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## PERCEIVED NEEDS OF PARENTS OF CRITICALLY ILL CHILDREN

By

Linda D. Scott

### A THESIS

Submitted To Grand Valley State University in partial fulfillment of the requirements for the degree of

## MASTER OF SCIENCE IN NURSING

Kirkhof School of Nursing

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Thesis Committee Members:

Andrea Bostrom, Ph.D., R.N.

Donna Larson, Ph.D., R.N.

Sandra Portko, Ph.D., R.N.

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#### ABSTRACT

# PERCEIVED NEEDS OF PARENTS OF CRITICALLY ILL CHILDREN

By

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The purpose of this study was to (a) identify the perceived needs of parents of critically ill hospitalized children, (b) identify parental needs as perceived by critical care nurses, and (c) identify the differences in these perceptions.

A descriptive research design with a non-probability convenience sample was used. The sample consisted of 30 parents or primary caretakers of critically ill children and the responses of 30 pediatric critical care nurses. Data were obtained by a structured interview technique. Data analysis included a comparison of the relationship of parental total scores and the nurses' total scores. No significant differences were found between the two groups by a two-tailed paired t-test.

The specific perceived needs identified by the parent and nurse were analyzed using rank ordering of needs and the Wilcoxon matched-pairs signed ranks test. The parents and nurses identified similar needs; however, significant differences were identified between parent/nurse matched pairs.

#### Acknowledgements

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#### CHAPTER 1

#### INTRODUCTION

Parents frequently encounter maturational and situational crises as their children grow and develop. Often these crises are quickly resolved, with minimal effort, utilizing ordinary coping mechanisms. However, critical hospitalization of a child is a situational crisis that may be perceived as a significant threat or stressor to the parents.

Perception is an individual's interpretation of reality and is subjective and personal (King, 1981). Any situation may be perceived differently by the individuals involved and their interpretation will determine their resultant behavior (King, 1981). As perceived parental stress increases, the family becomes more disorganized. The parents will react to regain equilibrium through normal coping and defense mechanisms. Since the experience of having a critically ill child is unique, the parents may not have developed adequate coping skills to regain homeostasis (McClowery, 1992).

Identified parental needs by critical care nurses often determine which parental needs will be addressed during the hospitalization (Kleinpell & Powers, 1992). The degree of the child's illness, the parents' perception of the situation along with each of their prior experiences, and the support systems utilized during the experience are important areas to assess. Recognition and an understanding of parental reactions,

along with accurate assessment of parental needs, are crucial in considering nursing interventions that alleviate stress and assist the family to regain organization and equilibrium. Parental reactions to crisis, stress and anxiety, loss of control and alterations in parental role are often encountered and are frequent nursing diagnoses.

When perceived parental needs are not accurately identified or addressed, parental coping strategies may be impaired. Parental anxieties may be conveyed to the child and hinder recovery (Turner, Tomilson, & Harbaugh, 1990). Incongruence in identified perceived parental needs may result in disagreements in the plan of care for the family. In order to facilitate family-centered pediatric critical care nursing, the perceived parental needs must be accurately identified, prioritized and incorporated into the plan of care for the family.

#### Statement of the Problem

Historically, the primary focus and efforts of critical care nurses have been directed to the physiological needs of their patients. During the critical periods of hemodynamic stabilization, the needs of family members are often considered insignificant. Once the critical period is resolved, attention may be given to family members. Often, the nurse provides the family with what the nurse perceives as important, and not what the family may perceive as a priority.

More recently, critical care nurses have involved family members as well as the patient in the plan of care. Several research studies have been conducted to ascertain the perceived needs of family members of critically ill adults. However, in the pediatric population, research has been limited to noncrisis hospitalization. Recent research studies have begun to explore unexpected pediatric critical care admissions and parental needs. The present study was initiated to (a) identify the perceived needs of parents of critically ill hospitalized children, (b) identify parental needs as perceived by critical care nurses, and (c) identify the differences in perceived needs between parents and critical care nurses to ascertain the accuracy of nursing assessments.

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#### **CHAPTER 2**

#### LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

The focus of the literature review concerned the perceived needs of relatives of critically ill patients. The theoretical framework for this research study was based on crisis theory and King's (1981) conceptual framework for nursing.

#### Review of the Literature

Molter (1979) conducted an exploratory, descriptive research study to identify the needs of relatives of critically ill patients, the importance of these needs to the relatives and if the identified needs were being met. Molter used a structured interview technique to develop the Critical Care Family Needs Inventory (CCFNI), which consists of 45 family need statements. Structured interviews were conducted with 40 family members of critically ill patients who met the eligibility criteria for the research study. The operational definition of critically ill patients used were patients admitted to the critical care unit for at least three days and then transferred to the floor for 48 hours or less. The subjects were 18 years or older, related to the patient and had visited the patient while in the critical care unit. Each of the 45 need statements were read to the subjects who were asked to respond by rating the need statement by its importance utilizing a Likert-like scale from 1 (not important at all) to 4 (very important). The subjects were also asked to respond to whether the need was fulfilled and who fulfilled it.

Review of the findings indicated that for each of the 45 needs, at least one person considered the need very important. The ten most important needs were (1) to feel there is hope, (2) to feel that hospital personnel care about the patient, (3) to have the waiting room near the patient, (4) to be called at home about changes in the condition of the patient, (5) to know the prognosis, (6) to have questions answered honestly, (7) to know specific facts concerning the patient's progress, (8) to receive information about the patient once a day, (9) to have explanations given in terms that are understandable, and (10) to see the patient frequently (Molter, 1979).

Molter's findings in relation to need fulfillment indicated that only four needs were not met consistently (less than 50% of the time) when the subject had identified the need as important. Those unmet needs were identified as (1) the need to talk to the doctor at least once a day, (2) the need to be told about chaplain services, (3) the need to have a place to be alone while in the hospital, and (4) the need to have someone help with financial problems (Molter, 1979).

The findings in relation to the source of need fulfillment indicated that the needs were met by nurses in 20 of the need areas. Seven of the need areas were met by physicians. According to Molter (1979), frequently the subjects did not expect health care personnel to be concerned about them. The subjects perceived the only responsibility of health care personnel was to care for the patient, and not the family.

The study conducted by Molter established the foundation for further research in the identification of needs of family members of critically ill patients. The limitations of the study were the small sample size and the introduction of a new investigational instrument.

Other research studies have been conducted concerning perceived needs of family members in the adult and pediatric population. Dockter (1988) compared perceived needs of family members of critically ill patients to nurses' perception of family needs. The sample consisted of one adult family member for each patient (n=32) and nurses who provided direct care to the patients (n=23). The CCFNI was utilized as the investigational instrument for the family questionnaire. The instrument utilized for the nurses was equivalent to the family questionnaire except for semantic modifications. The questionnaire items were divided into four categories: (1) preparation/physical anxiety, (2) anxiety, (3) participation/information, and (4) emotional support.

The findings in this study revealed that families and nurses had similar perceptions related to anxiety and preparation for visitation. Both groups perceived the families as anxious and not prepared for the patient's condition, the patient's appearance or the hospital environment. Using Chi-square analysis, several statistically significant disagreements in perceptions were obvious. Ninety-one percent of family members indicated a desire to participate in the patient's care, while 56.5% of the nurses perceived that families did not desire to participate in the care of the patient ( $X^2 = 8.62$ ; d.f. = 1; p < 0.003). Seventy-seven percent of the nurses perceived that families were not allowed enough time to visit, while 97% of the family members perceived visiting times were adequate ( $X^2 = 8.02$ ; d.f. = 1; p < 0.004). Fifty percent of the nurses indicated that family members were comfortable expressing their feelings to nurses in comparison to 19% of the family members who

perceived they were comfortable expressing their feelings ( $X^2 = 6.06$ ; d.f. = 1; p < 0.01) (Dockter, 1988).

Freichels (1991) sought to compare perceived needs of family members and their level of importance at different time intervals. Assessment of the perceived needs of family members were obtained by using the CCFNI. The questionnaire was completed within the first 72 hours of admission to the intensive care unit and repeated 7 to 10 days post-admission. A convenience sample of 111 subjects was initially included in the study. A total of 41 subjects completed the questionnaire at both time intervals. Data obtained from the remaining 70 subjects were not included in the study.

The results of Freichels's (1991) study indicated that 8 of the 10 most important needs identified in the first testing interval were consistent with Molter's (1979) findings (Table 1). Molter indicated that the need to have the waiting room near the patient and the need to see the patient frequently were in the 10 most important needs. These needs were not identified in the 10 most important in Freichels's (1991) study. Instead, among the 10 most important needs revealed by Freichels were the need to be assured that the best care possible was being given to the patient and to know exactly what was being done for the patient. Comparison of rank ordering of importance in Molter's 1979 study indicated that the need to feel there was hope was the most important, while in Freichels's 1991 study, the need to have questions answered honestly was the most important.

#### Table 1

#### Comparison of Molter's 1979 Study Results to Friechels's 1991 Study: Initial Assessment

Molter's 1979 Study	Freichels's 1991 Study				
Ten Most Important Needs at Admission	Ten Most Important Needs at 72°				
1. To feel there is hope.	1. Have questions answered honestly.				
2. To feel that hospital personnel care about the patient.	<ol> <li>Know specific facts concerning the patient's progress.</li> </ol>				
3. To have the waiting room near the patient.*	3. Assured that the best possible care is being given.**				
<ol> <li>To be called at home about changes in the condition of the patient.</li> </ol>	4. Called at home with changes in the patient's condition.				
5. To know the prognosis.	5. Feel that hospital personnel care about the patient.				
6. To have questions answered honestly	6. Know the expected outcome.				
<ol> <li>To know specific facts concerning the patient's progress.</li> </ol>	7. Have explanations given that are understandable.				
8. To receive information about the patient once a day.	3. Feel that there is hope.				
9. To have explanations given in terms that are understandable.	9. Receive information about the patient once a day.				
10. To see the patient frequently.*	10. Know exactly what is being done for the patient.**				

Note. \* = Items not contained in Friechels's 1991 Study.

**\*\*** = Items not contained in Molter's 1979 Study.

Eight of the 10 most important needs at 7 to 10 days post admission (Table 2) were not different from those of the initial assessment within 72 hours of admission. However, there was a difference in ranking of importance during the second assessment. The two needs that were different were knowing how the patient is being treated medically and to see the patient frequently. Thirty-two of the 44 statements demonstrated a decrease in importance. Freichels (1991) suggested that this may be due to the initial crisis event and that families were unable to differentiate areas of importance during the initial crisis.

