

**NEEDS OF FAMILY MEMBERS  
OF CRITICALLY ILL BRAIN-INJURED PATIENTS  
DURING THE ICU EXPERIENCE**

by

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### **Abstract**

This descriptive exploratory study was designed to determine the perceived importance of selected needs of family members of critically ill brain-injured patients. In addition, the personal/demographic factors which may have influenced the needs of these family members were investigated, as well as the reasons family members perceived these needs as important or unimportant.

A convenience sample of one family member for each of 15 critically ill brain-injured patients was selected from two tertiary care hospitals and the community. Family members were interviewed using a pre-determined interview guide and asked to verbally rate 20 need statements on a four-point Likert-type scale. Generally, family members perceived all 20 needs to be important. However, the importance of each need was influenced by the family members' personal/demographic factors. No significant statistical relationship was found between personal/demographic factors and the family members' perceptions of the importance of selected needs. However, the findings of the study suggest that family members relate their needs to their present experience, and thus individual assessment of family members' needs is crucial.

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## CHAPTER ONE:

### INTRODUCTION

#### Background to the Problem

As a result of increasing use of knowledge and technology by paramedics, personnel in trauma centers and personnel in neurosurgical units, many more brain-injured patients and their family members are seen in the Intensive Care Unit (ICU) than in previous years (Olson & Henig, in press). These patients and family members require highly advanced medical and nursing care.

Critical care nurses are competent in providing care for brain-injured patients. However, they are not always able to provide such effective care for family members, who often remain on the periphery where little consideration is given to the impact of the ICU experience on them (Holub, Eklund & Keenan, 1975).

Over the past two decades, researchers have become interested in the needs of family members of critically ill patients (Daley, 1984; Gillis, 1981; Molter, 1976). However, the needs of family members of critically ill brain-injured patients have only recently been explored (Mathis, 1984; Mauss-Clum & Ryan, 1981).

It is well accepted that an unexpected serious injury or illness threatens a patient's physical and psychological well-being. It is less obvious, however, that the illness or injury may threaten the well being of the patient's family members. A critical illness can tax the ability of family members to maintain normal functioning (King & Gregor, 1985). It can precipitate a crisis for individual family members and have a negative impact on the whole family.

Thus, the family members must develop effective coping patterns to deal with this stressful event (King & Gregor, 1985; Lust, 1984). Otherwise, increased fear, anxiety, and frustration may result (Daley, 1984; Jillings, 1981; King & Gregor, 1985).

In addition, research has shown that family members' stress often transfers to the patient and can adversely affect the patient's response to treatment (Daley, 1984; Fowler Byers, 1983; Olsen, 1970; Rasie, 1980). Substantial research has also shown that attitudes of family members may have a profound effect on the patient's reaction to the medical regimen, the emotional adaptation to the illness or injury, and the response to the rehabilitation process (Adsett & Bruhn, 1968; Chatham, 1978; Lasater & Grisanti, 1975; Schwartz & Brenner, 1979; Wishnie, Hackett & Cassem, 1971). Therefore, it seems essential that family members receive effective help in coping during the acute phase of a patient's illness. To provide such help, it would be necessary to know the needs of family members during the Intensive Care Unit experience.

When family members hear that their loved one is a patient in an "Intensive Care Unit" they exhibit fear and anxiety (Doerr & Jones, 1979; Gillis, 1981). The ICU environment, with its unfamiliar noises, its strange-looking machines, and its constant bustle of nurses, physicians and support staff, is a frightening experience for many family members. When they hear that a family member is a patient in an ICU, people frequently, and often accurately, perceive that the patient is on the edge between life and death. This perception is further verified if the patient is receiving mechanical ventilation (Gillis, 1981).

Nurses in an adult intensive care unit often meet with the family members of the critically ill patient, yet potentially helpful interventions to assist them do not always take place (Geary, 1979). According to Bedsworth and Molen (1982), the role of the critical care nurse involves assisting both patients and their family members to cope with new and often life-threatening situations. Yet nurses in ICUs often direct all their attention toward physiologically-based interventions and the psychosocial needs of family members are often ignored or forgotten, although the intention of providing family support is present (Daley, 1984).

A variety of reasons are given for lack of nursing support received by family members during an ICU experience. Nurses cite feelings of inadequacy and lack of knowledge about dealing with family members as possible causes (Bedsworth & Molen, 1982). They also cite lack of available time to spend with family members and, most importantly, lack of understanding of the family members' needs. Although the needs, fears, and frustrations of family members are not well documented (Dracup & Breu, 1978; Roberts, 1976), the critical care nurse remains responsible for providing supportive care to family members (Gillis, 1981). To provide such care, therefore, it is necessary to know the needs of family members during the ICU experience.

The literature indicates that little is known about the needs of family members of critically ill patients in general (Daley, 1984), and much less is known about the needs of family members of critically ill brain-injured patients (Mathis, 1984). Specific information about the needs of family members of critically ill brain-injured patients is useful, since the unique

nature of individual disease processes often poses special problems (Benoliel, 1983). The intent of this research, therefore, is to examine the needs of family members of a specific patient population: critically ill brain-injured patients.

### **Statement of the Problem**

It has been theorized that if the needs of family members of critically ill ICU patients are unmet, there may be a negative effect on the patient's recovery (Fowler Byers, 1983; Roberts, 1976). Research has suggested that family members of critically ill brain-injured patients may perceive the importance of some needs in a different way than family members of critically ill patients in general (Mathis, 1984). However, research to date has mainly sought quantitative measurement of specific needs; no attempt has been made to elicit reasons for ratings given to individual responses.

### **Purpose of the Study**

The purpose of this study was to expand on the findings of previous researchers (Molter, 1976; Mathis, 1984) who investigated the perceived needs of family members of critically ill patients. It was the intent of this study to identify the perceived importance of needs of family members of critically ill brain-injured patients during the ICU experience. In addition, this study investigated why these needs are perceived as important or unimportant and examined demographic factors which may influence the needs of family members during the ICU experience.

### **Research Questions**

The present study addressed the following research questions:

1. How do family members of critically ill brain-injured patients rate the importance of selected needs?

2. What factors are associated with the rating of importance or lack of importance for selected needs?
3. How do family members of critically ill brain-injured patients explain their perception of the importance of selected needs?

### **Significance to Nursing**

Knowing the perceived importance of the needs of family members of critically ill brain-injured patients may enable nurses to more fully understand the needs of family members during the ICU experience. Knowing the demographic factors that influence needs and the rationale for ratings of the importance of the needs may also enhance the nurses' understanding of the experience. This understanding will direct nurses in assisting family members to deal with the ICU experience. Once family members can utilize effective coping patterns to deal with the ICU experience, they are less likely to unconsciously transfer their stress to the patient; rather, family members will be better able to support the patient and enhance the patient's recovery.

### **Definition of Terms**

Family member - any individual, 19 years of age or older, who has visited the patient in the ICU and has been identified by health care professionals as having a significant relationship with the patient.

Critically ill brain-injured patient - a person, 19 years of age or older, who has sustained a sudden and unexpected brain injury through traumatic or vascular accident. The patient must have been in the ICU for at least three days and then on a general nursing unit or in a step-down unit for 72 hours or less. The patient must have been unresponsive to verbal command for at least 4 hours after the accident.

Intensive care unit - a specialized unit, within the hospital, where critically ill brain-injured patients receive intensive nursing and medical care.

Need - an awareness by the family member of a physical, psychological, or social requirement which, if met, relieves his stress to some degree and partially restores his equilibrium (Mathis, 1984).

### **Methodology**

A descriptive exploratory research design, using ratings and descriptive data, was employed to investigate the research questions. One family member for each of 15 critically ill brain-injured patients was interviewed on one occasion. Data were gathered using a structured interview guide. Data analysis included descriptive statistics and descriptive analysis of the subjective data.

### **Assumptions**

1. It is assumed that family members of critically ill brain-injured patients have needs regarding their experience in the acute phase of the patient's illness.
2. It is assumed that the use of a tool to rate the importance of needs is a valid means by which to gain knowledge of family members' priorities.
3. It is assumed that the use of open-ended questions is one means by which to gather data which explains why family members rate needs as they do.
4. It is assumed that by providing the family members with the opportunity to identify needs that were not addressed by ratings, all relevant needs will be examined.

5. It is assumed that family members will accurately identify, retrospectively, the perceived importance of, and the rationale for, selected needs during the ICU experience.

### **Limitations**

The limitations of this study are as follows:

1. The small sample size and the convenience method of sample selection limit generalizability of findings.
2. The characteristics of the various ICU settings may have influenced the family members' perceptions of their needs.
3. The variability in time span since the family members' experience with the ICU may have altered their perception.
4. The data collection instruments used in this study were not tested for reliability.
5. The age of the subjects and patients may have influenced the subjects' perception of their needs.

### **Conclusion**

This chapter has described the background to the problem, introduced the problem statement and purpose, identified research questions and discussed the assumptions and limitations of this study. A review of literature pertinent to this study will be provided in Chapter 2. Chapter 3 includes a description of the research methodology; Chapter 4 presents the analysis of data, and Chapter 5 provides a discussion of the findings in relation to the research questions. The summary, conclusions, nursing implications and recommendations for further research are contained in Chapter 6.



## **CHAPTER TWO: REVIEW OF THE LITERATURE**

### **Introduction**

This chapter will review literature pertinent to this study. The purpose of the literature review is to summarize what is known about the needs of family members of critically ill patients, particularly brain-injured patients. This review will therefore demonstrate how this study adds to what is not known and also expand upon what is known.

The selection of literature includes both experiential and research-based publications. The literature review is divided into four sections. The first section discusses what is known about the needs of family members when a patient is hospitalized for a serious illness. The second section includes research studies that have examined the needs of family members when a patient is hospitalized in the ICU. Section three examines the effect of family members on the patient's hospitalization experience and recovery process. Finally, section four discusses the needs of family members of brain-injured patients during hospitalization and then specifically during the ICU phase of the hospitalization.

### **Needs of Family Members of Seriously Ill Patients**

#### **During Hospitalization**

Researchers consider serious illness resulting in hospitalization a crisis for the family (Anbogast, Scratton & Krick, 1978; Daley, 1984; Gillis, 1981; Molter, 1979). Shock, disbelief, fear, and anxiety are common reactions when a family member is faced with a serious illness in another family member. Often, usual coping skills of the well family members are insufficient to deal with

this crisis successfully (Gillis, 1981). The needs of family members are influenced by the severity of the patient's condition, the family's environmental supports, their previous experience with the hospital environment, and their financial circumstances (Daley, 1984; Elliott & Smith, 1985; Fowler Byers, 1983; Molter, 1979). Family members' needs must be identified and met so that family members do not negatively affect the patient's recovery process (Daley, 1984; Fowler Byers, 1983; Olsen, 1970; Rasie, 1980).

Hampe's (1975) study of the needs of spouses of terminally ill patients addressed the needs of family members. Her purposes were to determine whether spouses could recognize their own needs, and whether spouses perceived that nurses had helped them meet their needs. Twenty-seven spouses were interviewed using a semi-structured interview technique. The study's findings indicated that spouses could identify their own needs. Eight central needs of these grieving spouses were identified: (1) the need for information about the patient's condition, (2) the need for information about possible impending death, (3) the need to be with the patient, (4) the need to be helpful, (5) the need for comfort and support of family members, (6) the need to ventilate emotions, (7) the need for assurance of the comfort of the patient, and (8) the need for acceptance, support, and comfort from health professionals (Hampe, 1975).

Data were obtained about the reasons why spouses perceived needs as important. Spouses expressed that certain needs were important, especially when they were unmet. For example, one spouse explained that the need for patient comfort was important since his spouse was miserable in an

uncomfortable environment. This study focused only on spouses of patients with a chronic, terminal illness. As Hampe (1975) suggested, it would be valuable to conduct a similar study with spouses of acutely ill patients.

A second study relating to the needs of family members of a fatally ill adult patient was conducted by Freihofer and Feldon (1976). The purpose of this exploratory study was to identify nursing behaviors which provided support, comfort and ease of suffering to family members of a fatally ill hospitalized adult patient. Using a Q-sort methodology, 25 family members were asked to order 88 descriptive statements pertaining to three areas: (1) nursing behaviors that promoted the patient's comfort and hygiene, (2) nursing behaviors that indicated understanding of the emotional needs of the patient, and (3) nursing behaviors that indicated understanding of the impact on the family members of the grief, grieving, and loss.

