, 44 new items were added to the list and previous items were revised.

Following this pilot study, members of the Pediatric Nursing Research Section, formed under the auspices of Nurse Faculty Research Development in the Midwest, a project based at the University of Illinois, became consultants in the development of the instrument. With the assistance of this group of nurses, the 100 items were collapsed into a 79-item questionnaire. Seven dimensions of the pediatric intensive care unit environment--Sights and Sounds, Procedures, Child's Appearance, Child's Behavior and Emotional Response, Staff Communication, Staff Behavior, and Parental Role Alteration--were conceptualized. A 5-point Likert-type scale was developed to assess parental perceptions of stress level for each item with a "1" meaning "not stressful," a "5" meaning "extremely stressful," and a "0" point to reflect "not experienced."

Psychometric Evaluation

Test-retest technique was used to provide a measure of stability of the parental stressor scale. The instrument was administered to 17 parents twice within 48 hours of the first administration. The resultant correlation coefficients for each of the dimensions were: Sights and Sounds, .58; Child's Appearance, .86; Child's Behavior and Emotional Response, .88; Procedures, .73; Staff Communication, .85; Staff Behavior, .90; and Parental Role Alteration, .92. The coefficients for all of the dimensions except Sights and Sounds support the stability of the instrument over time.

The psychometric properties of the instrument were evaluated further in a project funded by the American Nurses' Foundation. In this study, 165 parents of children recently discharged from pediatric intensive care units in four midwestern hospitals were asked to complete the instrument along with the State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch & Lushene, 1970), and a personal-social questionnaire.

Cronbach's alpha was computed for the total instrument and for the conceptualized dimensions. An alpha coefficient of .96 was obtained for the total instrument; dimensional subscale coefficients ranged from .69 to .95 with only two of the dimensions coefficients under .80. The results provided a measure of adequacy of and the commonality of the item included to support both its reliability and construct validity (Nunnally, 1978).

In order to help establish the validity of the PSS, Pearson correlation analyses were performed with scores from the eight conceptualized dimensions of the instrument and State Anxiety scores. It was hypothesized that parental stress occasioned by the ICU environment would correlate positively with the total level of stress engendered by the ICU experience. Correlation coefficients ranged from .27 to .46; all were statistically significant at $p < .01$. These significant correlations between the

dimensions of the stressor scale and another measure of stress provide support for the construct validity of the scale. This test of validity meets Nunnally's criteria for construct validation in that state anxiety is a well defined measure of stress and the relationship between perceived anxiety and stress is unarguable (Nunnally, 1978).

Factor analysis was used to assist in assessing the adequacy of the sampling domain, to aid in data reduction, and to assess the construct of the instrument. Principle component factor analysis with Varimax rotation was performed on the 165 subject responses to the 79 items on the instrument. An inter-category correlation matrix was used in computation of the factor matrix to help compensate for "Not Experienced" (0) responses on the process items defining the eight dimensions of the ICU.

The initial factor analysis provided 22 factors with eigenvalues greater than one, explaining 75% of the variance in the data. Application of Cattell's (1978) screen test suggested that eight factors might identify the combination of variables accounting for most of the variance in the data. As solutions in exploratory factor analysis seeking conceptual clarity, analyses were performed rotating eight, six and five factors. Items without salient loadings ($< .40$) were removed. Patterning and structure of the factors were examined and, in general, the criteria for selection were the conceptual clarity of the factor, eigenvalues, the unifying structure of the factors, and the factor loadings of the items. The six factor solution was judged to satisfy best the above criteria. The cluster of variables in the six factor solution explained 67% of the variance in the data.

The factors identified in analysis which were related to the conceptualized dimensions were: Sights and Sounds, Procedures, Staff Communication, and Parental Role Alteration. The two conceptualized dimensions Child's Behavior and Child's Emotions loaded saliently on one factor named Child's Behavior and Emotions. Select items from Staff Behavior and Staff Communication emerged as a separate factor with items defining a concept of alienation, renamed Anomie. Items from the conceptualized dimension Child's Appearance did not emerge as a separate factor; rather, the items loaded on the three other factors: Sights and Sounds, Procedures, and Child's Behavior and Emotions.