#### Table 2

#### Comparison of Molter's 1979 Study Results to Freichels's 1991 Study: Second Assessment

Molter's 1979 Study	Freichels's 1991 Study Ten Most Important Needs at 7-10 Days			
Ten Most Important Needs at Admission				
1. To feel there is hope.	1. Have questions answered honestly.			
2. To feel that hospital personnel care about the patient.	2. Assured that the best possible care is being given.			
3. To have the waiting room near the patient.	3. Know the expected outcome.			
4. To be called at home about changes in the condition of the patient.	4. Explanations given that are understandable.			
5. To know the prognosis.	5. Called at home with changes in the patient's condition.			
6. To have questions answered honestly.	6. Feel that there is hope.			
7. To know specific facts concerning the patient's progress.	<ol><li>Feel that hospital personnel care about the patient.</li></ol>			
8. To receive information about the patient once a day.	<ol> <li>To know specific facts concerning the patient progress.</li> </ol>			
<ol> <li>To have explanations given in terms that are understandable.</li> </ol>	9. To know how the patient is being treated medically.			
10. To see the patient frequently.	10. To see the patient frequently.			

The 10 least important needs identified by Freichels's 1991 study were related to support of comfort in both assessment intervals. This may be indicative of the inability or lack of desire to meet personal needs during the time of crisis. The 10 least important needs identified were (1) to be encouraged to cry, (2) to be alone at any time, (3) to have good food available in the hospital, (4) to be told about chaplain services, (5) to have another person with the relative when visiting ICU, (7) to have comfortable furniture in the waiting room, (8) to have the bathroom near the waiting room, (9) to be told about someone to help with family problems, and (10) to have someone help with financial problems (Freichels, 1991). The same needs were identified during the second assessment interval with minimal difference in ranked order of importance.

Kleinpell and Powers (1992) sought to determine the needs of families of critically ill relatives and the level of satisfaction with how their needs were met. The study further focused on comparing the identified family needs, order of importance, and satisfaction with the nursing personnel involved. The sample consisted of 64 family members and 58 nurses. The CCFNI was utilized to obtain identification of perceived needs of the family members and the nursing personnel.

The results of a two-way analysis of variance in this study indicated significant differences between the two groups (F = 50.93; p < 0.01). Although family members and nurses identified similar important needs, there was a significant difference between overall rank importance and satisfaction rankings (F = 49.40; p < 0.02) as shown in Table 3 and Table 4.

Kirschbaum (1990) sought to identify the needs of parents of critically ill children and the perceived importance of these needs. The sample consisted of 41 parents who were interviewed 24 hours prior to their child's transfer to a noncritical care unit. Data were obtained utilizing the CCFNI with the addition of 8 needs for use in pediatrics. The additional 8 needs were based on a review of the literature and expert opinion from a panel of specialists.

#### Table 3

### Kleinpell and Powers's 1992 Study: Overall Rank Importance

Identified by Family Members		<u>Ten Highest Needs</u> Id	lentified by Nurses
1. Have questions and	wered honestly.	1	. Have questions answered honestly.
2. Called with change	s in the patient's condition.	2	. Receiving explanations.
3. Knowing the paties	nt's progress.	3	. Knowing the patient's prognosis.
4. Knowing what was	done for the patient.	4	. Knowing what was done for the patient.
5. Knowing the treats	nent.	5	. Feeling hospital personnel care for the patient.
6. Being assured that	the best care was given.	6	. Calling the family about changes.
7. Knowing the prog	losis.	7	. Being assured that the best care was given.
8. Feeling there was	hope.	8	. Feeling there was hope.
9. Knowing what was	being done.	9	. Receiving daily information.
10. Receiving daily in	formation.	10	). Knowing about the patient's progress.

#### Table 4

### Kleinpell & Powers' 1992 Study: Overall Satisfaction

dentified by Family Members	Identified by Nurses
1. Being assured that the best possible care was given.	1. Having a telephone near the waiting room.
2. Feeling that there was hope.	2. Being assured that family members could leave.
3. Knowing the treatment.	3. Feeling that hospital personnel cared.
4. Feeling that hospital personnel cared.	4. Being assured that the best care was given.
5. Having a telephone near the waiting room.	5. Having another person available when visiting.
6. Knowing what was done for the patient.	6. Having a bathroom near the waiting room.
7. Knowing about the patient's progress.	7. Having the waiting room near the patient.
8. Having questions answered honestly.	8. Having friends for support.
9. Knowing what is being done.	9. Feeling there was hope.
0. Seeing the patient.	10. Knowing the patient's prognosis.

The rating of the added 8 pediatric needs in order of importance were (1) being recognized as important to my child's recovery, (2) maintaining a sense of family togetherness by having my ill child's siblings visit, (3) having help in supporting my ill child's reaction to the intensive care unit, (4) taking time to maintain the marital relationship with my spouse, (5) having a place to sleep near the intensive care unit, (6) being able to talk to other parents whose child is critically ill or has survived a similar illness, (7) receiving help in responding to the reactions of my ill child's siblings, and (8) protecting myself from sights or procedures that my child is experiencing (Kirschbaum, 1992).

Comparison of total rank ordering of importance of Kirschbaum's (1990) study to Molter's (1979) study indicated similarities in the 10 most important needs as shown in Table 5. The similarities were consistent with Molter's findings using the original need statement from the CCFNI, while the differences were indication of the incorporation of the 8 pediatric need statements.

#### Table 5

Molter's 1979 Study	Kirschbaum's 1990 Study				
10 Most Important Needs	10 Most Important Needs				
1. Feeling there is hope.	1. Knowing how my child is being treated medically.				
2. Feeling that hospital personnel care.	2. Feeling that there was hope.				
3. To have the waiting room near the patient.	3. Being assured that the best care was given.				
4. To be called at home about changes in the condition of the patient.	4. Knowing specific facts concerning my child's progress.				
5. To know the prognosis.	5. Having questions answered honestly.				
6. To have questions answered honestly.	6. Knowing exactly what is being done for my child.				
7. Knowing specific facts about the patient's progress.	7. Being called at home about changes in my child's condition.				
8. Receiving information once a day.	8. Feeling that hospital personnel care about my child.				
9. Explanations given that are understandable.	9. Knowing my child's prognosis.				
10. To see the patient frequently.	10. Receiving information at least once a day.				

#### Comparison of Molter's 1979 Study Results to Kirschbaum's 1990 Study

Strengths and limitations. The strengths of these studies include continued replication of Molter's (1979) original study in various patient populations. This increases the potential for greater representativeness of the general population. Along with this, frequent utilization of the CCFNI and its utilization in various settings supports its validity and use as a diagnostic instrument (Freichels, 1991).

The main limitation of these studies was the use of small samples. Nonprobability convenience sampling was used in all the studies, therefore generalizations to larger populations must be made with extreme caution. The studies generally excluded family members who were unable to visit or who were psychologically unable to cope with visiting a critically ill family member. Several characteristics of the family and patients were not addressed consistently which may have influenced the perceived needs of family members. These characteristics included (1) patient prognosis, (2) relationship to the patient, (3) previous experience or history with hospitalizations, especially if they have been exposed to the hospital environment for prolonged periods, and (4) socioeconomical and/or ethnic variables.

#### Conceptual Framework

<u>Crisis theory</u>. Crisis theory postulates that when individuals are exposed to certain conditions or stressors in their environment that exceed their abilities to problem-solve or cope with those demands, an imbalance or crisis occurs. During this period of disorganization and anxiety, many abortive attempts are made to seek resolution (Caplan, 1971). The effect of the exposure to such conditions or stressors is dependent on the individual's perception of the event.

According to crisis theory, a crisis event may be perceived as a danger (Aguilera & Messick, 1986). When exposed to the crisis event, normal coping and defense mechanisms utilized by the family may be inadequate to restore organization and equilibrium. Danger arises when individuals within the family structure are dramatically influenced by prolonged, negative effects of the crisis on their mental and physical well-being (Woolley, 1990).

Crisis events may be perceived as an opportunity as well (Aguilera & Messick, 1986). During crisis events, individuals may become more sensitive and receptive to therapeutic crisis intervention. The goal of crisis intervention is to assist individuals toward normalcy. Movement toward normalcy can provide situational control, promote coherence and restore equilibrium in the family structure. The individuals

may learn new coping mechanisms that will assist them when exposed to other crises in the future (Woolley, 1990).

King's conceptual framework for nursing. King's (1981) conceptual framework for nursing consists of three interacting, open systems: (1) individuals as personal systems, (2) two or more individuals forming interpersonal systems, and (3) larger groups, with common interests, forming social systems. According to King, individuals are in constant, dynamic interaction with each other and their environment to maintain health. Interference in the ability to adjust to internal or external stressors, or a change in role function, results in a biological, psychological or social state of illness.

Concepts integral to King's conceptual framework include interaction, transaction, perception of control and role integrity. King's theoretical conceptualization of interaction is the process of perception and communication. Perception and communication occur between people and their environment, and between two people. This interaction is represented by verbal and nonverbal behaviors that are goal directed (King, 1981).

Transaction is the communication process that occurs and facilitates the delivery of information required for the care, cure, and recovery of clients. The nurse and client interact and transact toward identification of mutual goals. As the interactive process continues, mechanisms to achieve the goal are established. Once the mechanisms are established, both parties move toward goal completion and evaluation (King, 1981).

The concept of control is theorized as a facet of power that each individual strives to obtain. Individuals are controlling beings, according to King's assumptions. When one loses the sense of control, disorganization occurs and the individual is unable to participate in the decision making process (King, 1981).

The conceptualization of role integrity entails a set of behaviors that are expected when occupying a position in a social system (King, 1981). The family is viewed as a social system, with organized boundaries that provide the primary social environment for individual members. A change or illness of one family member impacts the remaining family members and role integrity. The critical illness of a child may be perceived as a major life stressor that alters role integrity. Parents experience role revision, from the parent of a previously well child to the parent of a child who is critically ill (Jay & Youngblut, 1991). Inability to accept or adjust to role revision may precipitate a crisis within the family structure (Freichels, 1991).

Educating and preparing parents for alterations in parental role assists the parents to find ways in which they may continue to fulfill accustomed parental roles. The ability to function in accustomed parental roles will allow parents time to adapt to the role changes required during the hospitalization of a critically ill child (Miles, Carter, Spicher, & Hassenein, 1984).

Often pediatric critical care nurses feel that parents are unable to participate in the care of their child. Many parents, however see this as a priority need. When parents desire to participate in the care of their child during critical hospitalization, permission should be made possible. Participation in their child's care assists the

parents in retaining a sense of competency and mastery of parental role function (Kruger, 1992).

Integration of crisis theory and King's framework. Crisis theory and King's conceptual framework for nursing are congruent in providing the theoretical foundation to examine the perceived needs of parents of critically ill children and parental needs identified by pediatric critical care nurses. Crisis theory provides the framework for identification of adaptive and maladaptive behaviors indicative of stressors and crisis events.

