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Parental perceptions of nursing interventions and personal coping responses in the pediatric intensive care unit

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Parental Perceptions of Nursing Interventions and Personal Coping Responses in the Pediatric Intensive Care Unit

by

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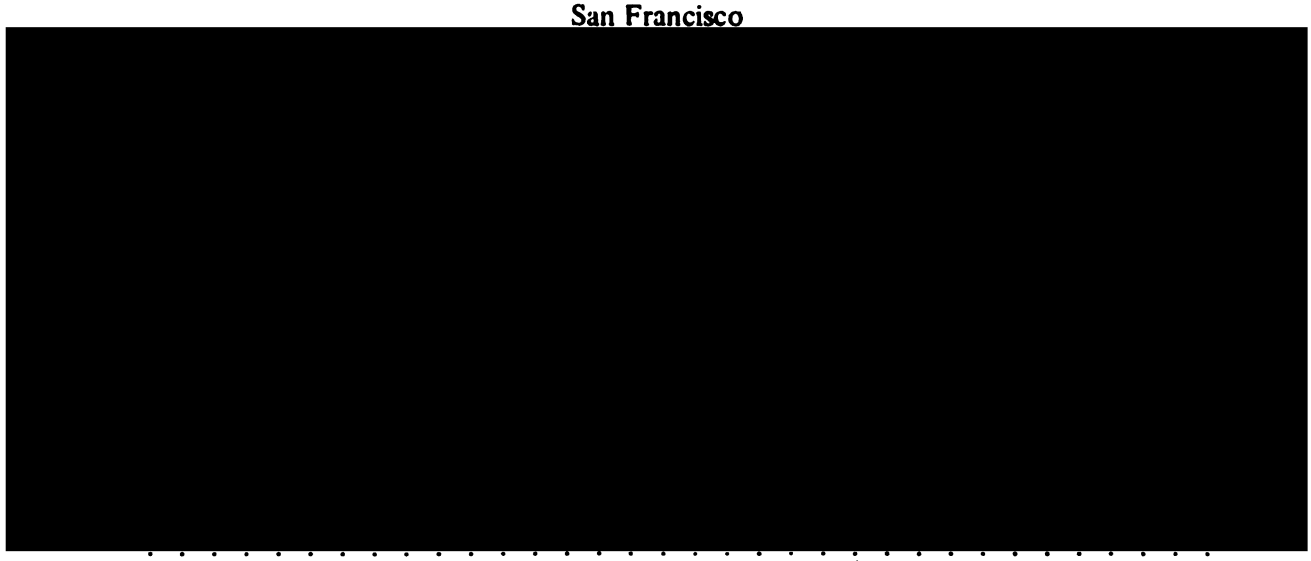

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ABSTRACT

Elizabeth Galvin

The purpose of this research was to identify nursing interventions and parental coping patterns perceived as helpful by parents of children hospitalized in the PICU. The conceptual framework for this research was a parental stress and coping model developed by Miles & Carter (1983). Their model integrated theoretical elements of work done by Selye, Lazarus, Roy, and Moos. In this multi-centered descriptive study, thirty parents of twenty critically ill children completed a study questionnaire entitled the Parental Coping Scale: PICU. Parent participants were interviewed following questionnaire completion. The nursing interventions and coping responses were categorized and ranked according to the frequency and percentage of responses.

Results: Parents most frequently identified "being treated with genuine caring and concern" as very or extremely helpful in promoting their coping in the PICU. The personal coping response most frequently used, and reported as moderately or extremely helpful, was "making sure their child received proper care."

Conclusions & Implications: The results of this study suggest that nursing interventions which render emotional support and information impact parental coping in the PICU. Of the personal coping responses, parents most frequently used problem focused strategies, and saw them as most helpful. These findings emphasize the importance of integrating parental emotional support strategies and communication into the nursing plan of care. In addition, they indicate that nurses may facilitate parental coping through promotion of problem focused personal coping responses.

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CHAPTER I

INTRODUCTION

The admission and subsequent hospitalization of one's child in a pediatric intensive care unit (PICU) can be an extremely stressful experience for parents. In the critical care unit the patients and their families are exposed to a variety of unfamiliar sights and sounds, and procedures are often done with a sense of immediacy. Parents are often called upon to make critical decisions regarding the well being of their child and may experience feelings of shock, helplessness, anger, despair, anxiety, fear, and guilt as a result of their child's critical illness (Miles & Carter, 1983; Rothstein, 1980). Although some families have well established support systems and coping mechanisms, the type of crisis that parents experience during their child's critical illness may render familiar coping patterns ineffective. In this situation, it is the PICU nurse who is in the unique position to interact with the parents of critically ill children, assess their stress and coping behaviors, and intervene to facilitate parental coping in the PICU environment.

The existence of parental stress in the ICU environment has been discussed in the literature (Jay, 1977; Lewandowski, 1980; Lybarger, 1979; Miles, 1979; Miles & Carter, 1982, 1983, 1985). Investigators who have examined the PICU environment have determined that changes in the parental role, fears about outcome of the admission, and environmental stimuli are some of the sources of parental stress (Carter, et al., 1985, Miles, et al., 1984, Lewandowski, 1980; Miles & Carter, 1982, 1983, & Jay, 1977; Johnson, Nelson, & Brunnquell, 1988). There are, however, few studies that have examined parental coping responses and the resources that facilitate parental coping in the PICU. In addition, there are few fully developed parental response theories to guide nurses' interventions when dealing with the parents of critically ill children (Miles & Carter, 1983, 1985).

Statement of the Problem

The hospitalization of a critically ill child can create a situational crisis for parents, (Wolterman & Miller, 1985) and consequently place them in a particularly vulnerable position. Even for parents who are adept at dealing with other life crises, a child's critical illness may create a situation which is foreign to their everyday experience. In the unique environment of the PICU, parents lack familiar cues to guide their behavior. During this time of increased need, parents may be more receptive to and benefit from nursing interventions aimed at facilitating their coping abilities. Currently, however, it is not known what specific nursing interventions and personal coping strategies are found helpful by parents of children in the PICU. Through identification and promotion of nursing interventions and coping responses found helpful to parents, nurses have an opportunity to positively influence the parents' PICU experience.

Significance

The importance of focusing nursing interventions on parental needs and adaptation has been recognized by past researchers (Kasper & Myanmathi, 1988; Miles & Carter, 1985; Wolfer & Visintainer, 1975). Because the parents play a vital role in the adaptation of the child and entire family to the hospitalization, interventions aimed at facilitating parental coping may ultimately affect the child and his ability to adjust to his/her hospitalization (Miles & Carter, 1985; Lybarger, 1979; & Wolfer & Visintainer, 1975). In addition, interventions aimed at assisting parents to cope with a crisis-induced disequilibrium can foster the establishment of a "new balance" of personal growth and maturation, which may give rise to an ability to meet future crises (Moos, 1984).

In the past, because of the rapid advancement in medical technology, major nursing care emphasis was placed on physiologic monitoring, new life-saving techniques, and the physical care of children (Miles, 1979). More recently, however, pediatric intensive care has become an established subspecialty, with standards of practice to guide medical and

nursing management of patients' physical problems. As the physical care of critically ill children has become more "routine," nursing research in the PICU has begun to shift its focus to the psychosocial care of children and their families. This area of research is still in the developing stages with many arenas yet to be explored.

Since this realm of research is so young, it is important to pursue the exploration of new questions and to replicate the early work of previous investigators. Through replication of others' work, findings can be validated and generalized to the larger pediatric ICU population. In addition, through research replication, established research tools achieve increased reliability and validity, and a solid theoretical foundation for our nursing assessments and interventions can be established.

Study Objectives

The objectives of this study were to:

1. replicate a previous research study by Miles & Carter (1985), "Coping Strategies Used by Parents During Their Child's Hospitalization in an Intensive Care Unit;"
2. identify the nursing interventions and parental coping strategies that were perceived as helpful by parents of children hospitalized in the pediatric intensive care unit;
3. determine the frequency with which specific nursing interventions were offered and parental coping responses were used during a child's pediatric intensive care hospitalization.

Study Questions

The following research questions that were explored.

1. What nursing interventions do parents perceive as helpful to them in coping with their child's hospitalization in the pediatric intensive care unit?

2. What personal coping strategies are used by parents during their child's pediatric intensive care hospitalization?

Definition of Terms

For the purposes of this research, the following terms have been defined by this investigator:

Nursing Interventions- The actions taken by nurses in providing care to a patient or a patient's family. These actions are guided by an assessment of the patient and his/her family and a plan to meet their needs. Nursing interventions include, but are not limited to, communication, emotional support, teaching and the provision of physical care.

Parent- The birth or step parent of a child.

Child- A male or female individual from birth to sixteen years.

Coping- The behavioral processes used to manage or modify a stressful event.

Personal Coping Strategies- An individual's unique set of responses that are used to deal with or modify a stressful event. These responses may be appraisal-focused, problem-focused, or emotion-focused in nature.

Study Assumptions

The assumptions upon which this research was based were:

1. parents experience stress when they have a child hospitalized in the pediatric intensive care unit;
2. parents use the process of coping to deal with the stress of their child's pediatric intensive care hospitalization; and
3. parents of children hospitalized in the pediatric intensive care unit are able to assess the helpfulness of nursing interventions and their own coping responses.

Limitations

The limitations imposed upon this study by this investigator included:

1. the inclusion of only parents who spoke, read, and wrote English;
2. the inclusion of only birth or step parents;
3. the choice of two study sites rather than a multicenter approach;
4. the use of a limited time frame within which to include study subjects (2-7 days after the child's PICU admission date).

Delimitations

This study was not limited by the following:

the sex, race, or socioeconomic status of the study participants.

Summary

The PICU was identified as a potentially stressful environment for parents due to factors such as the acuity of the child's illness, changes in parental role, fears about outcome, and unfamiliar sights and sounds. Parents in this environment reportedly experience feelings of shock, helplessness, despair, anxiety, and guilt as a result of their child's critical illness (Miles & Carter, 1983; Rothstein, 1980). Nurses in the PICU in are a unique position to intervene with parents, but lack interventions based on fully developed parental response theories and scientific research. The objectives of this study were to replicate an earlier parental coping study and to determine the frequency and helpfulness of nursing interventions and parents' personal coping responses.

CHAPTER II

REVIEW OF THE RELEVANT LITERATURE

Most of the literature that addresses parental stress and coping in the intensive care environment has been written in the past two decades. Prior to this time it was not uncommon for children to be cared for in adult intensive care units, be treated as "little adults," and experience prolonged separation from their parents (Hedenkamp, 1980). With the evolution of pediatric intensive care units, the unique needs of children and their families have begun to be addressed, as investigators closely examine the impact of critical illness on the child and his parents (Lewandowski, 1980; Miles, 1979; Philichi, 1989).

Since a child's intensive care hospitalization is so remote from the ordinary experiences of most people, even stable families need help in coping with the situation (Rothstein, 1980). The parents are the members of the critically ill child's family who usually need the most assistance (Philichi, 1989). Parents play a key role in the emotional support of their child during hospitalization, and their ability to cope with the situation can affect the child's recovery process (Hendenkamp, 1980; Lybarger, 1979; Wolfer & Visintainer, 1975). If stress induced by the child's hospitalization is not successfully dealt with, the parents' ability to provide support to the child may be compromised. This may lead to an escalation of anxiety and result in delayed recovery. Although the critical care nurse's responsibilities are demanding, an understanding of parental stress and coping is essential to effective care planning.

The nursing literature which addressed parental stress and coping in the PICU included: an appraisal of the PICU environment; research which identified parental needs, sources of stress, and parental coping patterns; and identification of nursing interventions that facilitate parental coping in the PICU. This literature will be further examined and will be followed by a discussion of the conceptual framework of this study.

The PICU Environment

The PICU environment has been described by Lybarger (1979) as one that can be anxiety-producing for patients, families, and staff. With the advent of modern technology, the PICU setting is one that is characterized by the sounds of beeps and buzzers from electrocardiography equipment, hisses from ventilators, and ringing from infusion pumps. Staff often reflect urgency in their rapid movement and communication in the PICU, while the background may contain the sounds of crying children as they undergo painful procedures. Patients in the PICU are often subject to sleep and sensory deprivation, overstimulation, separation from parents, and total disruption of familiar routines. A critically ill child may be connected to numerous machines, be immobilized by tubes and equipment, and be disfigured from burns, scarring, or edema. Out of his usual domain, the child has no way of predicting what will happen to him or understand what is happening. In addition, he may not be able to verbally communicate due to intubation or move due to pharmacologic paralyzing agents (Lybarger, 1979).

Stevens (1981) emphasizes that although there is variation among units, the primary objective of caregiving in the PICU is meeting the immediate physical needs of the child. With this as a primary objective, the physical layout of the unit is arranged to maximize staff efficiency in care delivery. Many PICUs are open wards which expose the child and family to a wide variety of sensory stimuli such as bright lights, monitors, and other unfamiliar mechanical devices (Stevens, 1981). Frequently there is little space or privacy provided for parents who face limited availability to their child due to environmental constraints and PICU visiting restrictions. Although the nursing staff is often aware of the child's and family's need for preparation and psychosocial support in this environment, they may lack the time and resources to effectively meet these needs.

Parents arrive in this environment often times unprepared for the type of sights and sounds they may experience, let alone the intensity of an environment where children die in spite of advanced life saving and supportive techniques. Frequently the admission of a

child to a PICU is an unplanned event where an opportunity for parental preparation is lacking (Eberly, et al., 1985). Within minutes or hours, parents are faced with intense fears about the future well-being of their child (Miles, 1979). Even when an admission is planned and parents are oriented to the PICU setting, the experience of seeing their child in a state over which they have no control may induce feelings of helplessness, guilt, and anger (Lewandowski, 1980; Miles, 1979; Rothstein 1980).

Parental Stressors in the PICU

According to Stevens (1981), the nurse can anticipate that the child and his/ her family will encounter a number of predictable stressors during their stay in the PICU. These stressors include the child's illness, sleep deprivation, the lack of a familiar setting and routine for the child, the imposed separation of the child from his/her family, environmental stimuli, and the therapeutic and diagnostic procedures performed. These stressors, Stevens suggests, arise from the routines and physical aspects of the environment and the conditions surrounding the child's critical illness. Although Stevens recognized the need for liberal visiting privileges in the PICU, she recommended that parents probably should not be in constant contact with their critically ill child because of the emotional impact it may have on them (parents).

