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The Needs of Family Members in Crisis

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THE NEEDS OF FAMILY MEMBERS IN CRISIS

By

Melanie A. Burghgraef

A THESIS

**Submitted to
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in partial fulfillment of the requirements for the
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ABSTRACT

THE NEEDS OF FAMILY MEMBERS IN CRISIS

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The needs of family members of patients with severe brain injury were investigated using a descriptive-correlational design. A convenience sample of family members ($N = 23$) were surveyed with the Critical Care Family Needs Inventory (CCFNI). Need statements from the CCFNI were rank ordered, and a total score for the CCFNI was calculated. The majority of the top ranked needs consisted of assurance and information needs, which is consistent with other research using the CCFNI. Descriptive statistics were used to compare the results from this study with Lorenz's study (1995).

Furthermore, this investigation attempted to reveal a relationship between family needs and the patient Glasgow Coma Scale level (GCS). A weak inverse relationship was shown between the patient's GCS and family needs, however this relationship was not statistically significant ($p > .05$).

Dedication

This thesis is dedicated first and foremost to my husband, Gary. You have been witness to the stress often associated with this project. Thank you for being supportive, patient, and understanding.

Secondly, I would like to dedicate this study, as well as my career as a nurse, in loving memory of Judith Hainen: my grandmother, who was a nurse to the very end.

Acknowledgements

I would like to offer a special thanks to the following individuals. First, to my mother and father, who encouraged me to pursue a masters degree. Second, to Dr. Linda Scott and Dr. Kay Kline, who offered advise and guidance for this project.

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CHAPTER 1

INTRODUCTION

Study Focus

The needs of family members of critically ill patients have been a topic for study throughout the last 20 years. Lorenz (1995) studied the needs of 60 family members of 35 critically ill patients. Through replication of Lorenz's study, the needs of family members of critically ill patients have again been investigated. However, while Lorenz's study included family members of critically ill patients with varying diagnoses, this study has addressed a specific population comprised of family members of patients with severe brain injury. The many reasons why this topic continues to merit investigation will be identified.

Critical Event

Family members of critically ill patients experience high levels of stress, anxiety, and uncertainty (Halm, 1992). This emotional distress results when individuals are faced with the potential for loss of life, as well as other stressors associated with critical care hospitalization. Furthermore, when the precipitating event is sudden, which may occur with severe brain injury, even the most stable of families can collapse under the anxiety which results from the crisis (Bouley, von Hofe, & Blatt, 1994; Hickey & Leske, 1992; Johnson & Roberts, 1996). If family members cannot overcome this anxiety, then they may be unable to adapt to the situation; response to the crisis will be ineffective (Hickey

& Leske, 1992; Johnson & Roberts, 1996).

Stressors Encountered

The possibility of losing a loved one is enough to produce emotional distress. However, these families are faced with many other stressors that contribute to anxiety. Financial needs, whether related to loss of income, lack of insurance, or the expenses of critical care hospitalization, add to this anxiety. An individual with a severe brain injury usually requires a lengthy hospitalization, and will likely need extensive rehabilitation or life-long convalescence.

Likewise, the intensive care unit (ICU) environment may cause undue stress (Halm, 1992; Kleiber et al., 1994). Strange equipment and tubes, visitation restrictions, and other critically ill patients with grieving families can contribute to family anxiety (Leske, 1986, 1992; McClowry, 1992). This is especially true with the population of clients with severe brain injury. Medical treatment of those with severe brain injury requires the utilization of high-tech equipment, as well as strict limitations on visitation to avoid over-stimulating the patient.

Furthermore, changes in family roles and geographic distance from home contribute to family stress. All of these stressors individually and as a whole, along with inadequate family support and ineffective coping mechanisms may interfere with adaptation to the crisis (Halm, 1992).

Research Findings

Many researchers have explored the needs of families of critically ill patients (Engli & Farmer, 1993; Farukawa, 1996; Henneman & Cardin, 1992; Hickey & Leske, 1992; Jamerson et al., 1996; Koller, 1991; Leske, 1986, 1992; Lorenz, 1995; Mendonca &

Warren, 1998; Norheim, 1989; Price, Forrester, Murphy, & Monaghan, 1991). The majority of these researchers used the Critical Care Family Needs Inventory (CCFNI) for the research tool. Five need categories have been identified with the Critical Care Family Needs Inventory (CCFNI): (a) information, (b) assurance, (c) support, (d) proximity, and (e) comfort (Leske, 1986). Information and assurance needs have consistently been ranked high in previous studies (Henneman & Cardin, 1992; Hickey & Leske, 1992; Koller, 1991; Leske, 1992; Lorenz, 1995). While other studies have shown that the need to feel there was hope was ranked highly important, two studies (Lorenz, 1995; Price et al., 1991) found a decrease in the importance of this need. Otherwise, a meta-analysis by Leske (1992) did not reveal any substantive differences in findings: when ranking the importance of family needs, the major themes remain the same.

Justification for Replication of Research

While there are many research studies that address family needs in general, there have only been two studies which look specifically at the needs of family members of patients with acute brain injury (Engli & Farmer, 1993; Mathis, 1984). These two studies found significant differences in the importance of needs for this population. Since these findings contradict what other studies have found (that there are not any significant differences in family needs in relation to the patient diagnosis), then this study is needed to support or refute these findings.

Other studies looking at brain injury have found that hope plays an important role in regards to family coping, adaptation to the injury, recovery, rehabilitation potential, and even withdrawal of life support (Bouley et al., 1994; Johnson & Roberts, 1996). However, as previously mentioned, the studies by Price et al. (1991) and Lorenz (1995)

found the need to hope was not ranked as highly important as it had been in previous studies. Due to this discrepancy, it is beneficial to study the population of family members of patients with brain injury and examine if they rank the need to hope as highly important.

Other researchers have recommended continued research of family needs due to the ever-changing structure of the family unit within our society (Hickey & Leske, 1992). Untraditional families in today's society may be comprised of single parents or members not legally or biologically related; there are also many elderly living alone without support of children (Hickey & Leske, 1992). Therefore, this study has attempted to examine a variety of family members, and look for any positive or negative correlation between the relationship of the family member and the ranking or importance of needs.

Furthermore, other variables should be considered with the severe brain injury population, such as the patient's Glasgow Coma Scale (GCS) level and code status (Bouley et al., 1994; Lorenz, 1995). The GCS rates an individual's level or severity of coma, with a score of 3 meaning the deepest level of coma to a score of 12 meaning fully awake or non-comatose. Families may have different needs based on the severity of the brain injury. The GCS is one method to assess this severity.

The code status of a patient may have an impact on the needs of families as well. If a patient is complete Do Not Resuscitate (DNR), their family members may have accepted the possibility of the patient dying. Therefore, they may rank needs differently from others. For example, comfort needs may be more important than information needs.

Purpose of This Study

The purpose of this study has been to examine the needs of family members of

patients with severe brain injury by replicating the study of Lorenz (1995). This study will benefit nursing practice by increasing the awareness of the needs of families, thereby incorporating these needs into an individualized care plan of the patient with severe brain injury and their families. It will benefit nursing research through replication, thereby strengthening or refuting previous findings.

CHAPTER 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

The Roy Adaptation Model

The Roy adaptation model (RAM) was used as the conceptual framework for this study. According to Roy (1980), there are eight scientific assumptions or “givens” in the RAM, which provide a basis for theorizing and research:

1. The person is a bio-psycho-social being.
2. The person is in constant interaction with a changing environment.
3. To cope with a changing world, the person uses both innate and acquired mechanisms, which are biologic, psychologic, and social in origin.
4. Health and illness are one inevitable dimension of life.
5. To respond positively to environmental changes, the person must adapt.
6. The person’s adaptation is a function of the stimulus exposed to and one’s adaptation level.
7. The person’s adaptation level is such that it comprises a zone that indicates the range of stimulation that will lead to a positive response.
8. The person is conceptualized as having four modes of adaptation: physiologic, self-concept, role function, and interdependence. (p. 180-182).

According to Lutjens (1991), “Roy’s model is a systems model that focuses on

outcomes...[and] adaptation is viewed as both a process and a product or end-state” (p. 8). The process of adaptation can be described in the following way: stressors (crises) produce stress, which trigger the use of coping behaviors to assist with alleviating the stress. The coping behaviors produce either adaptive or ineffective responses to the stress or crisis, which will lead to an end-state of adaptation or mal-adaptation.

Lutjens (1991, p. 9-10) explains the five key concepts in the RAM: person, goal, health, environment, and nursing activities (or the nursing process), as shown in Figure 1. The RAM conceptualizes the person as having the ability to respond to changes in their environment through use of coping mechanisms, which will assist them in adapting to their environment or to change. The goal of nursing is to promote adaptation. This is accomplished by using the nursing process to identify ineffective or effective coping responses, and by assisting individuals with the adaptation process. Attainment of this goal will contribute to the overall health of the individual. Health is a state or process in which an individual is trying to achieve their maximum potential.

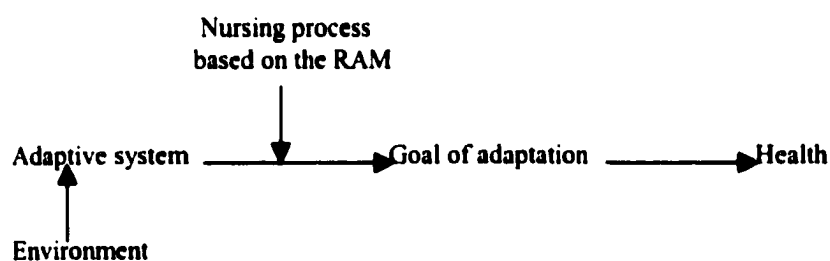


Figure 1. Relationships between the key concepts of the RAM. From Introduction to Nursing: An Adaptation Model (p. 40), by Sr. C. Roy, 1984, Englewood Cliffs, NJ: Prentice Hall. Copyright 1984 by Prentice Hall. Reprinted with permission of Prentice Hall.

In addition to the five concepts above, the theory of person as an adaptive system (which was developed from the RAM), further describes the environment and person (see

Figure 2). As previously stated, changes in an individual's environment will cause that individual to respond to the changes. The environment consists of "external and internal stimuli that act as stressors.... [the stimuli are] categorized as focal, contextual, and residual" (Lutjens, 1991, p. 13). The focal stimulus is the provoking situation or catastrophic event that prompts an individual to seek relief. Lutjens describes the contextual stimuli as "all other stimuli present in the situation ... that contribute to the effect of the focal stimulus" (p. 13). Residual stimuli are the general, unknown factors that may be affecting an individual, but may not have a direct effect on the focal stimulus (Frederickson, 1993, p. 39; Lutjens, 1991, p. 14).