No attempt was made to achieve orthogonality by removing all variables with less than salient loadings and rotating the remaining variables into a terminal orthogonal solution. It was felt that the sample with its preponderance of infants and planned cardiac surgery was not sufficiently representative to assess all items. Instead, the results from the factor analysis, along with results from the item analysis and correlations matrix, were used for instrument revision.

Instrument Revision

In the process of instrument revision, items that were age or case specific were examined closely for their relevance to the concept being measured; some were removed while some were modified. Items that were highly correlated with each other and were semantically analogous were combined. Items that were not loading

saliently on any factor and were not conceptually clear were removed. New stressors pointed out in the open ended questions following each dimension were added.

The revised instrument included 62 items conceptualized as measuring seven dimensions of the ICU environment. As indicated by the factor analysis, the two dimensions Child's Behavior and Child's Emotions were collapsed into one dimension. The dimension Staff Behavior was renamed Anomie and included several items from the Staff Communication dimension. The conceptualized dimension, Child's Appearance, which did not emerge as a separate factor, was retained awaiting further analysis.

Further Psychometric Evaluation

The revised instrument with 62 items was given to 510 parents of children hospitalized in five midwestern intensive care units. Factor analysis using BMDP 4M was performed with a two-step regression used to impute values for the "Not Experienced" (0) categories (Dixon, 1981; Frane & Hill, 1974). Principle components was used as the method of factor extraction followed by Varimax rotation. In initial analysis, the number of factors to be rotated was not specified. Fourteen factors emerged with eigenvalues greater than 1.0, explaining 70% of the variance. Before rotation of the factors, the 62 items were reduced to 39 based on the following criteria for removal: extreme standard scores; inter-item correlation less than 0.3; measures of sampling adequacy (MSA) less than Kaiser's optimum of 0.8; and factor loadings less than .40 (Frane & Hill, 1974).

The eight-factor solution was examined for patterning and structure, conceptual clarity, factor loadings, percentage of variance explained, squared multiple correlations (SMC), MSA, and communalities. In the eight-factor solution, three items related only tangentially to the environment loaded alone on factor eight. It was decided to delete these items, leaving the seven-factor solution as best meeting the criteria.

The seven factors resulting from Varimax rotation of the remaining 36 variables explained 68% of the variance in the data. All variables loaded significantly at .40 or above on only one of the seven factors. Variables for the seven rotated factors in columns of decreasing order of variance explained by the factors are found in Table 1.

Alpha coefficients were computed for the seven factorized dimensions and the total instrument. Dimensional subscale coefficients were as follows: Child's Appearance, .92; Sights and Sounds, .83; Procedures, .86; Staff Communication, .99; Child's Behavior & Emotions, .97; Anomie, .72; and Parental Role Alteration, .99. An alpha coefficient of .95 was obtained for the total instrument. These results provide support for the internal consistency and construct validity of the instrument (Nunnally, 1978).

Pearson correlation coefficients were computed between each of the PSS dimension scores and another measure of stress. State anxiety scores from Spielberg's State-trait Anxiety Inventory correlated significantly at $p < .0001$ with all of the

PSS dimensions; the correlation coefficients were: Child's Behavior and Emotions, .42; Parental Role Alteration, .39; Staff Communication, .31; Procedures, .36; Sights and Sounds .29; Anomie, .34; and Child's Appearance, .37. These findings provide further support for the construct validity of the instrument.

Scoring

As factor scores computed for the seven orthogonal factors correlated highly with their respective raw scores (coefficients ranged from .86 to .90), raw scores can be used in data analysis. The PSS:PICU can be scored using the seven dimensions as subscales or a total PSS:PICU stress score can be computed using all 37 items.

It is recommended that the mean dimension or total score for each subject be computed by dividing the sum of the dimension or total scores by the number of items rated "1" or above. This compensates for the "O - Not - Experienced T" scores and for any missing data. The group means are then calculated from the individual mean scores. Thus the range for dimension and total scores is one to five, proving equality of expected values for comparison purposes.

The PSS:PICU is protected by copyright and may not be copied or used without written consent.