In their study, Freihofer and Feldon (1976) found that five of Hampe's (1975) eight identified needs of grieving spouses were the basis for the most desired nursing behaviors (Freihofer & Felton, 1976). The "need to ventilate emotions," the "need for comfort and support of family members," and the "need for acceptance, support and comfort from health professionals" were considered of less importance. Aside from age and religion, this study did not examine demographic factors that might influence the family members' responses. Furthermore, there was no opportunity for the subjects to provide a rationale for their ratings.

Following Hampe's suggestion about conducting a similar study with spouses of acutely ill patients, Dracup and Breu (1978) conducted a research study with spouses of critically ill coronary patients. The purpose of the

study was to design and implement a nursing care plan to meet the needs of these spouses. Twenty-six spouses were involved in the study; 13 spouses received no consistent nursing interventions, whereas 13 spouses received specific nursing interventions as devised by the staff nurses. Data from the tape-recorded interviews with the first group revealed that the needs were similar to the eight needs identified in Hampe's (1975) study. This baseline data set was used to devise a standardized nursing care plan aimed at meeting the needs of spouses of critically ill patients.

The second group of 13 spouses was interviewed after the nursing care plan had been instituted for at least three days. The study revealed that the needs of spouses were met more consistently when a standardized nursing care plan was implemented. The nursing care plan included such interventions as providing a primary nurse for each shift, flexible visiting hours, and a consistent sharing of information between nurse and spouse. Thus it was found that family members' needs were more consistently met when nurses were provided with knowledge about caring for family members of critically ill patients (Dracup & Breu, 1978).

This study considered the needs of family members by, firstly, allowing the family members to identify their needs and, secondly, by devising and implementing a plan to meet these needs. Although this study provided a good foundation for identifying the needs of a critically ill patients' family members, it was specific to coronary patients. Also, the researchers investigated the family members' perception of their needs and not their perception of the importance of their needs. This study did not examine demographic factors that might influence the family members' response.

These studies have provided an insight into the needs of family members of seriously ill hospitalized patients. The following section will examine the research studies on the needs of family members when a patient is hospitalized in the ICU.

### **Needs of Family Members During the ICU Phase of Hospitalization**

The literature indicates many factors that influence the needs of family members during the ICU experience. Some of those most frequently mentioned are: (1) the severity of the patient's illness, (2) the unfamiliarity of the ICU environment, (3) the possible temporary relocation of family members, (4) the financial concerns related to loss of work and increased expenses, (5) the disruption of sleep, and (6) the witnessing of other families losing a loved one (Daley, 1984; Elliott & Smith, 1985; Fowler Byers, 1983; Hampe, 1975; Molter, 1979). There is agreement in the literature that family members of critically ill patients in the ICU have specific needs. This discussion will examine the available literature about family members' needs.

Three research studies which are non-specific for disease entity relate to the needs of family members of critically ill patients during the ICU experience. The first of these is based on Hampe's (1975) study. Molter (1976) investigated the needs of family members of acutely ill patients in the ICU. Unlike Hampe, Molter expanded her subject group to include family other than spouses. She used an exploratory descriptive research design to identify the needs of these subjects. Forty family members of patients who had initially been in the ICU for three days or longer and then on a general ward for forty-eight hours or less were asked to rate the importance of

forty-five need statements. These need statements were developed from Hampe's findings of eight central needs of grieving spouses. The rating system was a four-point Likert-type scale. The study's findings revealed that "relatives were able to identify easily the needs they had while the patients were in the intensive care unit" (Molter, 1979, p. 337). This finding was consistent with that of Hampe. A major finding of Molter's (1976) study was a consistently identified need for hope. Other important needs related to receiving adequate and honest information, and feeling that health professionals cared about the patient. However, both Molter's and Hampe's studies were non-specific for the disease condition of the patient population. In addition, neither of these studies gathered demographic data that might have explained any potential influences upon the family members' responses. Although Hampe did gather some data to explain why family members perceived needs as important, Molter did not investigate this aspect.

A second study, similar to Molter's (1976), was conducted by Daley (1984). This study involved asking family members of ICU patients to rate their needs during the initial seventy-two hour period of the patient's hospitalization in the ICU. The structured interviews were conducted within this time period. An instrument using 46 need statements and a Likert-type rating scale was utilized in this study. Daley included forty family members in her sample and used an interview guide similar to Molter's. Similar findings were revealed in both studies. The difference in the findings was that the need for hope, which was ranked highest in Molter's study, was rated slightly lower by Daley's sample. The need for information about the patient ranked highest among Daley's subjects. Daley suggests that this

difference might be due to the fact that Molter's study was retrospective; that is, the data were collected within the first 48 hours after the patient was out of ICU.

Although Daley's (1984) study examined the needs of family members of critically ill patients, it too was non-specific for disease condition and did not gather demographic data that might explain any potential influences upon the family members' responses. As with Molter's (1976) study, Daley's study did not ask family members to provide a rationale for their ratings.

A third study relating to the needs of family members of patients in the ICU was completed by Gillis (1981). The purpose of this study was to explore the expressed needs of family members of patients in an ICU, and the perceived importance of these expressed needs, according to the age of the family member and the age of the patient. A descriptive design was used, with a convenience sample of 51 family members. The semi-structured interviews were conducted within the first three to ten days of the patient's ICU admission. The interview schedule was developed by Gillis (1981) based upon a review of the literature. It covered two content areas: self-care needs and psychosocial needs. The schedule consisted of 55 questions. A five-point Likert-type scale was used to evaluate the importance of each need.

The study findings indicated that the self-care needs for physical health and for hygiene were important, while the needs for activity and rest were not important. The four categories of psychosocial needs were considered important and were ranked as follows: (1) the need for information, (2) the need to be with the patient, (3) the need for care involvement, and (4) the need for support and discussion of feelings. There was no relationship

between the importance of a need and the age of the subject or the age of the patient. Although this study examined the perceived importance of needs by family members of ICU patients, it was, once again, non-specific for disease entity.

The subject of needs of family members of ICU patients has received considerable research attention within the last ten years. It is now well established that serious illness and hospitalization represent a crisis, or at least a potential crisis, for the family members (Daley, 1984; Gillis, 1981; Molter, 1979). Several research studies that identify the specific needs of spouses and family members in general have been described. The studies, however, are non-specific for disease entity.

The following section will examine the relationship between the needs of family members during the ICU experience and the effect on the patient's hospitalization and recovery process.

### Effect of Family Members on the Critically Ill Patient's Recovery Process

An abundance of research supports the belief that involvement of nursing staff with family members benefits patients, family members, and staff members (Gardner & Stewart, 1978; King & Gregor, 1985; Lust, 1984; Rasie, 1980). Rasie (1980) suggests that family members' anxiety and worry often are transferred to the patient, as the family members look to the patient for reassurance. On the other hand, calm family members can aid patients in dealing with their fears about the ICU environment and the illness. They can also help orient the patient to reality, for what is more familiar and real than a patient's family member (Rasie, 1980)?



Over the last decade, several studies have been conducted which involved family members of patients with specific diseases or forms of medical or surgical intervention. The following are two studies which deal with the effect of family members on the patient's recovery.

Chatham (1978) suggested that effective involvement of patients and their family members in the ICU improved the psychological state of the open-heart surgery patient. To test this theory, she undertook an eight week clinical study to determine if the quality of patient-family member interaction following open-heart surgery would influence the patients' behavior. The study involved a control and an experimental group each consisting of 10 males aged 45 to 64 years. The family member who most consistently visited the patient was selected for the study. In all cases, it was a spouse. These ten spouses were instructed to use specific gestures and mannerisms when interacting with their mates in the ICU. Each spouse used eye contact, frequent touch, and verbal orientation to time, person and place while visiting the spouse for 10 minutes, three times each day. These instructions were the only difference between the two groups. An eleven item "Behavioral Checklist" was used to rate the patients' behaviors on a five-point Likert-type scale. The findings revealed that involvement of family members who had been instructed in their interaction with the patient favorably affected certain patient behaviors. The subjects in the experimental group were more oriented, more appropriate, less confused, had fewer delusions, and slept longer than the subjects in the control group.

This study supported the involvement of family members with critically ill post open-heart surgery patients. These findings provided sufficient

evidence that trained involvement by family members in the care of any critically ill patient is beneficial to the patient (Chatham, 1978). Chatham noted that all family members in the experimental group were anxious and concerned about what they could do to promote their family member's recovery. The family members, however, identified that they lacked direction and knowledge of what they could do to be helpful. This seems to indicate that family members may have needs for education on how to be helpful to the patient.

A second study, by Doerr and Jones (1979), examined the effect of preparing family members for the Coronary Care Unit (CCU) experience upon the state anxiety level of the CCU patient. Conducted in an 18-bed CCU, the study included an experimental group in which the family members were prepared for visiting the subject, and a control group in which there was no such preparation. Each group consisted of six subjects. The family members who were prepared for visiting the CCU received an information booklet which contained answers to what are considered the most commonly asked questions from family members about the CCU. The findings indicated that there was no significant difference on pre-visitation state anxiety level scores between the experimental and control group. Post-visitation state anxiety scores, however, demonstrated a statistically significant difference. Patients whose family members were prepared for visitation showed a significant mean decrease on the State Anxiety Scale between pre and post-visitation state anxiety level scores. However, the patients whose family members did not receive preparation for visitation showed a mean increase on the State Anxiety Scale. Doerr and Jones therefore concluded that family member

preparation significantly reduced the amount of anxiety transferred from the family member to the patient.

The two studies by Chatham (1978) and Doerr and Jones (1979) were based on the assumption that family members had specific needs, and research was conducted to determine the effect, on the patient, of meeting these needs. However, there is little published research to confirm the perceived needs of family members of critically ill patients. Further, the literature has focused on identifying needs from the health care professional's perspective (Daley, 1984). More research is needed that examines the special needs of family members of critically ill patients with specific diseases to determine if their needs are different from other family members of ICU patients.

The final section will examine the needs of family members of patients with a specific disease entity -- brain-injured patients.

#### **Needs of Family Members of Brain-Injured Patients**

This final section is divided into two parts. In the first part, the needs of family members of non-ICU, but hospitalized, brain-injured patients will be discussed. In the second, a review of two studies of family members of critically ill brain-injured patients during the ICU experience will be presented.

During the last decade, research on family members of critically ill patients has included a patient population not previously considered, that is, critically ill brain-injured patients. Rogers and Kreutzer (1984) state that recent advances in the treatment of brain injury have contributed to substantial increases in survival rates, and thus have been instrumental in

initiating research interest in this condition. "Recently, professionals have begun to recognize the special needs of family members following brain injury" (Rogers & Kreutzer, 1984, p. 343).

A pilot project done in 1981 involved a family support group for hospitalized, non-ICU, brain-injured patients. Quinn, Ford and Mazzaway (1981) identified that family members of brain-injured patients have special needs due to the nature of the patient's disease or illness. The patient's physical dysfunctions, which impair both basic physical functions and the higher processes of the mind, along with the psychosocial alterations the patient experiences, create special needs for family members. Quinn and colleagues (1981) developed a family support group to allow family members the opportunity to express their thoughts and feelings about their experiences, expectations and needs. The family members' evaluation of the group provided insight into their needs and concerns. The need for basic information on such topics as parking, location of cafeteria, availability of chaplains, and visiting hour times was identified. Other important needs concerned open visiting hours, knowing what was happening to the patient in terms of medical and nursing care, and knowing how to access information about their loved one.

Although Quinn's (1981) study did not investigate the needs of family members of brain-injured patients during the ICU experience, the findings are similar to the needs that were identified for family members of ICU patients. This suggests that the needs of family members may be similar regardless of the type of injury or illness of the patient. It also suggests that because of the physical and psychological alterations of the brain-injured patient, these

family members may have ongoing needs that are similar to those of family members of ICU patients. However, the available research is minimal, and further studies need to be conducted before definite conclusions can be made.

Two studies have examined the needs of family members of critically ill brain-injured patients. The first study was a retrospective one, whereas the second was conducted while the patients were still in the ICU.