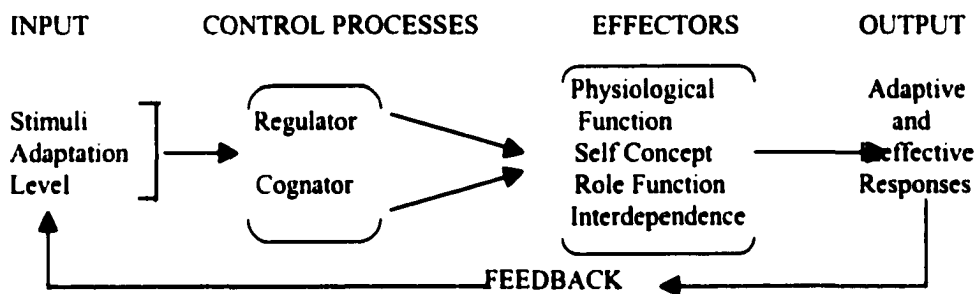


Figure 2. The person as an adaptive system. From Introduction to Nursing: An Adaptation Model (p. 30), by Sr. C. Roy, 1984, Englewood Cliffs, NJ: Prentice Hall. Copyright 1984 by Prentice Hall. Reprinted with permission of Prentice Hall.

The combined effect of the focal, contextual, and residual stimulus is called the adaptation level (Lutjens, 1991, p. 14). This adaptation level is constantly changing, which represents how individuals have the ability to cope with a changing environment in a positive manner. Stimuli falling outside of the range of the level of adaptation will invoke an ineffective response. However, this level of adaptation can be changed by using coping mechanisms, thereby allowing an individual to respond to stimuli more effectively.

“Coping refers to the use of behavior in response to stimuli” (Lutjens, 1991, p. 15). Each individual employs a set of coping mechanisms that were either inherited or acquired ways of responding to a changing environment. According to Roy (1984), there are two types of coping mechanisms: regulator and cognator. Regulator coping mechanisms deal with physiological stimuli, whereas cognator coping mechanisms deal with psychosocial stimuli, such as cognition, judgement, and emotion (Lutjens, 1991, p. 15). Perception allows us to define and give meaning to these stimuli (Frederickson, 1993, p. 40). Furthermore, the perceptions of the stimuli will fall into four categories (four adaptive modes): physiological, self-concept, role function, and interdependence (Lutjens, 1991, p. 15-16). These modes, which are referred to as “effectors”, are a “manifestation(s) of coping mechanisms that can be observed and measured” (Lutjens, 1991, p. 16).

The general goals of the person are survival, growth, reproduction, and mastery (Frederickson, 1993, p. 39). Behaviors that contribute to these goals are considered adaptive responses, those not contributing are considered ineffective responses (Lutjens, 1991, p. 16).

Model Concepts in Relation to This Study

Individuals with severe brain injury and their families have been assessed using the RAM. The five key concepts of the RAM (person, goal, health, environment, and nursing activities) can be explained in the following way (see Figure 3). The family (as a whole and as individuals) is the person. The family has the ability to respond to changes in their environment. Environment not only consists of the physical environment (hospital and ICU unit), but also their personal or cognitive environment (family structure). They can

utilize coping mechanisms to respond to this change; either with coping mechanisms that they already possess (past hospital experiences, or inherited responses), or new coping mechanisms which they have learned. Nurses utilize the nursing process to assess whether the family coping mechanisms are falling within their adaptation level (within the range of effective responses that lead to adaptation). It is with the nursing process that the Critical Care Family Needs Inventory (CCFNI) has been used to explore what needs are most important to family members so that specific interventions can be provided which target these needs. The ultimate goal is adaptation to the brain injury. Attaining this goal contributes to the “health” of the family.

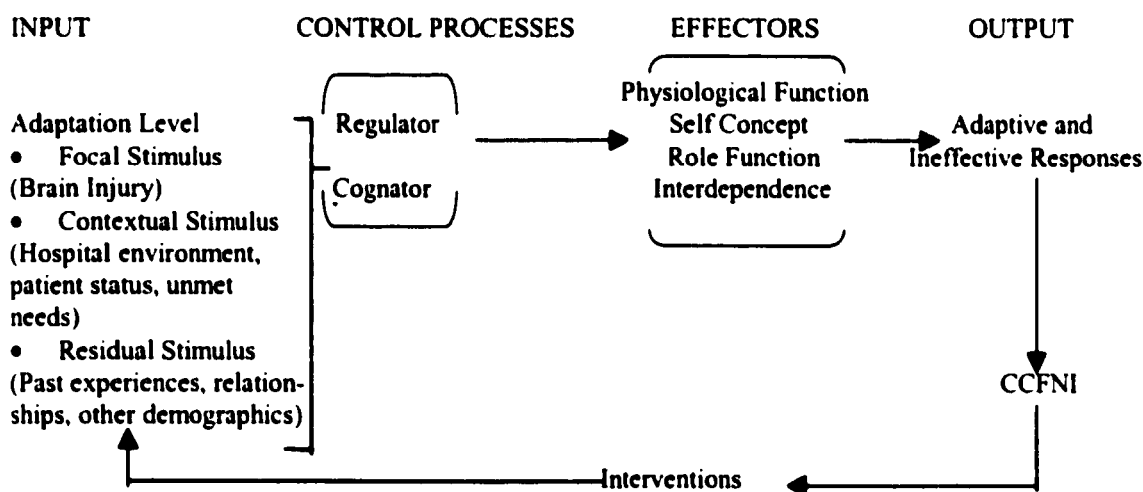


Figure 3. Concepts in relation to the study variables. From Introduction to Nursing: An Adaptation Model (p. 30), by Sr. C. Roy, 1984, Englewood Cliffs, NJ: Prentice Hall. Copyright 1984 by Prentice Hall. Adapted with the permission of Sr. C. Roy.

The focal stimulus is the critical event: severe brain injury. The contextual stimuli include the hospital environment (i.e., equipment, waiting rooms, staff), and the patient’s status (i.e., level of coma, other injuries). Residual stimuli may include past experience with a hospitalization, relationship with the injured patient, financial status etc., and all other demographics which in time may have a direct effect on the needs of family

members (some may become contextual or focal). While there is much agreement in the literature that many of these residual stimuli have a direct impact on coping and adaptation (and should then be labeled as contextual), many studies that have examined family needs with the CCFNI have not found any significant correlation with these demographics and how the needs on the CCFNI are ranked (Engli & Farmer, 1993; Farukawa, 1996; Hickey & Leske, 1992; Koller, 1991; Leske, 1986, 1992; Norheim, 1989). This study has examined if there is any correlation between demographic variables and the needs of the subjects, thus clarifying which of these stimuli are in fact contextual.

Whether or not these stimuli are classified as focal, contextual or residual, they cause an individual to respond. As a result, many needs arise when family members respond to the crisis that occurs when their relative develops a severe brain injury.

In summary, family members utilize coping mechanisms to respond to the crisis of brain injury. Depending upon their level of adaptation, these responses will be effective or ineffective. Nurses have the unique ability to assist families to learn coping skills that will promote adaptation to the crisis. This study has surveyed families regarding what their most important needs are at the time of crisis, if these needs are being met, and who is responsible for meeting their needs. If family needs go unmet, it may interfere with their ability to deal with their situation. By meeting family needs, nurses are assisting them with the adaptation process.

Literature Review

The Crisis

When a patient is admitted to the intensive care unit (ICU), the effects of this event are not only overwhelming for the patient, but also for the family. It has been well

documented that an ICU hospitalization causes anxiety and stress (Halm, 1992; Jamerson et al., 1996; Kleiber et al., 1994; McClowry, 1992). Even a planned admission to the ICU, such as elective coronary bypass surgery, can be stressful for family members (Norheim, 1989). The stress and anxiety is even more severe when an admission to the ICU is unexpected or sudden, such as what may occur with a severe brain injury (Johnson & Roberts, 1996). This stress develops from a variety of sources: fear of death or the unknown, the ICU environment, financial difficulties, lack of support, and role changes within the family.

Foremost, the family must deal with the possibility that the patient may not survive. Kleiber et al. (1994) conducted a study of 52 family members who kept a daily log of emotions and responses to the ICU hospitalization of a relative. The dominant theme or emotion within the first day of admission to the ICU was fear of the unknown or unexpected. Furthermore, the family must make difficult decisions when a family member is admitted to the ICU. Mirr (1991) studied the decisions made by 19 family members of patients admitted to the ICU with brain injury. Within the first 24 to 48 hours of admission to the ICU, families were making treatment decisions on behalf of the injured relative. By the end of a week, some families were faced with the decision to discontinue life support or consider organ donation. Bouley et al. (1994) described the anxiety and stress of family members who have decided to withdraw life support and stop medical treatment. Several needs that develop in response to this decision include the need for families to be reassured that their relative will continue to receive emotional and physical care.

Second, the ICU environment is a source of anxiety in family members (Halm, 1992;

McClowry, 1992; Jamerson et al., 1996). The appearance of the patient connected to various tubes and monitors, along with the noise of high-tech equipment can be very disturbing to families. Visitation is often restricted, and when it is allowed, families are forced to communicate with the patient while other health providers are present or while being observed through the glass doors of the room. Likewise, privacy cannot be found in the crowded waiting rooms, which are filled with other visitors and strangers. Health care providers, as well as their routines, are foreign to family members and add to their stress.

Third, the family of the ill patient may be dealing with financial difficulties. Covinsky et al. (1994) interviewed 2,129 patients and their families in regard to the impact of the patient's illness at 2 and 6 months after hospital discharge. Thirty-one percent of families reported that the patient's illness had caused them to lose most of their life savings; in 20% of the cases at least one family member had to make a major life change; and 29% of families indicated that they had lost their main income source. Mirr's study (1991), which explored the decisions made by family members of patients with brain injury, revealed that family members were making a large number of financial decisions within the first few days of the admission to the hospital. Financial needs may include any of the following: hospital bills (especially when there is lack of health insurance), child-care, lodging and travel (while the patient is hospitalized), rehabilitation costs, and loss of primary or secondary income.

Fourth, there is a shifting of roles and responsibilities the moment a family member becomes hospitalized. The impact of this varies depending on how primary a role the patient had in the family unit. For example, there will be more of an adjustment for the rest of the family if the hospitalized patient was the wife and mother of four dependent

children, rather than if the patient is a child. The family must assume the patient's responsibilities along with their own, which further contributes to the level of stress.

Finally, how the family functions as a support system for the patient and each other can have a negative or positive impact on the crisis. Studies have shown that an ineffective support system can negatively impact the rehabilitation potential of a critically ill individual (Bouley, von Hofe, & Blatt, 1994; Halm, 1992; Johnson & Roberts, 1996). It is not always the case that a family has lack of support because they are dysfunctional; it may be due to distance of the hospital from other family members or friends in their support system. Furthermore, it is reasonable to deduce that if the family does not have adequate support during the crisis of an ICU hospitalization, then the patient will not have adequate support. A good support system allows individuals to deal with crisis more effectively (Halm, 1992).

In summary, the many stressors associated with hospitalization in the ICU are not always a result of the crisis. Some, if not many, of these stressors may be present prior to the crisis. The individuals who are experiencing stress prior to the hospitalization will face overwhelming difficulty in dealing with this situation.

Adaptation

The accumulation of the stress associated with this crisis can interfere with a family's ability to cope with the situation. Ultimately, it can have a negative impact on the patient's recovery. Many family needs arise in the face of such stress. If these needs go unmet, then the family will be unable to adapt to the crisis (Johnson & Roberts, 1996).