Based on her observation of parents in the critical care environment, Miles (1979) identified three major stressors for all parents. These were fear regarding the outcome of their child's illness (including fear of death, brain damage, and disfigurement), anxiety about coping with a new, strange environment, and concern about their parental role. She identified the nursing assessment of parental resources, anxieties, and needs as the cornerstone to understanding how a family is coping with the stress of their child's intensive care hospitalization.

In 1982, Miles and Carter identified a lack of research regarding parental stressors, and subsequently embarked on a research study which identified sources of parental stress

in the PICU. Based on clinical observations, interviews with parents, a review of the literature, and input from expert PICU nurses, eight dimensions of the PICU were identified as potential stressors to parents. These eight dimensions included: sights and sounds, the child's appearance, the child's behavior and emotional responses, procedures, staff communication, staff behaviors, and parental role deprivation. The findings of this study were used to develop a 79-item instrument, the Parental Stressor Scale: Pediatric ICU (PSS: PICU), designed to measure parental perceptions of stressors in the PICU environment. The conceptual basis of this tool was derived from Selye's theory of stress and Roy's model of nursing practice. The tool's reliability and validity were tested in a pilot study and further established in larger studies involving five Midwestern pediatric intensive care units.

Each of the dimensions of the PICU environment identified by Miles and Carter could potentially stimulate parental stress. The dimension "sights and sounds" included such items as the sounds of monitors, equipment and machinery, alarms, bright lights, and the sights of other children in the room. The "child's appearance" referred to the use of tubes, restraints, and equipment and also the presence of bruises, cuts, incisions, covered eyes, puffiness, and nakedness. The "child's behavior and emotional responses" which contributed to parental stress included the items confusion, rebellion, whining, demanding behavior, withdrawal, unresponsiveness, discomfort from pain, loss of bowel and bladder control, fear, anger, sadness, and depression. The dimension "procedures" encompassed a variety of treatment techniques that may be performed while a child is in an intensive care unit. These included: suctioning, giving injections, starting and running intravenous fluids, taking vital sign measurements, and maintaining tubes and lines. Some of the procedures included are performed frequently, while others are continuous.

Miles and Carter identified "staff communication" and "staff behavior" as potentially stressful for parents. The items included in "staff communication" described aspects of parent-staff communication that were perceived as stressful because of how the

communication was carried out. Items in this category included explaining things too fast, using words not understood, offering inconsistent information, and talking too much about matters not related to the child. "Staff behaviors" incorporated behaviors that had been observed by the parents but did not directly relate to staff communication. These behaviors included rushing around, joking and laughing, acting as if they did not like the child or did not understand his needs or behaviors, looking worried about the child, and acting distant. Aspects of the parental role comprised the last dimension of the PICU environment described by Miles and Carter. Items included in this category were separation from the child for long periods; lack of opportunity for caretaking, nurturing, and protecting; and inadequate support in helping the child through crisis.

Parents who participated in this study were interviewed after their child's discharge from the ICU, and therefore may have forgotten some of the stressful aspects of their PICU experience. Despite this limitation, the findings of this study are important since it was the first attempt by researchers to systematically examine and describe parental stressors in the PICU environment. In addition, this study laid the groundwork for future research in the area of parental stress and coping (Carter, et al., 1985; Eberly, et al., 1985, Johnson, Nelson, & Brunnquell, 1988; Miles, et al. 1984,; Miles & Carter, 1985) and validated previous clinical and anecdotal findings.

Parental stressors were examined in later studies using the Parental Stressor Scale: Pediatric Intensive Care. In 1984, Miles, Carter, Spicher, and Hassanein designed a study to examine possible differences in the perceived stress stimuli and the overall stress impact between mothers and fathers. Their findings suggested that mothers and fathers found the total ICU experience equally stressful. Based on their results, the need to prepare both parents for the child's behavioral changes and for their altered parental roles was emphasized.

In a similar study, Eberly, Miles, Carter, Hennessey, and Riddle (1985) compared the stress response of parents whose children were admitted to a PICU under planned and

unplanned circumstances. They also examined parents' perception of PICU environmental stressors based on the child's admitting condition (planned vs. unplanned). The instruments used in this study were the Speilberger State-Trait Anxiety Inventory and the Parental Stressor Scale: Pediatric Intensive Care (PSS: PICU; with 62 items rather than the original 79). Their sample consisted of 510 parents of 350 children from five Midwestern Hospitals. Parents of children with unexpected ICU admissions had greater stress scores on all dimensions of the PSS: PICU and a higher state anxiety score on Speilberger's State-Trait Anxiety Inventory. These parents also had higher mean scores on all ICU dimensions and were significantly more stressed by four aspects of the ICU environment. These four aspects were the overall sights and sounds of the unit, the child's appearance, changes in the child's behavior and emotion, and parental role alterations. These findings differ from an earlier study by Carter, Miles, Buford, and Hassanein (1985) in which the only difference that was found between parents of children admitted to the ICU under emergency conditions and parents of children admitted for planned surgery, or relapse of a chronic disease, was a higher stress score for the dimension procedures. This earlier study's sample size was 165 (55 fathers and 110 mothers) as opposed to the large sample used in Eberley, Miles, Carter, Hennessey, and Riddle's work. A significant finding of both studies was that aspects of the parent-child relationship/parental role revision was perceived as the most stressful aspect of the ICU admission.

A concensus among studies was that alterations in the parental role contributed most to the stress experienced by parents in the PICU setting. The exceptions to this finding were described in two recent studies (Johnson, Nelson, Brunnquell, 1988; Tichy, et al., 1988). In the first study that examined parents' and nurses' perceptions of parental stressors in the pediatric intensive care unit, Johnson et al. found that parents were most stressed by their child's behavioral and emotional responses. The study setting emphasized a philosophy of care which guided staff to alleviate the environmental aspects of the stressors related to parental role change. This philosophy, Johnson suggested, may have

accounted for parental role alteration being rated fourth among dimensions of the ICU which contributed to parental stress.

In the second study, Tichy and colleagues (1988) compared children's and parents' perception of stressors in the pediatric intensive care unit. Parents who participated in this study indicated that both environmental and physical stressors were equally prominent and important (39% and 39%). Psychological and social stressors were cited at 16% and 5 % respectively. Social stressors denoted disruption of relationship with others, family and friends, concern with school, and play deprivation. According to this categorization method, parental role alteration would be considered a social stressor and would have contributed least to parental stress in the PICU. The methodology employed in this study may have limited the generalizability of its findings. Rather than using an established research tool, data for this study were gathered using semi-structured interviews. The interviews were conducted after the child's discharge from the PICU, so parents may have forgotten details of their PICU experience. Although the research transcripts were coded independently with a reported interrater reliability of 87%, the interpretation of findings was done by the researchers themselves. In addition, the authors reported that parent participants were often confused as to whether they were rating their own stress or that experienced by their child.

Patterns of Parental Response/Parental Coping in the PICU

Although the experience of having a critically ill child hospitalized in a PICU is unique to individual parents, patterns of parental reactions to PICU setting have been observed and described by a number of authors (Jay, 1977; Lewandowski, 1980 Miles, 1979; Miles & Carter, 1985; Philichi, 1989; & Rothstein, 1980). The reactions observed among parents varied depending upon a number of variables. These variables included the circumstances of the child's admission, severity of the child's illness, past experiences and

coping styles of the parent, environmental stimuli, quality of communications, and emotional support systems (Etzler, 1984).

In his examination of parental reactions to the PICU, Rothstein (1980) identified three separate phases that characterize the experience parents undergo when they have a child hospitalized in a pediatric intensive care unit. This progression includes the phases of shock and disbelief, anticipatory waiting, and elation or mourning. When faced with a child's ICU admission, parents initially undergo a period of overwhelming shock and disbelief accompanied by feeling of helplessness. This phase may last as long as the child is unstable, and may be intensified by sleep deprivation. During this time it is common for parents to seek explanations and causes of the illness. They may experience self-blame as they review the course of events leading to the child's hospitalization. They often question whether they could have done something to prevent their child's critical illness.

As the child begins to stabilize, the initial phase of shock merges with anticipatory waiting. Parents then start to focus on the future and possible outcome of the illness. During this time it is not uncommon for parents to focus on seemingly insignificant changes in vital signs and clinical findings in hope of seeing some immediate improvement in their child's condition. By this time parents may have a better understanding of the pathophysiology and disease process, and begin to ask questions reflecting their new knowledge base.

After the anticipatory waiting, the parental reaction may be one of elation or mourning depending on the outcome of the PICU hospitalization. If the child recovers and is discharged to a pediatric ward, parents may experience feelings of mixed relief and anxiety. Anxiety over discharge may result because the child will no longer receive the close monitoring and attention that the parents have grown accustomed to in the ICU. If, however, the child has a prolonged recovery, stays in a prolonged comatose state, or dies when he was previously healthy, the parent may have feelings of ambivalence, guilt, anger, or depression.

Based on informal clinical observations, Jay (1977) described the progression of parental reactions to the PICU as a series of parental role changes termed parental role revision. Rubin's theory of maternal role acquisition provided the theoretical framework for examining parental role revision and nursing interventions in the PICU environment. Elements of parental role revision evident in the PICU included parental griefwork, role play, mimicry, and identity. Jay also identified the concept of touch progression. Touch progression was described as a process of parental adaptation which correlated with parents assuming caretaking roles in the PICU. Touch progression preceded the stages of mimicry and identity, and referred to the amount and quality of touching as it evolved from stroking to holding.

The concept of griefwork refers to the grieving done by parents for their previous role (parent of a well child). Before a parent can assume the role of parent of an acutely ill child, he or she needs to grieve for their lost role. Acquisition of this role can take time as parents come to terms with the loss of control they have over their child, the child's illness, and hospitalization. During this period the parents' ability to hear, understand, and remember may be very limited due to the crisis they are encountering. After completing their griefwork, parents move through the phases of role play and mimicry. During these phases, parents base their interactions with their child on their observations of other parents and on nursing caretaking behaviors. Parents in these phases feel more comfortable being near their child and assuming aspects of their child's care. When parents are ready to proceed from simple to complex caretaking functions, they have reached the third stage of identity. By this point parents are ready to assume their revised identity, parent of a sick child (Jay, 1980).

Lewandowski (1980) described a series of behavioral manifestations that were observed as parents coped with their child's critical illness. In her work, Lewandowski examined the coping styles of parents whose children had undergone open heart surgery. Observations of 59 parents occurred during the parents' first postoperative visit with their

child in the pediatric intensive care unit. Parents were also interviewed following surgery. The five predominant behavioral manifestations of parental coping were immobilization, visual survey, withdrawal (physical or emotional), restructuring, and intellectualization.

Lewandowski described immobilization as a frequent initial reaction to seeing one's child in an ICU. When immobilized, parents adapt to the situation by maintaining distance from it. Parents may delay their approach to the child's bedside during their initial visits to the ICU as a means of distancing themselves. This distancing enables parents to appraise the situation, increase their feelings of security and control, and gather together necessary resources. Another strategy parents used to increase their level of comfort in the ICU was visual survey. Through a visual scanning of the environment, parents orient themselves to the sights and sounds they encounter. This process may be necessary so that parents are able to concentrate on verbal explanations of the environment and their child's critical illness. A third method of approach used by parents was withdrawal. The withdrawal reaction is either nonresponsive, passive behaviors or actual physical withdrawal. Delay in parental approach in all three reactions may give parents a sense of control over how quickly they interact with the child and the environment (Etzler, 1984).

The reaction, restructuring, consists of parents focusing on one aspect of their child's care, since attention to the overall situation could potentially be too overwhelming. Restructuring may have been the parent's strategy for mastering the situation, one aspect at a time (Lewandowski, 1980). A reaction Lewandowski reported to have seen most often with fathers of critically ill children was intellectualization. Intellectualization is a coping strategy that rationalizes the child's illness and prognosis on an intellectual level (Etzler, 1984). This type of response was evidenced by a parent's intense interest in the equipment, vital signs, lab values, and technical aspects of care. Lewandowski suggested that the parent may focus on the technical and intellectual aspects of care since that may be easier to deal with at the time than the possibility of their child's death.

Lewandowski did not report information concerning the research tool, sample, methodology, or data analysis of her study. These omissions lead to doubts regarding the reliability and validity of her findings. It is significant, however, that the parental responses to the PICU environment cited by Lewandowski were similar in content to those described by Rothstein and Jay. In addition, later research and narrative literature identify similar parental responses to the ICU environment (Broome, 1985; Miles and Carter, 1985; Philichi, 1989; Philichi 1989).

While Lewandowski described coping responses observed early in a child's ICU hospitalization, other investigators looked more comprehensively at the parents ICU experience. In 1985, Miles & Carter (1985) examined the coping strategies used by parents during their child's hospitalization in an ICU. Their approach to examining parental coping was more systematic than previous studies by other investigators. The purpose of their study was to identify staff behaviors and parental coping patterns found helpful to parents during their child's hospitalization in a PICU. Subjects were 21 mothers and 15 fathers of 27 hospitalized children. This study used a retrospective self-report method in which parents were asked their perception regarding the use and helpfulness of selected coping behaviors, as well as whether or not these staff behaviors were experienced.

Results of this study showed the staff behavior seen as most important by the largest number of parents was "being permitted to stay with their child as much as possible." An evaluation of the overall findings regarding personal coping strategies revealed that parents most frequently used problem-focused coping strategies and that these strategies were seen as most helpful. Problem-focused coping strategies were those that helped the parent deal with the consequences of their child's ICU admission such as information seeking, going home to rest, and being near their child as much as possible. The coping response perceived as moderately to extremely helpful by almost all (92%) of the parents was "being near my child as much as possible." Emotion-focused coping

responses such as crying, seeking comfort from others, and accepting their child's illness as God's fate, were used by a smaller percentage of parents than the other categories.

The staff behavior and parental coping response most frequently viewed by parents as moderately or extremely helpful related to the parental role. This findings was closely tied with previous research findings which indicated that parental role alteration was the most stressful aspect of PICU. Based on this apparent relationship, Miles and Carter advocated the use of nursing interventions which maintain aspects of the parental role in the ICU, such as less stringent visiting policies.