A pilot study by Mauss-Clum and Ryan (1981) examined the needs of family members of veterans participating in an outpatient Brain Injury Rehabilitation Unit. This was a retrospective study involving family members of male patients only. Patients had experienced either traumatic brain injuries, vascular accidents, or conditions such as Alzheimer's disease or Parkinson's disease. Questionnaires composed of short answer questions were completed by thirty family members. Family members were asked to identify the needs they had felt during the period when the patient was in the ICU. The needs most commonly identified by this method were: (1) the need for a clear explanation of the patient's condition, (2) the need to discuss realistic expectations for the patient's progress, (3) the need for hope, (4) the need for financial counselling, and (5) the need for information about community resources. The needs for financial and resource counselling were noted as important, but not of immediate concern during the ICU period. Again, no background information was sought which might explain why subjects identified particular needs as important or unimportant.

The needs identified by Mauss-Clum and Ryan (1981), as well as Quinn and colleagues (1981), are similar to the needs reported for family members of all critically ill patients regardless of their medical condition. Rogers and

Kreutzer (1984), however, promote the view that family members of critically ill brain-injured patients have different needs than family members of other kinds of critically ill patients. Elliott and Smith (1985) claim that the unresponsiveness of the brain-injured patient, the unpredictability of outcome, and the prolonged recovery period place unusual stress upon the family members of this group of patients. Mathis (1984) supports this view and suggests that the difference in family members' perceptions of need importance may be due to lack of communication. This lack of communication is often a result of the diminished physical response that family members receive from brain-injured patients due to their unconscious state.

To determine if there was a difference between the needs of family members of critically ill ICU patients with and without brain injury, Mathis (1984) conducted a comparative descriptive research study. This study utilized an instrument consisting of forty-five need statements. This instrument was similar to the one Molter (1976) used to assess the needs of family members of critically ill patients. Mathis' sample consisted of two groups. She selected fifteen family members of critically ill patients without an acute brain injury and eleven family members of critically ill patients with an acute brain injury. The findings revealed that both groups identified similar needs but the ranking of the needs varied slightly. Of the ten most important need statements for each group, two items were ranked differently. Family members of patients with an acute brain injury identified as important the need to be told how their relative was being treated medically and the need to feel accepted by hospital personnel. Family members of patients

without an acute brain injury identified those needs, but ranked them lower in importance. In contrast, they ranked as very important both the need to know their relative's chances of becoming well and the need to have explanations given in understandable terms. Apart from these differences, the remaining eight needs identified for both groups were identical and also similar to Molter's findings.

It is interesting to note that more than half of the family members in Molter's (1976) and Mathis' (1984) studies reported four need statements to be unimportant. These four statements were: (1) to have visiting hours changed because of special conditions, (2) to talk to someone about negative feelings, (3) to be encouraged to cry, and (4) to have another person along with them when visiting the relative at the bedside. It is reasonable to suppose that each of these need statements may have been rated as unimportant because of factors in the setting of the particular study. For example, subjects' ratings in regard to visiting hours may have been due to the fact that the particular ICU had open visiting hours. The reason why these needs were unimportant was not explored in either study. To conclude that these needs were generally unimportant to family members of critically ill patients would be premature.

A study that expands on Mathis' (1984) study, by repeating the use of ratings and asking why family members rate needs as important or unimportant, would add depth to the findings of previous researchers. Another aspect that has not been examined adequately involves demographic data that might identify factors influencing the family members' ratings. Relevant demographic variables as suggested in the literature would include

(1) the patient's condition, (2) the family member's personal environmental supports, (3) the family member's previous exposure to the ICU, and (4) the family member's personal circumstances such as financial loss (Daley, 1984; Elliot & Smith, 1985; Fowler Byers, 1983; Molter, 1979).

This section has discussed literature about the needs of family members of brain-injured patients. The literature suggests that family members of critically ill brain-injured patients have special needs. It also suggests that these family members perceive the importance of needs differently than family members of non-brain-injured critically ill patients.

### Summary

This literature review has discussed four areas related to the needs of family members of seriously ill patients. In the first section, three studies which investigated the needs of family members of seriously ill hospitalized patients were reviewed. The findings of these studies illustrate the common needs family members face when a patient is hospitalized. Section two examined several research studies, that verify the findings discussed in section 1, with a specific patient population: ICU patients. These studies, however, did not investigate the family members' rationale for their perceived importance of needs, nor did it examine demographic factors that may influence the perceived importance of these needs.

The next section reviewed literature relating to the effect of family members on the patients' hospitalization and recovery process. This literature supported the view that if needs of family members of critically ill patients are unmet, there may be a negative effect on patients' recovery (Fowler Byers, 1983; Roberts, 1976). The final section presented a review of literature related



to a specific patient population, brain-injured patients. This section was divided into two parts. The first part reviewed literature relating to needs of family members of hospitalized, brain-injured patients. The second part examined research relating to the needs of family members of brain-injured patients who are hospitalized in an ICU. This literature suggested that family members of critically ill brain-injured patients may have the same needs as those of other critically ill patients. However, other research suggested that there may be differences in the perceived importance of needs for these two groups of family members.

Research to date has sought mainly quantitative measurement of specific needs; no attempt has been made to elicit reasons for ratings given to individual responses. Hampe's research (1975) was the only study that examined why family members, specifically spouses, perceived needs as important. Her study, however, did not involve a rating scale, nor did it examine needs that may have been perceived as unimportant. No subsequent study has addressed the perceived importance of needs of family members of critically ill patients while eliciting the family members' rationale and examining influencing demographic data. Therefore, this thesis is designed to provide such documentation.

This chapter has provided an overview of relevant literature pertaining to the subject of the perceived importance of needs of family members of critically ill brain-injured patients. The following chapter will detail the methodology used to investigate this question.

## CHAPTER THREE: RESEARCH DESIGN

### Introduction

This study used an exploratory descriptive design to describe the perceived importance of selected needs of family members of critically ill brain-injured patients. The exploratory descriptive design was the most appropriate since the researcher's intent was to describe what exists in terms of frequency of occurrence (Polit & Hungler, 1983). Data were gathered by means of a structured interview using a predetermined schedule. The sample, setting for the study, data collection procedures, interview schedule, ethical review process, and approach to data analysis will be described in this chapter.

### Sample

A convenience sample of one family member for each of 15 critically ill brain-injured patients was selected for this study.

The criteria for subject selection were as follows:

1. The family member was at least 19 years of age.
2. The family member had visited the patient in the intensive care unit.
3. The family member was identified by nursing staff as having a significant relationship with the patient.
4. The family member spoke fluent English.

As indicated in Chapter One, the critically ill brain-injured patient has been defined as a person, 19 years of age or older, who was in an ICU for at least three days and then on a general nursing unit or in a step-down unit

for 72 hours or less. The definition further required that the patient must have had a period of unresponsiveness to verbal command for at least four hours following the traumatic or vascular brain injury. Due to difficulties in obtaining subjects for the study, several of the criteria in the definition of the critically ill brain-injured patient were changed.

The first criterion to be altered concerned the amount of time the patient was hospitalized on a general unit or in a step-down unit. Initially, the time period was 72 hours or less. However, only the first subject interviewed met this criterion. The next three potential subjects were lost to the study since they did not visit their family members within the first 72 hours that the patient was on the ward. Thus, the restrictive time period was eliminated. Due to further difficulties seeking access to family members of hospitalized brain-injured patients, family members of brain-injured patients in the community were included. The time period was therefore expanded to a maximum of five years post-trauma.

The second criterion that was adjusted concerned the age of the critically ill brain-injured patient. The original definition stated that the patient was 19 years of age or older. However, due to the limited number of potential subjects, and the time constraints of the researcher, this criterion was changed to include patients 15 years of age or older.

Thus, the following revised definition of the critically ill brain-injured patient was used to guide the data collection for the study: a person, 15 years of age and older, who had sustained a sudden and unexpected brain injury through traumatic or vascular accident. The patient must have been in the ICU for at least three days. The patient must have been unresponsive to

verbal command for at least four hours after the accident.

The sample of 11 females and four males was interviewed within a three-month period. Thus, a total of 15 subjects were involved in data collection.

The relationships of the subjects to the patients varied. There were four wives, two husbands, six mothers, one brother, one son, and one daughter.

Data were collected on 11 subjects whose relatives were still patients in the acute care hospital. For three of these subjects, data were gathered within the first week after the patients were discharged from the ICU. For the remaining eight subjects, the time ranged from two weeks to 14 months after the patient was discharged from ICU. The remaining interviews included family members of four patients who had been living in the community for two to five years since their ICU experience.

### Setting for the Study

The setting for the study varied. Eleven of the subjects were interviewed in one of two hospitals and three subjects were interviewed in their homes. The remaining subject was interviewed at the University of British Columbia since this was convenient for her.

Two hospitals in the British Columbia Lower Mainland were used for data collection. The ICU setting in each hospital was slightly different. In one hospital, a general ICU was the setting. This ICU was a ten bed unit where all critically ill patients received intensive nursing and medical care. It received approximately ten brain-injured patients each month. In the other hospital, a neurosurgical ICU was the setting. However, the neurosurgical ICU had been opened to full capacity only four months before data collection.

Therefore, patients who had sustained their injury prior to this time had been cared for initially in the general ICU that was similar to the ICU previously described. The neurosurgical ICU was an eight bed unit specifically for brain-injured patients who needed intensive nursing and medical care. Thirteen of the patients had been cared for in one of these three ICUs. The remaining two patients had been in ICUs in other parts of Western Canada. The family members' descriptions of these ICUs were similar to the general ICUs used in this study. Thus, all 15 subjects were judged to have had a similar ICU experience.

### **Ethics and Human Rights**

Permission to conduct this study was obtained from the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects, and four tertiary care hospitals in British Columbia.

Ethical considerations in relation to the way in which the subjects were approached and the nature of the consent form were addressed in the following manner. Subsequent to receiving a written (Appendix A) and verbal description of the study, subjects who had agreed to participate in the study were asked to sign a letter of consent (Appendix B). All subjects were informed that their participation was voluntary. The researcher assured subjects that confidentiality would be maintained, that they could withdraw from the study at any time, and that withdrawing from the study would in no way affect the care of themselves or their family members. Subjects' names were not mentioned on the audio-tapes, written on the questionnaires, or included in the thesis. The audio-taped recordings of the interviews were

erased, and the questionnaires were destroyed upon completion of the written reports.

### Data Collection Procedure

After approval was granted from each hospital, the researcher met with the Head Nurse of both the neurosurgical ward and the ICU. At this time the study was explained, and a copy of the proposal was provided. Daily telephone calls to the ICU were made in order to identify potential subjects. When subjects were identified by the Head Nurse, the researcher visited the hospital and placed an "Information Sheet" (see Appendix A) on the patients' chart. Once the patients were transferred to the Neurosurgical Ward, the researcher contacted the Charge Nurse to see if the "Information Sheet" had been given to the family member. If the family member agreed, the researcher made telephone contact to arrange a mutually convenient interview time.

This approach was ineffective, primarily because the family members visited when the Charge Nurse was off duty, and staff nurses were less reliable about distributing the forms. Only one subject was recruited by this approach within one month. Thus, a second approach was devised to avoid missing potential subjects. Once the patients were transferred to the neurosurgical ward, the researcher visited the hospital and remained on the ward during visiting hours. This approach also proved ineffective since the identified potential subjects did not visit before the first three days on the ward had passed. At this time it was decided that changes in the subject selection criteria were necessary to permit the study to be conducted.

For the first two months, the researcher had approval at only one hospital and was awaiting approval at the second. Because of the aforementioned delays in recruitment two additional hospitals were approached for approval to conduct this study. Concurrently, subjects were recruited through informal networking. That is, an information letter explaining the study and requesting subjects was posted in the graduate student study room at U.B.C. The criterion that the critically ill brain-injured patient was to have been on the ward less than three days was deleted. Thus, family members of brain-injured people in the community were also recruited for the study. In these cases the researcher's colleagues obtained verbal consent from potential subjects they knew, and then the researcher made telephone contact to arrange a mutually convenient interview time. A total of four subjects were recruited in this manner.