Often, patients are too ill to be conscious of their surroundings or the current events; they may not experience emotional distress the same as their families. Hence, family

members are likely to need more emotional or psychological care than the patient (Hickey & Leske, 1992). The anxiety experienced by the family will be manifested in their emotions as they respond to this crisis. These responses will be either effective or ineffective. The nurse is in a primary role to assess family needs and coping mechanisms.

Research on Family Needs

There have been many studies on the needs of family members of critically ill patients over the last 20 years. These descriptive-exploratory studies have used convenience sampling methods with the Critical Care Family Needs Inventory (CCFNI), or a modified version of it, as the main research tool to quantify families' needs (Engli & Farmer, 1993; Furukawa, 1996; Koller, 1991; Leske, 1986, 1992; Lorenz, 1995; Mendonca & Warren, 1998; Molter, 1979; Norheim, 1989; Price et al., 1991).

Molter (1979) developed a tool to assess the needs of family members of critically ill patients. This 4-point Likert-type scale consisted of 45 need statements, which were to be ranked from "not important" to "very important". During structured interviews, Molter read the tool to 40 relatives of critically ill patients and recorded their individual responses. She also obtained demographic data to describe the subjects (age, sex, education, and occupation). Interviews were conducted on a general care unit after the patient had transferred from the ICU. Besides the 45 item tool and demographics questionnaire, Molter also asked which of the needs were met and by whom. The need "to feel there is hope" was ranked highest. Needs pertaining to information, assurance, and proximity comprised the ten most important needs. Subjects did not identify any needs that were not already included on Molter's list. There were some indications that the variables of age and socioeconomic status correlated with how needs were ranked.

However, due to the small sample size, Molter was unable to determine any statistical significance.

In cooperation with Molter, Leske (1986) modified Molter's tool by randomly arranging the 45 need statements and adding an open-ended question which asked subjects to identify any needs not included on the tool. This modified version was called the Critical Care Family Needs Inventory (CCFNI). Leske used the CCFNI to survey the needs of 55 family members of 20 critically ill patients. Like Molter's study (1979), the tool was read to subjects in an interview. However, the interviews were conducted within 72 hours of admission to the ICU, and a consensus of family member responses was recorded. A demographic questionnaire asked information concerning subject and patient age, gender, and race, as well as patient diagnosis, family member relationship to the patient, and previous ICU experience. Most of the patients in this study were admitted secondary to a traumatic event. However, there were no significant relationships between demographic variables and the ranking of needs. Unlike Molter, Leske did not study if needs were met and by whom; and again, no new needs were identified with this study. This study substantiated Molter's findings that "the need to feel there is hope" was ranked highly important. Although the order of needs ranked was different from Molter's study, the top ten needs were almost identical. Leske placed the 45 need statements into the following 5 categories: (a) information, (b) assurance, (c) support, (d) proximity, and (e) comfort. Many researchers have sought to replicate these original studies by Molter and Leske, or have conducted similar research with modified procedures.

Norheim (1989) studied the responses of 68 family members of 30 patients who underwent coronary artery bypass graft surgery for the first time. That study was

conducted over a 40-day period at a 434-bed Midwest hospital. Besides completing the CCFNI, family members were also asked to indicate which needs had been met and by whom. The tool was administered in the waiting room while the patient was in surgery. Information and assurance needs were ranked the highest, as well as the need to feel there is hope. The majority of the family members were spouses (30%), female (68%), and had a mean age of 48 years. There were no significant correlations between demographic variables and the ranking of needs.

Koller (1991) studied the needs of 30 family members of 22 critically ill patients. The CCFNI was used as the research tool, along with a 7-item semi-structured questionnaire and the Jalowiec Coping Scale (to assess coping behaviors used by family members). The top-ten needs centered around assurance, information, and proximity needs; the highest ranked need was "the need to know the patient's prognosis". The only significant relationship found between coping methods and needs was the use of optimistic coping style and the need for support. Previous studies have shown that the need to feel there is hope is often ranked highly important (Leske, 1986; Molter, 1979; Norheim, 1989). It is interesting that hope was the most frequently used coping method in Koller's study. Koller felt that the nature of the critical illness may effect the way in which needs are ranked and recommended that future research look at the needs of family members of patients who are acutely ill versus chronic or terminally ill. Some of the limitations with Koller's study were that it was conducted in one ICU, that coping behaviors change over time and may depend on perception, and that the variable of denial may exist when completing the tools. Furthermore, the sample was 80% female and not a good representation of the entire population.

Price et al. (1991) investigated the needs of 213 family members of 114 hospitalized patients in several ICU's at a large teaching hospital. Similar to other results, information and assurance needs were ranked the highest; all of the top 6 needs identified in previous studies were ranked within the top 12 needs of the study by Price et al. (Leske, 1986; Molter, 1979). However, the need "to feel there is hope" was ranked significantly less important than it had been in other studies, though still within the top 12 needs.

Leske (1992) conducted a latitudinal analysis of family need studies in which all investigators had used the CCFNI within 72 hours of hospitalization to the ICU. Demographic data included family member age, gender, education level, occupation, race, prior ICU experience, and the family member's relationship to the patient. Information regarding patient age, gender, race, and diagnosis was also obtained. Leske concluded that although the needs of family members have been classified and clustered slightly different from study to study, the major themes remain the same. The needs from the categories of assurance and information are always ranked the highest, while comfort needs are consistently ranked the lowest.

Lorenz (1995) studied the needs of 60 family members of 35 critically ill patients with varying diagnoses. The top three need categories were assurance, information and proximity. Similar to Price's et al. findings (1991), Lorenz's study also found hope to be less important of a need, but still ranked within the top ten needs.

Medonca and Warren (1998) reported the needs of 52 family members of critically ill adults. The CCFNI was used as the research tool, along with a demographic questionnaire and a new tool adapted from the CCFNI: the Needs Met Inventory (NMI). The NMI asked if the 45 needs were met, which was similar to the variables studied by Molter

(1979) and Norheim (1991). The CCFNI was administered to the families 18 to 24 hours after admission, and the NMI was administered to the families on the following day (36 to 48 hours after admission). There was a significant positive relationship between support on the CCFNI and comfort on the NMI. A negative correlation was found between the education level of the family member and support: as the level of education decreased, the family member's perceptions of how well support needs were met increased. The top nine needs identified in Mendonca and Warren's study were likewise perceived as most important in previous studies. Of the top three need categories, assurance needs were not perceived as met, while the other two categories, information and proximity needs, were perceived as being met. In contrast to other research on family needs, there was one new need identified by Mendonca and Warren that wasn't included on the CCFNI: to be treated with dignity.

With the exception of Koller (1991), all of these studies concluded that there were no significant relationships between the ranking or importance of needs and patient diagnoses (Leske, 1986, 1992; Lorenz, 1995; Mendonca & Warren, 1998; Molter, 1979; Norheim, 1989; Price et al., 1991). However, some of these studies that have included patient diagnosis as a demographic variable do not clearly indicate the ratio of patients with brain injury to those without brain injury (Leske, 1986; Lorenz, 1995; Mendonca & Warren, 1998). Without knowing there is a fair representation of all patient diagnoses, one cannot generalize findings to all populations.

In contrast, two studies, which specifically looked at the population of brain injury, did find significant differences (Engli & Farmer, 1993; Mathis, 1984). Using the CCFNI, Mathis (1984) compared the needs of 26 family members with and without severe brain

injury. Although the two groups agreed on what needs were important or not important, there was a statistical significant difference on the degree of importance placed on each of the needs by the two groups (there was variability in whether a need was slightly important, important, or very important). The need "to feel there is hope" was ranked number one in Mathis's study.

Due to a lack of research which identified needs for specific patient populations, Engli and Farmer (1993) replicated the study by Mathis (1984). Like other studies on family needs, they also had family members identify if needs were being met and by whom. One family member per patient was asked to participate in the study. The investigator approached 23 family members of patients without brain injury, of which 6 subjects completed the tool; and 22 family members of patients with brain injury, of which 8 subjects completed the tool. Engli and Farmer found that the top three needs were different between the two groups. Despite these differences, the remaining 7 needs out of the top 10 need statements were similar. The high similarity in the rank ordering of the need statements between the two groups is consistent with Mathis's findings. Like other studies, information needs were ranked the highest for both groups. Engli and Farmer's study further supported the results from Mathis's study by revealing that there was a significant difference in the perceived importance of needs between the two groups. Although the rank order of needs was similar between the two groups, family members of patients with brain injury place a higher degree of importance of needs when compared with family members of patients without brain injury (significant at the 0.001 level). For example, while the top 10 needs were similar between the two groups, the group consisting of family members of patients with brain injury rated needs as very important

more frequently than the other group, who rated needs as just important. In contrast to Mathis's findings, the need "to feel there is hope," while still very important of a need to the families, was not ranked within the top 10 needs of family members of patients with brain injury.

Another study of family needs targeting a specific population is the research conducted by Furukawa (1996). Furukawa adapted the CCFNI to include needs referring to terminal illness and death. The adapted CCFNI was comprised of need statements that subjects agreed or disagreed were fulfilled. Several months after the death of a relative, family members were asked to complete the adapted CCFNI and to identify who met their needs. Of these 80 subjects, 36 completed questionnaires were returned to the investigator. Furukawa did not discuss any demographics (whether or not they were even obtained) with her final report. The majority of subjects felt their needs were met 80 to 97% of the time. However, only 66% felt that there was hope (the lowest rating). This finding does not come as a surprise, given the population Furukawa was investigating.

Of the studies which also investigated the concept of who was meeting family needs, most identified nurses as the most likely to meet needs (Furukawa, 1996; Molter, 1979; Norheim, 1989). However, Mendonca and Warren (1998) reported that doctors met the needs of the family members the majority of the time. More investigation into this area is beneficial due to this discrepancy.

In addition to the quantitative research on family needs, qualitative research has likewise contributed to the study of family needs. Kleiber et al. (1994) enlisted 52 adult family members of critically ill patients to complete daily logs, which consisted of probing questions regarding feelings, support and changes within the previous 24 hours.

These journals were completed daily until the patient transferred from the ICU. Eight of the 52 subjects had family members in the ICU longer than 3 days. Fearfulness was the predominant theme, and second, the provision of information was frequently addressed in the daily logs. Kleiber et al. discovered that there were differences in the responses of family members based on the type of ICU. This finding may support the concept that needs of family members differ depending on the type of diagnosis.

Another qualitative study was conducted by Jamerson et al. (1996), who recruited family members of critically ill patients within 2 to 6 months after discharge. Of the 20 subjects, 18 were female. Data collection occurred during a focus group interview and an unstructured interactive individual interview. There were only two subjects participating in the focus group interview. Results included the important needs also found in other studies: information and privacy. Respect and dignity were also important needs identified, consistent with the need "to be treated with dignity", which was the new need identified in Mendonca and Warren's study (1998). Jamerson et al. reported specific factors inducing family crisis during an ICU hospitalization which included role alterations, isolation from other family members, financial constraints, transportation problems, and the fear of losing a loved one.