King's (1981) conceptual framework for nursing allows for theoretical operation of the concepts of crisis theory as well as a process for application in the clinical arena. Through the process of interaction and transaction, nurses can identify the perceived needs of parents of critically ill children, as well as adaptive and maladaptive coping abilities. The continued process of interaction and transaction with the parents will assist in strengthening coping abilities that the parents possess while establishing new coping abilities for future experiences. The congruency of crisis theory and King's conceptual framework enables nurse clinicians to view the client holistically with incorporation of the parents in a plan of care for the family.

Pediatric critical care clinicians are in an optimal position for interacting and transacting with parents and families to provide crisis interventions and stabilization. When nursing interventions are based on parental needs as they are perceived by the critical care nurse, energy may be utilized by the nurse addressing nonexistent needs or needs already met by others (Molter, 1979). Accurate identification of parental

needs, with incorporation of parental needs into the plan of care, will provide a holistic approach to meeting the critical needs of the child as well as the parents.

King's (1981) process of interaction affords the pediatric critical care nurse the opportunity to accurately assess parental needs. During these interactions, acknowledgment and verbalization of parental uncertainties and fears can occur. Nurses can utilize transactions to provide parents with the information and education necessary to understand their child's illness and prognosis, the environment, and the roles of health care professionals. Information decreases parental uncertainty and fear, resulting in a reduction of stress which minimizes escalation of the crisis event. Nursing interventions focused on accurately identified needs can lead families to regain organization, equilibrium and control. This will allow families to learn new coping mechanisms while promoting family coherence and support as hypothesized in crisis theory and King's (1981) conceptual framework for nursing.

#### **Objectives and Hypothesis**

<u>Objectives of the study</u>. The purpose of this study was to (a) identify the perceived needs of parents of critically ill hospitalized children, (b) identify parental needs as perceived by critical care nurses and (c) identify the differences in perceived needs between parents and critical care nurses.

<u>Hypothesis</u>. The needs of parents of critically ill children as identified by the parents will differ from parental needs perceived by pediatric critical care nurses.

<u>Definition of terms</u>. The theoretical and operational definitions of concepts employed in this research study are:

critically ill child - newborn through 15 years of age, admitted to the critical care unit

for 36 to 84 hours, for a first time catastrophic illness.

*catastrophic illness* - a first time acute onset of an illness or a surgical procedure requiring hemodynamic monitoring, observation and/or stabilization in a critical care unit.

parent(s) - a specific role in the family structure that focuses on the care of the children in the family unit (Thomas, Bernard, & Sumner, 1993). For the purpose of this study, the parent was the primary caretaker of the critically ill child. The primary caretaker may be the parent, adult sibling or designated significant other. *family* - the basic structural and functional unit of society; a social system with organized boundaries, roles and positions, that provides the primary social environment for individual members (King, 1981). For the purpose of this study, a family may be a dyad, consisting of the critically ill child and the primary caretaker. *pediatric critical care nurse* - a diploma, associate, or baccalaureate prepared registered nurse employed in a pediatric critical care unit for at least one year. *crisis* - an imbalance that occurs when environmental demands exceed the abilities of individuals and their social resources to cope with those demands. For the purpose of this study, the unexpected critical hospitalization of a child was the situational crisis. *needs* - the perceived requirements of family members of critically ill children identified using the CCFNI modified for pediatrics.

#### CHAPTER 3

#### METHODOLOGY

#### Design

A descriptive research design was utilized for this study to identify the perceived needs of parents of critically ill children and contrast them to the parental needs identified by critical care nurses. Data were obtained by a structured interview technique.

#### Selection of Subjects

A non-probability convenience sample was utilized for this study, consisting of 30 parents or primary caretakers of critically ill children and 30 pediatric critical care nurse responses. Seven of the nurses participated in the study twice with different families.

Parents were selected from a metropolitan Midwestern hospital in which their critically ill child (newborn through fifteen years) was hospitalized for 36 to 84 hours in the critical care unit. The parent(s) were 18 years or older. All parents spoke and understood the English language.

Parents were not selected for inclusion in this study if their child died during the hospitalization or if the nurse and/or researcher determined that inclusion would compromise a parent's emotional well-being. Parents of critically ill children admitted as the result of suspected child abuse were excluded, as well as parents of premature infants and children with disorders requiring regular, intermittent hospitalizations.

#### Characteristics of the Subjects

Parent/primary caretaker sample. Thirty parents or primary caretakers participated in this study. Twenty-six of the respondents were parents (86.7%) of a child in the pediatric intensive care unit (PICU). Three of the respondents were grandparents (10.0%) with one respondent being an aunt of one of the children (3.3%). The majority of the respondents were female (73.3%). The age of the respondents ranged from 18 to 51 years with a mean of 31.6 years (s.d. = 9.2).

Approximately 46.7% of the respondents had attended or completed high school education. Sixteen of the respondents had attended college (53.3%), with ten of the respondents successfully completing a college degree (33.3%). Three of the respondents had participated in graduate studies.

The employment status of the majority of respondents was split between fulltime employment and homemakers. Forty percent of the respondents were employed full-time, while another 40% were homemakers. Twenty-five of the respondents had at least one other child at home. The distance from the hospital ranged from 1 to 90 miles with a mean distance of 30.6 miles (s.d. = 23.7). Hours of visitation in the PICU ranged from 2 hours to 24 hours (mean 18.0) with 11 (36.7%) of the respondents staying at the hospital 24 hours per day.

The parents or primary caretakers of 21 children participated in the study. Data collection occurred between 36 to 72 hours of admission to the PICU with a mean data collection time at 47.5 hours. The ages of the children ranged from 3 months to 168 months (14 years) with a mean age of 47.5 months or 4 years (s.d. = 11.0). Thirteen of the children admitted to the PICU had never been hospitalized before. Eight of the children were admitted for respiratory illnesses. Other diagnoses included emergency surgery, complications from scheduled surgery, dehydration, ingestion of a substance, seizures, head injuries or injuries received from being in a motor vehicle accident. Table 6 depicts the number of children admitted for each diagnosis and their ages.

#### Table 6

#### Pediatric Admission Diagnoses

Diagnosis	Ages	Total Number of Cases
Respiratory Illness	3 months to 23 months	8
Surgery - Emergent	3 months to 5 years	4
Surgery - Scheduled	16 months to 11 years	2
Motor Vehicle Accident	6 years to 8 years	2
Head Injury/Altered Consciousness	5 years to 14 years	2
Seizures	2 years	1
Iron Ingestion	2 years	1
Dehydration	7.5 years	1

The parents or primary caretakers were asked to indicate how ill they perceived their child to be at the time of the structured interview. A linear scale of 0 to 100 was used with 0 denoting not very ill to 100 denoting critically ill. The perceived degree of illness ranged between 23 to 100 with a mean of 65.2 (s.d. = 20.4) and a median of 59.5. Table 7 shows the admission diagnosis and age of each child and how each parent perceived his/her child's illness.

#### Table 7

Diagnosis	Age	Perceived Degree of Illness Identified by the Parent				
		First Parent Participant	Second Parent Participant			
1. Dehydration	7.5 yr.	46	54			
2. Iron Ingestion	2 yr.	50	23			
3. Head Injury	5 yr.	57				
4. Seizures	2 yr.	45	49			
5. Altered Consciousness	14 yr.	91	100			
6. Surgery - Scheduled	11 yr.	100				
7. Surgery - Scheduled	16 mo.	30				
8. Motor Vehicle Accident	8 yr.	77	56			
9. Motor Vehicle Accident	6 yr.	84				
10. Surgery - Emergent	3.5 mo.	59				
11. Surgery - Emergent	8.5 mo.	50				
12. Surgery - Emergent	4 mo.	50	46			
13. Surgery - Emergent	5 yr.	90				
14. Respiratory Illness	23 mo.	97				
15. Respiratory Illness	6 mo.	60	85			
16. Respiratory Illness	7 mo.	68				
17. Respiratory Illness	4 mo.	57				
18. Respiratory Illness	5 mo.	75				
19. Respiratory Illness	3 mo.	67				
20. Respiratory lliness	3.5 mo.	55	86			
21. Respiratory Illness	3 mo.	65	83			

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#### Perceived Degree of Child's Illness Identified by Each Parent

<u>Nurse sample</u>. Pediatric critical care nurses who were currently employed in a pediatric critical care unit in a metropolitan Midwestern hospital were included in this study. The majority of the nurses participating in the study had been a registered

nurse for at least seven years and held an associate degree in nursing. Critical care nurses with advanced nursing degrees were excluded from the study.

Seventy percent of the nurses were employed in a full-time position. The critical care nurses were registered nurses employed in the pediatric critical care unit for 12 to 264 months with a mean 124.8 months or 10 years.

The majority of the nurse respondents were female (86.7%). The age of the nurse respondents ranged from 24 years to 46 years with a mean age of 36.7 years (s.d. = 6.8). Approximately 60% of the nurse respondents had one or more children.

Fifty-three percent of the nurse respondents had experienced having an adult family member in a critical care unit. None of the nurse respondents had ever been a patient in a critical care unit or had any of their own children in a critical care unit. Instruments

The four instruments that were utilized in this study included (1) a demographic data tool for parents (Appendix A); (2) a demographic data tool for pediatric critical care nurses (Appendix B); (3) the Critical Care Family Needs Inventory (Molter, 1979), modified to pediatrics (Kirschbaum, 1990), and (4) the Critical Care Family Needs Inventory modified to reflect the pediatric critical care nurses' perception of parental needs. Permission for use of the CCFNI with any modifications for this study was obtained from the author (Appendix C). The instruments were coded to determine which instruments were completed by the parent(s) and the nurse involved in the child's care. Leske (1991) replicated Molter's research study to establish psychometric properties, as well as construct validity through factor analysis. Data from 677 CCFNI were analyzed using factor analysis. The five-factor solution of the CCFNI subdivided the need statements into five conceptual categories. Support, comfort, information, proximity, and assurance. A panel of 10 experts in the field of critical care family needs reviewed the five categories and assigned labels to them. Exploratory stepwise factor analysis was performed to summarize the interrelationships among the items of the CCFNI to establish construct validity (Leske, 1991).

Replication of Molter's research study has also established reliability as indicated by internal consistency coefficients ranging from 0.90 to 0.95 (Freichels, 1991; Leske, 1991; Mathis, 1984; Rodgers, 1983). The psychometrics of the modified version of the CCFNI were not verified by Kirschbaum (1990), however internal consistency for utilization in this study was established. An internal consistency coefficient of 0.93 was determined from 41 valid cases. Nineteen cases had missing data on at least one of the 53 need statements and were not considered in establishing reliability. Reliability coefficients of 0.70 or greater are sufficient in making group comparisons (Polit & Hungler, 1991). Content validity was established for the 8 need statements added to the CCFNI by Kirschbaum (1990).