Philichi (1989) identified and described the family's responses and behavior during a child's intensive care hospitalization. Family adaptability, cohesion, and coping mechanisms were measured using a conceptual framework which included general systems theory, the circumplex model of family adaptation and development, Hill's ABCX model, and a family coping model. In her study, fifty parents of 30 critically ill children hospitalized in the PICU participated. Data for her study were collected through use of the Family Adaptability and Cohesion Evaluation Scales (FACES-III) , McCubbin's Family Crisis-Oriented Personal Evaluation Scales (F-COPES), and a demographic data sheet. FACES-III measures family adaptability and cohesion. It is 20-item instrument designed to obtain data from each adult member of the family. In completing FACES-III, each participant rated described behaviors in the family from 1 (almost never) to 5 (almost always). The F-COPES tool was designed to assess problem-solving and behavioral strategies that aid families in difficult or problematic situations. It includes thirty questions that require the parent to indicate the extent of agreement or disagreement on a 5-point Likert scale. This instrument identifies coping behaviors which are categorized into five areas of family coping and scored as subscales (Philichi, 1989).

Results of this study indicated that the majority of families fell into the balanced categories of adaptability and cohesion (as measured by the FACES-III). The parents' perceptions of their coping strategies, as measured by F-COPES, were significantly higher

than established norms. The coping strategies that were used significantly more frequently by parents in the study than in the normative sample were: mobilizing of the family to acquire and accept help, passive appraisal, and acquiring social support (Philichi, 1989). Correlations between the types of coping mechanisms and family adaptability and cohesion were not significant.

These findings suggested that families utilize many coping mechanisms when dealing with their child's ICU hospitalization. Since the sum coping scores were higher than the norms available for the F-COPES instrument, the researcher suggested that families were mobilized by the potential crisis situation. The coping strategies that were most frequently used were those that nurses could help facilitate through consultation with social services and chaplaincy. Based on her findings, Philichi recommended the use of in-hospital support groups as a means of assisting families to acquire help.

Nursing Interventions

As parents move through phases of response and adjustment to the PICU environment, the PICU nurse is in a unique position to assess their perception of the illness or injury, their coping mechanisms, and their ability to be involved in the care of their child throughout the hospitalization (Broome, 1985). Based on this assessment, intervention strategies can be devised. A number of authors have discussed specific nursing interventions and nursing management strategies that may assist parents in dealing with the stress they encounter in the PICU (Broome, 1985; Curley, 1988; Jay, 1977, Miles, 1979; Proctor, 1987; & Rennick, 1986). One central theme placed importance on assisting the parents in establishing their parental role within in the ICU environment (Carter, Miles Buford, & Hassanein, 1985; Jay, 1977; Miles & Carter, 1985; Miles, 1979; & Rennick, 1986). These interventions included preparing the parents for the sights and sounds in the PICU and their child's appearance, reuniting the child an parent as soon as possible; informing the parents of their rights in a supportive, caring manner; and involving them in

the care of their child. Broome (1985) and Proctor (1987) emphasized the importance of maintaining liberal visiting policies to encourage parents' involvement with their critically ill children, thereby increasing parents' sense of confidence and control.

Another important theme of nursing interventions was to provide information to the parents (Jay, 1977; Miles, 1979; Miles & Carter, 1983). This involves teaching parents about the physical environment of the unit and anticipated behavioral and emotional changes their child may experience. Although informing the parents about the child's diagnosis and specific treatment measures is considered to be the responsibility of the physician, the nurse can be helpful by clarifying physician's explanations. In addition, nurses can provide information about specific nursing measures related to the child's treatment.

Helping parents cope with their feelings regarding their child's hospitalization was also cited as an important nursing intervention (Miles, 1979; Rothstein, 1980). Nurses can accomplish this by helping parents feel free to express their feelings, understand the relationship between their emotional state and the crisis, and realize the normalcy of their feelings. Catharsis of feelings and an understanding of one's emotional state helps parents to clarify their problems, lower their anxiety, reduce their feelings of confusion, and free their energy for adaptive problem solving (Miles, 1979).

Curley, in 1988, described the effect of using a nursing mutual participation model of care (NMPMC) on parental stress in the pediatric intensive care unit. Using a quasi-experimental design to determine the effectiveness of this intervention strategy, Curley concluded that perceived environmental parental stress was reduced through use of this intervention. The NMPMC is a four-step process originally designed for use in the outpatient setting. The four steps were comprised of: open-ended questions to establish a caring atmosphere, direct questioning to ascertain parental goals and expectations, assessment of the individual's perceptions of illness and issues surrounding the child's hospitalization, and determination of the parents' suggestions and preferences. The

specific interventions included in this model were supportive activities to facilitate the development of parental trust, providing information about the child's illness and the PICU environment, anticipatory guidance, preparation for admission, providing physical and psychosocial resources, and assisting in the reestablishment of a parental relationship through visitation and participation in care (Curley, 1988).

Since the NMPMC incorporated many parental support strategies, it was difficult to determine the degree to which specific interventions impacted parents' perception of stress. It is likely that a combination of interventions, tailored to the individual parent's need, and offered at repeated intervals (in this case as soon as possible after admission and daily), are more effective in reducing parental stress than isolated interventions. The results of this study emphasized the importance of providing consistent parental support while a child is hospitalized in the PICU environment. They also suggested that primary nursing, in combination with the NMPMC could provide a uniquely individual, trusting, and mutually rewarding nurse-parent relationship. In her discussion, Curley concluded that parents and caregivers, working together, respecting each others' roles, can be a very effective team. In this arrangement the nurse acts as a caregiver, support person, and role model for parental behavior. When parents are individually ready they are invited to participate in care activities that they find personally rewarding and, with the PICU nurse's guidance, help with new activities. Ultimately, through use of this type nursing intervention strategy, which is flexible and individualized, parental stress can be alleviated and satisfaction with care maximized.

Summary of the Literature

The PICU was described by a number of authors as a potentially stressful environment due to a number of environmental stimuli (Eberly, 1985; Carter et al., 1985; Lybarger, 1979; Miles, 1979; Miles & Carter, 1982, Miles, et al. 1984, Stevens, 1981). These stimuli included sights and sounds within the ICU, staff and parent communication,

the circumstances surrounding the child's illness, and the child's physical, emotional, and behavioral changes. The stress and anxiety that parents encounter in this environment are compounded by the physical layout of the unit and restrictions on visiting and caregiving activities (Broome 1985; Proctor 1987; Stevens, 1981).

The elements of the environment which contribute to parental stress were termed "parental stressors." Parental stressors were discussed in the literature in the 1970's (Miles, 1979) and early 1980's (Stevens, 1981), but not systematically examined until 1982 (Miles & Carter, 1982). In their 1982 study, Miles and Carter identified eight dimensions of the PICU that were potential sources of parental stress. An outcome of this study was the development of the Parental Stressor Scale: PICU (PSS: PICU). Using this tool, later researchers were able to determine differences in perceived parental stress based upon the parents' relationship to the child and the child's admitting condition (Carter et al., 1985; Eberly et al., 1985; Miles et al., 1984). A finding common to these studies was that alterations in the parental role contributed most to perceived parental stress. Two recent studies did not support this finding(Johnson, Nelson, Brunnquell, 1988; Tichy et al., 1988), possibly due to differences in the the methodologies employed.

Jay (1977) and Rothstein (1980) described parental reactions to their PICU experience. Based on their clinical observations, these authors identified distinct phases of adjustment that parents encounter during their child's ICU stay. Parental stress and coping styles in the PICU were initially discussed in the research literature by Lewandowski (1980). In her study of parents whose children underwent open heart surgery, Lewandowski identified five behavioral manifestations of parental coping. These included immobilization, visual survey, withdrawal, restructuring, and intellectualization (Lewandowski, 1980). Parental coping in the PICU was also examined by Miles and Carter (1985) and Philichi (1989). In the Miles and Carter study, parents most frequently identified staff behaviors which supported the parental role as most helpful. Parents that participated in this study also reported that they most often used problem-focused coping

responses, and found them the most helpful. Philichi compared parental coping strategies with that of a normative sample. Her findings suggested that families were mobilized by the potential crisis of a child's ICU hospitalization, and coped by acquiring and using available resources.

Nursing interventions that were identified to alleviate parental stress and facilitate parental coping in the PICU focused on reestablishing the parental role (Carter et al., 1985; Jay, 1977, Miles & Carter, 1985; Miles, 1979; & Rennick, 1986). This could be accomplished, researchers suggested, by involving parents in the care of their child. Information giving, communication, and emotional support strategies were also identified as important nursing measures (Jay, 1977; Miles, 1979; Miles & Carter, 1983).

The Conceptual Framework

The conceptual framework used to examine parental stress and coping in the PICU was a model developed by Miles & Carter (1983). This model presented variables that interact with stimuli to affect an overall response to stress in the PICU setting. It was based on four theories of stress and illness and included: Selye's theory on stress, Lazarus's cognitive-phenomenological theory on stress and coping, Roy's model of nursing, and Moos' theory on coping with illness.

The concept of stress. According to Selye, stress is the nonspecific result of any demand upon the body, be the effect mental or somatic (Selye, 1982). Stress can occur under a variety of dissimilar situations such as emotional arousal, fear, fatigue, pain, concentration, or humiliation. However, no one factor can be pinpointed as the cause of the reaction since people may face quite different problems, but their bodies react in a similar, stereotypical pattern. Identical biochemical changes in the body enable individuals to cope with a variety of increased demands on vital activity, in an attempt to adapt to environmental conditions and sustain life. This ability to adapt to the environment is,

however, finite so that if the body is exposed to prolonged stress, a stage of exhaustion will ensue.

Stressors, as discussed by Selye, are any agent or experience that may cause stress and can be either mental or physical in nature. Either type require readjustment by the individual. A stressor for one person may not be a stressor for another. The impact of the stressor depends on the individual's perception of the power of the stressor, the conditioning factors that an individual brings to the situation, and the coping mechanisms that the individual has available to help him adapt. (Selye, 1982).

Parallel to the ideas of Selye, are those of Lazarus. In his definition of stress, emphasis is placed on the relationship between the person and the environment, which takes into account characteristics of the person on the one hand, and the nature of the environmental event on the other. (Lazarus, 1984). Psychological stress results when the relationship between the person and the environment is appraised by the person as taxing or exceeding his/her resources, and endangering his/her well being. The judgment that a particular person-environment relationship is stressful hinges on cognitive appraisal.

Lazarus emphasized that cognitive appraisal, the individual judgement regarding the significance of events, accounts for individual and group differences in the degree and kind of reaction to stress. In addition, it is this ability to make cognitive appraisals regarding situations that accounts for the dynamic process of coping. Coping processes, according to Lazarus, are not random, but are a function of continuous appraisals and reappraisals of the shifting person-environment relationship. Shifts may be the result of coping efforts directed at changing the environment, or coping directed inward that changes the meaning of the event or increases understanding. They may also be the result of changes in the environment that are independent of the person and his or her coping activity. Regardless of its source, any shift in the person-environment relationship will lead to a reevaluation of what is happening, its significance, and what can be done. (Lazarus, 1984).

The concept of coping. Coping as a dynamic process has also been discussed by Roy (1976). She utilized the term coping mechanisms to describe the control processes of the person as an adaptive system (Galbreath, 1985). She believed that the degree of environmental change and the person's pattern of coping determine the individual's ability to adapt. She further contended that the condition of the person or the individual's state of coping is that person's adaptation level. The person's adaptation level, according to Roy, will determine whether a positive response to internal or external stimuli will be elicited. The person's adaptation level is determined by focal, contextual, and residual stimuli. Those stimuli immediately confronting the person are the focal stimuli. Contextual stimuli are all other stimuli of the person's internal and external world that influence the situation and are observable, measurable, or subjectively reported by the person. Residual stimuli are the characteristics of the person that are relevant to the situation, but are elusive or difficult to measure objectively (Galbreath, 1985). The goal of nursing interventions, according to this model, is to manipulate the focal, contextual, or residual stimuli impinging on the person so that adaptive responses are promoted.

In his examination of coping with physical illness, Moos identified coping strategies as a vital, interrelated link between stress and adaptive functioning. He identified three dimensions of coping as appraisal-focused, problem-focused, and emotion-focused. Appraisal-focused coping involves attempts to understand and find a pattern of meaning in a crisis such as through logical analysis, cognitive redefinition, or cognitive avoidance or denial. Problem-focused coping seeks to confront the reality of the crisis by dealing with its tangible consequences and trying to construct a more satisfying situation. Major types of problem-focused coping skills are seeking information and support, taking problem solving action, and identifying alternative rewards. Emotion-focused coping seeks to manage the emotion provoked by a crisis and to maintain affective equilibrium through affective regulation, emotional discharge, or resigned acceptance. Moos believes that during a life crisis an individual's cognitive appraisal, definition of the adaptive tasks

involved, and selection and effectiveness of coping skills, are influenced by demographic and personal characteristics, aspects of the illness, and features of the physical and social environment (Moos, 1984).

There appears to be a consensus among these theorists that an individual's response to stress is a result of complicated interaction between a number of variables. These variables include environmental stimuli, characteristics of the situation, personal factors, coping responses, and perception of the power of the stressor (Miles & Carter, 1983). Utilizing this conceptual framework, parental stress and coping in the PICU environment will be addressed.

Parental stressors in the PICU. In the PICU environment, potential parental stressors arise from three sources: personal/family background factors, situational conditions and environmental stimuli. The parents' response to stress is the result of a complex set of interactions between stressors from these three sources, as mediated by the parents' cognitive appraisal of the situation and their coping responses, and the resources available to help them cope.

The personal/family background factors sources of stress correspond to Roy's residual stimuli and Lazarus's personal factors. These include characteristics of the parent including the parent's propensity to anxiety, the parent's level of self esteem and self concept; concurrent events that may be sources of stress; and past experiences with an intensive care unit, death, or illness of the child. Situational conditions correspond to Selye's internal stressors and Roy's focal stimuli. In the ICU they include the child's illness itself, the uncertainties of the child's chances of survival, the future, and the duration of the child's illness and hospitalization. Selye, Roy, and Lazarus cite major sources of stress as arising from the environment. Environmental stressors arise from the physical and psychosocial environment of the intensive care unit. They include sights and sounds in the ICU, procedures done to the child, the child's appearance, the child's

behavior and emotional responses, staff communication, staff behavior, and the inability of parents to perform their parental role (Miles & Carter, 1982).