Approval was eventually received from the second hospital, and again the Head Nurse of the ward and ICU were approached. In several cases, the Head Nurse of the ward identified potential subjects and obtained verbal consents to participate in the study. The researcher then made either personal or telephone contact with the subjects, and arranged a mutually convenient interview time. In the remaining cases, the researcher either approached potential subjects in the hospital and gave them the "Information Sheet" or left it at the patients' bedside. If personal contact was made, verbal consent was obtained, and an interview time was established. If the "Information Sheet" was left at the bedside, the researcher made personal or telephone contact three to four days later.

A list of potential subjects was generated by the Head Nurses to aid the researcher in subject recruitment. If, for any reason, the Head Nurses felt that a family member should not be approached, this request was respected. At one hospital, the neurosurgeons requested to be informed if their patients' family members were involved in the study. This was accomplished by telephoning their offices.

Only two family members who were approached refused to participate in the study. One family member was returning "up north" that day, so he was unable to participate. The second family member who refused did not explain her reasons.

The data collection procedure, unlike the subject recruitment procedure, was consistent. At the beginning of the interview, the researcher reviewed the purpose of the study. She assured subjects that confidentiality would be maintained, that they may withdraw from the study at any time, and that withdrawing from the study would in no way affect their family member's medical or nursing care. The family members were also given an opportunity to ask the researcher any questions about the study. Once all questions were answered, the researcher obtained the family member's written consent, and a copy was given to the family member. The interviews were conducted in a private room on the neurosurgical ward, in the subjects' home, or, in one case, at the university.

The interviews ranged from 30 to 60 minutes in length with the majority taking 45 minutes. In the case of the hospital interviews, the ward staff was told the whereabouts of the family members. This was done to assure family members that they could be reached immediately if necessary.



Demographic data were obtained from the patients' medical records and from the subjects at the beginning of the interviews. Data concerning the patient's age, diagnosis, onset of brain injury, and the length of time the patient was unresponsive to verbal command were obtained from the medical records. Data concerning the subject's relationship to the patient, the subject's usual and present living arrangements, and the subject's familiarity with the city, hospital, and ICU were obtained from the subjects at the beginning of the interview.

All subjects were easily able to recollect their needs during the ICU experience. In addition to clearly articulating the perceived importance of selected needs during the ICU experience, subjects whose family members had been discharged from hospital were eager to express their frustration at the lack of community resources for brain-injured people. The researcher listened to their comments and empathized with their situation. The content of these discussions provided implications for further research.

### **Interview Schedule**

Data were obtained from audio-taped interviews and the patients' medical records. The researcher developed a structured interview schedule (Appendix C) since no single previously developed instrument was found that would elicit the required data. The guide consisted of twenty need statements that the subjects were asked to rate verbally on a four-point Likert-type scale. The four choices of responses to the statements were presented on a five-by-eight inch card and given to the subjects for easy reference. The researcher recorded the ratings. After rating each statement, the subjects were asked to explain the rationale for their rating. The

open-ended question allowed for richer and fuller responses that enabled the researcher to understand why family members perceived the needs as important or unimportant.

The twenty need statements which comprise the interview guide were drawn from the studies by Molter (1976) and Mathis (1984). Although Molter and Mathis used forty-five need statements, twenty were selected for this study. This researcher felt that asking subjects to provide rationale for ratings of more than twenty need statements would be inappropriate because of the amount of time and concentration required by the subjects. The twenty need statements selected for this study included the ten most important needs in Molter's and Mathis' studies as well as the four unimportant needs identified in their studies. The remaining six needs were selected from Molter's and Mathis' interview guides. The selection was based on the researcher's clinical experience.

Sequencing of the need statements was intended to arouse the subjects' interest and provide comfort in the interview context. General demographic information was collected at the beginning to give the subjects time to feel comfortable with being interviewed. Need statements relating to the physical environment were placed at the beginning of the interview, whereas those of a more personal, sensitive nature were placed at the end. The structured format of the interview schedule was designed to maintain objectivity and reduce interviewer bias.

### **Reliability and Validity**

The twenty need statements in the proposed interview guide were used in Molter's (1976) and Mathis' (1984) studies. In Molter's study, the need

statements were developed by the researcher through a literature review and then examined by a panel of experts. A similar approach was used by Mathis to establish content validity; a list of needs compiled by nurses was reviewed by two ICU nurses and a nurse who had a relative in the ICU. In order to assure content validity, this study's interview guide was submitted to a neurological nursing clinical instructor and two ICU staff nurses. No additional need statements were recommended.

As with Molter's (1976) and Mathis' (1984) studies, an interview schedule using a Likert-type scale was used in this study. However, Molter did not address the issue of reliability, and Mathis stated that she tested for reliability using Cronbach's coefficient alpha. However, Mathis did not say what reliability she was testing. Based on the information provided by Molter and Mathis, it is difficult to ascertain reliability of the proposed interview guide. However, Likert-type scales are usually considered relatively reliable (Nunnally, 1970) in rating such concepts as the importance of needs.

### Data Analysis

The interviews were reviewed by the researcher as data were collected. An item by item descriptive analysis of the open-ended questions was done to determine the nature of the responses. Responses similar in content were grouped and categorized. Then the frequency of responses was tabulated and analyzed to explain the ratings.

Descriptive statistics were used to analyze the data obtained from the rating of need statements as well as the demographic data. The data obtained from ratings were summarized using three methods of rank ordering as described by Molter (1976). The relative order of ranking was considered

in relation to Molter's and Mathis' (1984) ranking where appropriate.

### **Summary**

This chapter has presented the research methodology examining the sample, setting, ethical considerations, data collection procedure, interview schedule, and finally data analysis. The following chapter will present the findings of this study.

## CHAPTER FOUR: PRESENTATION OF FINDINGS

### Introduction

This chapter will present the findings of this study. The first section describes the sample population, including the patients as well as the family members. The second section presents the results of the study in relation to the first research question; that is, how do family members rate the importance of selected needs? Section three addresses the findings in relation to research question two, which asks what factors are associated with the ratings of need importance. The final section presents the findings related to the family members' rationale, research question three.

### The Sample

#### Selected Characteristics of the Subjects

This section will present descriptive statistics on the patients' and family members' demographics.

Relationship to Patient. One family member for each of 15 patients participated in the study. The relationship of the family member to the patient varied but all were related through kinship or marriage. Table I presents a summary of the subjects' relationships to patients.

All subjects were recruited by the Head Nurse of the ICU or, in the case of subjects obtained in the community, by the researcher's nursing colleagues.

Living Accommodations of Subjects. Of the sample population, 9 subjects (60.0%) normally lived with the patient; the other 6 did not. Eleven subjects (73.3%) were visiting the patient in an ICU located in their hometown. Two subjects (26.7%) had to relocate with the patient to a

**Table I**  
**Subjects' Relationship to Patients**

| RELATIONSHIP | FREQUENCY<br>N = 15 | PERCENT |
|--------------|---------------------|---------|
| Mother       | 6                   | 40.0    |
| Wife         | 4                   | 26.7    |
| Husband      | 2                   | 13.3    |
| Brother      | 1                   | 6.7     |
| Son          | 1                   | 6.7     |
| Daughter     | 1                   | 6.7     |

tertiary care hospital in another city since the patients required advanced medical technology that was unavailable in their hometown. The remaining two subjects were in a major city other than their hometown when the injury occurred. These subjects stayed with the patients until they were able to transfer to a hospital in their hometown. Hence 4 subjects (26.7%) had to deal with an unfamiliar city and hospital environment.

Supports. An examination of the subjects' personal support revealed that all but one subject had support available at the time their loved one was in ICU. The subject who lacked personal support had to relocate to a neighbouring province and had no family or friends with her most of the time that her son was in ICU. All other subjects had family, friends, or both available during the ICU experience.

Previous ICU Experience. A final factor that was examined concerned the subjects' previous experience with an ICU. Two subjects (13.3%) were

nurses and thus were familiar with this environment through their profession. Five subjects (33.3%) had a previous experience with an ICU environment with another ill family member. Eight subjects (53.3%) had no previous ICU experience. A summary of the data relating to the subjects' living accommodations, supports, and previous experience with an ICU are presented in Table II.

### **Selected Characteristics of the Patients**

Family members of 15 patients were involved in this study. Selection criteria for the critically ill brain-injured patient were that they be 15 years of age or older, and in an ICU for at least three days after sustaining a sudden and unexpected brain injury through traumatic or vascular accident. An additional criterion was that the patient had been unresponsive to verbal command for at least four hours after the accident.

Gender and Age. The patients included ten males and five females. They varied in age from 15 to 68 years with a mean of 35 years and a median of 29 years. Complete data on the patients' gender and age are included in Table III.

Type of Injury and Patient Selection. All patients sustained their brain injury through trauma, vascular accident, or both. One patient was hospitalized following a car accident which involved a single motor vehicle. On examination, a ruptured cerebral aneurysm was diagnosed, but it was impossible to conclude if the ruptured aneurysm had caused the motor vehicle accident or the reverse. Ten patients (66.7%) sustained a brain injury as the result of trauma, specifically a motor vehicle accident (MVA) and four patients (26.7%) received a brain injury as the result of a vascular accident, specifically a ruptured cerebral aneurysm.

**Table II**  
**Subjects' Living Accommodations, Supports**  
**and Previous ICU Experience**

| CHARACTERISTIC                                  | FREQUENCY | PERCENT |
|---|-----------|---------|
| Living Accommodations:                          |           |         |
| Lives with patient                              | 9         | 60.0    |
| Lives elsewhere                                 | 6         | 40.0    |
| Total   | 15        | 100.0   |
| Hometown ICU                                    | 11        | 73.3    |
| Out of town ICU                                 | 4         | 26.7    |
| Total   | 15        | 100.0   |
| Supports:                                       |           |         |
| Family  | 3         | 20.0    |
| Friends   | 1         | 6.7     |
| Family and Friends                              | 10        | 66.7    |
| None  | 1         | 6.7     |
| Total   | 15        | 100.0   |
| Experience with ICU:                            |           |         |
| Previous ICU experience<br>with a family member | 5         | 33.3    |
| Previous ICU experience<br>through work         | 2         | 13.3    |
| No previous ICU experience                      | 8         | 53.3    |
| Total   | 15        | 100.0   |



Table III  
Distribution of Subjects by Sex and Age

|         | FREQUENCY | PERCENT |
|---------|-----------|---------|
| SEX:    |           |         |
| Male    | 10        | 66.7    |
| Female  | 5         | 33.3    |
| Total   | 15        | 100.0   |
| AGE:    |           |         |
| 15 - 19 | 4         | 26.7    |
| 20 - 29 | 4         | 26.7    |
| 30 - 39 | 2         | 13.3    |
| 40 - 49 | 1         | 6.7     |
| 50 - 59 | 1         | 6.7     |
| 60 - 68 | 3         | 20.0    |
| Total   | 15        | 100.0   |

The sample was obtained through patients presently in the hospital and through ex-patients who were now back in the community. Eleven (73.3%) of the patients were still hospitalized when their family member was interviewed for this study. The remaining four (26.7%) had been discharged from hospital for two to five years.

Time in ICU and Time Since Injury. All 15 patients were in the ICU for a minimum of six days. The range was from six to 40 days, with a mean of 17.7 and a median of 18 days.

The time since the patients' injuries ranged from nine days to five years. The mean and median were 391.1 and 119.0 days, respectively. It appeared

that, for this sample, the ratings of the perceived importance of need statements did not differ over time. Complete data of the number of days in ICU and the number of days since injury are reported in Tables IV and V.

**Table IV**

**Days in ICU**

| DAYS    | FREQUENCY | PERCENT |
|---------|-----------|---------|
| 6 - 10  | 4         | 26.7    |
| 11 - 15 | 3         | 20.0    |
| 16 - 20 | 3         | 20.0    |
| 21 - 30 | 3         | 20.0    |
| 31 - 40 | 2         | 13.3    |
| Total   | 15        | 100.0   |

**Table V**

**Days Since Injury**

| DAYS        | FREQUENCY | PERCENT |
|-------------|-----------|---------|
| 0 - 10      | 1         | 6.7     |
| 11 - 20     | 2         | 13.3    |
| 21 - 40     | 2         | 13.3    |
| 41 - 70     | 1         | 6.7     |
| 71 - 100    | 1         | 6.7     |
| 100 - 200   | 2         | 13.3    |
| 201 - 500   | 3         | 20.0    |
| 501 - 1000  | 1         | 6.7     |
| 1001 - 1802 | 2         | 13.3    |
| Total       | 15        | 100.0   |

This section has provided descriptive statistics on the demographics of the patients and family members involved in this study. The following section will present the results of the study in relation to the first research question.