#### Human Subject Considerations

In order to conduct this research study, permission was obtained from Grand Valley State University Human Subjects Committee and the Nursing Research Committee at the metropolitan Midwestern hospital.

#### Data Collection Procedures

Current patient census in the pediatric critical care unit were reviewed to ascertain eligibility for inclusion in the study. The parents were contacted by the researcher or designee, no earlier than 36 hours nor greater than 84 hours, following admission of their child to the critical care unit. Parents were approached privately to obtain their consent to participate in the study (Appendix D).

All participants were told that the purpose of the study was to identify parental needs of critically ill children. A script for approaching subjects was read to each potential participant, identifying the researcher as a graduate nursing student from Grand Valley State University (Appendix E). All participants were informed that participation was voluntary and that confidentiality, as well as anonymity would be maintained. All participants were informed of the approximate time involved and that they could discontinue their participation at any time. Any and all questions were answered prior to obtaining consent for participation in the study. Each participant was given a signed copy of the consent form, including the name and telephone number of the researcher.

Upon receiving consent to participate in the study, an appointment was made with the parent to conduct the interview as soon as possible. The structured interviews were conducted in a private consultation room annexed within the pediatric intensive care unit. If more than one parent participated in the study, the interviews were completed separately, to minimize bias.

In order to reduce the amount of time the structured interview would take, response cards were used depicting (1) not important, (2) slightly important, (3)

important, and (4) very important. Participants were able to point to desired responses and the chosen responses were recorded on the questionnaire.

Pediatric critical care nurses, assigned to the critically ill child whose parent participated in the study, were contacted separately, following shift reports, to obtain their consent for participation in the study (Appendix F). A script to approach nurses caring for parents participating in the study was used (Appendix G). If more than one parent participated in the study, the primary nurse was asked to complete one interview questionnaire, identifying perceived needs of one parent. An associate nurse was asked to complete an interview questionnaire for the second parent participating in the study.

All the nurses participating in the study were interviewed immediately before or after the family interview. Due to time and work constraints, an alternative was established to have the nurses complete the questionnaire, returning it to the researcher within 24 hours. A self-addressed, stamped envelope was to be given to nurses for assistance and convenience in completing the questionnaire. Implementation of the alternative mechanism for data collection was not necessary in this study.

#### Benefits and Risks to Subjects

It was determined that the participants in this study would not receive any direct benefit from their participation. However, this research study may assist health care practitioners develop a better understanding of the needs of parents of critically ill children, as well as the services that could provide assistance to parents. Results of this study were made available to the participants if requested. The risks involved for the participants were minimal. If the parents became emotionally upset or vulnerable during the structured interview, the researcher discontinued the interview process. The interviews were also discontinued if the parents displayed signs of cognitive and physical exhaustion. All of the interviews that were initiated, were completed without difficulty.

The parents did not voice concerns about possible interference in the care or services that their child may receive as a result of participating in this study. The researcher informed the parents that this would not occur prior to obtaining consent for participation in the study and documentation was included in the consent form (Appendix D).

During the structured interview process, some of the parents identified concerns or questions beyond the scope of the research study that required attention. The researcher assisted in finding the answers to the parents' questions. Additionally, each parent participating in the study was provided with a written list of resources that were available in the community.

Confidentiality and anonymity of all participants were maintained. The researcher conducted the interviews in a private area. The researcher coded the data sheets for each participant (parent and nurse) to maintain confidentiality.

The nurses did not voice concerns about possible job jeopardy as a result of participating in this study. The researcher did inform the nurses that this would not occur prior to obtaining consent for participation in the study, with documentation included in the consent form (Appendix F).

#### CHAPTER 4

#### RESULTS

The purpose of this research was to (a) identify the perceived needs of parents of critically ill hospitalized children, (b) identify parental needs as perceived by critical care nurses, and (c) identify the differences in perceived needs between parents and critical care nurses to ascertain the accuracy of nursing assessments. Data analysis was accomplished utilizing the Statistical Package for Social Sciences (SPSS/PC+) software.

#### **Hypothesis**

The hypothesis for this study was: The needs of parents of critically ill children as identified by the parents will differ from parental needs perceived by pediatric critical care nurses. Statistical analyses used in this study were a paired sample t-test, ranked order of perceived importance and the Wilcoxon matched-pairs signed-ranks test. Significance was set at p < .05 for all tests.

Data analysis included a comparison of the rank ordering of needs according to perceived importance by the parents/primary caretakers and the critical care nurses. Rank ordering of need statements were based on a median response for the ordinal data obtained during the structured interview process. The median score for the majority of need statements was 4. The final rank order of importance identified by the parents (Appendix H) and the critical care nurses (Appendix I) was determined by the statistical mean of the need statement which was consistent with Molter's (1979) study. Table 8 depicts the 15 most important need statements identified by the parents.

#### Table 8

#### Rank Ordering of Most Important Needs Identified by Parents

		Percent of Respondents					
ten	1	Not Imp (1)	Sl. Imp (2)	Imp (3)	Very Imp (4)	Mean Rank	
1.	To know the expected outcome.	0%	0%	0%	100%	4.000	
2.	Have questions answered honestly.	0%	0%	0%	100%	4.000	
3.	Know how their child is being treated medically.	0%	0%	0%	100%	4.000	
4.	Assured that the best care is given.	0%	0%	0%	100%	4.000	
5.	Called at home about changes in condition.	0%	0%	0%	100%	4.000	
5.	Feel that hospital personnel care.	0%	0%	0%	100%	4.000	
7.	To visit at any time.	0%	0%	3.3%	96.7%	3.967	
8.	Receive information once a day.	0%	0%	3.3%	96.7%	3.967	
9.	To see their child frequently.	0%	0%	3.3%	96.7%	3.967	
0.	Recognized as important to their child's recovery.*	0%	0%	3.3%	96.7%	3.967	
1.	Knowing specific facts concerning their child's progress.	0%	0%	6.7%	93.3%	3.933	
12.	To know why thing were done for their child.	0%	0%	10.0%	90.0%	3.900	
13.	Feel that there is hope.	0%	0%	10.0%	90.0%	3.900	
14.	Knowing exactly what is being done for their child.	0%	0%	10.0%	90.0%	3.900	
5.	Explanations given that are understandable.	0%	3.3%	6.7%	90.0%	3.867	

Note. \* = Need statement not identified by critical care nurses.

The first six need statements identified by the parents were perceived universally as being very important. However, no need statement had 100% agreement as most important by the nurse respondents. Table 9 represents the 15 most important parental needs identified by the critical care nurses.

The review of the data analysis indicated that the parents and critical care nurses identified similar needs and that at least one person from each group considered each need statement very important. Fourteen of the 15 most important needs were identified by both groups with differences in how each group perceived the ranked importance of the need statement. The mean rank of the 15 most important needs identified by the parents ranged from 3.867 to 4.000 compared to 3.767 to 3.933 identified by the nurse respondents.

Each individual group identified a need that was not ranked as a priority among the opposite group. The parents perceived the need to be recognized as important to their child's recovery (mean rank = 3.967) while the critical care nurses identified this need with a mean rank of 3.667. The nurses perceived the need for the parents to assist with their child's care (mean rank = 3.833) compared to the mean rank of 3.667 identified by the parents.

In comparison to Molter's (1979) study and Kirschbaum's (1990) study, the research findings are consistent (Table 10). There were 3 need statements indicated in the first 15 most important needs in Molter's (1979) study that did not appear in Kirschbaum's (1990) study. The results of Kirschbaum's (1990) study indicated that the parents perceived the need to visit at any time, knowing how their child was being treated medically, as well as being recognized as important to their child's recovery

#### Rank Ordering of Most Important Needs Identified by Critical Care Nurses

			Percent of Respon	idents	
item	Not Imp (1)	Sl. Imp (2)	Imp (3)	Very Imp (4)	Mean Rank
1. To know how their child being treated medically.	is 0%	3.3%	0%	96.7%	3.933
2. Have questions answered honestly.	0%	0%	6.7%	93.3%	3.933
3. Assured that the best care is given.	0%	0%	6.7%	93.3%	3.933
4. Receive information once a day.	0%	0%	6.7%	93.3%	3.933
5. Feel that there is hope.	0%	0%	6.7%	93.3%	3.933
6. To know the expected outcome.	0%	0%	10.0%	90.0%	3.900
7. Knowing exactly what is being done for their child	0%	3.3%	6.7%	90.0%	3.867
8. To visit at any time.	0%	0%	13.3%	86.7%	3.867
9. To see their child frequently.	0%	0%	13.3%	86.7%	3.867
10. To know why thing were done for their child.	e 0%	0%	13.3%	86.7%	3.867
1. Explanations given that are understandable.	0%	0%	13.3%	86.7%	3.867
12. Called at home about changes in condition.	3.3%	0%	6.7%	90.0%	3.833
<ol> <li>Knowing specific facts concerning their child's progress.</li> </ol>	0%	3.3%	10.0%	86.7%	3.833
<ol> <li>Assist with my child's care.*</li> </ol>	0%	0%	16.7%	83.3%	3.833
<ol> <li>Feel that hospital personnel care.</li> </ol>	0%	0%	20.0%	80.0%	3.800

Note. \* = Need statement not identified by the parents.