Acknowledgements

Development of this instrument was supported by grants from the Research Committee, School of Nursing, University of Kansas and the American Nurses' Foundation--Nursing '80 Scholar Award. Consultation for this project was made feasible by Research Grant No. 5D10 NU 2500, Nurse Faculty Research Development in the Midwest, supported by the U.S. Health Resources Administration, Public Health Service, Division of Nursing. Nurse Faculty Consultants were: Carolyn Aradine, University of Rochester; Ardene Brown, Marquette; Charlotte Spicher, University of Connecticut; Irene Riddle, St. Louis University School of Nursing; and Tamara Williams, Case Western Reserve University. The authors wish to acknowledge the statistical consultation of Steve Zyzanski, Psychometrician Department of Family Practice, Case Western Reserve University; Ruth Hassanein, Associate Professor, Department of Biometry, School of Allied Health, University of Kansas; and Jeff Bangert, Academic Computing Center, University of Kansas.

Appendix E



LYCOMING COLLEGE
WILLIAMSPORT, PA 17701-5192

Dear Participant,

I am a senior nursing student at Lycoming College. As part of my course requirements for an Honor's Project, I am continuing a research study that I performed last semester as a requirement for Nursing 435, Nursing Research. That research study examined the sources of stress of NICU mothers at the Geisinger campus of Penn State Geisinger Health Systems. the purpose of this study is to examine the sources of stress of mothers with children hospitalized in an intensive care unit, an intermediate unit, or one of the general pediatric floors at the Geisinger campus. I am asking for participation from mothers visiting their child in either PICU, IC, CH2, or CH3. Mothers must meet the following criteria: 1) have a child who has been hospitalized in PICU, IC, CH2, or CH3 for at least eight hours 2) visited the child at least once prior to filling out the questionnaires and 3) read and speak English. I am asking you to participate in this study by filling out two questionnaires which will take approximately twenty minutes to complete.

If at any time during your participation you become uncomfortable with the questionnaires, you have the right to withdraw from the research study. Withdrawal from the study will not prejudice your child's future care in any way. In addition, there are no foreseeable immediate or long-term discomforts, hazards, or risks with participation in this research study. However, if any problems arise during or after participation in this study, you may contact Kathy Herman, PICU social worker, at (717) 271-6263, for support. If Kathy is unavailable, please call the 24-hour hospital switchboard number at (717) 271-6211 for assistance.

D E P A R T M E N T O F N U R S I N G
PHONE • 717-321-4250 FAX • 717-321-4389 E-MAIL • nursing@lycoming.edu

03/24/98 TUE 12:04 [TX/RX NO 62821]



LYCOMING COLLEGE
WILLIAMSPORT, PA 17701-5192

Participation in this study is voluntary. You will not be paid or given other compensation for participating. In addition, no special benefits will be derived from participating in this study. All information on the forms will remain confidential and will only be used for research purposes. Accounts of the research will only be available to Lycoming College's Nursing Department, Geisinger Medical Center, and the author of the instrument that is used in the study. Anonymity and privacy will also be ensured throughout the study.

The protocol for this study has been approved by the Geisinger Institutional Review Board. The Review Board consists of professional people and lay members whose responsibility is the protection of human subjects in research. For further information regarding your rights as a subject, call Carolin Frey PhD, Chairman of Geisinger's Institutional Review Board, at (717)271-8663.

If any questions should arise, please feel free to contact Gayle Forsht, (717) 321-4428. In addition, the principal investigator of the study, Julia Sim, Clinic Research Nurse Coordinator, can be reached at (717)271-5807.

The researcher will remain available during the time you are filling out the questionnaires. If you are interested in the results of this study, you may request information by contacting Gayle at (717)321-4428..

Thank you for your time and cooperation in assisting me with my research study. By completing the attached questionnaires, you are giving the researcher your consent to participate in the study. By participating, you are allowing the researcher to use your results in her study.

Sincerely,

Gayle Forsht

D E P A R T M E N T O F N U R S I N G
PHONE • 717-321-4250 FAX • 717-321-4389 E-MAIL • nursing@lycoming.edu

Appendix F

Script

Hello, my name is Gayle Forsht. I am conducting a research study on the sources of stress for mothers who have children hospitalized. The study involves filling out two questionnaires – one a demographic survey and the other questionnaire is the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU). I am anticipating that it will take about 15 minutes to complete. The only criteria that I have for participation is that you can read and speak English, your child has been hospitalized for at least eight hours, you have visited your child at least once prior to participating, and your child is monitored. Participation is completely voluntary and if you choose to participate you may withdraw from the study at any point if you become uncomfortable. There are no obvious risk factors associated with participating in the study although there is a potential for the questionnaire evoking some emotional feelings. Kathy Herman, PICU social worker, has volunteered to be available if anyone needs to speak to her. All data will remain confidential throughout the study and your name is collected only for Geisinger protocol. The study has been approved by the Institutional Review Board. Would you be willing to participate?