### **Ratings of Selected Needs of Family Members of Critically Ill Brain-Injured Patients**

Research question one asked "How do family members of critically ill brain-injured patients rate the importance of selected needs?" To answer this question, the subjects were asked to rate 20 need statements on a four-point Likert-type scale. Four categories were used in assigning values to the degree of perceived importance of the need statements. These were:

- |    |                    |                         |
|----|--------------------|-------------------------|
| 1. | Not Important      | Category value number 1 |
| 2. | Slightly Important | Category value number 2 |
| 3. | Important          | Category value number 3 |
| 4. | Very Important     | Category value number 4 |

The method of rank ordering used by Molter (1976) was adopted for this study. The number of responses in each category was multiplied by the category value number for each need statement. A total score for each need was calculated by adding the numbers obtained in the previous step. Thus, a total score for each need for all subjects in all categories was obtained. The possible range of scores was 15 to 60. For this study, the range of scores was 28 to 60. The ranking of the 20 need statements is presented in Table VI. In ordering the subjects' ratings of need statements several statements received the same rank. That is, need statements 2, 3, and 4 received the same value. In addition, need statements 6 and 7, and 8, 9, 10, and 11 received the same

value. Finally, need statements 17 and 18 received the same rank.

**Table VI**

**Ranking of Perceived Importance of Needs**

**From Most Important to Least Important**

- 
- |     |   |
|-----|---|
| 1.  | To have been given information every day about the patient.                               |
| 2.  | To have been able to visit at any time.   |
| 3.  | To have had questions answered honestly.  |
| 4.  | To have felt there was hope.  |
| 5.  | To have known that I would be called at home about changes in the patient's condition.    |
| 6.  | To have been reassured that the best possible care was being given to the patient.        |
| 7.  | To have known the prognosis.  |
| 8.  | To have known exactly what was being done for the patient.                                |
| 9.  | To have been told about how the patient was going to be treated medically.                |
| 10. | To have felt accepted by hospital personnel.  |
| 11. | To have felt that hospital personnel care about the patient.                              |
| 12. | To have had explanations given in terms that were understandable.                         |
| 13. | To have had a waiting room near the patient.  |
| 14. | To have had directions about what to do at the bedside.                                   |
| 15. | To have talked to someone about negative feelings such as anger or guilt.                 |
| 16. | To have had explanations of the environment before going into the ICU for the first time. |
| 17. | To have been assured that it was alright to leave the hospital for a short while.         |
| 18. | To have been encouraged to cry.   |
| 19. | To have had a place to be alone while in the hospital.                                    |
| 20. | To have had more than one or two people able to visit at the same time.                   |
- 

Second and third ranking methods, as performed by Molter (1976), were used to verify the initial rankings and identify any responder bias. The second method involved multiplying the number of responses in each category, except the "Not Important" category, with the category value numbers. The sum of the three categories was the total score for each need

statement, thus giving a total score for each need for all subjects in three categories. The possible range of scores was 0 to 60 and, for this sample, the range was 18 to 60. The only difference in rankings between the two methods was that, in method two, need statements 12 and 13 received the same rank. Thus, there was no major difference in results obtained with the two ranking methods.

The third ranking method involved multiplying the number of responses in the "Not Important" and "Very Important" categories with their respective values of one and four. The sum of these two categories gave a score for the need. The possible range was 15 to 60 and, for this sample, the range was 17 to 60, indicating a broad range of responses. There was no difference in the ranking among all three methods.

In comparing the results of this sample with Molter's (1976) sample of 40 family members of critically ill patients, the ranking varied slightly. Using the same ranking method, Molter's ten most important need statements are as follows:

1. To feel there is hope.
2. To feel that hospital personnel care about the patient.
3. To have the waiting room near the patient.
4. To be called at home about changes in the condition of the patient.
5. To know the prognosis.
6. To have questions answered honestly.
7. To know specific facts concerning the patient's progress.
8. To receive information about the patient once a day.
9. To have explanations given in terms that are understandable.
10. To see the patient frequently.

In comparing the first ten most important needs, all but three were identical. One of these three needs (number 7) was not included in this study since it was combined with another need--that is, the need to have known exactly

what was being done for the patient. The wording of statements eight and ten was changed slightly, but the meaning was similar.

The differences between the findings of this study and Molter's (1976) lies in the perceived importance of the need statements. Both samples identified the needs as important, but the relative degree of importance varied. In Molter's (1976) study, the most important need for the family members of critically ill patients with various diseases was to have hope. In this study, the most important need for family members of critically ill brain-injured patients was the need to receive information daily about the patient. The need for hope, along with the needs to visit at any time and to receive honest answers to questions, was the second most important need. In Molter's (1976) sample, the need to receive information daily about the patient received a lower priority and was ranked as the eighth most important need statement.

The data from Mathis' (1984) study were used to compare the findings of this study with those of a similar sample population--that is, family members of critically ill brain-injured patients. In order to compare the studies, the results of Mathis' study had to be rank ordered using Molter's method. This was possible since the raw data were available in the written report (Mathis, 1984). Once again, the same category values were used, and the number of responses in each category was multiplied by the category value number. A total score of the need statement for each of 11 subjects whose family member had sustained an acute brain injury was then calculated by adding the four categories. The possible range of scores was 11 to 44. The following need statements were ranked as the ten most important

by this sample:

1. To feel that hospital personnel cared about my relative.
2. To know exactly what was being done for my relative.
3. Reassurance that the best possible care was being given to my relative.
4. To have my questions answered honestly.
5. To know I would be called at home if there were any changes in my relative's condition.
6. To feel there was hope.
7. To feel accepted by hospital personnel.
8. To be told about how my relative was going to be treated medically.
9. To have specific facts concerning my relative's progress.
10. To receive information about my relative's condition at least once a day.

Of the ten most important need statements in Mathis' (1984) sample and this study's sample, two need statements differed. In Mathis' (1984) study, the needs to have open visiting hours and to be informed of the prognosis were not ranked among the first ten as they were in this investigator's study. On the other hand, two needs that were included in Mathis' (1984) findings were the need to feel that hospital personnel care about the patient and the need to be given specific facts concerning the patient's progress. It must be noted that, in this investigator's study, the need to have felt that hospital personnel cared about the patient received the same ranking as needs 8, 9, and 10. Thus, the need statements 8 to 11 inclusive had identical scores; all but one of Mathis' (1984) needs were in this study's top ten need statements.

Of the four least important needs in this investigator's study, three were the same as the needs in Mathis' (1984) sample of family members of patients with an acute brain injury. However, the need to be assured that it is acceptable to leave the hospital for a short while received a higher priority in Mathis' (1984) findings than in this study's findings.

Thus, the rankings of this investigator's study and those of the previous

researchers are quite similar. Eight needs -- within the ten most important needs -- were the same for all three studies.

This section has presented the findings related to research question one and compared them with the findings of two similar studies. It appears that family members of critically ill patients have similar areas of concern when their loved ones are in the ICU. The following section will present the findings of this study in relation to the factors associated with the rating of needs and the subjects' rationale for their ratings of the perceived importance of selected need statements.

### **Factors Associated with the Rating of Need Statements**

Research question two asks "What factors are associated with the rating of importance or lack of importance for selected needs?"

To identify common factors among the demographic data, these data were analyzed in relation to the subjects' ratings. That is, common factors among subjects who selected the same need rating were identified and categorized. Along with this method, any factor that may have influenced a specific subject's or groups of subjects' ratings and/or rationale was also analyzed and related to the subjects' ratings of all needs. The investigator found that there were no significant statistical relationships between the demographic data and the subjects' ratings of need statements.



### **Family Members' Perception of the Importance of Selected Needs**

Research question three asks "How do family members of critically ill brain-injured patients explain their perception of the importance of selected needs?" This section will present the distribution of ratings for each need statement and the rationale that subjects provided for their ratings. This investigator found that the relationship between the ratings and the rationale was inconsistent. Most needs were rated as important or very important by all subjects. The slight variation in ranking was due to the ratings of several subjects who consistently selected lower ratings. Also, explanations revealed that most subjects rated a need as not important because the need was unmet, not because it was unimportant. Hence, some subjects based their ratings of need importance on whether the need was met in their specific case. Other subjects based their ratings on whether the need was important to them during the ICU experience.

As the findings for each need statement are presented, the inconsistencies between the ratings and the rationale will be evident. These inconsistencies are not apparent in the first five need statements. In some instances, subjects selected identical ratings yet provided different rationale. This indicated that subjects not only perceived their needs differently, they also interpreted need statements and ratings differently. In other instances, subjects selected different ratings and yet provided rationale which reflected similar beliefs.

These inconsistencies raise serious questions about the usefulness of rating need statements. Previous researchers (Mathis, 1984; Molter, 1976), who used similar rating scales, concluded that family members were easily

able to identify their needs. Analysis of the data of this study leads the investigator to believe that this conclusion may be misleading. This study's findings suggest that family members can easily explain their own experiences. However, since the ratings are inconsistent with the rationale, it is not appropriate to make important distinctions among perceived levels of importance of family members' needs. In other words, it appears that all needs are highly important but for different reasons.

Because the value of using rating scales as a method of data collection is questionable in this area of study, the ratings and the subjects' rationale will be reported separately. Thus, the explanations will not be presented in relation to the ratings as originally intended. Instead, the responses to the question, "Why is the need important/unimportant for you?" have been categorized according to similar themes and will be presented in this fashion. For the first five need statements, however, these inconsistencies are not evident as subjects' ratings and rationale are similar.

**NEED 1: To have been given information every day about the patient**

All 15 subjects rated this statement as very important.

The rationale they provided revealed two themes: wanting to know and not knowing what to expect. Eight subjects (53.4%) stated that they needed information because they cared so much about their loved one, and they felt better knowing what was happening. Six subjects (40%) explained that information was very important because they didn't know what to expect. "I didn't know what to expect so I needed information from the people who knew," stated one mother. One subject explained that information was very important because "it didn't happen for me, it was like pulling teeth trying to

get information. It was so distressing." This is an example of a family member rating a need as very important when the need was unmet.

**NEED 2: To have been able to visit at any time**

Fourteen subjects (93.3%) rated this need as very important, and 1 subject rated it as important.

All subjects reported that they had unrestricted visiting hours when their family members were in the ICU. Three subjects explained that they needed to work. These subjects worked either on shifts or entirely during the daytime, so the open visiting hours were important. Twelve subjects (80%) reported that being able to visit at any time was an incredible "relief." Subjects provided such explanations as "it felt better to be able to see her breathing" or "it meant so much for us to be there for him." Another subject stated, "It stopped the panic to know I could see him whenever I wanted."

**NEED 3: To have had questions answered honestly**

All but one subject rated this statement as very important.

Fourteen subjects who described themselves as "realists," or people who "need to know the truth," stated that honesty was important because "the truth is easier to deal with." These subjects explained that "it helped to know where things stood so we weren't disappointed." One subject stated that she wanted a "padded" truth. That is, she didn't want to hear bad news, so she would let her husband get information about their daughter and then he could tell her the truth "in a soft, kind way."

**NEED 4: To have felt there was hope**

As with the previous two needs, all subjects rated this need as very important and important.

The rationale provided by 13 subjects (86.7%) was that "hope is all you have to hang on to" or "you need something." Another subject stated that hope was very important "because hope comes from within the individual [patient] and I know he won't give up." The remaining subject stated that her hope came from her "faith" and her "faith" was really important to her.

**NEED 5: To know that I will be called at home about changes in the patient's condition**

All subjects rated this need as important or very important.

One subject expressed that he was never at one place and thus he was difficult to reach. However, he did say that there was always another family member who could be contacted, so it was still important for his family to be notified. Knowing that family members would be called about changes in the patient's condition was important because it "felt good to know you would be kept informed." One subject added that "it helped her sleep." Four subjects (26.7%) explained that they felt a bond of trust with the nurses, and that was important.