Summary and Implications for Study

There has been extensive research into the needs of family members of critically ill patients. Most of the descriptive, exploratory research has used the CCFNI, or some modified form of it, as the main research tool. Information and assurance needs are consistently the highest priority of family members, whether the research has been quantitative or qualitative. Studies have included a wide variety of demographics as study

variables, and the convenience samples have ranged from small to large. While most of the research has occurred while the patient has been in the ICU less than 72 hours, other studies have been retrospective with similar results.

Although the majority of research on family needs offer similar results, there remain several inconsistencies. Foremost is the role that demographic variables have in the ranking or the importance of family needs. The studies by Engli and Farmer (1993) and Mathis (1984) show significant differences in the population of patients with brain injury when compared to those without brain injury. Many other researchers recommend studying family needs in relation to patient diagnosis and acuity (Halm, 1992; Jamerson et al., 1996; Kleiber et al., 1994; Koller, 1991; Molter, 1979). Therefore, these demographic variables have been investigated further in this study.

Second, the need statement "to feel there is hope" has been ranked differently in several studies. It has been documented that the concept of hope plays a very important role in successful rehabilitation of patients with severe brain injury (Fowler, 1995; Johnson & Roberts, 1996). Likewise, the concept of hope has been identified as a useful coping behavior for family members of patients with severe brain injury. The results from Mathis's study (1984) appeared to support this concept, since the need "to feel there is hope" was ranked number one. In contrast to this was the study by Engli and Farmer (1993), which showed that it was not ranked within the top 10 needs. Study limitations, such as small sample size and selection bias, may have skewed the results in the later study. Nevertheless, this study of the brain-injured population will be beneficial to support or refute the results from the other studies on the needs of family members of patients with brain injury.

Third, the composition of families is changing and expanding to include relationships that are not considered traditional. Bias exists in much of the research since the majority of subjects have been female and a spouse (Hickey & Leske, 1992; Leske, 1992).

Although convenience sampling does not allow the investigator to control such bias, more can be done to better represent the population. For example, by allowing more than just one family member to participate and expanding the selection criteria to include individuals who are not related to the patient legally or by blood, the sample may be more representative of current family structure.

Fourth, the acuity or status of the patient may effect the ranking or importance of family needs. Research is lacking in this area, and many of the investigators recommend that future research examine this (Koller, 1991; Lorenz, 1995; Price et al., 1991; Bouley et al., 1994). Therefore, the variables of Glasgow Coma Scale (GCS) level, which measures acuity, and patient code status have been examined in this study.

Research Questions and Hypotheses

Several research questions that have been asked with this study include:

- 1. What are the needs of family members of patients with severe brain injury when compared to family members of patients without brain injury?**
- 2. Are the needs of family members being met, and if so, by whom?**
- 3. Will there be a difference in the perceived importance of needs of family members, based on the code status of the patient?**
- 4. Will the GCS level of a patient have any correlation with the way that family members rank the importance of their needs?**

Two hypotheses originally conceived and considered in this study include:

1. There will be a difference in the perceived importance of needs based on the patient's code status.
2. As the GCS level of the patient decreases, the importance of family needs will increase.

In regards to the first question, it was expected that the ranking of family needs would be similar to the ranking of needs in the study by Lorenz (1995), with information and assurance needs being most important. However, it was further believed that family members of patients with severe brain injury would place more importance on needs when compared with the sample from the study by Lorenz (1995). This finding would be consistent with the results from the studies by Engli and Farmer (1993) and Mathis (1984).

Second, the CCFNI was modified in order to ask families if their needs were being met and who was responsible for meeting those needs. Other investigators have likewise adapted the CCFNI for this purpose (Furukawa, 1996; Mendonca & Warren, 1998; Molter, 1979; Norheim, 1989). These previous studies have shown that family members identify most of the 45 need statements from the CCFNI as being met. However, there has been some discrepancy in the results with regards to who is responsible for meeting the family member's needs.

Third, there should be significant differences in the ranking or importance of family needs based on the patient code status. Families are more apt to have different needs if their family member is made Do Not Resuscitate (DNR) or is having life support withdrawn. Their primary concerns may not center around information and assurance needs, such as the need "to be called at home about changes in the patient's condition" or

“to know how the patient is being treated medically”. Comfort and support needs may be ranked the highest. Therefore, in regards to the third question, it was believed that family needs would have been ranked differently according to the patient’s code status.

Fourth, it is reasonable to assume that there will be more stress and anxiety when a patient is more critically ill. This notion is supported by the Roy adaptation model which states that as internal and external environments change, such as with injury, then the level of satiety for any need changes (1980, p. 184). Similarly, the degree of change (severity of injury) will cause an excess of needs. In reference to the fourth question, it was hypothesized that as the GCS decreases, then the importance of family needs will increase.

Definition of Terms

1. **Family Members:** For the purpose of this study, a family member has included any adult, at least 18 years of age, who visited the patient in the ICU, and who was either related to the patient by blood or the law, or who has lived with the patient and/or was designated “the significant other.”

2. **Severe Brain Injury:** According to Jennet and Teasdale (1981), severe brain injury is defined as a brain injury followed by at least 6 hours of coma; coma is defined as not opening the eyes, not obeying commands, and not uttering any recognizable words. Given this criteria, the level of coma would be classified as 8 or below on the Glasgow Coma Scale. For this study, severe brain injury has been defined as any adult patient (at least 18 years of age) who was admitted to the ICU with a diagnosis which is characterized by brain injury, and has a Glasgow Coma Scale level of 8 or below. This injury was the result of acute cerebral vascular disease (a cerebral vascular accident), occlusion of

cerebral arteries (including a cerebral infarction, cerebral embolism, and cerebral thrombosis), intracerebral hemorrhage (including cerebral aneurysm), subarachnoid hemorrhage, malignant neoplasm of the brain, encephalitis (bacterial, viral, hemorrhagic, or idiopathic), or head trauma resulting in a skull fracture, cerebral laceration or contusion.

3. **Glasgow Coma Scale (GCS):** The scale developed by Teasdale and Jennett in 1974, which is a tool to evaluate the neurological status of patients with head injuries in the acute care setting. This scale allows the assessor to rate the patient in the areas of motor responsiveness, verbal performance, and eye opening. The total score ranges from 3 to 15, with the lower the score meaning the more severe the injury or level of coma; and the higher the score meaning the less severe the injury or level of coma (Flannery, 1998).

4. **Code Status:** The code status of the patient is determined by the patient or their legal guardian and the patient's primary physician. Unless otherwise defined in the chart, all patients are considered full code. The term full code implies that everything will be done to save the patient in the event of a cardiac or respiratory arrest: if the circumstance requires it, they will receive cardiopulmonary resuscitation (CPR), electrical defibrillation, emergency medications (vasopressors), a pacemaker, intubation, and mechanical ventilation. If the patient or legal guardian requests that certain medical interventions be omitted during a cardiac or respiratory arrest, the primary physician will indicate these decisions in the patient's medical record and the patient is considered partial Do Not Resuscitate (DNR) or complete DNR. Depending on the patient's condition, the family and physician may find it appropriate to withdraw life support or stop medical treatment. For example, the patient may be taken off a ventilator and

allowed to die.

5. **Critical Care Family Needs Inventory (CCFNI):** The CCFNI is the research tool developed by Molter in 1979 and later adapted by Leske in 1986. This tool is a 4-point Likert-type scale with 45 need statements, which family members of critically ill patients rate as (1) not important, (2) somewhat important, (3) important, or (4) very important.

6. **Family Needs:** Concerns, wants, or desires of family members that develop in response to crisis (or may have existed prior to the crisis). The importance of the needs that relate to the hospitalization of a family member in the ICU has been assessed in this study by using the CCFNI tool. Families were also asked if they had any needs not already identified on the CCFNI. Roy defines a need as "a requirement in the individual that stimulates a response to maintain integrity" (1980, p. 184).

CHAPTER 3

METHODOLOGY

Study Design

Nonexperimental research was conducted to identify the needs of family members of critically ill patients. This research replicated the study by Lorenz (1995), who surveyed 60 family members of 35 critically ill patients in adult medical/surgical ICU's. In Lorenz's study, the patients' diagnoses were mainly cardio-pulmonary in nature. However, this study only surveyed family members of critically ill patients with severe brain injury.

A descriptive-correlational design was used to compare this study's findings with the results from Lorenz's study (1995). This investigator will report any similarities or differences in the ranking and importance of needs between family members of patients with severe brain injury and family members of patients without brain injury. Unlike Lorenz's study, this investigation asked family members if their needs were being met and who was responsible for meeting their needs. Furthermore, this investigation has attempted to reveal any relationships between the dependent variable, which is family needs, and the independent variables, which are the patient's code status and Glasgow Coma Scale level.

Advantages of Nonexperimental Research

A nonexperimental design was the most appropriate research design for this study because it enabled the investigator to collect a large amount of data concerning a known

problem area in which it would be impossible to control or manipulate the independent variables (Polit & Hungler, 1997). It was not possible to control the level of coma or acuity of a patient, and even though it would have been possible to manipulate the code status (e.g., patient 001 will be full code, patient 002 will be DNR), it certainly would not have been ethical. Similarly, due to such ethical constraints, the investigator was not likely to obtain cooperation or permission to conduct true experimentation in the hospital setting. Furthermore, it would have been difficult to control the environment of a hospital, where there are numerous employees, volunteers, and visitors that have the potential to manipulate or influence the results.

Another advantage to using a nonexperimental design was that the atmosphere of the study would remain more realistic when compared to a study with an experimental design, which requires a very controlled setting. In this particular study, the investigator was trying to capture the true feelings of family members (what needs they perceive as most important and what other unidentified needs they may have); manipulation of this environment would have created an artificial atmosphere, which may have stifled the genuineness of the subjects.

Although an unrestricted environment can be beneficial to exploratory research, eliciting some control over the research situation strengthened the external validity of this study. A single investigator for this study approached all potential subjects in the same style and followed a written procedure so that there was less chance to influence the responses of subjects.

Finally, the exploratory nature of this study has helped to develop and refine hypotheses specific to this population. This design has enabled the researcher to elicit

descriptions and characteristics of family members of patients with severe brain injury. In an unrestricted setting, family members were able to determine what their needs were and who was responsible for meeting their needs, thus allowing nurses the potential to develop interventions specific to this group.

Disadvantages of Nonexperimental Research

Although a descriptive-correlational design was appropriate for this study and offered certain benefits, this type of design did have several disadvantages. The main shortcoming of nonexperimental research in comparison to experimental or quasi-experimental research was that the causal relationships between variables would be much weaker. When convenience or self-selecting methods are used to produce a sample, the sample may have different characteristics that influence or are related to the variables of the research problems. Consequently, there may be different explanations for the relationships between the variables. Therefore, when using a correlational design, all results should be considered tentative (Polit & Hungler, 1997).

Study Site and Subjects

Study Site and Sample Size

Following institutional review board approval, investigation took place on the adult intensive care units at a large, midwestern Level I trauma center, which is comprised of two separate campuses (a downtown campus and an east campus). Ultimately, data were collected only at the downtown campus due to time-constraints of the investigator and to a lack of patients who met the research criteria at the east campus. Adult family members of patients who had a severe brain injury were the population being studied.