#### Comparison of Parents' 15 Most Important Perceived Needs with Molter's (1979) and Kirschbaum's (1990) Studies

Molter's 1979 Study	Kirschbaum's 1990 Study	Scott's 1995 Study
15 Most Important Needs	15 Most Important Needs	15 Most Important Needs
1. To feel there is hope.	1. Knowing how my child is being treated medically.*	1. To know the expected outcome.**
<ol> <li>To feel that hospital personnel care about the patient.</li> </ol>	2. Feeling that there was hope.	2. To have questions answered honestly.
3. To have the waiting room near the patient.	3. Being assured that the best care was given.	3. To know how their child is being treated medically.*
<ol> <li>To be called at home about changes in the condition of the patient.</li> </ol>	<ol> <li>Knowing specific facts concerning my child's progress.</li> </ol>	4. Assured that the best care is being given.
5. To know the prognosis.	5. Having questions answered honestly.	5. To be called at home about changes in their child's condition.
6. To have questions answered honestly	6. Knowing exactly what is being done for my child.	6. To feel that hospital personnel care about their child.
7. To know specific facts concerning the patient's progress.	7. Being called at home about changes in my child's condition.	7. To visit at any time.*
<ol> <li>To receive information about the patient once a day.</li> </ol>	8. Feeling that hospital personnel care about my child.	8. To receive information at least once a day.
<ol> <li>To have explanations given in terms that are understandable.</li> </ol>	9. Knowing my child's prognosis.	9. To see their child frequently.
10. To see the patient frequently.	10. Receiving information at least once a day.	10. To be recognized as important to their child's recovery.*

#### Table 10 (continued)

#### Comparison of Parents' 15 Most Important Perceived Needs with Molter's (1979) and Kirschbaum's (1990) Studies

Molter's 1979 Study	Kirschbaum's 1990 Study	Scott's 1995 Study	
15 Most Important Needs	15 Most Important Needs	15 Most Important Needs	
11. To feel accepted by the hospital staff.	11. Knowing why things were done for my child.	11. To know specific facts concerning their child's progress.	
12. To have a bathroom near the waiting room.	12. Seeing my child frequently.	12. To know why things were done for their child.	
13. To be assured that the best possible care is being given to the patient.	<ol> <li>Being recognized as important to my child's recovery.*</li> </ol>	13. To feel that there is hope.	
<ol> <li>To know why things were done for the patient.</li> </ol>	14. Having explanations that are understandable.	14. To know exactly what is being done for their child.	
<ol> <li>To know exactly what was being done for the patient.</li> </ol>	15. Visiting at any time.*	15. To have explanations that are understandable.	

Note. \* = Items not contained in Molter's (1979) study. \*\* = The item not contained in Molter's (1979) or Kirschbaum's (1992) study.

were among the 15 most important needs. This was consistent with the findings from this research study. This may be the result of the adaptation of the CCFNI to a pediatric critical care setting. This present study also identified knowing the expected outcome as a need. Knowing the expected outcome was not among Molter's or Kirschbaum's description of the 15 most important needs.

The 10 least important needs identified by the participants were ranked in descending order beginning with the least important need statement. The 10 least important needs identified by the parents are shown in Table 11. The median score for these need statements was 2.

A description of the least important parental needs identified by the critical care nurses are depicted in Table 12. The median score on these low ranked needs was 3. Both groups identified similar needs as least important, however the parents perceived the needs with less importance than the critical care nurses. The mean ranks of the 10 least important needs identified by parents ranged from 2.100 to 2.731 compared to a range of 2.733 to 3.033 identified by the critical care nurses.

Both groups were congruent in their identification of support systems and spiritual needs as least important. These findings are consistent with previous research that indicates that family members perceive support and comfort needs with decreased priority (Molter, 1979; Friechels, 1991; Kirschbaum, 1992).

### Rank Ordering of Least Important Needs Identified by Parents

	Percent of Respondents						
	Not Imp	Sl. Imp	Imp	Very Imp	Меап		
tem	(1)	(2)	(3)	(4)	Rank		
1. Having someone with them when visiting the PICU.	40.0%	23.3%	23.3%	13.3%	2.100		
2. Have someone concerned with their health.	36.7%	23.3%	26.7%	13.0%	2.167		
3. To have a pastor visit.	36.7%	16.7%	26.7%	20.0%	2.300		
4. To be told about chaplain services.	20.0%	36.7%	30.0%	13.3%	2.367		
5. Have someone help with financial problems.	17.2%	41.4%	17.2%	24.1%	2.483		
<ol> <li>Help in responding to the reactions of their ill child's siblings.</li> </ol>	14.3%	32.1%	35.7%	17.9%	2.571		
7. To talk to the same nurse every day.	13.3%	26.7%	46.7%	13.3%	2.600		
<ol> <li>To talk to other parents whose child is critically ill or survived a similar illness.</li> </ol>	13.3%	26.7%	40.0%	20.0%	2.667		
9. A place to be alone while in the hospital.	13.3%	26.7%	40.0%	20.0%	2.667		
<ol> <li>Time to maintain the marital relationship.</li> </ol>	15.4%	23.1%	34.6%	26.9%	2.73		

Iten	n	Not Imp (1)	Percent of Re Sl. Imp (2)	spondents Imp (3)	Very Imp (4)	Mean Rank
1.	To be told about chaplain services.	10.0%	16.7%	63.3%	10.0%	2.733
2.	Having someone with them when visiting the PICU.	20.0%	16.7%	26.7%	36.7%	2.800
3.	To have a pastor visit.	13.3%	13.3%	50.0%	23.3%	2.833
4.	Having visiting hours changed for special conditions.	28.6%	0%	21.4%	50.0%	2.929
5.	To talk to other parents whose child is critically ill or survived a similar illness.	3.4%	24.1%	· 48.3 <i>%</i>	24.1%	2.931
6.	Help in responding to the reactions of their ill child's siblings.	6.7%	10.0%	63.3%	20.0%	2.967
7.	To talk to the same nurse every day.	0%	26.7%	46.7%	26.7%	3.000
8,	A place to be alone while in the hospital.	6.7%	13.3%	53.3%	26.7%	3.000
9.	Time to maintain the marital relationship.	4.0%	24.0%	40.0%	32.0%	3.000
10.	To be alone whenever they want.	3.3%	13.3%	60.0%	23.3%	3.033

#### Rank Ordering of Least Important Needs Identified by Critical Care Nurses

Using rank ordering of needs, the relationship of individual needs identified by parent/nurse pairs were analyzed with the Wilcoxon Matched-pairs Signed-Ranks Test. There were twelve need statements in which there was a significant difference in perceived importance (p < 0.05) as shown in Table 13. In the matched pairs, the parents perceived the first 4 of 12 statements more important (mean rank ranged from 3.50 to 8.96) than the nurse counterpart (mean rank ranged from 0.00 to 7.00). The

#### Relationship of Individual Needs Identified by Parent/Nurse Matched Pairs

ltem	Nu	Number of Ranks Nurse < Parent (Mean Rank)		Number of Ranks Nurse > Parent (Mean Rank)		$\frac{2\text{-tailed }p}{p} = .05$	
<ol> <li>Feel that hospital personnel care about their child.</li> </ol>	6	(3.50)	0	(0.00)	-2.20	.0277	
2. Recognized as important to their child's recovery.	9	(5.00)	0	(0.00)	-2.66	.0077	
3. A place to sleep near the PICU.	13	(8.85)	3	(7.00)	-2.43	.0151	
<ol> <li>Having the waiting room near the child.</li> </ol>	13	(8.96)	3	(6.50)	-2.51	.0121	
<ol> <li>Having explanations of the environment before going into the PICU for the first time.</li> </ol>	1	(5.50)	11	(6.59)	-2.63	.0086	
<ol> <li>Assured that its alright to leave the hospital.</li> </ol>	2	(6.00)	11	(7.18)	-2.34	.0192	
7. To talk about their feelings.	4	(6.50)	13	(9.77)	-2.39	.0168	
8. Having comfortable furniture in the waiting room.	5	(8.00)	13	(10.08)	-1.98	.0475	
9. Help in supporting their ill child's reaction to the PICU.	7	(6.50)	12	(12.04)	-1.99	.0464	
10. Having someone help with financial problems.	4	(9.13)	16	(10.84)	-2.56	.0105	
<ol> <li>Having another person with them when visiting the PICU.</li> </ol>	4	(7.50)	15	(10.67)	-2.62	.0089	
12. Having someone concerned with their health.	2	(9.75)	20	(11.68)	-3.47	.0005	

Note. Items 1-4 were ranked higher by the parent in the parent/nurse matched pairs.

remaining 8 need statements were perceived as more important by the nurse (mean rank ranged from 6.59 to 12.04) than the parent (mean rank ranged from 5.50 to 9.75) in the matched pairs.

The paired sample t-test analyzed the parent need statement total scores (mean = 178.14) matched to the critical care nurses' total score (mean = 183.85). The analysis was done on 14 paired subjects with no missing data. Even though data analysis indicated differences in the ranking of individual need statements, there was not a significant difference between the two groups in the overall perception of family needs (t = 1.17; d.f. = 13; p = 0.265). Thus the research hypothesis was rejected.

#### **CHAPTER 5**

#### DISCUSSION AND IMPLICATIONS

The findings of this study did not support the hypothesis that the needs of parents of critically ill children as identified by the parents would differ from parental needs as perceived by pediatric critical care nurses. There were, however, a few exceptions that will be discussed further. Overall, the parents and the critical care nurses who participated in the study identified similar need statements, with some differences in ranked importance.

One are of difference was in the actual rank ordering of the highest six need statements. One hundred percent of the parents identified 6 need statements as most important (mean rank = 4.000). The parents indicated that knowledge of the expected outcome of their child's hospitalization and the medical treatment regimen were high priorities. Other priorities that were identified by the parents included honest answers, assurance that the best care was given by personnel who were concerned for their child's well-being. The parents also indicated that notification of any changes in the condition of their child was crucial.

In contrast, the critical care nurses perceived these 6 needs with slightly less importance. Approximately 97% of the nurses identified parental knowledge of the medical treatment regimen as the highest priority need. Ninety percent of the critical care nurses identified the need to know the expected outcome and notification of

changes in condition as very important. Ninety-three percent of the nurses indicated that it was very important for the parents to be assured that the best care was being given to their child, however only 80% of the nurse participants perceived the need to feel that hospital personnel cared was very important.

Nine of the 15 most important statements identified by the parents pertained to informational needs. The parents' need for information concerning their child's diagnosis, prognosis, treatment and progress may be indicative of the need to minimize uncertainty and fear in regards to the outcome of the critical hospitalization.

Although informational needs were identified as most important, the source of information varied in importance. The need to talk the doctor every day was identified by 86.7% of the parents as very important while only 13.3% identified the need to talk to the same nurse every day. This may be suggestive of the parental expectation that nursing personnel change frequently while the medical staff remains constant. Fifty percent of the parents indicated a desire to know about the types of hospital personnel involved in their child's care while 40% perceived that it was very important to know which staff members could give certain types of information.

The remaining 6 of the 15 most important needs identified by the parents were related to proximity and assurance. The need to see their critically ill child frequently was perceived by 96.7% of the parents as very important. Seventy percent of the parents indicated that it was very important to have the waiting room near their child while 73.3% felt it was very important to have a place to sleep near the pediatric intensive care unit. These results are suggestive of the parents' need to maintain close contact with their critically ill child.

Even though the pediatric intensive care unit had unrestricted visiting, 56.7% of the parents identified the need to have visiting hours start on time as very important. These results may be indicative of the parents' inability to process vast amounts of information during the initial situational crisis event. Another explanation may be related to the orientation to the PICU environment. Only 50% of the parents identified the need to be oriented to the PICU environment as very important. Since this need was perceived with less importance, the parents may not have been able to cognitively process information regarding visiting hours.