The inconsistencies between the subjects' ratings and rationale will be evident in the findings regarding the remaining needs. As mentioned previously, the ratings and the rationale will be reported separately.

**NEED 6: To have been reassured that the best possible care was being given to the patient**

One subject rated the need as slightly important, and the remaining fourteen subjects (93.3%) rated it as important or very important.

The explanations provided by all subjects revealed that being reassured that their loved one was receiving the best possible care was very important.

However, the family members did not all want to be reassured in the same way. One subject explained that "it really didn't help to hear someone reassure me as I felt he [patient] was being looked after well." This comment indicated that the subject misinterpreted the statement. That is, perhaps he viewed the word "reassured" to mean solely verbal reassurance. Other subjects talked about needing evidence that their loved one was receiving the best possible care. Eight subjects (53.3%) stated that seeing manifestations of good care such as the number of doctors around the patient, the hourly checks the nurse made on the patient, a clean bed, and well-groomed patient were all signs that their loved one was receiving the best possible care. On the other hand, four subjects (26.7%) said that when someone told them their loved ones had the "best doctor," they felt reassured. Finally, two subjects (13.3%) said that being assured that their loved ones were receiving the best possible care was important because it eased the subjects' minds so they could go home. All subjects related their own experiences when asked to provide a rationale for their ratings. In this instance, the family members' ratings were based on their specific experience.

**NEED 7: To have known the prognosis**

This need was identified as very important or important by all subjects.

The subjects provided various explanations when asked to explain their ratings. Nine subjects (60.0%) explained that an honest answer helped them to know what to expect. Two other subjects explained that they needed to know the prognosis in order to make decisions about discontinuing treatment. Other subjects also related the importance of the need statement to their own experience. One subject said he "wanted to know the prognosis because of a

previous bad experience." This subject had experienced the death of another brother with similar injuries. In contrast, one subject said that he "did not want to hear it [prognosis] in case it was bad." As well, two other subjects reported that although knowing the prognosis was very important, they realized that "they [the doctors] just don't know it."

**NEED 8: To have known exactly what was being done for the patient**

The ratings for this need included 14 subjects (93.3%) who rated it as very important or important, and one who rated it as slightly important. There were two distinct groups of explanations provided by the family members; one group did need to be told exactly what was being done for their loved one, and the other group did not. In the group who wanted to know, seven subjects (46.7%) explained that knowing exactly what was being done for the patient was very important because they were "concerned." Four other subjects gave explicit explanations such as "I'd think the worst if I didn't know," "it's easier to understand why they kept bugging him," "at least you knew something was being done," and "she [the patient] couldn't tell me so I needed to nurses to tell me." In contrast, the subjects who did not need to be informed of exactly what was being done for their loved ones stated that it was insignificant to know the details since they felt that the doctors and nurses knew what they were doing. Another subject said that she wouldn't know what was happening all day when she wasn't at the hospital and that didn't bother her.

**NEED 9: To have been told about how the patient was going to be treated medically**

This need was rated identically to the previous need; all but one subject rated it as important or very important.

Again, there are two distinct groups--that is, those subjects who wanted to be told how their family member was being treated medically and those who did not. Eleven subjects (73.3%) explained that they wanted this information because they were concerned. Statements such as, "I just wanted to know," and "it helps to know something is being done" were common. One subject stated that knowing how her loved one was being treated was necessary so that she could consent to the treatment. Another subject stated that he didn't have a lot of faith in doctors, so he wanted to know everything.

In contrast, two of the subjects who did not need to know exactly how the patient was being treated medically related their experience. One subject said that it was out of his hands and beyond his understanding, whereas another stated that as long as everything was being done for her family member, it didn't matter to her how it was being done.

**NEED 10: To have felt accepted by hospital personnel**

Once again, there was a distribution of ratings identical to need statements 8 and 9. There were two types of rationale based on the subjects' personal experiences. That is, some subjects felt accepted by hospital personnel and other subjects did not.

Of those 11 subjects who said that they were accepted by hospital personnel, five (33.3%) explained that they felt as if they were part of their

family members' care and that was a "warm, comforting" feeling. One subject stated that she "never felt otherwise." For this subject the need was not significant for her at that time because it was met. Another subject stated that she "did not care if the staff accepted her, "but it felt good to have a relationship with them," whereas another subject said that "getting to know the staff was good as they had the information I wanted." Other subjects shared their experience of wanting a positive environment between family members and staff, and another subject explained that if the staff accepted him, then they would probably understand and accept his ill family member.

The other four subjects did not feel accepted by hospital personnel. They all stated that their need was not met and they felt "in the way." The subjects used such terms as "distressing" and "upsetting" to describe their feelings.

**NEED 11: To have felt that hospital personnel care about the patient**

This need was rated as important or very important by all subjects.

The answers subjects provided, when asked why the need was important, suggested that they had interpreted the statement in more than one way. One daughter said, "It's not realistic to expect them [nurses] to care about every patient, as long as they care about their job." This subject probably interpreted the word "care" to mean that hospital personnel should care the same way a family member cares about the patient. On the other hand, all other subjects said that feeling that hospital personnel cared about the patient was important because it was comforting. These subjects provided a variety of explanations based on their personal experience. Seven subjects talked about the comfort they felt when they knew their loved one was



receiving "loving care." Two subjects elaborated on this by adding that they did not want the staff to think of their family member "as just another body." Another subject explained that it was comforting to feel that hospital personnel cared about his loved one because he felt "the patient would know if staff didn't care about him." Finally, two other subjects stated that the only reason they felt comfortable going home to sleep was because they felt the staff truly cared about their loved ones.

**NEED 12: To have had explanations given in terms that were understandable**

All but one subject rated this need as important or very important.

All subjects reported that explanations were given in understandable terms. The experiences that subjects shared related to their desire to understand what was happening to their loved ones. One subject did not identify this need as important because she "always understood." This is an example of a family member who rated a need as not important because it was met, not necessarily because it was unimportant. Thirteen subjects reported that understanding what was happening was very comforting. Several subjects elaborated on this by saying that the medical terminology and equipment "could really scare you if you didn't understand." Finally, one subject shared her experience of being an interpreter for her stepfather: "I have to understand so I can explain it to my stepfather."

**NEED 13: To have had a waiting room near the patient**

Three subjects (20.0%) rated this need as slightly important, whereas 12 subjects (80.0%) rated it as important or very important.

Only two subjects explained that they did not use the waiting room. One of these subjects left the hospital when she left the ICU, and the other stated that she would go to a pay phone to call people since she hated being alone.

Ten subjects talked about the comfort they felt by being close to their loved ones. Such comments as, "it was good to be close when you had to wait to get in the unit" and "it just felt better to be nearby," were common. Two subjects identified their most important reasons for wanting a waiting room near the patient. For example, one subject talked about the waiting room as a good place to "escape" and another described the waiting room as a good place to "catch the doctors." Finally, one subject expressed frustration that the waiting room wasn't close enough to the ICU. This was important to him because he spent "a lot of time waiting in the corridor."

In the ICUs in the Lower Mainland of British Columbia, the waiting rooms were in close proximity to the unit. However, if the family member was in the waiting room, the main door of the ICU was not visible. For the patients who were treated at other ICUs, the location of the waiting room in relation to the ICU is unknown. However, these subjects indicated that it was important to be close by.

**NEED 14: To have had directions as to what to do at the bedside**

Two subjects (13.3%) rated this need as not important, and 13 (86.7%) rated it as important or very important.

When subjects were asked why this need statement was important or unimportant, they related their answers to their personal experiences. Twelve subjects expressed that they wanted directions but again, they talked about

their own personal reasons. For instance, eight subjects explained that having directions made them feel better because "it was all so new and frightening." Another subject said that she felt useful when she was told she could bring the patient music and pictures. On the other hand, three subjects explained how distressed they felt since they did not receive any directions. These subjects stated that they felt "in the way." In contrast to the subjects who wanted directions, three subjects stated that they did not want to receive directions since they knew what they could and could not do. Two of these subjects talked about their critical care experience as nurses. The other subject discussed his knowledge about what to do at the bedside from a similar ICU experience.

From the subjects' comments, many family members evidently felt uncomfortable in the ICU. At least 11 subjects identified that they felt "in the way" or "frightened" by the ICU environment.

**NEED 15: To have talked to someone about negative feelings such as anger or guilt**

Three subjects (20.0%) identified this need as not important; two (13.3%) identified it as slightly important; ten (66.6%) identified it as important or very important.

Only five subjects said that they wished to discuss negative feelings with a professional. Of these five, four subjects explained that although they would have liked to discuss negative feelings, no one was available. The other subject said that a nurse had talked with her and that being prepared for negative feelings helped. In contrast, seven subjects rejected the idea of discussing feelings of anger and guilt with a health professional. These

subjects said that they would only discuss such feelings with their family members. All seven subjects said that "it was too personal to discuss with anyone but family." Two subjects denied having such feelings, and one expressed that he could not discuss it with his family since "they have their own problems." However, he did not verbalize a desire to discuss such feelings with a professional.

**NEED 16: To have had explanations of the environment before going into the ICU for the first time**

Four subjects (26.7%) identified this need as not important; one identified it as slightly important; ten (66.6%) identified it as important or very important.

Those subjects who had previous ICU experience either through their occupation or a similar experience with another family member did not find it helpful to receive an explanation of the ICU environment. However, those subjects who had no such experience indicated that when they received preparation "it was helpful." Three subjects explained that they were not prepared for their first visit to the ICU. Of these, two stated that "it didn't bother" them, whereas the other subject said "it would have helped to be prepared as to how he would look."

**NEED 17: To have been assured that it was alright to leave the hospital for a short while**

Five subjects (33.3%) rated this need as not important; two (13.3%) rated it as slightly important, and eight (53.3%) rated it as important or very important.

Once again, the subjects discussed their personal circumstances when asked to explain why the need statement was important or unimportant. Two subjects explained that being assured that it was alright to leave the hospital was irrelevant because they "left when they had to." Five other subjects said that it was not helpful to be assured that it was alright to leave the hospital because they "wanted to be there all the time." One of the subjects reported feeling "pushed out" when the nurses tried to encourage him to go home. In contrast, eight subjects expressed feeling "better" when they were assured that their loved ones would receive good care while they were away. Thus, those subjects who had to leave the hospital for other obligations did not require assurance that it was alright, whereas other subjects felt comfort in being assured it was permissible to leave.

**NEED 18: To have been encouraged to cry**

The distribution of ratings for this need was identical to the previous need. Five subjects (33.3%) rated it as not important; two (13.3%) rated it as slightly important, and eight (53.3%) rated it as important or very important.

According to the subjects' discussions, only some of those subjects who used crying as a coping behavior wanted to be encouraged to cry. Four subjects indicated that being encouraged to cry was helpful and one subject said she would have liked encouragement but did not receive it. On the other hand, six subjects reported that they cried easily, so encouragement was not necessary. Four other subjects also stated that encouragement to cry was not particularly helpful. These subjects provided such comments as, "crying is too personal to discuss with a stranger [nurse]," "I didn't want to cry," and "I couldn't cry because I was the strong one."

**NEED 19: To have had a place to be alone while in the hospital**

Five subjects (33.3%) identified this need as not important; three (20.0%) identified it as slightly important, and seven (46.7%) identified it as important or very important.

Three subjects expressed that they did not want to spend time alone when their loved ones were in the ICU. Two other subjects reported that they did not care to have a place to be alone while in the hospital. One of these subjects said that "she could be alone in a crowd," whereas the other explained that she would leave the hospital to be alone. In contrast, ten subjects expressed a desire to have a place to be alone. Half of the subjects wanted to separate from everyone, whereas the other half wanted a place to be alone with their own family. Comments such as "It's good to be alone," "It's important to have time alone with your family," "You need a place to think about what has been happening," and "It's good to get away from everyone" were common. Most subjects were not aware of a place, aside from the waiting room, where they could be alone.

**NEED 20: To have had more than one or two people able to visit the patient at the same time**

Ten subjects (66.7%) identified this need as not important, whereas two (13.3%) rated it as important, and three (20.0%) rated it as very important.