If yes:

I will let you read over the consent. By filling out the questionnaires, you are giving us your consent to participate. I will be available if you have any questions and will check back in a few minutes.

If no: Thank you for listening. Take care.

When collecting scripts:

Thank you very much for participating. Take care

Appendix G

To: University of Kansas Medical Center
School of Nursing
Office of Nursing Grants & Research

Sources of BB

REC 1/16/98
CK 510

From: Gayle Forsht

Name

BSN student - Senior

Position

Lycoming College Box 699

Address

Williamsport, PA 17701

I am seeking permission to use the instrument "Parental Stressor Scale: Pediatric Intensive Care Unit" for the following purpose:

to identify sources of stress of pediatric
mothers in a tertiary care hospital in
north central Pennsylvania & compare
results with results of previous study
related to NICU moms. AND/OR

I am seeking permission to translate this instrument into _____ (language). Upon completion, I will forward the translated "Parental Stressor Scale: Pediatric Intensive Care Unit" to The University of Kansas Medical Center School of Nursing in exchange for waiver of fee.

I agree upon request to send back to you the raw data from the instrument, along with selected personal data about the subjects for use in further testing of the reliability and validity of the instrument. It is understood that the data returned by you will not be used for any other purpose than instrument development.

Gayle T. Forsht
Signature

1-7-97
Date

We hereby grant permission for you to copy and use the "Parental Stressor Scale: Pediatric Intensive Care Unit" with the above noted stipulations.

Lauren S. Aaronson / bb 1-16-98
Lauren S. Aaronson, RN, PhD Date
Associate Dean for Research

Nursing Research Committee

Geisinger Medical Center

Danville, PA 17822

Research Agreement

I, Boyle E Forsht, understand that I must retain research raw data for a period of seven (7) years so that it can be accessed by the Nursing Research Committee and the I.R.R.B. if needed. A copy of your raw data must remain in the Nursing Research Committee office at Geisinger Medical Center.

I will be required to complete a one (1) year audit report for the I.R.R.B. The following information is required for this report:

- List of enrolled patients, which will include - medical record number, name, and date of enrollment and date of withdraw.
- Copy of the protocol (any changes must be documented)*
- Copy of consent form (any changes that were made must be documented)*
- Any adverse events that may have occurred (if applicable)
- Any publications from this study

I will be notified approximately two (2) months in advance of the date that this report is due.

* Any changes that are made in the protocol or consent form must be submitted to the Nursing Research Committee for submission to the I.R.R.B. If changes are not submitted this will be viewed as a violation of the I.R.R.B. guidelines and could terminate my study.

Boyle E Forsht
Applicant
Signature (printed)

Julia Sim
Chairperson, Nursing Research Committee
Signature (printed)

Boyle E Forsht
Signature

1-8-98
Date

Julia Sim
Signature

1-8-98
Date



LYCOMING COLLEGE

WILLIAMSPORT, PA 17701-5192

January 6, 1998

Julia Sim, Chair
Nursing Research Committee
Geisinger Medical Center
Danville, PA 17821

Dear Ms. Sim:

Thank you for taking the request of Gayle Forsht to the Nursing Research Committee for review and consideration. As you are aware, Gayle along with Kimberly Sheriff recently completed research on stressors in NICU mothers to meet requirements for the Nursing Research course taught by Dr. Doris Parrish. Gayle, an honors student, intends to expand this research to include stressors in PICU mothers as well as stressors in mothers with children in the general Pediatric areas, CH2 and CH3.

This letter is to confirm that I am the Advisor responsible for the project. It is my intent and responsibility to ensure that the research is conducted in an ethical and sound manner. I have every confidence that this will be the case with this study.

If you have any questions, please do not hesitate to contact me at 717-321-4226 (W) or 717-743-6607 (H).