Questionnaires were given to a convenience sample of 23 family members of 10

patients who met the following criteria:

- 1. Individuals were adult (18 years of age or older).**
- 2. Subjects were a family member(s) of an adult patient (18 years of age or older).**
- 3. The family member(s) were available on the unit to meet with the investigator and**

complete the surveys.

4. The patient of the family member had a primary diagnosis that was characterized by severe brain injury and a Glasgow Coma Scale level (GCS) of 8 or below.

5. The patient was admitted to the ICU less than 72 hrs. prior to the surveys.

6. The family member(s) were able to speak, read, and write English.

7. The primary investigator was not directly involved with the care of the patient.

A convenience sampling method was the least time consuming and most economical way to acquire information regarding this population. The number of subjects for this study was dependent upon the number of patients admitted with a severe brain injury. During the first 3 months of the study, there was a decline in the admission of patients with severe brain injury. Therefore, the data collection for this study was extended another 3 months in the hope that a larger sample might be obtained.

Over a 6-month period, 26 patients were admitted to the adult ICU's with a diagnosis characterized by brain injury. Of these 26 patients, 7 patients did not qualify to participate in this study for the following reasons. The GCS of three patients was greater than 8 after being admitted for 24 hours, hence they no longer qualified for this study. Two patients were less than 18 years of age. Another patient had been in the hospital greater than 72 hours at the time of their neurological decline. Finally, family members of one patient could not speak English. Of the remaining 19 patients that would have qualified for this

study, family members of 3 patients could not be reached within 24 to 72 hours of the patients' admission. Therefore, the investigator of this study approached family members of 16 patients. Of these 16 patients, 23 family members of 10 patients agreed to participate. There were usually one to three family members who chose to participate in this study. However, there was one patient who had five family members representing them in this study.

Sample Characteristics

Family members who completed the questionnaires were primarily female (65%), Caucasian (96%), and married (78%). Ages of the respondents ranged from 18 to 70, and had a mean age of 42.65 (SD = 13.46). The majority of the family members were first degree relatives: 26% were parents, 22% were siblings, and 22% were adult children. Other respondents identified themselves as significant other, spouse, friend, or sibling-in-law. Most of the family members had at least a high school education (87%), and a large portion had acquired some college education (56%). Eighty-seven percent lived within 60 miles from the hospital. Roughly half of the sample had previous ICU experience (48%) and for others, this was the first ICU experience (52%).

The patients were primarily male (90%) with ages ranging from 18 to 79 years (M = 18.09, SD = 25.58). The majority of patients had a diagnosis of intracerebral hemorrhage (70%). Only three of the patients had secondary diagnoses: two patients had multiple skeletal fractures, and one patient had drug overdose. Fifty percent of the patients had traumatic brain injury, while 50% of the patients had non-traumatic brain injury. The GCS of the patients ranged from 3 to 8, with a mean of 5.4 (SD = 1.84). All of the patients were full code except for one who was partial DNR.

Instruments

Two surveys were given to all subjects enrolled in this study: a demographic questionnaire and a modified version of the Critical Care Family Needs Inventory (CCFNI). The demographic questionnaire given to each participant consisted of the following: subject gender, race, age, marital status, relationship to patient, socioeconomic level, education level, travel distance to the hospital, and previous experience with ICU's. Also, the principle investigator collected information regarding the patient from the medical records, and included the following: patient age, gender, primary diagnosis, secondary diagnoses, code status, and GCS level.

The main tool that was used for this study was the CCFNI. The CCFNI, which was developed by Molter (1979) and later modified by Leske (1986), uses a 4-point Likert-type scale to rank 45 need statements in the following way: (1) not important, (2) slightly important, (3) important, and (4) very important. There are 5 subscales in which these 45 need statements are classified: (a) information, (b) assurance, (c) support, (d) proximity, and (e) comfort. Besides the 45 need statements, family members were also asked to describe any needs not identified by the CCFNI, as well as if each of the needs were met and by whom. This tool was used to measure the dependent variable, which was family needs.

Content validity of the CCFNI was initially established by a panel of graduate nursing students (Molter, 1979). However, Macey and Bouman (1991) questioned this claim given that the panel of "experts" consisted of graduate nursing students (who's specialty areas were not revealed). Therefore, in their evaluation of the CCFNI, another expert panel was assembled to examine the validity of this tool. A panel of experts comprised of

5 ICU nurse managers and 11 school of nursing faculty (two of which had PHD's in both family nursing and instrument development) felt that overall, the content of the CCFNI was valid. Likewise, other researchers that have used the CCFNI have found content validity, in that no new needs were identified in their studies (Koller, 1991; Lorenz, 1995; Norheim, 1989; Price et al., 1991).

Furthermore, Leske (1991) used factor analysis to show that the CCFNI has construct validity. However, in recent studies by Mendonca and Warren (1998) and Engli and Farmer (1993), the subjects identified several new needs. Mendonca and Warren reported that one subject cited the need "to be treated with dignity." In Engli and Farmer's study, a subject mentioned the need "to have assistance with discharge care at home." Therefore, this tool's content validity should continue to be tested and modified as necessary with a changing society.

Leske (1991) and Price et al. (1991) both found that the CCFNI was reliable; Chronbach's alpha coefficient for the total CCFNI was .92 and .94 respectively, showing that the CCFNI has internal consistency. Macey and Bouman (1991) used test-retest reliability to examine the CCFNI's internal consistency. The percentage of absolute agreement was the measurement test for this reliability and found that 39 of the need statements were above the 70% agreement level. Although Macey and Bouman admitted that this type of test does not allow for chance, and perhaps that offers an explanation for the 6 need statements which fell below the 70% agreement level. Overall, this study found that the CCFNI was reasonably reliable.

Macey and Bouman (1991) also looked at the CCFNI's readability. Using the Gunning Fog Index, the CCFNI had an index of 8.6. Thus, the CCFNI has a 9th grade reading

level, which places this tool in the "easy to read" category.

The CCFNI has been shown to be a reliable and valid tool throughout the last 20 years, with need for little modification. The readability is accurate for the majority of subjects who have participated in research of family needs. Those who have modified the CCFNI similar to this investigation have been able to show content validity (Furukawa, 1996; Mendonca & Warren, 1998; Molter, 1979; Norheim, 1989). Content validity was assessed in this study by reporting any new needs identified by subjects. One family member reported the need to have information containing Internet web sites that would provide additional information regarding the patient's injury or illness. Therefore, with only one new need reported, the content of this questionnaire can still be considered valid.

The reported reliability of the CCFNI may not apply to a modified version. Therefore, the reliability for the adapted questionnaire in this study was determined by using Cronach's alpha coefficient. Internal consistency was calculated to be .92. Since the estimated reliability was above .70, the minimally accepted value according to Polit and Hungler (1997), this modified questionnaire was considered to be reliable.

Procedure

Permission to conduct this study was obtained from the Human Subjects Committee at Grand Valley State University and the Spectrum Health Institutional Review Board. The researcher contacted the Spectrum Health adult ICU's daily to ascertain potential subjects for this study. Upon admission of a patient with severe brain injury to the ICU, the researcher decided if this patient met the criteria for participation in this study. If the patient did meet the study criteria, the researcher then contacted the family member(s)

either on the unit or by phone to arrange a time and place to meet.

Upon meeting with family members, the researcher explained the purpose of this study and obtained written consent from those willing to participate. A meeting time/place was established so that the researcher could collect the completed surveys. Following this meeting, the family members completed the CCFNI and the subject demographic questionnaire. The investigator obtained the patient demographic data while the family members were completing their surveys.

Subjects were assured of confidentiality: each patient was given a number, and the family member(s) of this patient a corresponding number. For example, the first patient admitted into the study was assigned a number of 001. The participating family members of this patient were assigned the numbers 001-01, 001-02, and so forth. No names were recorded.

There were few, if any, risks to subjects in regards to this study. Perhaps some individuals felt that answering a questionnaire was intrusive during such a stressful time or that it caused them to dwell on the stress of the situation. However, family members must often sit and wait during the first 24 to 48 hours following a patient's admission to the ICU. Perhaps taking 30 to 45 minutes to complete a survey was a welcome distraction.

The CCFNI survey and demographic questionnaire was completed between 24 and 72 hours of the patient's admission to the ICU. The data collection for this study occurred over a period of 6 months.

CHAPTER 4

RESULTS

Techniques

The data from this study were analyzed using the Statistical Package for the Social Studies (SPSS) for Windows. The level of significance was set at $p < .05$ for all tests. Data obtained from the subject and patient demographic questionnaires were used to describe the sample. The research questions and hypotheses are shown in Table 1.

Table 1
Research Questions and Hypotheses

Questions	Hypotheses
1. What are the needs of family members of patients with severe brain injury when compared to family members of patients without brain injury?	(none)
2. Are the needs of family members being met, and if so, by who?	(none)
3. Will there be a difference in the perceived importance of family needs based on the code status of the patient?	There will be a difference in the perceived importance of needs based on the patient's code status.
4. Will the GCS level of a patient have any correlation with the way that family members rank the importance of their needs?	As the GCS level of the patient decreases, the importance of family needs will increase.

Research Questions and Hypothesis

In regards to the first research question, the 45 need statements from the CCFNI were ordered by the median, and then ordered by the statistical mean; this resulted in a rank order of the overall scale and the five subscales (see Table 2). The most important needs were (a) to have questions answered honestly, (b) to be assured that the best care possible

is being given to the patient, and (c) to know specific facts concerning the patient's progress. The least important needs were (a) to have someone be concerned with my health, (b) to have visiting hours start on time, and (c) to be told about someone to help with family problems.

Table 2
Rank Order of Need Statements

Rank	Need Statement	Top 20 Needs	
		M	SD
1.	To have questions answered honestly	4.00	0.00
2.	To be assured that the best care possible is being given to the patient	4.00	0.00
3.	To know specific facts concerning the patient's progress	4.00	0.00
4.	To know why things were done for the patient	3.96	0.21
5.	To have explanations given that are understandable	3.96	0.21
6.	To feel that the hospital personnel care about the patient	3.96	0.21
7.	To talk to the doctor every day	3.91	0.29
8.	To know how the patient is being treated medically	3.91	0.29
9.	To know exactly what is being done for the patient	3.91	0.29
10.	To see the patient frequently	3.91	0.29
11.	To know the expected outcome	3.87	0.46
12.	To be called at home about changes in the patient's condition	3.87	0.46
13.	To receive information about the patient at least once a day	3.87	0.63
14.	To have the waiting room near the patient	3.74	0.75
15.	To visit at any time	3.70	0.56
16.	To have a telephone near the waiting room	3.65	0.65
17.	To feel there is hope	3.65	0.93
18.	To be told about transfer plans while they are being made	3.65	0.57
19.	To have friends nearby for support	3.52	0.79
20.	To know which staff members could give what type of information	3.52	0.79

Note. The mean scores (M) and standard deviations (SD) are based on the entire sample's responses to the CCFNI's four-point response scale in which 1 = not important, 2 = slightly important, 3 = important, and 4 = very important.