Four subjects explained that the patient didn't have more than two visitors, and six said that two visitors at one time were sufficient for the patient. On the other hand, one subject explained that her family was small so it would be good if they all visited together, whereas another subject explained that "it would be nice" if all her family could visit the patient at

the same time. Three subjects reported that their family needed to visit together so that they could support each other. Thus, people who did not have family members available did not identify this as a need. All of the ICUs involved in this study restricted visitors to two at the same time.

### Other Needs

At the end of the interview, the subjects were asked if there were any additional needs that were important at the time their family members were in the ICU. Approximately half (46.7%) of the sample identified additional needs. Several of these needs, however, were elaborations of the needs listed in the study's interview guide. For example, two subjects reported that they wanted to be given information freely, without requesting it. One of these subjects, as explained previously in this chapter, explained that getting information was like "pulling teeth." Thus, it is apparent that this need was very important for her because it was so difficult to have the need met.

Another subject expressed a desire for information on food, lodging, transportation and finances. This is again an elaboration of the need for information. In addition, the need to speak to the physician daily, addressed by another subject, is an elaboration of the need to receive information about the patient every day. These elaborations suggest the family members' strong desire to have these needs met due to their particular circumstances.

The following needs were also reported by individual subjects: the need to have the patient's dignity maintained; the need to have a happy environment when possible; and, finally, the need to have the next of kin determine who can visit the patient. Again, these specific needs were related to the subjects' experience. For example, the need "to have the next of kin

determine who can visit the patient" was mentioned by an adult child who was distraught because his mother, the patient's ex-wife, visited the ICU. The adult child wished to control his father's visitors since he was concerned about the possible negative effect of her presence on the patient.

### Summary

This chapter began with a description of the sample. Descriptive statistics were provided about the characteristics of the sample and the patients. Then the findings of the study in relation to the research questions were presented. To answer the first question, "How do family members of critically ill brain-injured patients rate the importance of selected needs?", the responses on a 20-item interview schedule were analyzed and rank ordered. The most important need for this sample was "the need to be given information everyday about the patient." The findings of this study were then compared to two other studies (Mathis, 1984; Molter, 1979). At least eight identical needs were identified among the three sample populations, although each study identified a different need as the most important one. Also, there was little differentiation amongst the top needs.

The findings of research question two, "What factors are associated with the rating of importance or lack of importance for selected needs?" were provided. That is, there were no significant relationships between demographic factors and the ratings of the selected needs. The findings of research question three, "How do family members of critically ill brain-injured patients explain their perception of the importance of needs?" were presented in section four. The subjects' explanations of their perception of the importance of needs were not consistent with the ratings for each need.



Additional needs that were specific to the subjects' circumstances were also described. The following chapter will discuss these findings.

## **CHAPTER FIVE:**

### **DISCUSSION OF FINDINGS**

#### **Introduction**

This chapter will discuss the results presented in Chapter 4. The first section briefly describes Moos' (1977) approach to examining a serious health injury or illness. The second section demonstrates how this approach was used in examining how family members of brain-injured patients deal with the ICU experience. The findings of the study are placed in three categories: information, support and environmental factors.

#### **Conceptual Framework**

Moos' (1977) theory of the perception of a serious health injury or illness as a life crisis (Figure 1) was used to help guide the analysis of this study's data. The parts of Moos' theory that were used include personal/demographic factors, cognitive appraisal, adaptive tasks and coping skills.

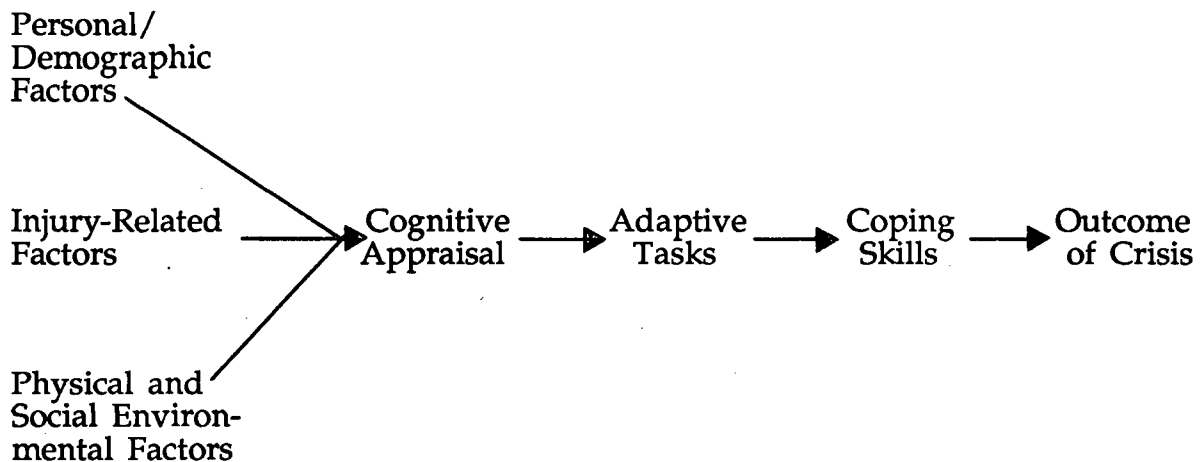
Moos (1977) theorized that people interpret events differently. This interpretation, referred to as cognitive appraisal, is influenced by three factors. The individual's personal/demographic factors are the only factors that were examined in this study. For example, when individuals are away from home and family to be with a critically ill family member, they will be influenced by the fact that they are in an unfamiliar environment without any family support. A priority for these individuals may be having information on where to obtain food and lodging rather than being called about changes in their family member's condition.

Each event or crisis, as well as being influenced by personal/demographic factors, calls upon individuals to perform basic adaptive tasks. Adaptive tasks comprise the things that individuals need to do to help them cope with a crisis or event. According to Moos (1977), adaptive tasks can be classified as illness related or general. Illness-related tasks involve the individual's physical well-being, whereas general adaptive tasks involve the individual's psychological well-being.

To accomplish the adaptive tasks, individuals use coping skills. Moos (1977) stressed that although a coping skill may be helpful in one situation, it may not be appropriate in another situation.

Figure 1.

**Conceptual Framework for a Serious Health Injury  
as a Crisis**



Parts of Moos' (1977) approach were helpful as they guided this researcher to examine specific individual factors. These specific factors influenced the family members' cognitive appraisal of the ICU experience and the coping skills they used to help meet their adaptive tasks. In light of

Moos' (1977) framework, the three areas of needs the family members expressed were related to three categories: information, support and environmental factors.

In using a needs approach to identify what is helpful to people with a brain-injured family member in an ICU, this researcher adapted an existing data collection instrument to ask them about the importance of their needs. In previous use, this type of rating instrument had not examined why the needs were important and therefore did not reveal the individual family members' rationale for perceived need importance. However, this investigator had observed clinically that because the family members' needs were truly individualized, a needs approach without requesting rationale was perhaps not the most comprehensive way to determine and to interpret the information. In this study, the ranking of the need statements revealed that discrimination among the twenty items was not extensive. That is, the twenty needs were closely ranked, and many needs received identical rankings. Therefore, merely having family members rate a need statement's importance and having the researcher rank the needs may not be as significant for an individual as identifying a specific need. A more useful approach to help identify what is important to family members during an ICU experience would be to examine family members' individual needs and how their personal situations affect their needs.

Family members' interpretations of what needs were important to them were influenced by personal/demographic factors. That is, at the time, some needs were more important than others to one family member because of the influencing personal/demographic factors. For example, three subjects who

had previous ICU experience did not identify a need to be prepared for their first visit to ICU. Since these family members knew what to expect in the ICU, this need was not as critical as it was for family members who did not have previous experience. For example, they did not have the need to receive directions about what to do at the bedside. Another example of the influence of personal/demographic factors was the situation of the mother alone in an unfamiliar city without family or friends. This woman had a critical need for information about where to find food, lodging, and transportation - a need not identified by other family members who had the close support of family and/or friends. According to Moos (1977), personal and demographic factors, such as seen in the preceding examples, influence individuals' responses to having an ill family member.

Although personal/demographic factors influenced family members' perceptions of what was important during an ICU experience, all family members had common requirements when they had a family member hospitalized in an ICU. As discussed in Chapter 4, these requirements can be categorized as information, support, and environmental factors. These major categories will be discussed starting with family members' need for information.

### Information

In this study, the family members' attempts to confront the reality of the ICU experience by seeking information demonstrated what Moos (1984) has called a problem-focused coping skill. A problem-focused coping skill views seeking information as a problem-solving action. By using this approach, family members try to construct a more satisfying situation.

The literature describes family members of critically ill brain-injured patients as having specific informational requirements (Daley, 1984; Hampe, 1975; Irwin & Meirer, 1973; Mathis, 1984; Molter, 1976). In this study, family members tried to meet their specific informational requirements and thus confront the reality of the ICU experience by requesting understandable information about their ill family member's condition on a daily basis. Family members required information because it helped them "feel better" and thus reduced their anxiety. This observation relates to Buchanan's (1981) observation that one method of reducing family members' anxiety is to provide information about the patient's condition.

This investigator discovered that family members' additional information requirements included: having questions answered honestly, knowing the prognosis, and knowing about specific medical and nursing interventions. While family members indicated that the preceding information was very necessary, they differed in how they wanted to receive that information. For example, although all family members indicated that having questions answered honestly was important, one family member stated that she wanted only good news from health professionals; only her husband could tell her bad news because he would "break it to her gently." This individual could have been protecting herself from dealing with unpleasant information. She was using social resources, such as her husband, to mediate and thus to protect herself. Although she valued honesty, she needed to receive honest, unpleasant information in a manner different from the study's other family members. In addition to seeking honest information, she was also seeking support. Moos (1977) observed that seeking information and emotional

support are coping skills often used simultaneously.

Another area related to information centered on the need to know the prognosis for the critically ill family member. Some family members needed to know their family member's prognosis to aid them in making decisions about treatment. Other family members wanted the information so they would know what to expect. One family member, however, indicated that he did not want to know the prognosis in case it was "bad." This person's brother had died a year previous from a brain injury similar to that suffered by this brother. His reaction may not have been denial of the severity of his relative's illness, but rather acknowledgement that he was not yet ready to deal with a negative prognosis. Lipowski (1970) has postulated that avoidance is a coping style used when an individual wishes to get away from the devastation of a family member's illness.

Other informational needs described in this study were: (1) to be called at home about changes in the patient's condition, (2) to receive information before the first visit to ICU, and (3) to receive directions about what to do at the patient's bedside. Two family members indicated that they would have appreciated having information about their ill relative volunteered by health professionals. In general, family members expressed a feeling of relief at knowing they would be telephoned about changes in the patient's condition. Other family members indicated that they valued knowing they would be informed of patient changes because it helped them to develop a bond of trust with the nurses. Hodovanic and Reese (1984) indicated that when family members know they will be notified of any changes in the patient's condition, they feel less apprehensive and fearful. Leavitt (1982) noted that

acceptance, availability, and responsiveness to family members' concerns helps establish a bond of trust between the nurse and the family members.

Findings from this study suggest that family members believed that the nurses were available and responsive to concerns if they indicated they would call families at home about any changes.

Having directions about what to do at the patient's bedside was relevant for most family members. The unfamiliarity of the environment was frightening to many of them. They indicated that they felt "in the way" when they did not know what to do at the bedside. However, they expressed feelings of comfort when they knew what they could do for the patient. According to Rasie (1980), family members need direction to help solve their dilemma of wanting to help but not knowing how to do so. Similarly, Lange (1978) suggested that family members feel helpless when they are left out or feel incapable of doing anything to help their loved ones. As one might expect, family members with previous ICU experience did not perceive the need for these directions as relevant for them.

In this study, seeking information was a coping skill used by all family members. However, they differed in the type of information they required as well as in how they wanted to receive the information. The next section will examine how family members used another coping skill, "seeking support." "Seeking support is often used in conjunction with "seeking information."

### Support

Another useful aspect of Moos' (1977) approach is that it identifies a group of coping skills closely related to the previously discussed coping skill of seeking information. These coping skills, referred to as "seeking support,"



involve the individual's ability to request emotional support and reassurance from family, friends, and health care personnel. In this study, all family members identified a need for support from family, friends, and health care professionals. Almost all subjects indicated a need to feel accepted by hospital personnel. Those who felt accepted described it as a warm, comforting feeling. King and Gregor (1985) suggested that family members often turn to nurses for support because their usual source of support is unavailable. In this study, family members who did not feel accepted by hospital personnel reported being very distressed by this lack of acceptance and support, a finding also reported by King and Gregor (1985).