Parental coping in the PICU. According to this model, stressors are mediated by cognitive appraisal of the situation, coping responses, and resources available. Parents in the ICU engage in cognitive appraisal of the situation which involves making an ever-changing set of judgements about the significance of the child's illness and admission to an ICU. Appraisals of the situation may be positive-benign or negative-threat or a combination of both. As the child's condition and aspects of the situation change, the appraisal of the situation will change depending on the parents perspective.

Coping behaviors also affect the parents' perception of the nature, meaning, and power of the stressor and the parents overall response to stress (Miles & Carter, 1983). The three dimensions of coping strategies, as identified by Moos, have been examined in relationship to the parent in the ICU. Appraisal-focused coping involves the parents' attempts to define and understand the situation in which they are confronted. They may attempt to find meaning in the crisis and favorably compare their situation to that of others. Problem-focused coping involves the parents attempt to deal with the consequences through problem solving and information gathering. Finally emotion-focused coping strategies are those that attempt to maintain an affective equilibrium possibly through denial, verbal expression, or resigned acceptance.

In addition to the above coping strategies, the parents' response to their child's illness is further mediated by the availability of resources from the environment or from the parents' personal network of resources. Included in the environmental resources are nursing interventions, the physical amenities of the ICU, and the potential support of other parents. The personal resources include the support of family and friends, financial resources to meet the expenses related to the child's illness, and personality characteristics such as positive self esteem and low propensity to anxiety.

Summary

Miles & Carter's conceptual framework examined the PICU environment , identified sources of parental stress, and described parental coping in the PICU (1983). Coping strategies and parental stress responses were also discussed in the research and narrative literature (Lewandowski, 1980; Stevens 1981; Rothstein, 1980; Miles & Carter, 1985; Philichi, 1989) In addition, researchers assessed the levels of parental stress in the ICU environment (Lewandowski, 1980; Miles & Carter, 1983). Although the narrative literature described nursing interventions aimed at decreasing parental stress, little research has been done that addresses the impact of nursing interventions on parental coping. This study examined nursing interventions and personal, parental coping responses using a framework which incorporated the dynamics of parental stress and coping in the PICU.

CHAPTER III

METHODOLOGY

The objective of this research was to replicate a research study previously conducted by Miles & Carter (1985), "Coping Strategies Used by Parents During Their Child's Hospitalization in an Intensive Care Unit." The purpose of replicating this research study was to validate the original researchers' findings and to further explore the research questions which follow.

1. What nursing interventions do parents perceive as helpful to them in coping with their child's hospitalization in the pediatric intensive care unit?
2. What personal coping strategies are used by parents during their child's pediatric intensive care hospitalization?

In addition to exploring the research questions, the frequency with which nursing interventions were offered and parental coping strategies were used was determined.

Research Design

A descriptive research design was used to explore the research questions. The variables examined were parental coping strategies and nursing interventions. The study participants were asked to complete a study questionnaire which identified the perceived helpfulness of nursing interventions and personal coping responses. Participants were also asked to determine how frequently specific nursing interventions were offered, and how frequently specific personal coping strategies were used. After questionnaire completion, the participants were offered an opportunity to discuss, with the investigator, any issues or concerns related to their child's hospitalization.

Pilot Testing

To determine the feasibility of the research protocol, a parent of a PICU patient was asked to complete a study questionnaire. The purpose of the questionnaire and directions for its use were explained to the "pilot study" participant. The participant was provided a private room for questionnaire completion, while the investigator remained available to answer questions regarding the research instrument.

After questionnaire completion, the participant stated that he/she believed the questionnaire was easy to complete, and that the directions were clear. In a follow-up interview, the participant described his/her experience of having a critically ill, hospitalized child. In addition, he/she identified the nursing interventions that he/she found helpful in coping with his/her experience. Through this test of the research protocol, the investigator was able to determine the approximate time needed to administer the research questionnaire and follow-up interview. Since there were no apparent problems encountered during this test, there were no changes made in the proposed study protocol.

Research Setting

This research was conducted in two pediatric intensive care units. One of the sites was the University of California-Davis Medical Center (UCDMC) which is a 450 bed, tertiary care, University teaching hospital. UCDMC is a referral center for Northern California and is a level I trauma center. The other site for data collection was Valley Children's Hospital (VCH) in Fresno, California. Valley Children's Hospital is a private, 190 bed institution, which specializes in the care of children. It is a pediatric referral center for Central California. Medical care at VCH is provided by private physicians and by residents from the University of California, San Francisco.

The two pediatric intensive care units are similar in size and patient population. UCDMC has eight pediatric critical care beds, while VCH has a nine bed PICU. The patient population of the two pediatric intensive care units consist of critically ill children,

newborn to 17 years of age. Both institutions admit pediatric critical care patients with a broad range of diagnoses. Patients are admitted to the two units after being seen in a clinic or emergency room, after intrahospital transfer (from a pediatric floor or emergency room), or after hospitalization at an outlying facility. UCDMC and VCH each have pediatric transport teams which transport critically ill children from hospitals in outlying areas. UCDMC also receives patients who have been transported by the hospital's helicopter transport team, LIFEFLIGHT. LIFEFLIGHT transports patients directly from the scenes of accidents and from hospitals within a 150 mile radius of Sacramento, California.

The PICU at UCDMC is staffed with registered nurses and student nurse externs who work 12 hour shifts. The majority of staff members work parttime (24-36 hours/week) and alternate weekends. Only the registered nurses are assigned patients, with the student nurse externs assisting with patient care and tasks. The regular PICU staff is supplemented with "per diem," registry, and travel nurses when the need arises. Occasionally LVNs from the "per diem" pool and registry receive a PICU assignment. The LVNs have a patient assignment and are supervised by an R.N. Patient assignments are based on acuity with all patients being either classified as 1:1 (one nurse/patient) or 1:2 (one nurse/two patients). The physician staff consists of an intern, family practice resident, two pediatric residents, and an attending physician. There is a resident physician in the unit, "on call," twenty -four hours a day.

Valley Children's Hospital PICU nursing staff's characteristics and composition are similar to that of the PICU at UCDMC. At VCH, however, there are no nurse externs employed in the PICU. In addition, there are several LVNs that are PICU staff members. VCH's PICU supplements their staff with registry personnel (R.N.s and LVNs) and travel nurses. LVNs at VCH are given patient assignments and are supervised by an R.N. Staff scheduling and patient assignment determination are the same as at UCDMC. The medical staff of the PICU at VCH is comprised of an intern, two pediatric residents, and an

attending physician/Intensivist. There is a pediatric resident "on call" twenty-four hours a day.

Human Subject's Assurance

The study protocol for this research was reviewed and approved by the following committees to assure that the rights of the study participants were protected:

1. The Nursing Research Committee of the University of California-Davis Medical Center, Sacramento, California;
2. The Human Subjects Review Committee of the University of California, Davis (Approval #89-260);
3. The Committee on Human Research of the University of California, San Francisco (Approval #H1989-03991-01); and
4. The Human Subjects Committee of Valley Children's Hospital, Fresno, California.

The study protocol was also reviewed and approved for use by the following Pediatric Intensive Care Unit nursing and medical administrators:

•Katie Breining, R.N., A.N. III, Pediatric ICU Nurse Manager, UCDMC

•Marilyn Ratkay, R.N., M.S., A.N. IV., Assistant Director: Maternal-Child Division, UCDMC

•Azad Sheikh, M.D., Pediatric ICU Medical Director, UCDMC

•Barbara Handley, R.N., Pediatric ICU Director, VCH

•Mark Cramolini, M.D., Pediatric ICU Medical Director, VCH

Parent participants at each institution were asked to sign an informed consent form prior to study participation (Appendix A). The consent described the purpose of the study, potential benefits, risks or discomforts from study participation, and an ensurance of confidentiality. The researcher's name and telephone number were provided on the consent form so that participants could contact the researcher if desired. The original signed and

dated consent form was kept by the researcher. Copies of the consent form were made. One copy was placed in the patient's chart, and the other was given to the study participant. Study participants were also asked to read and keep a copy of "The Experimental Subjects Bill of Rights" prior to their participation (Appendix B).

Sample

A convenience sample of thirty subjects was used for this study. Potential subjects were identified by the PICU charge nurse. Parents who were assessed to be in acute crisis were not selected as potential participants. Data collection was conducted between January 19, 1989 and September 3, 1989. The data collection days were determined based on the investigator's time and subject availability.

Inclusion criteria. The inclusion criteria included parents who:

1. were able to speak, read, and write English;
2. had a child hospitalized in the PICU for a minimum of 48 hours and were available up to one week after the PICU admission date to complete the study questionnaire.(originally parents were not included for participation until their child had been hospitalized for 72 hours; this time requirement was changed to increase the number of potential participants since many PICU patients were transferred or discharged within 72 hours of their admission); and
3. demonstrated a willingness to participate in the study as evidenced by their signature on an informed consent form.

One or both parents of a child could participate in the study. Caregivers, other than birth or adoptive parents, were not asked to participate (e.g., grandparents, babysitters, legal guardians, and foster parents). If a child had more than one set of parents, only the parents of the household in which the child resided were included. "Parents" were limited to a male/female dyad. It was not necessary that the parents be married or reside together.

Exclusion criteria. Parents were excluded from the study if:

1. Their child was hospitalized with the diagnosis of confirmed or suspected child abuse;
2. the researcher had cared for the hospitalized child during that admission;
3. the charge nurse and/or patient's nurse assessed that the parent was in acute crisis and too stressed to participate at that time; or
4. their child had been hospitalized in the PICU longer than one week.

Procedure

Parents who met the inclusion criteria were approached by the researcher between the second and seventh day of their child's hospitalization. The researcher requested the parent to participate after briefly describing the study's purpose and procedure. Parents who agreed to participate were given a consent form to sign in the researcher's presence, and given an opportunity to ask questions. Parents were given the option of completing the study questionnaire in a private conference room or in the patient's room. The researcher remained available in the PICU while the participant completed the study questionnaire. The average time for questionnaire completion was 25 to 40 minutes.

After questionnaire completion, the participant returned the questionnaire to the researcher in a sealed envelope. The participant was then given an opportunity to privately discuss, with the researcher, issues or concerns related to the research study or their child's hospitalization. Approximately half of the study participants chose to participate in the follow-up discussion. The follow-up discussions ranged in length from 15 minutes to one hour.

Study Instrument

The instrument used for this study was a three part questionnaire called the Parental Coping Scale: PICU (Appendix C). This questionnaire was developed by Miles and Carter (1985) for their study, "Coping Strategies Used by Parents During Their Child's

Hospitalization in an Intensive Care Unit." Permission to use this instrument was obtained from Margaret Miles, R.N., PhD. (Appendix D).

Part I of the scale was a nineteen item Likert scale which had two response categories per item. The first response category established whether the intervention was provided and if so, how frequently (1=not provided, 2=minimally provided, 3=frequently provided). The second rated the intervention in terms of its perceived helpfulness (1=not helpful, 2=minimally helpful, 3=moderately helpful, 4=very helpful, 5=extremely helpful). At the end of this section the participant was asked to indicate which three nursing interventions had been most helpful to them in coping with their child's hospitalization. In addition, the participant was asked to identify other interventions that were not listed, but were considered helpful. Part II of the research tool consisted of a list of coping responses that the parents were asked to examine and rate as 0=not used, 1=not helpful, 2= minimally helpful, 3=moderately helpful, 4=very helpful, and 5=extremely helpful. At the end of section II the participant was asked to list the three responses that were most helpful. This section also asked the participant to list additional responses that were found particularly helpful. The last section, Part III, requested demographic information regarding the parent, child, and the situation leading to the child's admission. In this section the parent was also asked to determine the seriousness of the child's current and admission condition.

The reliability and validity of this research tool was reported by its authors, Miles & Carter (1985), after it was used for their study. They reported the research tool to have "substantial content validity" based on its use for their study, two previous pilot studies, and a review of the literature. They further claimed that the coping section of the questionnaire has construct validity based on the use of a well defined conceptual framework. Investigator communication with Dr. Miles indicated that no further validity and reliability information has been documented since the previously mentioned 1985 study. In their research article, the authors recommended that studies with larger samples were needed to establish further validity and reliability of the research instrument.

Summary

In this descriptive research a convenience sample of thirty parents of critically ill children was used to explore the research questions. Parents completed a self report questionnaire within one week of their child's admission to a PICU. The questionnaire.indicated the frequency and helpfulness of nursing interventions and personal coping responses. Study participants were also given an opportunity to discuss, with the researcher, issues related to their child's critical illness and hospitalization.

CHAPTER IV

RESULTS

The purpose of this study was to assess the:

1. frequency and helpfulness of specific nursing interventions; and
2. frequency and helpfulness of personal coping responses used by parents in coping with their child's intensive care hospitalization.

The Pediatric Coping Scale: PICU questionnaire was completed by study participants. Parents completed the study questionnaire either while their child was hospitalized in the ICU, or after transfer to an acute care pediatric unit. All parents participated within seven days of their child's ICU admission. Descriptive statistics were used to describe the findings using the statistical analysis program, "StatView."

Sample

Thirty parents who met the inclusion criteria participated in this study. The study was conducted over an eight month period on data collection days determined by the researcher. Three parents who were eligible for participation did not participate. Of the three, one of the parents did not participate because he stated that he "felt too guilty about the reason his son was in the hospital" (the patient was hospitalized after being accidently struck by a car his father was driving). The two other potential participants consented to participate, but their child was transferred from the study site before they had an opportunity to do so.

Twenty-four of the study participants were parents of children hospitalized at the University hospital; the other six were parents of children hospitalized at the Children's hospital. All but six of the participants completed the study questionnaire while their child was still a patient in the pediatric intensive care unit. Parents who completed the

questionnaire after their child's transfer from the ICU did so within one week of their child's ICU admission.