The majority of the top ranked need statements fell into the subcategories of Assurance and Information needs (see Table 3). Whereas, the majority of least important need statements fell into the subcategories of Support and Comfort needs. The total need score for the CCFNI can range from 45 to 180, with the higher the score meaning the more importance placed on needs. The total need score reported as a mean for the CCFNI in this study was 150.05 (SD = 17.08).

Table 3
Mean Scores on the CCFNI Subscales

CCFNI Subscale	<u>n</u>	<u>M</u>	<u>SD</u>
Assurance	7	3.93	0.10
Information	8	3.64	0.32
Proximity	8	3.40	0.58
Comfort	6	3.19	0.32
Support	16	3.02	0.40

Note. Each of the CCFNI's 45 need statements fit into one of the 5 subscales. n = the number of need statements in each subscale.

The second research question was answered by computing frequencies and percents from the responses on the CCFNI. The majority of respondents felt their needs were being met (85%). Needs that were cited as not being met by more than 50% of the respondents fell into the subcategories of comfort, support, and proximity needs. These need statements were also ranked lower on the scale of importance, with the following means 2.48, 2.65, 2.91, and 3.09 (SDs = 0.95, 1.03, 0.95, and 0.90, respectively). However, there was only a response rate of 43%. The second part to this question, which was identifying who was responsible for meeting their needs, had an even lower response rate of 22%. Overall, staff were identified as being responsible for meeting the needs of family members (36%). Specifically, nurses (16%), doctors (11%), and medical social workers (4%) were the staff cited.

Due to the small sample size, there was not enough variability in patient code status (nine of the ten patients were full code). Therefore, the third research question could not be answered, and the corresponding hypothesis could not be tested. The fourth research question and hypothesis was tested by using Spearman's rho (see Table 4), which shows to what extent the patients GCS level is related to the perceived needs of family members. The ranking of needs and mean scores of subjects was compared to the patient's GCS level. An inverse relationship was found between patient GCS and the CCFNI's total

score and subcategories, except for the subcategory of comfort needs (there was a positive relationship shown between comfort needs and patient GCS). However, all of these relationships were weak (correlation coefficients were $< .70$), and the associated p values were not significant ($p > .05$). Therefore, the research hypothesis cannot be accepted.

Table 4
Correlation between Family Needs and Patient GCS

Family Needs	Patient GCS		
	N	r_s	p
CCFNI Total Score	20	-.117	.312
Assurance Needs	23	-.020	.463
Information Needs	23	-.234	.142
Proximity Needs	22	-.062	.392
Comfort Needs	23	.168	.222
Support Needs	20	-.217	.392

Note. N = number of valid responses from family members for each of the subcategories and the total CCFNI; r_s = correlation coefficient using Spearman's rho.

* $p < .05$

CHAPTER 5

DISCUSSION AND IMPLICATIONS

Discussion of Findings and Conclusions

Comparison with Previous Research

The purpose of this study was to identify the needs of family members of patients with severe brain injury. As expected, the top ranked needs were consistent with other studies: assurance and information needs continue to be ranked most important, while comfort and support needs continue to be ranked with less importance (Leske, 1992; Lorenz, 1995). In comparison to Lorenz's study, the "need to have questions answered honestly" was the most important need identified. Demographic characteristics of family members were similar between this study and other studies: respondents were primarily female, Caucasian, and married (Leske, 1992; Lorenz, 1995; Norheim, 1989)

The "need to feel there is hope" was ranked seventh in this study ($M = 3.65$, $SD = .93$), whereas this need was ranked ninth ($M = 3.53$) in the study by Lorenz (1995). Two of the respondents in the present study wrote comments next to this need, emphasizing the importance to maintain hope. This supports the study by Mathis (1984), where the "need to feel there is hope" was ranked number one. This finding also supports the well-documented role that the concept of hope plays in the population of severe brain injury (Fowler, 1995; Johnson & Roberts, 1996).

Furthermore, it was also believed that family members of patients with severe brain injury would place a higher degree of importance on needs when compared to family members of patients with other diagnoses (see Table 5). Previous studies have supported this belief (Engli & Farmer, 1993; Mathis, 1984). The CCFNI's total need score (reported as a mean) in this study was 150.05 (SD = 17.08), whereas the total need score from the 1995 study by Lorenz was 139.39 (SDs not reported; Lorenz's raw data was unavailable). However, this finding is not significant unless statistical testing can support it.

Table 5
Comparison of the Top Ten Needs with Lorenz's Study

Present Study (N = 23)		Lorenz's Study (N = 60)	
Rank	Need Statement	Rank	Need Statement
1	To have questions answered honestly (<u>M</u> = 4.00, <u>SD</u> = 0.00)	1	To have questions answered honestly (<u>M</u> = 3.93)
2	To be assured that the best care possible is being given to the patient (<u>M</u> = 4.00, <u>SD</u> = 0.00)	2	To know the expected outcome (<u>M</u> = 3.92)
3	To know specific facts concerning the patient's progress (<u>M</u> = 4.00, <u>SD</u> = 0.00)	3	To be called at home about changes in the patient's condition (<u>M</u> = 3.90)
4	To know why things were done for the patient (<u>M</u> = 3.96, <u>SD</u> = 0.21)	4	To feel that the hospital personnel care about the patient (<u>M</u> = 3.85)
5	To have explanations given that are understandable (<u>M</u> = 3.96, <u>SD</u> = 0.21)	5	To know specific facts concerning the patient's progress (<u>M</u> = 3.85)
6	To feel that the hospital personnel care about the patient (<u>M</u> = 3.96, <u>SD</u> = 0.21)	6	To know how the patient is being treated medically (<u>M</u> = 3.80)
7	To talk to the doctor every day (<u>M</u> = 3.91, <u>SD</u> = 0.29)	7	To be assured that the best care possible is being given to the patient (<u>M</u> = 3.80)
8	To know how the patient is being treated medically (<u>M</u> = 3.91, <u>SD</u> = 0.29)	8	To know exactly what is being done for the patient (<u>M</u> = 3.80)
9	To know exactly what is being done for the patient (<u>M</u> = 3.91, <u>SD</u> = 0.29)	9	To have explanations given that are understandable (<u>M</u> = 3.80)
10	To see the patient frequently (<u>M</u> = 3.91, <u>SD</u> = 0.29)	10	To receive information about the patient at least once a day (<u>M</u> = 3.77)

Note. The top ten needs identified in this study by 23 family members of 10 patients and the top ten needs identified in Lorenz's study (1995) by 60 family members of 35 patients. Top ten need statements are ranked in order of calculated mean. Values enclosed in parentheses represent mean value as recorded from the CCFNI's 4-point response scale. The present study has also included the corresponding standard deviation.

The majority of family members felt their needs were being met, which is consistent with previous research (Furukawa, 1996; Mendonca & Warren, 1998; Molter, 1979; Norheim, 1989). Staff, in general, were identified as being most responsible for meeting family needs. The second and third groups most likely to meet family needs were nurses and doctors, respectively. These results are also consistent with previous research. However, these findings must be considered tentative due to the very low response rate to the questions “Are your needs being met? If so, by whom?”

Relationship between Study Variables

Although an inverse relationship was shown between the patient’s GCS and family needs (as the GCS of the patient decreases, the perceived importance of family needs will increase), the relationship was very weak. This is most likely due to the sample size, as well as the sample characteristics. All of the patients represented in this study had a severe brain injury (GCS of 8 or less, accompanied by a diagnosis characterized by severe brain injury). Possibly, allowing patients with a higher GCS to participate would strengthen the relationship between GCS and family needs. This would provide a greater range of acuity, whereby family members may react different.

New findings

Two family members refused to rank the “need to talk about the possibility of the patient’s death.” This is not a revelation due to the timing of this study, which was between 24 and 72 hours of the patient’s admission into the ICU. Perhaps family members are still in shock at this point, and are not ready to deal with the possibility of losing a loved one.

Only one new need was identified in this study: the need to have information containing Internet websites where family members can research the patient's injury/condition. With improved technology, there are an increasing number of people who rely on computers to find information. It is important to keep assessing family needs as society changes.

Results in Relation to the Conceptual Framework

According to Roy (1980), individuals respond to change (crisis) in their environment by using coping mechanisms. Effective responses to stress will lead to adaptation. Nurses utilize the nursing process to assess whether coping mechanisms are effective. This study has used the CCFNI as an assessment tool to investigate family needs. Information and assurance needs have been shown to be most important to this population. Furthermore, a modified version of the CCFNI has shown that staff and nurses met the majority of these needs. Therefore, it would seem that in this particular setting, staff were promoting adaptation to the brain injury by meeting family needs.

Application to Nursing

Application to Practice

Nurses must incorporate the needs of family members into the care plan of the patient. Information and assurance needs have been shown to be the most important needs of family members within the first 72 hours of admission to the ICU. Therefore, family members should be provided with understandable, accurate, and timely information from the entire medical team (Bouley et al., 1994; Henneman & Cardin, 1992; Hickey & Leske, 1992). Nurses are in the unique position to facilitate the information process by arranging care conferences and providing family members with informational literature or

videos. With close proximity to the patient's bedside, nurses are also the most likely to be able to offer continued assurance regarding the patient's care and condition (Halm, 1992).

Research has shown the important role families have in the rehabilitation of a brain injured patient (Bouley et al., 1994; Johnson & Roberts, 1996). According to Roy (1984), individuals have the ability to respond to changes in their environment through the use of coping mechanisms, which will assist them in adapting to their environment or to change. As nurses, we must promote adaptation by using the nursing process to identify effective or ineffective coping responses. Individuals whose needs are not being met will be unable to respond effectively. This will ultimately interfere with the adaptation process.

Application to Administration

Results from this study and other research on family needs have shown family members rank information and assurance needs highest. Administrators need to focus on measures that will support these findings. Efforts should be made to recruit and retain ICU nurses. Management needs to keep nurses at the bedside where they can best meet patient's and family member's needs. The utilization of nurse practitioners or clinical nurse specialists may effectively support the bedside nurse when they are unable to meet family needs due to patient acuity. With different medical residents rotating through ICU's each month, advanced practice nurses can provide continuity of care throughout the course of the hospitalization.

Application to Education

It is important that the role of the nurse as patient and family educator be emphasized to nursing students. Inservices and orientation should provide nurses with the information gained from all of the research on family needs. If necessary, nurses who feel inadequate

at meeting the psychosocial needs of family members or patients should be provided with instruction through continuing education programs.

Limitations

Limitations Due to Sampling Methods

There are several limitations relevant to this study that may affect its external validity. Foremost is the size and characteristics of the sample. Other sampling methods would probably provide less bias than a convenience sample. However, these other methods would require more time than what is possible or necessary for this particular investigation. Techniques to improve the size of the sample were utilized. This included expanding the definition of the term family member to encompass individuals who were not thought of as blood relatives but who may have developed significant relationships with the patient. Likewise, more than one adult family member per patient was allowed to participate in this study.

Notification of potential subjects was another aspect of this investigation that became problematic. Initially, the investigator called the units of both campuses daily to inquire about new admissions. However, due to the size and atmosphere of the downtown campus ICU's, the busy charge nurses were not able to keep track of new admits who met the study criteria. As a result, several potential subjects were missed. A more effective means of notification was to personally visit the site on a daily basis. Though time consuming, this was the most accurate method to provide the researcher with potential subjects. After a month of calling the ICU at the east campus this investigator never received report of any admissions of patients who met the inclusion criteria. Since it was not possible to visit both campuses daily and there was an apparent lack of potential

subjects at the east campus, a decision was made to focus on the downtown campus as the only source for subjects.