One need statement identified by the parents as one of the 15 most important needs was not identified by the nurses. Being recognized as important to their child's recovery was identified as very important by 96.7% of the parents as opposed to 66.7% of the nurses. Being recognized as important to their child's recovery may facilitate the parents' need to regain loss of control and assurance while adjusting to role revision experienced during the unexpected critical hospitalization.

The need statement that the critical care nurses identified that was not among the parents 15 most important needs was the parent's need to assist with their child's care. The nurses may perceive that assistance in the care of the critically ill child serves as an intervention to facilitate recognition of the parents as important in the child's recovery, as well as to maintain parental roles. This seems to be of less concern to parents at this critical time.

The critical care nurses identified the same 9 informational needs as the parents among the 15 most important needs with differences in ranked importance. In conjunction, there were differences in perceived importance for sources of

information between the parents and the nurses. Twenty-seven percent of the nurses felt that it was important to talk to the same nurse every day while 80% identified the need to talk to the physician daily as very important. The nurses also perceived the need to know about the types of hospital personnel involved in the child's care (36.7%) as well as which staff members could provide certain information (30%) with less importance than the parents.

The need statements identified by the parents as least important are consistent with areas concerning support or comfort. The parents identified need statements concerning their health and situational support as least important while need statements regarding the physiological and psychological needs of their critically ill child as more important. Only 13.3% of the parents identified having someone concerned with their health as very important and was identified by the parents as the least important need. Low priority placement or neglect of self-care needs may be indicative of the parents' inability to recognize, confirm or focus attention on themselves during their child's critical hospitalization.

The 10 least important needs identified that the critical care nurses were consistent with need statements concerning support or comfort. However, 33.3% of the nurses ranked the need for someone to be concerned with the parent's health as very important. Both groups ranked spiritual needs among the least important. Affirmation of spiritual needs may be indicative of despair and/or denial of the severity of the critical hospitalization. Regardless of the low priority placed on spiritual needs, 46.7% of the parents and 63.3% of the nurses identified the need to verbalize about the possibility of the child's death as very important.

There were significant differences between the parent/nurse matched-pairs and the perceived importance of individual need statements. The parents identified 4 of 12 need statements with higher perceived importance than the critical care nurses. These need statements were related to assurance and proximity. The parents indicated that it was significantly important to be recognized as important to their child's recovery and to feel that hospital personnel cared about their child. The parents also identified having the waiting room near their child with a close place to sleep near the PICU. As parental roles become altered during the critical hospitalization, the parent may attempt to maintain the parental role function of protection through presence, vigilance and validation that hospital personnel care about their child both physically and emotionally.

The remaining 8 need statements were perceived as being significantly less important by the parents in the parent/nurse matched pairs. These needs can be classified as support or comfort needs that the parents consistently perceived with less priority than the critical care nurses. Situational support, financial assistance and self-care were areas that the parents perceived with less important than the nurses. This supports the parents priority focus on the care of their child rather than on their own care and comfort.

#### Relationship of Findings to the Conceptual Framework

According to the research findings, the pediatric critical care nurses were able to accurately assess and ascertain parental needs through interactions and transactions with family members based on the total scores of each group. King's (1981) key concepts provide a framework to structure the development of holistic family assessments in an interactive process. Concepts such as interaction and transaction that rely on interdependence, mutuality and anticipatory guidance, will facilitate the accurate assessment of the parental needs. Through accurate assessment of parental needs, the pediatric critical care nurse will be able to incorporate the family into the plan of care in order to initiate crisis intervention, stabilization and parental education. Based on these findings, these nurses were able to interact with the parents of their patients and, for the most part, accurately determine their needs.

Past experiences often determine how individuals perceive family functioning. Each individual has strong beliefs about how a family should function and respond to crisis situations. Each of us has experienced some facet of the family structure and its culture. Our experiences define our perspectives of families and the roles that individuals should assume within the family structure. These beliefs serve as our ideal for comparison for critique of adequate family functioning. If the comparison is unconscious, it may influence the accuracy of a nurse's assessment of the family (Thomas, Barnard, & Sumner, 1993). Over 50% of the pediatric critical care nurses who participated in this study had experienced having a family member in a critical care unit. This may help to explain the level of accuracy which parental needs were assessed.

Even though there was considerable accuracy in the prioritization of needs, there were significant differences in the perceived importance of 12 individual need statements among the parental/nurse matched pairs. These differences also may be attributed to prior experiences and individual perceptions concerning family functioning.

#### Relationship of Findings to Previous Research

Previous research using Molter's (1979) CCFNI has indicated a similar pattern in the perceived rank importance of the need statements. The numerical order of the perceived importance has varied to some extent in each study, however there are distinct similarities in each study.

Though patient populations have varied in these studies, informational, assurance and proximity need statements have consistently maintained higher importance for family members than support and comfort needs. Family members and nurses seem to identify similar needs, however the family members tend to rank the needs with higher importance than the nurses.

The majority of the participants in the present study were female in both groups. This is consistent with previous research studies. The present study lends support to the similarities of previous research conducted related to perceived needs of relatives.

#### Limitations and Recommendations

The findings of this research study are from a small, non random sample (parents: n = 30; critical care nurses: n=30), therefore the findings cannot be generalized beyond the present sample. Generalizibility would be facilitated using random sampling and a larger sample.

The time interval of data collection and patient prognosis could influence the research findings. The perceived needs identified by the parents may vary as coping mechanisms are implemented. Parental needs identified by critical care nurses can also be influenced by time and involvement with the family. Furthermore, individual values and how participants perceive families and family functioning, may impact their responses in this study.

The parents were able to indicate how ill they perceived their child to be at the time of data collection. A revised critical care nurse tool should include this indicator as well to determine if perceived illness of the child was similar between the parent and the nurse.

A limitation of the study was the limited number of male participants. The majority of the respondents in this study were female (parents: 73.3%; nurses: 86.7%). As such, the perception of the importance of needs of parents of critically ill children was primarily based on female responses. Further research is indicated to determine the influence of gender on perceived needs. Due to the small sample, age and gender correlations could not be analyzed.

The demographic and descriptive statistics did not include marital status, social support, income or culture/ethnicity as variables. Further studies should include these variables to determine their influence on the perceived needs of family members in order to determine accurate group comparisons and findings that can be generalized to larger populations.

#### **Implications for Nursing**

Generally, the parents tended to rate the majority of the need statements as important or very important. It is meaningful to note that even though a given need statement may have decreased perceived importance for this population, needs may increase in importance depending on situational events.

Information, assurance and proximity to the critically ill child were identified as priority needs of the parents in this study. By consistently incorporating these perceived needs identified by the parents into the plan of care, critical care nurses can assist the parents in the identification and fulfillment of support, comfort and self-care needs that have less perceived importance.

Nursing staff development programs for critical care nurses should focus attention on the abundant psychosocial needs of parents of critically ill children. Educational programs that assist nurses to address the personal and situational variables that parents experience during a critical hospitalization of one of their children are vital. As critical care nurses are more prepared to accurately assess and intervene with parents and families, it may facilitate improved parental adaptation to their child's hospitalization for a critical illness.

Nurse administrators should be cognizant of the parents' need for information, assurance, proximity, support and comfort. Provision of these needs are best met by critical care nurses who have interactive roles with parents and their children. It is the administrator's role to provide resources necessary to meet all levels of parental needs. It is important for the administrator to facilitate the nursing staff's maintenance of a supportive environment for parents of critically ill children. A supportive

environment incorporates information sharing, unrestricted visiting, comfortable furnishings, and self-care accommodations.

The establishment of flexible visiting policies promotes an environment conducive to meeting proximity needs of parents. From the results of this study, even within an environment that provides unrestricted visitation, parents may not understand or process information regarding visitation. Pediatric critical care nurses need to provide continual explanations, clarification and reinforcement to parents to minimize misconceptions related to visiting their child.

The importance of parents and parental roles in the recovery of a critically ill child must be recognized by nurses. Nurses should permit parental participation and decision making regarding the care of their child as much as possible to facilitate movement toward regaining parental control, adaption and crisis resolution.

It is important to note that the focus of this study was to identify perceived needs of parents of critically ill children identified by the parents and parental needs identified by pediatric critical care nurses. It was not the objective of this study to identify whether the needs were satisfied or who fulfilled the identified need. Further research in this area is warranted, as well as investigation of specific nursing interventions designed to assist family members to adapt to the critical illness of one of their children. Continued research in this area will contribute to the existing body of nursing knowledge and facilitate a more holistic approach to family-center care.

Appendices

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### APPENDIX A

Family Demographic Data

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Appendix A

Family Demographic Data

Code # \_\_\_\_\_

Date of Data Collection \_\_\_\_\_

Time of Data Collection \_\_\_\_\_

Admission Date \_\_\_\_\_ Time \_\_\_\_\_

Please provide the following information:

- 1. Patient's age \_\_\_\_\_
- 2. Your age \_\_\_\_\_
- 3. Your Sex

Male \_\_\_\_\_ Female \_\_\_\_\_

4. Your relationship to the patient

Parent
Grandparent
Brother
Sister
Other

- 5. Your years of formal education \_\_\_\_
- 6. Your Employment Status

Full time
Part time
Retired
Homemaker
Other

7. Approximately how many miles do you live from the hospital?

#### Family Demographic Data

Code # \_\_\_\_

- Approximately how many hours do you spend at the hospital each day? \_\_\_\_\_
- 9. Number of other children in your family \_\_\_\_\_
- 10. Is this the first hospital admission for your child?

Yes \_\_\_\_\_ No \_\_\_\_\_

How many admissions \_\_\_\_\_

- 11. Child's Diagnosis \_\_\_\_\_
- How ill do you perceive your child is today?Please mark an X on the line:

0\_\_\_\_\_100 not very critically ill ill

# APPENDIX B

Nurse Demographic Data

# Appendix B

# Nurse Demographic Data

Date of	f Questionnaire Completion
Time o	of Questionnaire Completion
Please	provide the following information:
1.	Your age
2.	Your Sex
	Male Female
3.	Your Education in Nursing (check the highest level
	completed)
	Diploma Associate Degree
	Baccalaureate
4.	Employment Status
	Full time Part time PRN
5.	Please indicate the approximate number of months
	that you have worked in PICU.
6.	Please indicate the approximate number of years
	as a RN
7.	What shift do you typically work?
	Days Evenings Nights

Code # \_\_\_\_\_

#### Nurse Demographic Data

Code # \_\_\_\_ Have you ever had an immediate family member in an 8. Intensive Care Unit? Yes \_\_\_\_ No \_\_\_\_ If yes, when \_\_\_\_\_ If yes, who \_\_\_\_\_ 9. Have you ever been a patient in an intensive care unit? Yes \_\_\_\_ No \_\_\_\_ If yes, when \_\_\_\_\_ 10. Do you have any children? Yes \_\_\_\_\_ No \_\_\_\_\_ If yes, how many \_\_\_\_\_ 11. Discrepancy of hours between completion of family and

nurse questionnaire\_\_\_\_\_

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### APPENDIX C

Permission Letter

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#### Appendix C

#### Permission Letter

Nancy C. Molter, RN, MN, CCRN President, AACN 16307 Hailfax San Antonio, Texas 78247

November 29, 1993

Linda D. Scott, RN, BSN 905 Craft Street Kalamazoo, Michigan 49001

I, Nancy Molter, give Linda D. Scott, permission to utilize my Critical Care Family Needs Inventory (CCFNI) and any modifications necessary for completion of her graduate thesis studies.