Demographic Data

Sample characteristics. The sample consisted of seventeen mothers (56.7%) and thirteen fathers (43.4%). The mean age of the participants was 32.2 years with a range of 20-50 years. The majority of participants were Caucasian (83.3%) and married to the natural parent of the child (79.3%) (Table 1). All but one of the participants fit into the defined marital status categories. This participant was divorced from a previous marriage, but was the parent of the hospitalized child. The races of other participants were Black (10.0%), Asian (3.3%), and "Other" (3.3%) (Table 2). Fifty-five percent of the sample reported an income of $30,000 or greater, with a median income range of $30,000-$40,000 per year (Table 3). The participants' mean number of years of formal education was fourteen, with a range of 11-18 years.

Patient characteristics. Twenty critically ill patients were represented by the sample of parents (ten of the children were represented by both parents). The mean age of the patients was 4.7 years, ranging from 17 days to 16.6 years. Sixty percent of the children were under three years of age (Table 4). Seventy percent of the children were hospitalized for an emergency condition, 20% because of trauma, and 10% for planned surgery. Table 5 further delineates the reason for a child's hospitalization based on the primary medical diagnosis. The most prevalent diagnoses based on this categorization were oncology related (35%).

Sixty-five percent of the children had not been hospitalized in an intensive care unit prior to this admission. Of those that had been previously hospitalized in an ICU, 50% had had only one previous admission. The greatest number of previous ICU admissions was three (Table 6). Seven of the children reportedly had health problems other than the primary diagnosis that prompted their ICU admission. The "other" health problems

included arthrogryposis, spina bifida, congenital muscle weakness, immunocompromise, and poor eye sight.

Table 1

Demographic Data: Marital Status of Participants

Marital Status	N	Percent
Married to Natural Parent	23	76.7%
Divorced from Child's Parent-Remarried	2	6.7%
Never Married	4	13.3%
Not Applicable	1	3.3%

Table 2

Demographic Data: Ethnicity of Sample

Race	N	Percent
White	25	83.3%
Black	3	10.0%
Asian	1	3.3%
Other	1	3.3%

Table 3

Demographic Data: Annual Family Income

Annual Income	N	Percent
$0-6,000	2	10.0%
$6-10,000	3	15.0%
$10-20,000	1	5.0%
$20-30,000	3	15.0%
$30-40,000	5	25.0%
> $40,000	6	30.0%

Table 4

Demographic Data: Descriptive Statistics of Patients' Age (Years)

From:	To:	N	Percent
0	3	12	60.0%
3	6	2	10.0%
6	9	3	15.0%
9	12	0	0.0%
12	15	2	10.0%
15	18	1	5.0%

Table 5

Reason for Child's Hospitalization

Emergency Conditions	N	Percent
Medical		
Foreign Body Aspiration	1	5 0 %
Pneumonia	2	10.0%
Asthma	1	5.0%
Leukemia	2	10.0%
Tumors	4	20.0%
Status Epilepticus	2	10.0%
Meningitis	1	5.0%
Hypertension	1	5.0%
Total	14	70.0%
Planned Surgical		
Scoliosis Repair	1	5.0%
Brain Tumor	1	5.0%
Total	2	10.0%
Trauma		
Burns	1	5.0%
Near Drown	1	5.0%
Multiple Trauma	1	5.0%
Head Injury	1	5.0%
Total	4	20.0%
TOTAL	20	100.0%

Table 6

Demographic Data: Number of Previous Admissions in an ICU

Previous ICU Admissions	N	Percent
One	3	50.0%
Two	1	16.7%
Three	2	33.3%

Additional Data

The time range in which parents answered the study questionnaire was 2-7 days following their child's ICU admission. The mean length of time that the child had spent in the ICU when the parent completed the study questionnaire was 4.2 days. Parents were asked to rate the seriousness of their child's condition on admission and at the time of questionnaire completion on a scale of one to five (one represented "moderately serious" to five which was "extremely serious"). The mean response at both time points was x=4. Seventy-five per cent of the parents reported that their child's ICU admission was totally unexpected; for the remaining 25%, the admission was planned.

One third of the sample (33.3%) reported that they were told what the ICU would be like before their child was admitted; the remaining majority (66.7%) were not told what ICU would be like prior to the child's admission. The amount of time that parents spent in the ICU during their child's hospitalization ranged from 3-24 hours/day with an average time of 13 hours/day. Parents indicated that the number of relatives/friends available to support and help them at the hospital during their child's ICU hospitalization ranged from 0-55. The mean number of support people was eleven and median number was eight.

Nursing Intervention Findings

This data set was derived from answers reported in section I of the Parental Coping Scale: PICU, a list of nineteen nursing interventions. Before the participants completed the questionnaire, the researcher emphasized that "staff behaviors" referred to nursing interventions. Parents were asked to concentrate on their experience with the nurses in the PICU so that their answers reflected their perceptions of nursing interventions offered by PICU nurses. Parents were asked to complete the "provided" and "helpfulness" scales which corresponded with each listed item. At the end of this section parents were asked to identify the interventions which they found most helpful. They were also asked to list additional nursing interventions that were not listed, but which they would have found helpful.

The responses to section I were categorized and listed in the order in which they appeared on the research questionnaire (Table 7 and Table 8). The four areas of categorization were: assistance with the parenting role, information/communication, emotional support, and good physical/technical care. This categorization method was chosen since it was used in the original study by Miles and Carter (1985).

Frequency and helpfulness of nursing interventions. All nursing interventions were reported to have been at least minimally provided (Table 7). Nine interventions were reported to have been provided to all participants who responded to those items on the questionnaire. The intervention least frequently provided was "being oriented to the ICU" (intervention reportedly not provided to 41.4% of participants). The intervention most often identified as frequently provided was "being allowed to stay with my child as much as possible" (92.9%).

Table 8 indicates the frequency with which each intervention was reported to have been provided (minimally plus frequently provided) and how helpful it was perceived to be. The nursing intervention most frequently identified as very or extremely helpful was "being treated with genuine caring and concern" (100.0%). The second most frequently

identified responses (as very or extremely helpful) were "allowing other family members to visit " (96.7%), "being given complete and understandable explanations about everything that is done to my child " (96.7%), and "being allowed to stay with my child as much as possible" (96.7%). "Having the staff sensitive to my child's needs" (96.6%) and "having the opportunity to share my feelings, worries or concerns" (96.6%) ranked third among those interventions that were very or extremely helpful. Most of the nursing interventions were identified as helpful. A small percentage of the participants rated the following interventions as "not helpful": "being allowed to stay with my child during painful or frightening procedures" (6.9%) "being oriented to the ICU" (6.9%), "preparing me for what to expect on a day to day basis" (3.3%), and "allowing other family members to visit " (3.3%). Table 9 lists the interventions in rank order based on the frequency with which they were identified as very or extremely helpful.

Parents were asked to identify the three most helpful interventions of the nineteen listed nursing interventions. The interventions that were listed by parents as most helpful were combined into one group to determine the overall frequency of responses (Table 10). Since not all parents identified three nursing interventions as most helpful to them, there was an 88.9% response rate to this particular section of the questionnaire. The three most frequently identified nursing interventions listed (rank was not indicated) were: "being treated with genuine caring and concern," "having all my questions answered honestly," and "being kept informed about the progress of my child." Table 10 lists these responses based on their frequency.

Additional nursing interventions. Parents were asked to identify and list other helpful nursing interventions that were not a part of the nineteen item list. Many of the additional interventions that were listed were similar in content to the interventions that appeared on the research questionnaire. Some of the parents responded with favorable comments about the nursing care they received rather than identifying additional nursing interventions. Table 11 presents the additional nursing interventions that were identified by

parents. The nursing interventions are grouped according to the previous categorization schema. An additional category was created for comments and interventions that did not clearly fit into a defined category.

Table 7

Nursing Intervention Frequency on the Parental Coping Scale: Pediatric ICU*

Nursing Interventions	Intervention not provided		Intervention minimally provided		Intervention frequently provided	
Assistance with Parenting Role						
•Being allowed to stay with my child as much as possible.	0	(0.0%)	2	(7.1%)	26	(92.9%)
•Having me do things for my child myself.	1	(3.4%)	7	(24.1%)	21	(72.4%)
•Being allowed to stay with my child during painful or frightening procedures.	7	(25.0%)	7	(25.0%)	14	(50.0%)
•Provided privacy while visiting.	1	(3.7%)	7	(25.9%)	19	(70.4%)
•Helping me to understand my child's behavioral and emotional reactions while in the ICU.	4	(15.4%)	0	(0.0%)	22	(84.6%)
Information/Communication						
•Being oriented to the ICU.	12	(41.4%)	9	(31.0%)	8	(27.6%)
•Being given complete & understandable explanations about everything that is done to my child.	0	(0.0%)	9	(32.1%)	19	(67.9%)
•Preparing me for what to expect on a day to day basis.	4	(14.2%)	5	(17.9%)	19	(67.9%)
•Having all my questions answered honestly.	0	(0.0%)	3	(10.7%)	25	(89.3%)
•Being able to telephone the unit anytime.	4	(15.4%)	0	(0.0%)	22	(84.6%)

*Because of missing data on some variables, percentages were not always computed on an N of 30.

Table 7 (continued)

Nursing Intervention Frequency on the Parental Coping Scale: Pediatric ICU*

Nursing Interventions	Intervention not provided		Intervention minimally provided		Intervention frequently provided	
Information/Communication						
•Being kept informed about the progress of my child.	1	(3.6%)	6	(21.4%)	21	(75.0%)
•Having explanations about the equipment and tubes near my child.	0	(0.0%)	3	(10.7%)	25	(89.3%)
•Knowing the names of staff caring for my child.	0	(0.0%)	3	(10.7%)	25	(89.3%)
Emotional Support						
•Having the staff sensitive to my child's needs.	0	(0.0%)	3	(11.1%)	24	(88.9%)
•Being provided with hope.	1	(3.7%)	11	(40.7%)	15	(55.6%)
•Being treated with genuine caring & concern.	0	(0.0%)	3	(10.7%)	25	(89.3%)
•Allowing other family members to visit.	0	(0.0%)	5	(17.9%)	23	(82.1%)
•Having the opportunity to share my feelings, worries, or concerns.	3	(10.7%)	3	(10.7%)	22	(78.6%)
Good Physical/Technical Care						
•Providing immediate attention to any changes in my child's physical condition.	0	(0.0%)	8	(28.6%)	20	(71.4%)

*Because of missing data on some variables, percentages were not always computed on an N of 30.

Table 8

Nursing Interventions on the Parental Coping Scale: Pediatric ICU-Frequency Data*

Nursing Interventions	Intervention provided	Intervention minimally-moderately helpful	Intervention very or extremely helpful
Assistance with Parenting Role			
•Being allowed to stay with my child as much as possible.	28 (100.0%)	1 (3.3%)	29 (96.7%)
•Having me do things for my child myself.	28 (96.5%)	2 (6.9%)	27 (93.1%)
•Being allowed to stay with my child during painful or frightening procedures.**	21 (75.0%)	5 (17.2%)	22 (75.9%)
•Provided privacy while visiting.	26 (96.3%)	4 (13.8%)	25 (86.2%)
•Helping me to understand my child's behavioral and emotional reactions while in the ICU.	23 (85.2%)	2 (6.8%)	27 (93.1%)
Information/Communication			
•Being oriented to the ICU.**	17 (58.6%)	7 (24.1%)	20 (69.0%)
•Being given complete & understandable explanations about everything that is done to my child.	28 (100.0%)	1 (3.3%)	29 (96.7%)
•Preparing me for what to expect on a day to day basis.**	24 (85.8%)	2 (6.7%)	27 (90.0%)
•Having all my questions answered honestly.	28 (100.0%)	2 (6.7%)	28 (93.4%)
•Being able to telephone the unit anytime.	22 (84.6%)	1 (3.6%)	27 (96.4%)

*Because of missing data on some variables, percentages were not always computed on an N of 30.
**Intervention reported as "not helpful" by a small percentage of the study participants.

Table 8 (continued)

Nursing Interventions on the Parental Coping Scale: Pediatric ICU-Frequency Data*

Nursing Interventions	Intervention provided	Intervention minimally-moderately helpful	Intervention very or extremely helpful
Information/Communication			
•Being kept informed about the progress of my child.	27 (96.4%)	3 (10.0%)	27 (90.0%)
•Having explanations about the equipment and tubes near my child.	28 (100.0%)	4 (13.3%)	26 (86.7%)
•Knowing the names of staff caring for my child.	28 (100.0%)	1 (3.3%)	29 (96.7%)
Emotional Support			
•Having the staff sensitive to my child's needs.	27 (100.0%)	1 (3.4%)	28 (96.6%)
•Being provided with hope.	26 (96.3%)	3 (10.3%)	26 (89.7%)
•Being treated with genuine caring & concern.	28 (100.0%)	0 (0.0%)	30 (100.0%)
•Allowing other family members to visit.**	28 (100.0%)	0 (0.0%)	29 (96.7%)
•Having the opportunity to share my feelings, worries, or concerns.	25 (89.3%)	1 (3.4%)	28 (96.6%)
Good Physical/Technical Care			
•Providing immediate attention to any changes in my child's physical condition.	28 (100.0%)	2 (6.7%)	28 (93.3%)

*Because of missing data on some variables, percentages were not always computed on an N of 30.
**Intervention reported as "not helpful" by a small percentage of the study participants.

Table 9

Rank Order of Nursing Interventions Reported as Very or Extremely Helpful*

Nursing Interventions	Intervention very or extremely helpful N	%
•Being treated with genuine caring & concern.	30	(100.0%)
•Being allowed to stay with my child as much as possible.	29	(96.7%)
•Being given complete & understandable explanations about everything that is done to my child.	29	(96.7%)
•Knowing the names of staff caring for my child.	29	(96.7%)
•Allowing other family members to visit.	29	(96.7%)
•Having the staff sensitive to my child's needs.	28	(96.6%)
•Having the opportunity to share my feelings, worries, or concerns.	28	(96.6%)
•Being able to telephone the unit anytime.	27	(96.4%)**
•Having all my questions answered honestly.	28	(93.4%)
•Providing immediate attention to any changes in my child's physical condition.	28	(93.3%)
•Having me do things for my child myself.	27	(93.1%)
•Helping me to understand my child's behavioral and emotional reactions while in the ICU.	27	(93.1%)
•Preparing me for what to expect on a day to day basis.	27	(90.0%)
•Being kept informed about the progress of my child.	27	(90.0%)
•Being provided with hope.	26	(89.7%)
•Having explanations about the equipment and tubes near my child.	26	(86.7%)
•Provided privacy while visiting.	25	(86.2%)
•Being allowed to stay with my child during painful or frightening procedures.	22	(75.9%)
•Being oriented to the ICU.	20	(69.0%)

*Because of missing data on some variables, percentages were not always computed on an N of 30.