All results should be considered cautiously when comparing it with a population other than what was represented in this study. Everyone in the sample was Caucasian with the exception of one individual who identified herself as an American-Indian. Likewise, some ethnic groups could not be represented because of the stipulation that all subjects be able to speak, read, and write English.

On the downtown campus of this facility, there was a reported average of four to five patients admitted each month to the surgical ICU who were in deep coma as the result of a severe brain injury. Likewise, there was a reported average of one to two patients admitted each month to the medical ICU with the same characteristics. This could have potentially provided a sample of 15 patients over a 3-month period. Therefore, there should have been an adequate number of patients that meet the study criteria. However, the investigator could not control the census. Due to a sudden decline in these admissions, the sample size was limited.

Furthermore, all of the patients were designated full code with the exception of one individual. This did not allow the investigator to compare family needs in relation to code status. A larger sample size with inclusion of different patient populations might provide a greater variability in patient code status.

Limitations caused by Threats to Internal Validity

Relative to this study, several threats to internal validity were considered, and if possible, controlled. There are four threats to internal validity that may contribute to limitations in this study: threat of history, threat of selection, threat of maturation, and

threat of mortality (Polit & Hungler, 1997). First, the threat of history exists when there are other events that occur with the introduction of the independent variable and which may influence the dependent variable. Roy (1984) describes these other events as residual stimuli, stimuli which may have an effect on the focal stimulus (family needs), but the presumed effect is not known. For example, besides the patient's injury, another catastrophic event may have occurred simultaneously, such as another family member dying. Both of these may have impacted the dependent variable of family needs, but it is not certain to what extent. The inability to control events beyond this study is a limitation that cannot be controlled. However, the demographic survey has helped reduce the threat of history with the inclusion of the question referring to other contributory events, such as whether or not the subjects had any previous ICU experience.

Second, the threat of selection occurs when there are preexisting differences between this population and the population in Lorenz's study (1995). Because convenience sampling was used in Lorenz's study and was also used in this study, the sample characteristics will not be identical. Although the demographics of these two samples appeared similar, Lorenz's sample was much larger than the sample in the present study. Furthermore, without Lorenz's raw data, it is not known exactly what the diagnoses were for the patients. Some of these patients may have had a brain injury. The comparisons made between this sample and Lorenz's sample are not entirely accurate, and it is an unfortunate limitation of this study that cannot be controlled. Because of this limitation, the findings from this study were also discussed and compared with findings from the studies by Engli and Farmer (1993) and Mathis (1984), who also researched the needs of family members of patients with severe brain injury.

Third, the threat of maturation may have been a possibility if the hospital implemented a new strategy or intervention to meet family needs during the course of this investigation. The introduction of interventions may have altered how families rank their needs. For example, if the needs of families were already being met, they may not have perceived a need as very important. The threat of maturation was somewhat controlled by maintaining communication between the researcher, staff educators, clinical nurse specialists, and unit directors. No new interventions specific to meeting family needs were implemented during the course of this study.

Fourth, there was a threat of mortality when family members decided to withdraw from the study. Furthermore, several family members either chose not to participate, or withdrew from the study. There was only one instance where an explanation was given to the investigator. One of the family members had agreed to participate in the study, but prior to completing the survey, the entire family had decided to withdraw medical support for the patient. Hence, that family member no longer wanted to participate, which is certainly understandable considering the patient's terminal status. Apart from this one situation, most of the family members who did not participate likely thought it to be too time-consuming during a very stressful situation. The investigator took steps to insure that families completed the surveys. Methods to promote follow-through with this study included meeting with family members face to face, providing a quiet place to talk and complete the questionnaires, and asking family members to complete the surveys subsequent to obtaining their permission.

Other Limitations

Another limitation to this study was the low response rate to the question “Are your needs being met? If so, by whom?” There are several possible explanations as to why this occurred. First, the unmodified CCFNI takes approximately 45 minutes to complete. Adding another part to it increases the amount of time involved by 15 to 20 minutes. Second, the unmodified CCFNI requires the respondent to place an X or check mark in the appropriate box of the 4-point scale. This modified version required the respondent to also write the word yes or no, as well as write a name or title of the individual meeting their needs. In an already stressful situation, this was probably more than the participants could manage. There might have been a better response to the modified version if choices had been already listed on the tool, which would have required the respondent to circle their choice.

Recommendations

Recommendations for Future Research Specific to Severe Brain Injury

Other studies have shown that the population of family members of patients with severe brain injury rank needs with greater importance than family members of patients with general medical-surgical diagnoses (e.g., cardio-thoracic, gastrointestinal, and orthopedic diagnoses; Engli & Farmer, 1993; Mathis, 1984). It would be beneficial to replicate this study with a larger sample. More variability in GCS should be included in future studies, so that family response to acuity can be better examined. Furthermore, a sample of family members of patients with brain injury should be simultaneously compared to a sample of family members of patients without brain injury. This would

provide a more scientific approach to support the research done by Engli and Farmer (1993) and Mathis (1984).

General Recommendations for Further Research on Family Needs

Several issues should be considered for future research on family needs of critically ill patients. The variable of code status should be investigated in regards to family needs, especially during the withdrawal of medical support. Nurses and other providers need to know what family needs are when the patient is terminal, so that they can assist them with the grieving process (Furukawa, 1996)

Second, needs should be continually reassessed over time. Most of the research on family needs has occurred during the first 72 hrs. of a patient's admission to the ICU. Family needs during the first 48 hrs. are likely to be different from their needs 3 weeks later. For example, support needs (which were ranked lower in this study) may become more important over time due to the financial and emotional strain involved with long-term care of a patient with brain injury.

Third, the CCFNI should continue to be re-evaluated as society changes, and questions adapted as necessary. Some of the need statements on the current CCFNI may not be applicable at certain institutions. The "need to have visiting hours start on time" is one such need. Many ICU's have instituted open visitation or individualized visitation plans. Also, this current study and Mendonca and Warren's study (1998) have identified two new needs: the need "to be treated with dignity" and the need "to have internet information available."

Fourth, a study looking at different methods to administer the CCFNI tool would be beneficial. Interview methods versus self-report methods, as well as whole family responses versus individual responses should be investigated.

Finally, specific interventions to meet family needs must be developed and tested. Bokinskie (1992) studied the effects of introducing a family care conference prior to transferring a patient from the ICU. Lopez-Fagin (1995) utilized the CCFNI as a regular assessment tool on a medical-surgical unit. According to Roy (1980), the goal of nursing is to promote adaptation. This goal can be accomplished by developing interventions that focus on meeting information and assurance needs of family members.

APPENDICES

Appendix A

Subject Demographic Questionnaire

Patient Demographics

Critical Care Family Needs Inventory

Consent Form

Explanation of Study

SUBJECT DEMOGRAPHIC QUESTIONNAIRE

1. What is your age? ____
2. What is your gender?
Male__ Female__
3. What category best describes your ethnic origin?
Caucasian__ African-American__ Asian__ American-Indian__ Hispanic__
Other__
4. What is your marital status?
never married__ married__ divorced__ widowed__
5. What is your relationship to the patient?
spouse__ parent__ brother/sister__ son/daughter__ grandparent__ grandchild__
nephew/niece__ aunt/uncle__ cousin__ significant other__ other _____.
6. What is the highest level of education that you have completed?
grade school__ some high school__ 12th grade__ some college__
2yr.college degree__ 4yr.college degree__ some graduate school__
masters degree__ doctoral degree__
7. What category best describes your annual income?
\$0 - 15,000.00__ \$15,001.00 - 25,000.00__ \$25,001.00 - 40,000.00__
\$40,001.00 - 60,000.00__ \$60,001.00 - 80,000.00__ \$80,001 - 100,000.__
over \$100,000__
8. How many miles is this hospital from your home?
less than 5 miles__ 6-10 miles__ 11-20 miles__ 21-30 miles__ 31-40 miles__
41-60 miles__ 61-100 miles__ over 100 miles__
9. What is your experience with an ICU?
this is my first experience__ this is my second (or more) experience(s)__

PATIENT DEMOGRAPHICS

1. Age ____
2. Gender ____
3. Primary Diagnosis _____
4. Secondary Diagnoses _____
5. Glasgow Coma Scale level ____
6. Code Status: Full Code ____ or as specified below ____
 - (1.) No Intubation ____
 - (2.) No Mechanical Ventilation ____
 - (3.) No CPR ____
 - (4.) No Defibrillation ____
 - (5.) No Vasopressors ____
 - (6.) No Pace-maker ____

CRITICAL CARE FAMILY NEEDS INVENTORY

DIRECTIONS: This survey will help us know what your needs are during this difficult period. Read each need statement and then check how important the need is to you at this time.

NEEDS STATEMENTS 1 = Not Important 2 = Slightly Important 3 = Important 4 = Very Important	1	2	3	4	Are your needs being met? If so, by whom?
1. To know the expected outcome.					
2. To have explanations of the environment before going into the critical care unit.					
3. To talk to the doctor every day.					
4. To have a specific person to call at the hospital when unable to visit.					
5. To have questions answered honestly.					
6. To have visiting hours changed for special conditions.					
7. To talk about feelings about what has happened.					
8. To have good food available in the hospital.					
9. To have directions as to what to do at the bedside.					
10. To visit at any time.					
11. To know which staff members could give what type of information.					
12. To have friends nearby for support.					
13. To know why things were done for the patient.					
14. To feel there is hope.					
15. To know about the types of staff members taking care of the patient.					
16. To know how the patient is being treated medically.					

NEEDS STATEMENTS 1 – Not important 2 – Slightly important 3 – Important 4 – Very important			3	4	Are your needs being met? If so, by whom?
17. To be assured that the best care possible is being given to the patient.					
18. To have a place to be alone while in the hospital.					
19. To know exactly what is being done for the patient.					
20. To have comfortable furniture in the waiting room.					
21. To feel accepted by the hospital staff.					
22. To have someone to help with financial problems.					
23. To have a telephone near the waiting room.					
24. To have a pastor visit.					
25. To talk about the possibility of the patient's death.					
26. To have another person with me when visiting the critical care unit.					
27. To have someone be concerned with my health.					
28. To be assured it is alright to leave the hospital for awhile.					
29. To talk to the same nurse every day.					
30. To feel it is alright to cry when I want to.					
31. To be told about other people that could help with problems.					
32. To have a bathroom near the waiting room.					
33. To be alone whenever I want.					
34. To be told about someone to help with family problems.					

NEEDS STATEMENTS 1 = Not Important 2 = Slightly Important 3 = Important 4 = Very Important					Are your needs being met? If so, by whom?
35. To have explanations given that are understandable.					
36. To have visiting hours start on time.					
37. To be told about chaplain services.					
38. To help with the patient's physical care.					
39. To be told about transfer plans while they are being made.					
40. To be called at home about changes in the patient's condition.					
41. To receive information about the patient at least once a day.					
42. To feel that the hospital personnel care about the patient.					
43. To know specific facts concerning the patient's progress.					
44. To see the patient frequently.					
45. To have the waiting room near the patient.					