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Sincerely,

Nancy C. Molter, RN, MN, CCRN

### APPENDIX D

Family Consent Form

#### Appendix D

#### Family Consent Form

Code # \_\_\_\_\_

"I have been asked to participate in a research study, investigating the needs of parents of critically ill children. The purpose of this study is to identify the needs of parents and the importance of the needs identified. This study will help to develop a better understanding of the needs of parents of critically ill children for health care practitioners and the services that could be more helpful to parents".

"I understand that if I agree to participate, I will be asked to complete a family needs questionnaire and to answer some general background information (such as age, education, and employment). It will take approximately thirty minutes to complete the questionnaire".

"I have been given a description of the discomforts and risks to me, which can be reasonably expected from participation in this study. I understand that participation in this study may reveal questions or concerns that are not a result of the research procedure. The researcher (Linda Scott) will attempt to answer my questions or refer me to the appropriate resources. However, the researcher (Linda Scott) is not committed to pay for any referrals or services required. In the event of any injury resulting from this research, no reimbursement, compensation, or free medical care is offered by the researcher (Linda Scott), Bronson Methodist Hospital or Grand Valley State University".

"I further understand that all information is confidential and my identity will not be revealed. My participation is voluntary. I am free to withdraw my consent and to discontinue my participation in this study at any time, without explanation. My decision to participate will not interfere with the care or services my child will receive. I understand that I will receive no direct benefit as a result of participating in this study".

"I have discussed this study with Ms. Scott and my questions have been answered to my satisfaction. If I have any further questions or concerns, I may call her at (616) 383-8312".

"I acknowledge that I have read and understand the above information, and I hereby consent to participate in this study. I have received a copy of this signed consent form".

Date

Participant's Signature

Date

**Researcher's Signature** 

### APPENDIX E

Script for Approaching Family Participants

#### Appendix E

#### Script for Approaching Family Participants

Hello. My name is Linda Scott. I am a registered nurse and a graduate student at Grand Valley State University. I have practiced in pediatric critical care nursing for twelve years and I am interested in the perceived needs of parents or primary caretakers of hospitalized critically ill children.

I am hoping to find 30 parents or primary caretakers who would be willing to respond to a questionnaire about their needs while their child is in the pediatric intensive care unit. The questionnaire will take approximately 30 minutes to complete. The decision to participate is entirely up to you. All your responses to the questionnaire will remain confidential. Your decision to participate or not to participate, will in no way affect the care or services your child will receive.

Do you have any questions about this study? Would you be willing to participate in this study? Would you like some time to think about participating in this study? When might I speak to you again?

### APPENDIX F

Critical Care Nurse Consent Form

#### Appendix F

#### Critical Care Nurse Consent Form

Code #

"I have been asked to participate in a research study, investigating the needs of parents of critically ill children. The purpose of this study is to identify the needs of parents and the importance of the needs identified. This study will help to develop a better understanding of the needs of parents of critically ill children for health care practitioners and the services that could be most helpful to parents".

"I understand that if I agree to participate, I will be asked to complete a family needs questionnaire and to answer some general background information (such as age, education, employment). It will take approximately thirty minutes to complete the questionnaire".

"I have been given a description of discomforts and risks to me, which can be reasonably expected from participation in this study. I understand that participation in this study may reveal questions or concerns that are not a result of the research procedure. The researcher (Linda Scott) will attempt to answer my questions or refer me to the appropriate resource. However, the researcher (Linda Scott) is not committed to pay for any referrals or services required. In the event of any injury resulting from this research, no reimbursement, compensation, or free medical care is offered by the researcher (Linda Scott), Bronson Methodist Hospital or Grand Valley State University".

"I further understand that all information is confidential and my identity will not be revealed. My participation is voluntary. I am free to withdraw my consent and to discontinue my participation in this study at any time, without explanation. My decision to participation will not interfere with my employment. I understand that I will receive no direct benefit as a result of participating in this study".

"I have discussed this study with Ms. Scott and my questions have been answered to my satisfaction. If I have any further questions or concerns, I may call her at (616) 383-8312".

"I acknowledge that I have read and understand the above information, and I hereby consent to participate in this study. I have received a copy of this signed consent form".

Date

Participant's Signature

Date

**Researcher's Signature** 

# APPENDIX G

Script to Approach Nurse Particpants

#### Appendix G

#### Script to Approach Nurse Participants

Hello. My name is Linda Scott. I am a registered nurse and a graduate student at Grand Valley State University. I have practiced in pediatric critical care nursing for twelve years and I am interested in the perceived needs of parents or primary caretakers of hospitalized critically ill children.

As the parents or primary caretaker of a child in the pediatric intensive care unit agrees to participate in this study, I would like a nurse involved in the care of the child to complete a questionnaire about their (the nurse's) identification of perceived parental needs. The questionnaires will be completed for 30 parents or primary caretakers. If more than one parent of a critically ill child chooses to participate in the study, one questionnaire would be completed for each parent by different nurses involved in the care of the child.

The questionnaire will take approximately 30 minutes to complete. The decision to participate is entirely up to you. All your responses to the questionnaire will remain confidential. Your decision to participate or not to participate, will in no way affect your employment status.

Do you have any questions about this study?

Would you be willing to participate in this study? If, not who would know the needs of these parents?

Would you like some time to think about participating in this study?

# APPENDIX H

Table 14:

Rank Ordering of Needs

Identified by Parents

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# Appendix H

# Table 14

Iten	1	Not Imp (1)	SI. Imp (2)	Percent of Respondents Imp (3)	Very Imp (4)	Mean Rank
1.	To know the expected outcome.	0%	0%	0%	100%	4.000
2.	Have questions answered honestly.	0%	0%	0%	100%	4.000
3.	Know how their child is being treated medically.	0%	0%	0%	100%	4.000
4.	Assured that the best care is given.	0%	0%	0%	100%	4.000
5.	Called at home about changes in condition.	0%	0%	0%	100%	4.000
6.	Feel that hospital personnel care.	0%	0%	0%	100%	4.000
7.	To visit at any time.	0%	0%	3.3%	96.7%	3.967
8.	Receive information once a day.	0%	0%	3.3%	96.7%	3.967
9.	To see their child frequently.	0%	0%	3.3%	96.7%	3.967
10.	Recognized as important to their child's recovery.	0%	0%	3.3%	96.7%	3.967
11.	Knowing specific facts concerning their child's progress.	0%	0%	6.7%	93.3%	3.933
12.	To know why things were done for their child.	0%	0%	10.0%	90.0%	3.900
13.	Feel that there is hope.	0%	0%	10.0%	90.0%	3.900
14.	Knowing exactly what is being done for their child.	0%	0%	10.0%	90.0%	3.900
15.	Explanations given that are understandable.	0%	3.3%	6.7%	90.0%	3.867
16.	To talk to the doctor every day.	0%	6.7%	6.7%	86.7%	3.800

# Table 14 (continued)

ltem	Not Imp (1)	Sì. Imp (2)	Percent of Respondent Imp (3)	l <u>s</u> Very Imp (4)	Mean Rank
<ol> <li>To be told about transfer plans while they are being made.</li> </ol>	0%	0%	20.0%	80.0%	3.800
<ol> <li>A place to sleep near the PICU.</li> </ol>	0%	0%	26.7%	73.3%	3.733
<ol> <li>To assist with my child's care.</li> </ol>	0%	3.3%	26.7%	70.0%	3.667
20. A telephone near the waiting room.	0%	6.7%	23.3%	70.0%	3.633
21. Waiting room near my child.	0%	10.0%	20.0%	70.0%	3.600
22. Knowing about the types of staff members taking care of my child.	0%	0%	50.0%	50.0%	3.500
<ol> <li>A specific person to call when unable to visit.</li> </ol>	7.1%	0%	32.1%	60.7%	3.464
24. A bathroom near the waiting room.	3.3%	10.0%	26.7%	60.0%	3.433
25. Feel accepted by the hospital staff.	6.7%	6.7%	26.7%	60.0%	3.400
26. Assured that its alright to leave the hospital.	0%	13.3%	36.7%	50.0%	3.367
27. To have visiting hours start on time.	3.3%	16.7%	23.3%	56.7%	3.333
<ol> <li>Explanations of the environment before going into the PICU for the first time.</li> </ol>	3.3%	13.3%	33.3%	50.0%	3.300
29. Directions as to what to do at the bedside.	6.7%	6.7%	40.0%	46.7%	3.267
30. To know which staff members could give what type of information.	6.7%	3.3%	50.0%	40.0%	3.233
31. Visiting hours changed for special conditions.	10.3%	10.3%	27.6%	51.7%	3.207
32. Maintain a sense of family togetherness by sibling visitation.	3.7%	18.5%	33.3%	44.4%	3.185

### Table 14 (continued)

	Not Imp	SI. Imp	rcent of Respondents Imp	Very Imp	Mean
Item	(1)	(2)	(3)	(4)	Rank
33. To feel its alright to cry when I want to.	3.4%	20.7%	31.0%	44.8%	3.172
34. Talk about the possibility of my child's death.	13.3%	10.0%	30.0%	46.7%	3.100
35. Friends nearby for support.	3.3%	23.3%	36.7%	36.7%	3.067
36. To be told about other people that could help with problems.	0%	16.7%	60.0%	23.3%	3.067
37. To talk about my feelings.	3.3%	33.3%	20.0%	43.3%	3.033
<ol> <li>To be alone whenever I want.</li> </ol>	6.7%	23.3%	33.3%	36.7%	3.000
39. Help in supporting my ill child's reaction to the PICU.	10.0%	13.3%	43.3%	33.3%	3.000
40. To protect myself from sights or procedures that my child is experiencing.	16.7%	13.3%	26.7%	43.3%	2.967
41. Comfortable furniture in the waiting room.	6.7%	23.3%	36.7%	33.3%	2.967
42. Good food available in the hospital.	6.7%	30.0%	30.0%	33.3%	2.900
<ol> <li>Told about someone to help with family problems.</li> </ol>	13.3%	16.7%	43.3%	26.7%	2.833
44. Time to maintain the marital relationship.	15.4%	23.1%	34.6%	26.9%	2.731
45. A place to be alone while in the hospital.	13.3%	26.7%	40.0%	20.0%	2.667
46. To talk to other parents whose child is critically ill or survived a similar illness.	13.3 <i>%</i>	26.7%	40.0%	20.0%	2.667
47. To talk to the same nurse every day.	13.3%	26.7%	46.7%	13.3%	2.600
<ol> <li>Help in responding to the reactions of their ill child's siblings.</li> </ol>	14.3%	32.1%	35.7%	17.9%	2.571
49. Have someone help with financial problems.	17.2%	41.4%	17.2%	24.1%	2.483