** Ranking based on percentage; this item had a total of 28 respondents.

Table 10

Nursing Interventions: Reported as Most Helpful

Nursing Interventions	N
•Being treated with genuine caring and concern.	16
•Having all my questions answered honestly.	10
•Being kept informed about the progress of my child.	9
•Allowing other family members to visit.	8
•Being allowed to stay with my child as much as possible.	7
•Providing immediate attention to any changes in my child's physical condition.	6
•Having the opportunity to share my feelings, worries, or concerns.	4
•Being provided with hope.	4
•Having the staff sensitive to my child's needs.	3
•Having explanations about the equipment and tubes near my child.	3
•Having me do things for my child myself.	3
•Provided privacy while visiting.	2
•Being able to telephone the unit anytime.	2
•Being given complete and understandable explanations about everything that is done to my child.	1
•Helping me to understand my child's behavioral and emotional reactions while in the ICU.	1

Table 11

Parental Coping in Pediatric ICU-Additional Nursing Interventions

Category	Nursing Intervention
Assistance with the Parenting Role	•Getting me and the child's father into housing. •Allowing me to get involved with certain procedures.
Emotional Support	•The way nurses kept my spirits up. •Keeping me laughing so I would not worry. •Nurses' warm understanding and giving of themselves. •All around caring for my child. •[Nurses'] sensitivity, gentleness, kindness, friendliness,"not reserved." •People telling me it was okay to cry and allowing me to do that without being embarrassed or further upset.
Good Physical/Technical Care	•Staff being knowledgeable. •Doing a good job of taking care of son and giving him the very best care he could possible receive. •Constant watch of child at all hour of day and night.
Other Interventions	•Casual dress [of nurses] instead of white uniforms. •Being able to live on hospital grounds for a fee I can afford. •Concern for patient's comfort. •[Nurses] maintained professional disposition. •Pleasant, sincere, professional business like manner in which daughter was treated; everyone offered help before it was asked for. •Willingness to "bend rules" when it came to visiting during "rounds" or procedures. •Letting my child watch T.V.

Parental Coping Response Findings

Table 12 presents the parental coping response data from section II of the study questionnaire. When completing this section of the questionnaire, parents identified responses as "not used", "used-not helpful", "used-minimally helpful," "used-moderately helpful," "used-very helpful," and "used-extremely helpful." Parents did not rate the helpfulness of a coping response unless they used it.. The responses are categorized as appraisal-focused, problem-focused, or emotion-focused to remain consistent with the reporting method used in the original study (Miles & Carter, 1985). The responses are listed on the table in the same sequence (per category) as they appeared on the study questionnaire.

Frequency and helpfulness of parental coping responses. All of the 21 listed personal coping responses were reportedly used by parents in coping with their child's PICU hospitalization. Three of the responses were used by all the parents surveyed. They were "believing that my child is getting the best possible care," "asking questions of the staff about my child," and "being near my child as much as possible." The least frequently used responses were "drinking" (3.3%) and "taking drugs to calm me" (3.4%).

The parental coping response that was most frequently identified as very or extremely helpful was "making sure my child is getting proper care" (100.0%). This was followed in frequency by "asking questions of the staff about my child" (93.3%) and "being near my child as much as possible" (90.0%). Table 13 presents the rank order of coping responses based on the frequency with which they were identified as very or extremely helpful. The responses that were not identified by any of the participants as very or extremely helpful were "taking.drugs to calm me" and "drinking." Ten of the responses were not found helpful by the parents who used them (Table 12). The response that was most frequently used and found not to be helpful was "trying to understand why this happened to my child (20.7% found this response not helpful).

Table 12

Parental Coping Responses on the Parental Coping Scale: Pediatric ICU-Frequency Data*

Coping Category	Response Used	Response not helpful	Response minimally-moderately helpful	Response very or extremely helpful
Appraisal-Focused				
•Believing that my child is getting the best possible care.	30 (100.0%)	0 (0.0%)	2 (6.7%)	28 (93.3%)
•Trying to understand why this happened to my child.	27 (93.0%)	6 (20.7%)	9 (31.0%)	12 (41.3%)
•Trying not to think too much about my child's problem.	20 (66.6%)	4 (13.3%)	9 (30.0%)	7 (23.3%)
•Having hope that all will be well.	29 (96.7%)	0 (0.0%)	5 (16.7%)	24 (80.0%)
•Refusing to believe in my own mind the seriousness of the situation.	11 (36.7%)	5 (16.7%)	3 (10.0%)	3 (10.0%)
Problem-Focused				
•Seeking as much information about the situation as possible	29 (96.7%)	0 (0.0%)	4 (13.3%)	25 (83.4%)
•Asking questions of the staff about my child.	30 (100.0%)	0 (0.0%)	2 (6.7%)	28 (93.3%)
•Talking with other parents in the waiting room.	24 (80.0%)	0 (0.0%)	12 (40.0%)	12 (40.0%)
•Going home to rest.	24 (80.0%)	3 (10.0%)	9 (30.0%)	12 (40.0%)
•Keeping busy.	26 (89.7%)	0 (0/0%)	10 (34.5%)	16 (55.2%)

*Because of missing data on some variables, percentages were not always computed on an N of 30.

Table 12 (continued)

Parental Coping Responses on the Parental Coping Scale: Pediatric ICU-Frequency Data*

Coping Category	Response Used	Response not helpful	Response minimally-moderately helpful	Response very or extremely helpful
Problem-Focused				
•Being near my child as much as possible.	30 (100.0%)	0 (0.0%)	3 (10.0%)	27 (90.0%)
•Making sure my child is getting proper care.	30 (100.0%)	0 (0.0%)	0 (0.0%)	30 (100.0%)
Emotion-Focused				
•Seeking help or comfort from family, friends, or community.	27 (93.1%)	0 (0.0%)	5 (17.2%)	22 (75.9%)
•Getting prepared to expect the worst.	22 (73.3%)	5 (16.7%)	7 (23.3%)	10 (33.3%)
•Sharing my concerns with the staff.	27 (93.1%)	0 (0.0%)	7 (24.1%)	20 (69.0%)
•Crying and expressing my feelings with others.	24 (80.0%)	1 (3.3%)	9 (30.0%)	14 (46.7%)
•Trying not to let myself get too emotional.	26 (86.7%)	1 (3.3%)	9 (30.0%)	16 (53.4%)
•Accepting my child's illness as God's will.	15 (51.7%)	2 (6.9%)	1 (3.4%)	12 (41.4%)
•Praying	28 (96.5%)	0 (0.0%)	3 (10.4%)	25 (86.2%)
•Taking drugs to calm me.	1 (3.3%)	1 (3.3%)	0 (0.0%)	0 (0.0%)
•Drinking.	2 (6.6%)	1 (3.3%)	1 (3.3%)	0 (0.0%)

*Because of missing data on some variables, percentages were not always computed on an N of 30.

Table 13

Rank Order of Coping Responses Reported Very or Extremely Helpful*

Coping Responses	Response very or extremely helpful N	%
•Making sure my child is getting proper care.	30	(100.0%)
•Believing that my child is getting the best possible care.	28	(93.3%)
•Asking questions of the staff about my child.	28	(93.3%)
•Being near my child as much as possible.	27	(90.0%)
•Praying	25	(86.2%)
•Seeking as much information about the situation as possible	25	(83.4%)
•Having hope that all will be well.	24	(80.0%)
•Seeking help or comfort from family, friends, or community.	22	(75.9%)
•Sharing my concerns with the staff.	20	(69.0%)
•Keeping busy.	16	(55.2%)
•Trying not to let myself get too emotional.	16	(53.4%)
•Crying and expressing my feelings with others.	14	(46.7%)
•Accepting my child's illness as God's will.	12	(41.4%)
•Trying to understand why this happened to my child.	12	(41.3%)
•Talking with other parents in the waiting room.	12	(40.0%)
•Going home to rest.	12	(40.0%)
•Getting prepared to expect the worst.	10	(33.3%)
•Trying not to think too much about my child's problem.	7	(23.3%)
•Refusing to believe in my own mind the seriousness of the situation.	3	(10.0%)
•Taking drugs to calm me.	0	(0.0%)
•Drinking.	0	(0.0%)

*Because of missing data on some variables, percentages were not always computed on an N of 30.

At the end of the coping response section parents were asked to identify the three responses that they found most helpful. Parents most frequently identified the responses "believing that my child is getting the best possible care," "being near my child as much as possible," and "praying" as most helpful in promoting their coping in the PICU. Table 14 lists the responses based on the frequency with which they were identified as most helpful. There was an 81.1% response rate to this part of the questionnaire since not all parents identified three coping responses as most helpful to them.

Additional coping responses. Parents were asked to list additional responses that they had found helpful. Several of the parents listed personal coping responses that were part of the twenty-one item list. Table 15 categories the additional responses as appraisal-focused, problem-focused, and emotion-focused responses. The responses that were repeated from the original twenty-one item list are not included.

Summary

Seventeen mothers and thirteen fathers participated in this study. Most participants were Caucasian, married to the natural parent of the child, had greater than a high school education, and a household income of $30,000-$40,000 per year. Twenty critically ill children were represented by the sample of parents. The children most frequently experienced an unplanned PICU admission due to an emergency medical condition. Their mean age was 4.7 years with a range of 17 days to 16.6 years.

The nursing interventions and personal coping responses were categorized with their frequency and perceived helpfulness indicated. All of the listed nursing interventions were at least minimally provided to parents. The intervention most frequently identified as very or extremely helpful was "being treated with genuine caring and concern." Parents used all of the listed personal coping responses in dealing with their child's critical illness. The coping response that was most frequently used and reported as very or extremely helpful was "making sure my child is getting proper care."

Table 14

Parental Coping Responses: Reported as Most Helpful

Coping Response Items	N
•Believing that my child is getting the best care possible.	16
•Being near my child as much as possible.	11
•Praying	9
•Seeking help or comfort from family, friends, or others from my community.	7
•Seeking as much information about the situation as possible.	7
•Asking questions of the staff about my child.	3
•Having hope that all will be well.	3
•Crying and expressing my feelings with others.	3
•Making sure my child is getting proper care.	3
•Talking with other parents about my child.	2
•Sharing my concerns and feeling with the staff.	2
•Trying not to let myself get too emotional.	2
•Accepting my child's illness as fate or as God's will.	2
•Trying not to thing too much about my child's problem.	1
•Going home to rest.	1
•Keeping busy.	1

Table 15

Parental Coping in Pediatric ICU-Additional Coping Responses

Category	Coping Response
Appraisal-Focused Coping	•Taking one day at a time. •Refusing doubts and negative thoughts. •Knowing that the staff cared for my well being.
Problem-Focused Coping	•Being able to live in the Kiwanis House [and be close to the hospital]. •Staying at the Ronald McDonald House [and be close to the hospital]. •To keep busy and be useful around him [patient]. •Having "quiet time." •Keeping myself looking nice...wearing makeup. •[Accepting] social worker's help. •Being able to talk with other parents. •Being able to talk and ask questions with the staff. •Being near my child as much as possible. •Asking questions of the staff about my child.
Emotional-Focused Coping	•Believing that God would heal my child. •Reading my Bible. •Listening to personal tapes from church. •Claiming the promises of God.

CHAPTER V

DISCUSSION

The aims of this descriptive study, based on a parental stress and coping model (Miles & Carter, 1983), were to determine parents' perceptions of nursing interventions and personal coping strategies in the pediatric intensive care unit. This study addressed the questions:

1. What nursing interventions do parents perceive as helpful to them in coping with their child's hospitalization in the pediatric intensive care unit?
2. What personal coping strategies are used by parents during their child's pediatric intensive care hospitalization?

Significance of Results

Nursing interventions/frequency. Parents reported that all of the nursing interventions were at least minimally provided. Nurses were perceived to have provided parental support through information giving and emotional support, assistance with the parenting role, and good physical and technical care of the child. This finding may be reflective of a high level of professionalism among the nursing staffs at the sites surveyed, or may be indicative of sensitivity problems with the study tool.

The intervention that was offered least often was "being oriented to the ICU through a tour with explanations about the various sights and sounds." This item may have been neglected due to the urgency of a child's admission, since a large percent of the children were admitted due to unplanned medical emergencies. In both of the sites surveyed, however, the monitoring equipment and unit are typically described to parents sometime during the child's ICU stay. Parents may not have perceived this to have been offered (even when explanations were given) since a formal tour of the ICU was not given to parents whose children experienced an unplanned PICU admission. Sixty-nine percent

of the parents reported that a tour of the ICU would be or was very-extremely helpful in facilitating their coping in the PICU. This finding was similar to that of Miles & Carter (1985) when 61% of their study sample reported that an ICU tour was considered very or extremely helpful. Miles and Carter suggested that more information was needed to determine the aspects of the ICU tour that may be considered helpful. It appears that further examination of the ICU tour and its relationship to parental coping in the PICU continues to be warranted.

Nursing interventions. The nursing intervention that was rated as very or extremely helpful by the largest number of parents was "being treated with genuine caring and concern." Although this staff behavior was cited as important in Miles and Carter's earlier study (1985), "being allowed to stay with my child as much as possible," was the most important. It is possible that history accounts for this difference in findings. Since the original study was completed, visiting policies in PICUs have become less restrictive. As a consequence, parents are often encouraged to spend time with their critically ill children and become more involved in their care.

Overall, nursing interventions which provided emotional support were perceived as most important to parents. This may have been because parental role support (through liberal visitation and encouragement to be involved in the child's care) was taken for granted by parents. In addition, good physical/technical care and communication may have been an expectation of parents in these critical care environments. Emotional support, however, may not have been expected in view of the multitude of complex physical needs exhibited by the critically ill children.