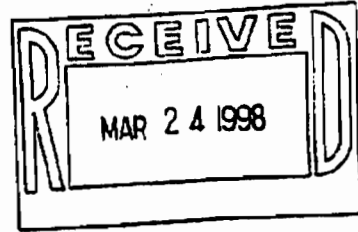
Respectfully,

Lori S. Lauver, MSN, RN, CNA
Professor, Pediatric Nursing - Lycoming College

Sources of 71



LYCOMING COLLEGE
 WILLIAMSPORT, PA 17701-5192



Cathy Betz
 Coordinator Institution Research Review Board
 Geisinger Medical Center
 Danville, PA 17821

Dear Ms. Betz:

Thank you for taking the time to speak to me today regarding the research proposal submitted by Gayle Forscht to the Institutional Research Review Board at Geisinger Medical Center. I appreciate your assistance in expediting the review process.

This letter is to confirm that I am the advisor responsible for the project. Therefore, it is my intent and responsibility to ensure that the research is conducted in an ethical and sound manner. In addition, I accept responsibility to ensure the research findings are reported to the Research Committee at Geisinger Medical Center.

If you have additional questions, please do not hesitate to contact me at 717-321-4226 (W) or 717-743-6607 (H).

Sincerely,

Lori S. Lauver, MSN, RN, CNA
 Professor, Pediatric Nursing
 Lycoming College

DEPARTMENT OF NURSING
 PHONE • 717-321-4250 FAX • 717-321-4389 E-MAIL • nursing@lycoming.edu

03/24/98 TUE 12:04 [TX/RX NO 6282]



March 31, 1998

Gayle Forsht
Lycoming College
Williamsport, PA 17701-5192

Dear Gayle Forsht

Congratulations your project entitled "Sources of Stress of Mothers with a Child Hospitalized in ICU or General Pediatric Area" has been approved by the Geisinger Medical Center Institutional Research Review Board. I have enclosed a copy of the approval letter for your files.

Please let me know when the data collection begins. It would also be very helpful to receive periodic updates on your progress with the project. When you have completed recruiting your patients notify me of the closing date and the number of patients recruited for the study. Since you will be graduating in May, please send the required one-year audit report information that was reviewed in the research agreement prior to graduation.

If you should have any questions or problems please feel free to call at 1-800-650-6831.

Best of luck!

Sincerely,

Julia Sim, R.N.
Chair, Nursing Research Council
Penn State Geisinger

MEMO

Date: March 12, 1998

To: Gayle Forsht

From: Nursing Research Council

Re: Study Proposal

Congratulations!

Your proposal entitled "Sources of Stress of Mothers with a Child Hospitalized in ICU or General Pediatrics Area" has been reviewed and accepted by the Nursing Research Council. It will now be forwarded to the Institutional Research Review Board (I.R.R.B.) for:

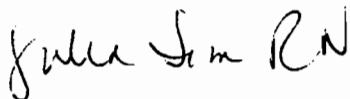
Expedited Review

Full Review

Full review will require you to present your study at an IRRB meeting. The research coordinator will notify you of the time and date.

For the expedited review, you will receive a memo from the research coordinator regarding the status of your proposal within two weeks.

Please continue to follow all the research guidelines that were reviewed with you at the initial meeting. Thank you for presenting your project to our council and best of luck.



Julia Sim, RN
Chairperson
Nursing Research Council
Penn State Geisinger



March 26, 1998

Julia Sim, RN, 14-01

RE: Your application dated March 13, 1998 regarding study # 98C-132: Sources of Stress of Mothers with a Child Hospitalized in ICU or General Pediatric Area

Dear Ms. Sim:

I have reviewed your request for expedited approval of the new study listed above. This type of study qualifies for expedited review under FDA and NIH (OPRR) regulations.

This is to confirm that I have approved your application. You must obtain informed consent from all subjects; however, the requirement to obtain signed written consent has been waived.

You are granted permission to conduct your study as described in your application effective immediately. The study is subject to continuing review on or before March 26, 1999, unless closed before that date.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Cathy A. Betz ((717) 271-8138; email: cbetz@psghs.edu; fax: (717) 271-6701) if you have any questions or require further information.

Sincerely,

Carol M. Frey, PhD

Carol M. Frey, Ph.D.
Chair, IRRB