#### Table 14 (continued)

		Per	Percent of Respondents Imp (3)		
Item	Not Imp (1)	Sl. Imp (2)		Very Imp (4)	Mean Rank
50. To be told about chaplain services.	20.0%	36.7%	30.0%	13.3%	2.367
51. To have a pastor visit.	36.7%	16.7%	26.7%	20.0%	2.300
52. Have someone concerned with their health.	36.7%	23.3%	26.7%	13.0%	2.167
53. Having someone with them when visiting the PICU.	40.0%	23.3%	23.3%	13.3%	2.100

# APPENDIX I

Table 15:

Rank Ordering of Needs

Identified by Critical Care Nurses

### Appendix I

### Table 15

Item	Not Imp (1)	S1. Imp (2)	Percent of Respondents Imp (3)	Very Imp (4)	Mean Rank
1. To know how their child is being treated medically.	0%	3.3%	0%	96.7%	3.933
2. Have questions answered honestly.	0%	0%	6.7%	93.3%	3.933
3. Assured that the best care is given.	0%	0%	6.7%	93.3%	3.933
4. Receive information once a day.	0%	0%	6.7%	93.3%	3.933
5. Feel that there is hope.	0%	0%	6.7%	93.3%	3.933
<ol> <li>To know the expected outcome.</li> </ol>	0%	0%	10.0%	90.0%	3.900
<ol> <li>Knowing exactly what is being done for their child.</li> </ol>	0%	3.3%	6.7%	90.0%	3.867
8. To visit at any time.	0%	0%	13.3%	86.7%	3.867
9. To see their child frequently.	0%	0%	13.3%	86.7%	3.867
10. To know why things were done for their child.	0%	0%	13.3%	86.7%	3.867
<ol> <li>Explanations given that are understandable.</li> </ol>	0%	0%	13.3%	86.7%	3.867
12. Called at home about changes in condition.	3.3%	0%	6.7%	90.0%	3.833
<ol> <li>Knowing specific facts concerning their child's progress.</li> </ol>	0%	3.3%	10.0%	86.7%	3.833
<ol> <li>To assist with my child's care.</li> </ol>	0%	0%	16.7%	83.3%	3.833
15. Feel that hospital personnel care.	0%	0%	20.0%	80.0%	3.800
16. To talk to the doctor every day.	0%	3.3%	16.7%	80.0%	3.767
17. Assured that its alright to leave the hospital.	0%	6.7%	13.3%	80.0%	3.733

### Table 15 (continued)

	Not Imp	Sl. Imp	rcent of Respondents Imp	Very Imp	Mean
tem	(1)	(2)	(3)	(4)	Rank
8. Explanations of the environment before going into the PICU for the first time.	0%	3.6%	21.4%	75.0%	3.714
<ol> <li>Recognized as important to their child's recovery.</li> </ol>	0%	0%	33.3%	66.7%	3.667
20. To be told about transfer plans while they are being made.	3.3%	0%	6.7%	90.0%	3.586
21. To talk about my feelings.	3.3%	3.3%	30.0%	63.3%	3.533
22. Talk about the possibility of my child's death.	3.3%	6.7%	26.7%	63.3%	3.500
23. Telephone near the waiting room.	3.3%	10.0%	23.3%	63.3%	3.467
24. To feel its alright to cry when I want to.	0%	6.7%	40.0%	53.3%	3.467
<ol> <li>Directions as to what to do at the bedside.</li> </ol>	3.3%	3.3%	43.3%	50.0%	3.400
26. Help in responding to the reactions of their ill child's siblings.	0%	3.3%	53.3%	43.3%	3.400
27. A specific person to call when unable to visit.	0%	0%	10.0%	43.3%	3.367
<ol> <li>Comfortable furniture in the waiting room.</li> </ol>	3.3%	10.0%	36.7%	50.0%	3.333
29. A bathroom near the waiting room.	3.3%	10.0%	36.7%	50.0%	3.333
30. A place to sleep near the PICU.	0%	20.0%	30.0%	50.0%	3.300
<ol> <li>To be told about other people that could help with problems.</li> </ol>	0%	13.3%	43.3%	43.3%	3.300
<ol> <li>Knowing about the types of staff members taking care of my child.</li> </ol>	3.3%	0%	60.0%	36.7%	3.30
33. Have someone concerned with their health.	0%	10.0%	56.7%	33.3%	3.23

### Table 15 (continued)

Item	Not Imp (1)		ercent of Respondents Imp (3)	Very Imp (4)	Mean Rank
34. To know which staff members could give what type of information.	0%	6.7%	63.3%	30.0%	3.233
35. Feel accepted by the hospital staff.	3.3%	13.3%	43.3%	40.0%	3.200
36. Told about someone to help with family problems.	3.3%	10.0%	50.0%	36.7%	3.200
37. To have visiting hours start on time.	22.2%	7.4%	0%	70.4%	3.185
38. Friends nearby for support.	0%	26.7%	30.0%	43.3%	3.167
39. Have someone help with financial problems.	3.3%	10.0%	53.3%	33.3%	3.167
40. Maintain a sense of family togetherness by sibling visitation.	3.4%	10.3%	55.2%	31.0%	3.138
41. Waiting room near my child.	0%	26.7%	33.3%	40.0%	3.133
42. To protect myself from sights or procedures that my child is experiencing.	13.3%	3.3%	46.7%	36.7%	3.067
<ol> <li>Good food available in the hospital.</li> </ol>	0%	16.7%	60.0%	23.3%	3.067
44. To be alone whenever they want.	3.3%	13.3%	60.0%	23.3%	3.033
45. Time to maintain the marital relationship.	4.0%	24.0%	40.0%	32.0%	3.000
46. A place to be alone while in the hospital.	6.7%	13.3%	53.3%	26.7%	3.000
47. To talk to the same nurse every day.	0%	26.7%	46.7%	26.7%	3.000
48. Help in responding to the reactions of their ill child's siblings.	6.7%	10.0%	63.3%	20.0%	2.967
49. To talk to other parents whose child is critically ill or survived a similar illness.	3.4%	24.1%	48.3%	24.1%	2.931

### Table 15 (continued)

Item	Percent of RespondentsNot ImpSl. ImpImpVery Imp(1)(2)(3)(4)		Mcan Rank		
50. Having visiting hours changed for special conditions.	28.6%	0%	21.4%	50.0%	2.929
51. To have a pastor visit.	13.3%	13.3%	50.0%	23.3%	2.833
52. Having someone with them when visiting the PICU.	20.0%	16.7%	26.7%	36.7%	2.800
53. To be told about chaplain services.	10.0%	16.7%	63.3%	10.0%	2.733

List Of References

#### List of References

- Aguilera, D. C., & Messick, J. M. (1986). <u>Crisis intervention: Theory and</u> <u>methodology</u>. (4th ed.). Mosby: St. Louis.
- Caplan, G. (1971). <u>An approach to community mental health</u>. Grune & Stratton: New York.
- Dockter, B., Black, D. R., Hovell, M. F., Engleberg, D., Amick, T., Neimier, D., & Sheets, N. (1988). Families and intensive care nurses: Comparisons of perceptions. <u>Patient Education & Counseling</u>. 12, 29-36.
- Freichels, T. A. (1991). Needs of family members of patients in the intensive care unit over time. <u>Critical Care Quarterly</u>, <u>14</u>, 16-29.
- Jay, S. S., & Youngblut, J. M. (1991). Parent stress associated with pediatric critical care nursing: Linking research and practice. <u>American Association of Clinical</u> <u>Nurses Clinical Issues in Critical Care Nursing</u>, 2, 276-284.
- King, I. M. (1981). <u>A theory for nursing: System, concepts, process</u>. New York: Delmar.
- Kirschbaum, M. S. (1990). Needs of parents of critically ill children. <u>Dimensions of</u> <u>Critical Care Nursing</u>, 9, 344-352.
- Kleinpell, R. M., & Powers, M. J. (1992). Needs of family members of intensive care unit patients. <u>Applied Nursing Research</u>, 5, 2-8.
- Kruger, S. (1992). Parents in crisis: Helping them cope with a seriously ill child. Journal of Pediatric Nursing, 7, 133-139.

- Leske, J. S. (1991). Internal psychometric properties of the Critical Care Family Needs Inventory. <u>Heart and Lung</u>, 20, 236-244.
- Mathis, M. (1984). Personal needs of family members of critically ill patients with or without acute brain injury. Journal of Neurological Nursing, 16, 36-44.
- McClowery, S. G. (1992). Family functioning during a critical illness: A systems theory perspective. <u>Critical Care Nursing Clinics of North America</u>, <u>4</u>, 559-564.
- Miles, M. S., Carter, M. C., Spicher, C., & Hassanein, R. S. (1984). Maternal and paternal stress reactions when a child is hospitalized in a pediatric intensive care unit. <u>Issues in Comprehensive Pediatric Nursing</u>, 7, 333-342.
- Molter, N. C. (1979). Needs of relatives of critically ill patients: A descriptive study. <u>Heart and Lung</u>, 8, 332-339.
- Polit D. F., & Hungler, B. P. (1991). <u>Nursing research</u> (4th ed.). Philadelphia: Lippincott.
- Rogers, M. (1983). Needs of relatives of cardiac surgery patients during the critical care phase. Focus, 10, 50-55.
- Thomas, R. B., Barnard, K. E., & Sumner, G. A. (1993). In S. Feetham,
  S. Meister, J. Bell, & P. Gillis (Eds.), <u>The nursing of families</u>. (pp.127-136).
  Newbury Park, Ca: Sage.
- Turner, M. A., Tomilson, P. S., & Harbaugh, B. L. (1990). Parental uncertainty in critical care hospitalization of children. <u>Maternal-Child Nursing Journal</u>, <u>19</u>, 45-62.
- Woolley, N. (1990). Crisis theory: A paradigm of effective intervention with families of critically ill people. Journal of Advanced Nursing, 15, 1402-1406.