Nursing interventions/additional responses. Although the content of many of the additional nursing interventions identified by parents was similar to those already listed, several additional themes emerged. Parents perceived nursing interventions that demonstrated caring about their child and concern for the child's comfort as important. In addition, parents suggested that their coping was facilitated when their child was cared for

by a nurse who behaved in a "professional" manner. Unfortunately parents did not elaborate and specifically indicate what behaviors were indicative of the professionalism that they found helpful. Finally, parents indicated that social service functions such as providing housing were helpful to them. This finding is similar to that of Philichi (1989) who determined that parents in the PICU use the strategy "mobilizing of family to acquire and accept help." more than a normative sample. Parents apparently are more willing to accept assistance (and perceive that it is helpful) when faced with their child's critical illness.

Parental coping responses/helpfulness. The personal coping response that parents most frequently reported as very or extremely helpful was "making sure my child is getting proper care." This response was the second most frequent response in the Miles and Carter study (1985) with "being near my child as much as possible" the number one response. However, the Miles and Carter study reported how frequently responses were found to be moderately to extremely helpful rather than very to extremely helpful. When coping responses are categorized by the same method as employed by Miles and Carter, the results between the two studies are similar. "Believing that my child is getting the best possible care," being near my child as much as possible," and "making sure my child is getting proper care" were rated by all (100%) of the participants of this study as moderately to extremely helpful. These were also the top three coping responses in the Miles and Carter study, but "being near my child as much as possible" was rated slightly higher (92%) than the other two responses (both reported at 86%).

Regardless of the categorization method employed, the coping responses that were found most helpful were those that increased the parents' sense of control or reinforced the belief that the child was receiving high quality nursing care. Parental vigilance was implied in the responses that were associated with the parents presence in the PICU. Quite possibly the above mentioned responses are all interrelated. Perhaps through their presence in the PICU (being near the child as much as possible) parents may perceive they are

making sure their child is getting proper care and therefore believe the child is getting the best possible care. In addition, by being present in the PICU, parents have an opportunity to develop a trusting relationship with the nursing staff which would foster a belief that the child is being well cared for.

Parental coping responses by category/frequency. In evaluating the overall findings regarding personal coping strategies used by parents, it appears that they most frequently used problem- focused coping responses. These responses were behavioral in nature and implied that the parent was actively dealing with the situation or consequences of his or her child's ICU hospitalization. These included information seeking, interaction with other parents, taking care of ones self, and being present and near the child in the PICU. This finding reinforces the importance of encouraging active parental involvement in caregiving as parents perceive an enhanced coping ability when they play an active role in their child's hospitalization.

The appraisal-focused coping responses were reportedly used less frequently than problem-focused coping responses. Those appraisal-focused responses that were used most frequently by parents were "believing that my child is getting the best possible care" and "having hope that all will be well." This finding, consistent with that of Miles and Carter, demonstrates that parents have a strong need to believe that the staff is capable of taking care of their critically ill child. These frequently used responses were also found very or extremely helpful by the parents that employed them . This was in contrast to the response "trying to understand why this happened to my child" which was used frequently by parents (93%), but not found very or extremely helpful (41.3%). Although parents engaged in determining the cause of their child's critical circumstance, it did not contribute as significantly to their coping abilities.

The least frequently used personal coping responses were the emotion-focused coping responses. Of these responses, "praying" and "sharing my concerns with the staff," and "seeking help or comfort from family, friends, or community" were most

frequently used. Miles and Carter also found these three responses as the most frequently used emotion-focused responses. In their study, however, "seeking help or comfort from family, friends, or community" and "sharing my concerns with the staff" were seen as helpful by less than half of their study sample. In this study all three responses were considered very-extremely helpful by a large percentage of participants (89.7%-93.1%). Parental support by staff, family, friends, and community may have improved since the time of the original study since parental stress and coping in the PICU environment are now better understood.

It is possible that the use of emotion-focused coping responses was underreported by the study participants. The emotion-focused coping responses included the items "taking drugs to calm me" and "drinking." Participants may have felt uncomfortable admitting drug or alcohol use even though they were assured of the confidentiality of individual findings.

Limitations

The following is a list of the study limitations.

1. The small sample size and the use of a convenience sample. Nonrandomization in sampling limited the external validity of this study and therefore decreased the generalizability of the findings.
2. Parents who were assessed to be overwhelmed were not asked to participate in the study. These parents' responses may have been very different from the parents who did participate. In addition, parents had to be present in the ICU for inclusion in the study. Due to the sample selection, it is not known how parents who were not present in the PICU dealt with their child's ICU hospitalization.
3. The term "staff behaviors" on the study questionnaire was changed to "nursing interventions." Parents may not have been able to separate their experience with PICU nurses from their experience with other staff members. In addition, the

"nursing interventions" listed on the study questionnaire were not all objective and, therefore, measurable. For example, the nursing intervention"being treated with genuine caring and concern" was a subjective appraisal of behaviors without stating what the actual observed nursing behaviors were.

4. This researcher made the assumption that parents were able to accurately assess their own coping. It is possible that parents in this situation were not able to assess their coping due to the stress of their child's hospitalization.
5. Parental coping may change depending upon the age of the child. In this study there was a broad range of ages (17 days to 16.6 years) represented. Differences in parental responses may have been due to in part to the uniqueness of parent-child relationship at different stages of the child's development. For example, parents of younger children may have believed that their coping was enhanced by being with the child as much as possible whereas parents of older children may not have found this to be as significant to their personal coping.
6. Children hospitalized in the PICU were there under planned and unexpected conditions. Previous research has shown a difference in parental perceptions of the PICU environment based on whether or not the child was admitted emergently or under planned circumstances (Eberly, et al., 1985).
7. Even though the researcher did not care for the patients prior to parents' participation in the study, the Hawthorne effect may have influenced parental responses on the study questionnaire. It is possible that parents identified the researcher with the nursing staff and responded to the questionnaire accordingly.
8. The use of a research tool whose reliability and validity have not been well established. Although the questionnaire was used in a pilot and larger study, its reliability and validity have not been determined or published by its authors.

Implications for Nursing

Although the findings of this study suggest that a variety of nursing interventions facilitate parental coping in the PICU, emotional support was especially important to parents. Providing emotional support to families who are potentially experiencing a situational crisis takes time and energy. This study's findings support the development of acuity systems that integrate psychosocial aspects of care so that nurses in the PICU have sufficient time to offer parents emotional support when it is needed.

Because of the wide variety of parental responses to the PICU environment, it is important that nurses assess parental coping on an individual basis. However, based on these findings, care planning that emphasizes emotional support strategies and parents' use of problem focused coping responses may facilitate parental coping in the PICU. Interventions that offer emotional support include: encouraging parents to express feelings and concerns which demonstrates sensitivity to their needs; allowing other family members to visit; being sensitive to the child's needs (including the child's response to pain); and treating the parent and child with respect, honesty, caring, and concern. Problem-focused parental coping responses to be emphasized are: encouraging parents to ask questions about their child and promoting parental vigilance by being with the child as much possible and making sure their child is getting proper care. By promoting problem-focused parental coping the PICU nurse encourages parental involvement in the child's care, demonstrates respect for the unique parent-child relationship, and may increase the aspect of control the parent feels he/she has over the situation.

Recommendations for Future Research

The following are areas of further and related research to be explored, based on findings from this study.

1. Replication of this work using a larger sample size and:

a) incorporation of group comparisons based on the parents' socioeconomic status, relationship to the child, age of the child, and reason for the child's hospitalization (expected vs unexpected and chronic vs acute diagnosis), to determine if these variables influence parental coping in the ICU; and

b) a refined research tool which more clearly identifies behaviors indicative of the nursing intervention "caring and concern."

2. Conduct a study to explore:

a) parental coping in the non-English speaking population to determine cultural variations; and

b) parental coping in parents not present in the PICU.

Summary

The overall findings of this study were similar to those of the original study, "Coping Strategies Used by Parents During Their Child's Hospitalization in an Intensive Care Unit, by Miles and Carter (1985). In this study nursing interventions that related to emotional support were most frequently identified as very or extremely helpful, whereas in the earlier study, interventions related to the parental role were most important. In both studies parents most frequently used problem-focused coping responses, and found them more helpful than appraisal and emotion-focused coping responses.

The results of this study emphasized the importance of incorporating parental emotional support strategies into the nursing plan of care. They also suggested that nurses may facilitate parental coping in the PICU by promoting problem-focused coping responses. Further research using larger sample sizes to explore the variables that influence parental coping was recommended.

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APPENDICES

APPENDIX A

CONSENTS

HSRC Log No. 89-260 Page 1 of 2

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

UNIVERSITY OF CALIFORNIA, DAVIS

Title of Study: Parental Perceptions of Nursing Interventions and Personal Coping Responses in the Pediatric Intensive Care Unit.

Investigators: Elizabeth Galvin, R.N., B.S.N.
Pediatric Intensive Care Unit
University of California, Davis
(916) 453-2994

Marilyn Savedra, R.N., D.N.S.
Dept. of Family Health Care Nursing
University of California, San Franciso
(415) 476-4555

Purpose: You are asked to participate in a research study. We hope to learn what nursing interventions and personal coping strategies you have found helpful in coping with your child's hospitalization in the pediatric intensive care unit (PICU).

Procedures: If you decide to participate, we will ask you to complete a questionnaire. The questionnaire will be given to you in a private conference room and will take about twenty minutes to complete.

Alternatives: You may chose not to participate in this research study.

Risks: There is a small risk that you may experience emotional discomfort when asked to recall the experience of your child's hospitalization. You may skip any question that causes you discomfort.

Benefits: You may receive no benefit from this study. However, you will be given an opportunity to discuss, with the nurse researcher, any concerns related to your child's hospitalization after you have completed the questionnaire. Also, knowledge gained from this study may be used to help improve the care of patients and their families in the future.

_____
Participant's Initials

Confidentiality: Individual information will not be shared, but group information may be shared with the PICU nursing staff so that the care of critically ill children and their families can be evaluated. Absolute confidentiality cannot be guaranteed since research documents are not protected from subpoena.

Costs/Compensation: There will be no compensation or cost to participants of this study.

Right to Refuse or Withdraw: You may refuse to participate and you and your child will still receive the care you would receive if you were not in the study. You may change your mind about being in the study and quit after the study has started.

Questions: If you have any questions, please ask us. If you have additional questions later, you may contact us by telephone anytime at the following numbers:

Elizabeth Galvin, R.N.
(916) 453-2994 or

Katie Breining, R.N.
PICU Head Nurse
(916) 453-5561 or

PICU Charge Nurse
(916) 453-2994

You will be given a signed and dated copy of this form to keep.
You will also be given a copy of the Experimental Subject's Bill of Rights.

YOUR SIGNATURE, BELOW, WILL INDICATE THAT YOU HAVE DECIDED TO PARTICIPATE AS A RESEARCH SUBJECT AND THAT YOU HAVE READ THE INFORMATION PROVIDED ABOVE, AND THE BILL OF RIGHTS.

_____ _____
Date Signature of participant or legal representative

_____ _____
Date Signature of investigator

HSRC Log No. H1989-03991-01 Page 1 of 2

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

VALLEY CHILDREN'S HOSPITAL

Title of Study: Parental Perceptions of Nursing Interventions and Personal Coping Responses in the Pediatric Intensive Care Unit.

Investigators: Elizabeth Galvin, R.N., B.S.N.
Pediatric Intensive Care Unit
University of California, Davis
(916) 453-2994

Marilyn Savedra, R.N., D.N.S.
Dept. of Family Health Care Nursing
University of California, San Franciso
(415) 476-4555

Purpose: You are asked to participate in a research study. We hope to learn what nursing interventions and personal coping strategies you have found helpful in coping with your child's hospitalization in the pediatric intensive care unit (PICU).

Procedures: If you decide to participate, we will ask you to complete a questionnaire. The questionnaire will be given to you in a private conference room and will take about twenty minutes to complete.

Alternatives: You may chose not to participate in this research study.

Risks: There is a small risk that you may experience emotional discomfort when asked to recall the experience of your child's hospitalization. You may skip any question that causes you discomfort.

Benefits: You may receive no benefit from this study. However, you will be given an opportunity to discuss, with the nurse researcher, any concerns related to your child's hospitalization after you have completed the questionnaire. Also, knowledge gained from this study may be used to help improve the care of patients and their families in the future.

_____
Participant's Initials

Confidentiality: Individual information will not be shared, but group information may be shared with the PICU nursing staff so that the care of critically ill children and their families can be evaluated. Absolute confidentiality cannot be guaranteed since research documents are not protected from subpoena.

Costs/Compensation: There will be no compensation or cost to participants of this study.

Right to Refuse or Withdraw: You may refuse to participate and you and your child will still receive the care you would receive if you were not in the study. You may change your mind about being in the study and quit after the study has started.

Questions: If you have any questions, please ask us. If you have additional questions later, you may contact us by telephone anytime at the following numbers:

Elizabeth Galvin, R.N.
(916) 453-2994 or
(209) 225-3000, ext. 1159 or

Roberta Bavin, R.N., M.N.
Pediatric Critical Care Nurse Specialist
(209) 225-3000, ext. 1159 or

PICU Charge Nurse
(209) 225-3000, ext. 1159

You will be given a signed and dated copy of this form to keep.
You will also be given a copy of the Experimental Subject's Bill of Rights.

YOUR SIGNATURE, BELOW, WILL INDICATE THAT YOU HAVE DECIDED TO PARTICIPATE AS A RESEARCH SUBJECT AND THAT YOU HAVE READ THE INFORMATION PROVIDED ABOVE, AND THE BILL OF RIGHTS.

_____ _____
Date Signature of participant or legal representative

_____ _____
Date Signature of investigator

APPENDIX B

EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

UNIVERSITY OF CALIFORNIA, DAVIS

EXPERIMENTAL SUBJECT'S

BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a medical research study. As an experimental subject, you have the following rights:

1) To be told what the study is trying to find out;

2) To be told what will happen to you and whether any of the procedures, drugs, or devices is different from what would be used in standard practice;

3) To be told about the frequent and/or important risks, side effects or discomforts of the things that will happen to you for research purposes;

4) To be told if you can expect any benefit from participating and, if so, what the benefit might be;

5) To be told other choices you have and how they may be better or worse than being in the study;

6) To be allowed to ask any questions concerning the study, both before agreeing to be involved and during the course of the study;

7) To be told what sort of medical treatment is available if any complications arise;

8) To refuse to participate at all or to change your mind about participating after the study is started. This decision will not affect your right to receive the care you would receive if you were not in the study;

9) To receive a copy of the signed and dated consent form;

10) To be free of pressure when considering whether you wish to agree to be in the study.