Are there any other needs that you have? If so please write them below.

THE NEEDS OF FAMILY MEMBERS IN CRISIS

CONSENT FORM

This is a research study looking at the needs of family members of patients hospitalized in the intensive care unit (ICU). The knowledge gained may help nurses and physicians to provide additional support in areas of identified need to the family members who are in crisis as a result of a critical illness. There will be up to 60 participants in this study.

I acknowledge that:

1. Participation in this study will take approximately 45 minutes of my time, and will involve the completion of two questionnaires within the next 24 to 72 hours.
2. As part of this study, limited chart information will be recorded. No patient identifiers will be used.
3. I have been selected for participation because I have a family member who is in the ICU.
4. It is not anticipated that this study will lead to any physical or emotional risk to myself or to the ill family member. The benefit may be additional support to future family members of patients in similar circumstances.
5. My confidentiality will be protected to the extent permitted by law.
6. A summary of the results will be made available to me upon my request.
7. My participation in this study is voluntary as indicated by my signature, and I may withdraw at any time without fear or prejudice.
8. A copy of this signed consent form will be given to me.
9. I hereby authorize the investigator to release the information obtained in this study to scientific literature. I will not be identified by name.
10. If I have any questions or concerns relative to this study I may contact the primary investigator, Melanie Burghgraef (616-458-8526).
11. If I have any questions or concerns regarding my rights I may contact Paul Huizenga at Grand Valley State University (616- 895-2472) or Human Rights representative Linda Pool (616-391-1291).

My signature indicates that I have agreed to voluntarily participate in this study. The study and consent form have been explained to me, and my questions have been answered to my satisfaction.

Participant Signature

Date

Witness

Date

___ I am interested in receiving a summary of the study results.

Explanation of Study

Hello. My name is Melanie Burghraef. I am a registered nurse and a graduate student at Grand Valley State University. I am conducting a study on the needs of family members of patients hospitalized in the ICU with severe brain injury. I understand that you have a family member who was admitted to the ICU with **[diagnosis]**. Let me first express my concern for you and your family during this time.

The staff at this hospital are doing everything they can to care for your family member **[friend]**. They also want to do everything they can to meet your needs. The study that I am conducting will ask you to rate the importance of your needs. The results from this study can be used to develop specific interventions for meeting the needs you feel are the most important.

Participation in this study will take approximately 45 minutes. You will be asked to complete a 45-item questionnaire. These 45 items consist of “need statements” that you will be asked to rank as “not very important” to “highly important”. You will also be asked to complete a demographic questionnaire that asks questions about your background. These two questionnaires need to be completed within the next hour. After you have finished, I will pick up the completed forms.

Participating in this study is voluntary, and at any time you may withdraw from this study. Your participation in this study will not effect **[the patient]** in any way: they will continue to receive the same care and treatment regardless of your involvement in this study. I will be obtaining information regarding **[the patient's]** age, gender, medical diagnosis and status. This study does not involve any experimentation or intervention on **[the patient]**. Six family members per patient are allowed to participate. All names will

be kept confidential. Would you [any of you] agree to participate?

[if “yes] Thank you for agreeing to do this. I will give you the two questionnaires to complete at this time. When you are finished, I will be back to collect the questionnaires.

Will **[time]** give you enough time?

If you would like me to, I would be happy to share your most important needs with the nurse taking care of **[patient]**. If there are any needs that you have that are not identified on the questionnaire, please write them at the bottom of the form. If you have any questions regarding this study, please contact me at 616-458-8526. You may also contact Paul Huizenga from Grand Valley State University at 616-895-2472 or **[contact from Spectrum]** from Spectrum Health at **[phone number]**. Thank you for your time and cooperation with this study.

[if “no”] Thank you for taking the time to talk to me. I hope that your **[patient]** recovers quickly, and that you and your family will find strength in this difficult time.

Appendix B

Letter of Consent to use the CCFNI Tool

Letter of Consent to use Figures from the Roy Adaptation Model

Letter of Consent to use Figures from the Roy Adaptation Model

Letter of Approval from the Human Subjects Research Review Committee at G.V.S.U.

Letter of Approval from the Nursing Research Committee at Spectrum Health.

Letter of Approval from the Institutional Review Board at Spectrum Health

Letter of Approval from the Human Subjects Research Review Committee at G.V.S.U.

Nancy Molter
16307 Halifax
San Antonio, TX 78247
January 25, 1999

Melanie A. Burghgraef
61 Benjamin Ave, S.E.
Grand Rapids, MI 49506

Dear Melanie,

Please feel free to use Critical Care Family Needs Inventory for your research, giving Jane Leske and myself appropriate referencing. You may adapt the tool to meet the needs of your research but it may affect the psychometrics of the tool. Data concerning the psychometrics of the tool can be found in Jane's article published in the May 1991 issue of Heart & Lung, Vol 20(3): 236. I've enclosed a copy of the tool that is scored by calculating the means for each item. There is no total score. I then ranked the items according to their mean. Jane has identified the dimensions of needs and it is easy to discuss them in those terms.

I encourage you to look at evaluating a specific intervention rather than just describing the needs perceptions of the family. This has been done in a number of settings. Needs are really not different. It is time that we now look at the effect of selected interventions. For example, how does a specific care plan for incorporating families into the care affect their perceptions of needs being met? Kathy Dracup and Chris Breu did a study similar to this. Currently, most journals will not publish research related to describing needs unless it is in a population not previously studied. I know of no such population in the US.

Good Luck in your studies.

Sincerely,

A solid black rectangular box redacting the signature of Nancy Molter.

Nancy Molter



BOSTON COLLEGE

SCHOOL OF NURSING

March 3, 1999

Melanie A. Burghraef
61 Benjamin Avenue, SE
Grand Rapids, MI 49506

Dear Melanie:

I received your letter discussing your use of the Roy Adaptation Model as the theoretical ground for your thesis topic on family needs of severe brain injured patients. I am pleased to know of your interest in the model and this important clinical issue.

Specifically, this letter is to grant your requests: (1) to adapt the model to fit your thesis topic; (2) to use diagrams of the Roy Adaptation; and (3) to include any adapted versions of diagrams on the model. I am pleased to provide these permissions to include any additional work for educational purposes.

Best wishes with your thesis research. Please send an abstract when the study is completed.

Sincerely,

A black rectangular redaction box covering the signature of Callista Roy.

Callista Roy, PhD, RN, FAAN
Professor and Nurse Theorist

PEARSON EDUCATION

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Michelle Johnson
Permissions Administrator
Legal Division

July 23, 1999

Melanie A. Burghgraef
61 Benjamin Ave. SE
Grand Rapids, MI 49506

Dear Ms. Burghgraef:

You have our permission to include tow figures from our text, INTRODUCTION TO NURSING by Roy, in your master's thesis.

You may credit our material as follows:

Roy, Sr. Callista, INTRODUCTION TO NURSING: An Adaptation Model,
©1984, pp.30, 40. Reprinted by permission of Prentice Hall, Upper Saddle River, New Jersey.

Sincerely,



Michelle Johnson
Permissions Administrator



**GRAND VALLEY
STATE UNIVERSITY**

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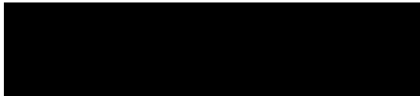
October 8, 1999

**Melanie Burghraef
61 Benjamin Ave. SE
Grand Rapids, MI 49506**

Dear Melanie:

The Human Research Review Committee of Grand Valley State University is charged to examine proposals with respect to protection of human subjects. The Committee has considered your proposal, **The Needs of Family Members in Crisis, and is satisfied that you have complied with the intent of the regulations published in the Federal Register 46(16)8386-8392, January 26, 1981.**

Sincerely,



**Paul A. Huizenga, Chair
Human Research Review Committee**



Spectrum Health

Downtown Campus

100 MICHIGAN STREET NE GRAND RAPIDS MI 49503-2560
616 391 1774 FAX 391 2745 www.spectrum-health.org

October 20, 1999

Melanie Burghgraef BSN, RN
61 Benjamin Ave., S.E.
Grand Rapids, MI 49506

Dear Melanie,

The Nursing Research Committee has completed the review of your research proposal, "*The Needs of Family Members in Crisis*" at the October 19, 1999 committee meeting. I am pleased to inform you that your proposal has received approval from our committee.

You are ready to proceed to the Hospital Research and Human Subjects Committee. Contact Linda Pool at the Cook Institute (391-1291) for those arrangements.

As per Nursing Research Committee policy, you will be assigned a sponsor who will serve as a resource to you during this study. Donna Garrett MSN, RN will serve in that capacity. Please contact her at 391-2966 when you are ready to begin data collection, and keep her informed of your progress during the study.

Upon completion of your research study, we will look forward to an oral and /or poster presentation in a format appropriate to the topic and in timing with other educational offerings. We also encourage you to present your findings via conference presentations and publication.

Please feel free to call me if you have any questions or need further clarification. I can be reached at 391-1676.

Sincerely,

Jan Hodges, MSN, RN
Manager, Nursing Education, Advanced Practice, and Research
Chairperson, Nursing Research Committee

c: **Dr. Kay Kline, KSON, GVSU**
Linda Pool, Research Office
Donna Garrett, Cardiovascular CNS



Spectrum Health

Downtown Campus

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616 391 1774 FAX 391 2745 www.spectrum-health.org

December 3, 1999

Melanie A. Burghraef, BSN, RN
61 Benjamin Ave., SE
Grand Rapids, MI 49506

Dear Ms. Burghraef:

By means of the expedited review process your project entitled, "The Needs of Family Members in Crisis", was given approval by the Spectrum Health Research and Human Rights Committee. The Spectrum Health number assigned to your study is #99-212.

This approval does not include the awardence of any monies for your study.

Please be advised that any unexpected serious, adverse reactions must be promptly reported to the Research and Human Rights Committee within five days; and all changes made to the study after initiation require prior approval of the Research and Human Rights Committee before changes are implemented.

The Research and Human Rights Committee and the F.D.A. requires you submit in writing, a progress report to the committee by November 1, 2000, and you will need reapproval should your study be ongoing at that time. Enclosed are some guidelines, entitled "Protocol Points", for your convenience in working with your study.

If you have any questions please phone me or Linda Pool at 391-1291\1299.

Sincerely,


Jeffrey S. Jones, M.D.
Chairman, Spectrum Health Research and Human Rights Committee

JSJ/jfn

c: Jan Hodges, MSN, RN
File



**GRAND VALLEY
STATE UNIVERSITY**

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January 4, 2000

**Melanie Burghraef
61 Benjamin Ave. S.E.
Grand Rapids, MI 49506**

Dear Melanie:

Your proposed project entitled *The Needs of Family Members in Crisis* was approved as an expedited study on October 8, 1999.

Your modifications, recently submitted for this proposal, have been reviewed and approved.

Sincerely,

[Redacted signature]

**Paul A. Huizenga, Chair
Human Research Review Committee**

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