If you have other questions, please ask the researcher or research assistant. In addition, you may contact the Human Subjects Review Committee, which are concerned with protecting volunteers in research projects. You may reach the committee office by calling (916) 752-2075, from 8:00 am to 5:00 pm, Monday through Friday, or by writing to the Human Subjects Review Committee, Office of Research, 275 Mrak Hall, University of California, Davis, California 95616.

OR-208/1980

E. BILL OF RIGHTS FOR HUMAN PARTICIPANTS IN A MEDICAL STUDY

You have the right to be informed of:

1. The nature and purpose of the study.

2. The procedures that will be followed in the medical study, and any drug or device that will be used.

3. Any discomforts and/or risks that could be reasonably expected from the study, if any.

4. Any benefits to you that could reasonably be expected from the study, if any.

5. Any appropriate alternative procedures, drugs or devices, if any, that might be advantageous to you, and what their compared risks and benefits are.

6. The types of medical treatment that are available to you, if any, after the study if complications should arise.

7. Ask any questions concerning the study or the procedures involved.

8. Withdraw your consent to participate in the medical study at any time, without prejudice to you or your medical care.

9. Be given a copy of the signed and dated written consent form.

10. Decide to consent or not to consent to a medial study without any pressure.

If you have other questions, you should ask the researcher or the research assistant. In addition, you may contact the Human Subjects Committee, which is concerned with protection of volunteers in research projects. The researchers may be reached at the number provided in the consent form, or you may write directly to Martin Goldsmith, M.D., Valley Children's Hospital, 3151 N. Millbrook, Fresno, California 93703.

APPENDIX C

STUDY INSTRUMENT

PARENTAL COPING SCALE: PICU

Admittedly, having a child in an intensive care unit (ICU) may be a stressful event. In order to better plan for ways to reduce parental stress, We are interested in learning your perception of staff behaviors while your child was in the ICU. We are also interested in learning about your own behavioral and emotional responses that were effective in reducing your stress.

Below is a list of nursing behaviors which you may have found helpful while your child was in the intensive care unit. By "staff" We mean the nurses who worked with you and your child.

1) Please indicate on the scale to the left (PROVIDED), how often you received this help. On this scale, circle a "1" if it was not provided, a "2" if the service was provided minimally, and a "3" if the service was provided frequently.

2) Indicate on the scale to the right (HELPFUL), how often this nursing intervention (behavior) was to you. On this helpfulness scale, the number "1" represents not helpful, the number "5" represents extremely helpful. The numbers "2", "3" and "4" represent degrees of helpfulness between not helpful and extremely helpful. If staff did not provide the experience listed, indicate how helpful you think it would have been.

SCALE

"1"- Not Provided "2"- Minimally Provided "3"- Frequently Provided

"1"- Not Helpful "2"- Minimally Helpful "3"- Moderately Helpful "4"- Very Helpful "5"- Extremely Helpful

	PROVIDED	HELPFUL
If the item was provided frequently circle "3" on the scale to the left; if it was found to be extremely helpful, circle "5" on the scale to the right	1 2 3	1 2 3 4 5
If the item was not provided at all, circle "1" on the left scale and indicate on the right how helpful you think it would have been (in this case, very helpful)	1 2 3	1 2 3 4 5
1. Being allowed to stay with my child as much as possible	1 2 3	1 2 3 4 5
2. Being oriented to the ICU environment through a tour with explanations about the various sights and sounds .	1 2 3	1 2 3 4 5
3. Having the staff sensitive to my child's needs	1 2 3	1 2 3 4 5
4. Helping me to do some things for my child myself (e.g., bathing feeding, or holding)	1 2 3	1 2 3 4 5
5. Being given complete and understandable explanations about everything being done to our child	1 2 3	1 2 3 4 5
6. Being provided with hope	1 2 3	1 2 3 4 5
7. Preparing me for what to expect on a day to day basis	1 2 3	1 2 3 4 5
8. Being allowed to stay with my child during painful or frightening procedures	1 2 3	1 2 3 4 5

ID# _ _

SCALE

"1"- Not Provided "2"- Minimally Provided "3"- Frequently Provided

"1"- Not Helpful "2"- Minimally Helpful "3"- Moderately Helpful "4"- Very Helpful "5"- Extremely Helpful

	PROVIDED	HELPFUL
9. Being treated with genuine concern and caring	1 2 3	1 2 3 4 5
10. Having all questions answered honestly	1 2 3	1 2 3 4 5
11. Being able to telephone the unit at any time	1 2 3	1 2 3 4 5
12. Helping me to understand my child's behavioral and emotional reactions while in the ICU	1 2 3	1 2 3 4 5
13. Providing immediate attention to any change in my child's physical condition	1 2 3	1 2 3 4 5
14. Being kept informed about the progress of my child	1 2 3	1 2 3 4 5
15. Providing privacy for me while visiting my child	1 2 3	1 2 3 4 5
16. Allowing other family members to visit my child	1 2 3	1 2 3 4 5
17. Having explanations about the equipment and tubes on or near my child	1 2 3	1 2 3 4 5
18. Knowing the names of the staff caring for my child	1 2 3	1 2 3 4 5
19. Having the opportunity to share my feelings, worries, or concerns with the staff		

List the three staff behaviors which you found most helpful:

1. _____

2. _____

3. _____

Were there other staff behaviors which have not been listed that you would like to mention as helpful to you?

_____

_____

_____

ID# _ _

COPING RESPONSES

We are also interested in learning about **your own behavioral and emotional responses** that were effective in reduction of your stress while your child was in the ICU.

Below is a list of coping responses which may be helpful to some parents during a time of stress. After each item, indicate how helpful the response was to you. If you did not use that particular response, circle "0".

SCALE

"0"- Not Used "1"- Not Helpful "2"- Minimally Helpful "3"- Moderately Helpful "5"- Extremely Helpful

	HELPFUL
1. Seeking help or comfort from family, friends, or others from my community	0 1 2 3 4 5
2. Believing that my child is getting the best care possible	0 1 2 3 4 5
3. Seeking as much information about the situation as possible	0 1 2 3 4 5
4. Trying to understand why this happened to my child	0 1 2 3 4 5
5. Trying not to think too much about my child's problem	0 1 2 3 4 5
6. Asking questions of the staff about my child	0 1 2 3 4 5
7. Talking with other parents about my child	0 1 2 3 4 5
8. Getting prepared to expect the worst	0 1 2 3 4 5
9. Taking drugs to calm me	0 1 2 3 4 5
10. Having hope that all would be well	0 1 2 3 4 5
11. Sharing my concerns and feelings with the staff	0 1 2 3 4 5
12. Refusing to believe in my own mind the seriousness of the situation	0 1 2 3 4 5
13. Drinking	0 1 2 3 4 5
14. Being near my child as much as possible	0 1 2 3 4 5
15. Praying	0 1 2 3 4 5
16. Crying and expressing my feelings with others	0 1 2 3 4 5
17. Going home to rest	0 1 2 3 4 5
18. Trying not to let myself get too emotional	0 1 2 3 4 5
19. Accepting my child's illness as fate or as God's will	0 1 2 3 4 5
20. Making sure my child is getting proper care	0 1 2 3 4 5
21. Keeping busy	0 1 2 3 4 5

Coping Responses (continued)

List the three responses that were most helpful to you:

1. _____

2. _____

3. _____

Were there other responses which you found particularly helpful?

_____

_____

_____

Following Are Some Questions About You, Your Family And Your Child's Illness:

1. What was the reason for your child's admission to the ICU?

_____

2. Does your child have any other health problems? (circle one)

   1. Yes
   2. No

2a. If yes, what was it?

_____

3. How many days was your child in the ICU?

_____
Days in the ICU

4. Was the admission of your child to the ICU, in general: (circle one)

   1. Expected or planned
   2. Totally unexpected

5. Admittedly, all children in ICU's are acutely ill. We are interested in knowing how serious you felt your child's condition was when admitted to the ICU. (circle one)

Moderately Serious				Extremely Serious
1	2	3	4	5

5a. How serious do you feel his/her condition is now? (circle one)

Moderately Serious				Extremely Serious
1	2	3	4	5

6. Has your child previously been hospitalized in an ICU? (circle one)

1. Yes
2. No

6a. If yes, how many times?

_____
Number of hospitalizations

7. On the average, how many hours per day did you spend at the hospital during your child's admission to the ICU?

_____
Hours per day

8. Please indicate the number of relatives/friends available to support and help you at the hospital during your child's ICU admission?

_____
Number of people

9. Did anyone tell you what the ICU would be like before your child was admitted? (circle one)

1. Yes
2. No

10. What is your age at your nearest birthday?

_____
Age in years

11. Please give the number of years of formal schooling that you completed (include grade school, high school, vocational school, college, etc.).

_____
Number of years

12. What is your relationship to the child who has been ill? (circle one)

1. Father
2. Mother
3. Stepfather
4. Stepmother
5. Adoptive Father
6. Adoptive Mother

13. Circle the number that represents your **present** martial condition.

1. Married to natural parent of child
2. Married to adoptive parent of child
3. Divorced from parent of child -- remarried
4. Divorced from parent of child -- single
5. Never married
6. Widowed
7. Separated

14. What is the closest to what you would call yourself? (circle one)

1. White
2. Black
3. Hispanic/Mexican American
4. Oriental
5. Other

15. What is the job of the principal wage earner of the family?

_____

16. Circle the income range that best describes your family's annual income:

1. $0 - $6,000/year
2. $6,000 - $10,000/year
3. $10,000 - $20,000/year
4. $20,000 - $30,000/year
5. $30,000 - $40,000/year
6. over $40,000/year

17. How old is your child who is in the ICU?

_____ Years _____ Months

APPENDIX D

STUDY INSTRUMENT CONSENT

TO: Elizabeth Sullivan
Name of Student and/or Faculty

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

RE: Use of instrument: Parent Coping Scale
Name of instrument

Name of study: _____

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

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

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

_____

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

_____

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

Margaret S. Miles
Signature of author

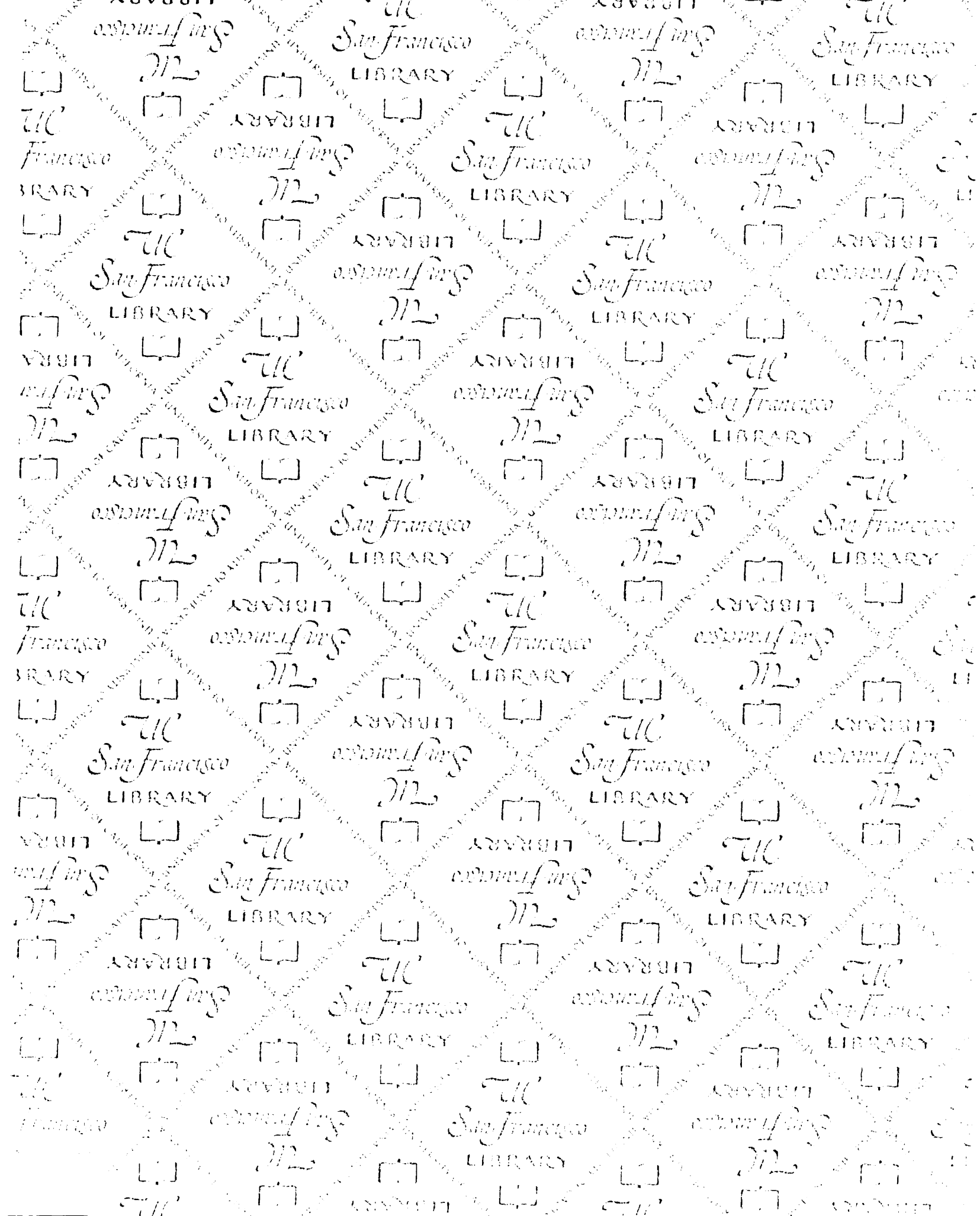
5/6/88
Date

_____
Signature of student/faculty

_____
Date

_____
Address

_____
Phone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