Like the family members in Molter's (1976) and Mathis' (1984) studies, many family members in this study did not want to discuss feelings of anger and guilt with a health professional. While King and Gregor (1985) observed that nurses needed to encourage family members to ventilate their feelings, it was noted by this investigator, and also by other researchers (Mathis, 1984; Molter, 1976), that not all family members want to share their emotions with nurses.

In this study, the family members who did not feel accepted by hospital personnel also did not wish to express feelings of anger or guilt to health professionals. Many subjects also said they would talk about feelings of anger or guilt only with their family. According to Thomas (1978) it is unlikely that family members will share their true thoughts or feelings with a health care professional unless they have already developed a bond of trust. Mauss-Clum and Ryan (1981) reported that a relative or friend is usually most helpful in providing emotional support at the time of such a critical

injury. Cozac (1985) also noted that while family members needed support from those who knew them best - family and friends - they additionally needed support from health care professionals.

Just as it was difficult for many family members to discuss feelings of anger or guilt with anyone but their family and close friends, it was also difficult for them to cry in front of people other than family and close friends. For example, some family members in this study reported that crying in front of a stranger (a nurse) was something they could not do. These family members were using the coping skill of "seeking support."

In expressing a need to feel there was hope, these family members were identifying a need for support and information. The subjects wanted hopeful, rather than pessimistic, information about their ill family member. Hopeful information about the patient's condition provided support for them in dealing with their crisis. According to Korner (1970), the more uncertain the situation, the more an individual needs hope as a defense against his fears and anxieties. Perhaps this explains why the need for hope is frequently reported in the literature as an important need for family members of critically ill patients in ICU (Mathis, 1984; Molter, 1976). Family members of critically ill ICU patients are dealing with an uncertain situation in terms of the ultimate outcome. In contrast, family members of terminally ill patients did not identify hope as an important need (Hampe, 1975); family members of terminally ill patients had a greater certainty of the ultimate outcome of the situation than do family members of ICU patients.

Many family members wanted support from hospital personnel in terms of assurance for themselves about their ill family member. For example, all

family members required reassurance that their ill relatives were receiving the best possible care. However, family members differed in the way they preferred to receive that reassurance. Some family members wanted verbal reassurance, whereas others preferred non-verbal reassurance, such as observations of manifestations of good nursing and medical care. Leavitt (1982) reported that a nurse's competence and concern in relieving discomfort and improving vital functions of a critically ill patient reduced the family member's feelings of anxiety. Two family members in this present study specifically noted that receiving reassurance that their ill relative was receiving the best possible care "helped ease their minds." Family members also expressed feelings of reassurance in knowing that their relative had the "best physician." According to the literature, having confidence in the physician is one way to reduce an individual's fear (Thurer, Levine & Thurer, 1980).

Approximately one-half of the subjects in this study reported that being assured that it was all right to leave the hospital for a short while was comforting. These subjects were "seeking support" in an attempt to cope with their situation. Some of those who did not find such assurance helpful explained that it made them feel as if they were being pushed away. According to Leavitt (1982), many family members feel helpless when they are not physically close to their ill relative. These family members cope with the crisis of the ICU experience by "being there." As Leavitt (1982) reported, "being there" is a coping strategy used to reduce the family members' feelings of helplessness and anxiety. Several other family members, however, indicated that this particular assurance was irrelevant, for they left the hospital when necessary to attend to other commitments. Two family

members reported that they had returned to work while their ill relative was still a patient in ICU. Cozac (1985) observed that family members of critically ill patients distracted themselves as a coping strategy. Distraction was used in an "attempt to alleviate or attenuate the uncomfortable feelings experienced as a result of uncertainty" (Cozac, 1985, p. 65). According to Cozac (1985) this was accomplished by going to work. Going to work may also be helpful because it enables individuals to maintain a sense of competency. They leave an environment such as an ICU where they often feel helpless and seek out work where they feel more competent and in control.

Along with receiving assurance that their family member was receiving the best possible care, all the subjects in this study wanted to know that hospital personnel cared about their ill relative. This was also found to be true in several previous studies (Irwin & Meier, 1973; Mathis, 1984; Molter, 1976). The family members in this study expressed feelings of relief and comfort in knowing that the staff cared about their loved ones.

Seeking support from family, friends and health care professionals is a necessary coping skill for family members of critically ill brain-injured patients. Individuals differed, however, in the type of support they wanted as well as in the manner in which they wished to receive the support.

### **Environmental Factors**

The third group of factors are environmental. Many family members in this study identified particular environmental requirements that were important for them, such as, for example, a waiting room close to the ICU, open ICU visiting hours, having more than two visitors at a time, or having a place to be alone.

A nearby waiting room was relevant for most family members since it gave them a sense of relief to be close to their loved one. One family member, however, indicated that a nearby waiting room was less important than access to a telephone. This family member needed to call upon her family and friends, who were not in close proximity, for support when she was not in the ICU. Lust (1984), in describing a similar finding, suggested that one of the greatest comforts to family members is the availability of a telephone so that they can easily call relatives and friends. Perhaps if the waiting room had a telephone, this individual also would have expressed a need for a waiting room close to ICU. Thus, one important factor in the environment is the availability of a telephone.

Open visiting hours were an essential requirement for all family members. They expressed feelings of relief when they knew they could visit their loved ones at any time. This finding is contradictory to Gardner and Stewart's (1978) observation that family members usually stay at the hospital because they feel emotionally obligated to do so. In this study, however, all family members indicated a necessity for open visiting hours. Although not all family members wanted open visiting hours for the same reason (some family members found it more convenient because of their work schedule), the important issue is that the environmental requirement of open visiting hours was important to all family members. Lust (1984), however, found that families rarely identified more flexible visiting hours as a need when they were asked an open-ended question about needs. This investigator specifically asked family members about the importance of open visiting hours, as did Molter (1976) and Mathis (1984), which perhaps explains why the family members could easily identify and discuss the importance of open

visiting hours. It may also be that the response to this question about open visiting hours differs depending on the time post-hospitalization at which it was asked.

Certain environmental factors affected only some of the family members. For example, not all family members indicated that it was important to have more than two visitors at one time. The family members who stated that it was necessary were those who had small families and wished to visit their ill relative together so they could support one another. The family support was an important way for them of coping with the ICU experience.

The findings of this study indicate that family members deal with the ICU experience by using coping skills which focus on the three factors of information, support and environment. As Moos (1977) theorized, a health crisis typically requires a combination of coping skills to meet the adaptive tasks successfully.

### Summary

This chapter has discussed the findings of this study in light of Moos' (1977) approach to examine a serious health injury or illness. In interpreting the findings it was useful to organize the data under the categories of information, support and environment. It was also helpful to refer to Moos' (1977) structure of cognitive appraisal, personal/demographic, adaptive tasks and coping skills when discussing how family members dealt with the experience of having a brain-damaged family member in the ICU.

The following chapter will provide a summary of this study as well as discuss the conclusions and nursing implications that arise from these findings.

## CHAPTER SIX: SUMMARY, CONCLUSIONS, AND IMPLICATIONS FOR NURSING

### Introduction

This study was designed to identify the perceived importance of selected needs of family members of critically ill brain-injured patients during the ICU experience. In addition, this study examined personal and demographic factors for possible influence on the family members' ratings of need importance. The rationale for family members' perceptions of need importance was also investigated. This chapter will present a summary of the study, conclusions, and implications for nursing practice, education, research, and administration.

### Summary

The findings of several previous research studies suggested that family members of critically ill patients in ICU may have special needs. However, there had been no research study that has examined the perceived importance of selected needs for these family members. As well, there had not been a study that examined the reasons for family members' perceptions and the possible influencing demographic or personal factors. Experiential and research-based literature further suggested that family members of critically ill brain-injured patients might perceive the importance of some needs in a different way than do family members of critically ill patients in general. This study was conducted to examine the perceived importance of selected needs of family members of critically ill brain-injured patients and to explain why such needs are perceived as important.

A descriptive exploratory design was used to address the research questions. The study was conducted in two tertiary care hospitals in the British Columbia Lower Mainland and also in subjects' homes or another convenient setting. Data were collected from a convenience sample of one family member for each of 15 critically ill brain-injured patients who met the sample criteria. Subjects were interviewed only after the patient was discharged from the ICU. A structured interview, using a predetermined schedule, was used for data collection. Data analysis consisted of descriptive statistics and rank ordering of need statements. The findings, related to ranking, were compared to similar studies conducted by Molter (1976) and Mathis (1984). In addition, an item-by-item descriptive analysis of the rationale provided by subjects was completed. Responses similar in content were grouped and categorized.

Family members ranked all 20 needs very closely together; indeed many needs received identical ratings. When the findings, related to ranking, were compared with those of Molter (1976) and Mathis (1984), there were many similarities. That is, eight of the ten most important needs were identical. Therefore, to conclude that family members of critically ill brain-injured patients in ICU perceive the importance of needs differently than do family members of other critically ill ICU patients would be misleading. The most important need for this study's sample was the need "to have been given information every day about the patient." Two other important needs were the need for support from family, friends and health care professionals and the need for the availability of environmental factors, such as a waiting room.



With regard to factors associated with the rating of importance for selected needs, there was no statistical relationship between demographic/personal factors and the ratings. However, examination of how family members of critically ill brain-injured patients explained their ratings of the importance of selected needs revealed significant findings.

These findings suggest that the exclusive use of a rating scale is not the most useful method of data collection for identifying need importance. Although the ratings indicated slight differences in perceived importance, the explanations of the ratings indicated that all of the needs were important to most people, but for different reasons, dependent on their personal/demographic factors. The family members' needs during the ICU experience were highly individualized according to unique characteristics of each situation.

### **Conclusions**

The generalizability of this study's findings is limited by the small sample size, the convenience sampling method, and the time variability among subjects since their ICU experience. However, the findings of this study did identify some trends and suggest the following conclusions:

1. Family members of critically ill brain-injured patients have similar needs during an ICU experience.
2. Family members require information, a support network, and environmental resources to help them cope with the ICU experience.
3. The differences in the importance of these needs depends on the individual's personal/demographic factors and thus are individual to each family member.

4. The exclusive use of a Likert-type rating scale for identifying need importance does not provide comprehensive information about the needs of family members of critically ill brain-injured patients. More useful are the additional reasons family members provide to explain their ratings about how family members cope when their loved ones are in an ICU.
5. Family members of critically ill brain-injured patients utilize a variety of coping strategies to deal with the experience of having a family member in the ICU.

These conclusions have many implications for nursing practice, education, research, and administration. These will be discussed in the following section.

### **Implications for Nursing**

The findings of this study suggest implications for nursing practice, education, research and administration.

### **Implications for Nursing Practice**

The findings suggest that family members of critically ill brain-injured patients have many important and similar needs when their relatives are in an ICU. However, the importance of these needs varies, depending on the particular family member's perception of the need, and his/her personal situation. Family members interpret needs differently and thus perceive their importance differently. Therefore, nurses should not assume that all family members of critically ill brain-injured patients perceive their needs in the same way. This knowledge will direct the nurse to gather information about the family members' personal situation and how this affects their perception of their needs during the ICU experience. Assessment should include

gathering knowledge on how the family member wishes to receive information, how often, from whom, and what type of information. Other assessment areas should include gathering information about what type of support the family member wants, as well as what environmental services are important to the family.

All family members of critically ill brain-injured patients have a need for information. However, family members differ in the content and manner in which they wish to receive information. Therefore, nurses must initially ask the patient's significant family member what kind of information is most helpful for them and how they wish to receive that information. The findings indicate that some family members are not ready to hear "bad news," for they are probably using a protective coping mechanism. Other family members want specific details about the nursing and medical care their loved one is receiving. Thus, it is important that nurses provide family members with the opportunity to tell the nurses what type of information they need. It is also important that the nurse then individualizes the content, frequency, and timing when providing the information.

The findings indicate that family members of critically ill brain-injured patients require support and acceptance from other family members and health care professionals when their relative is in an ICU. If family members are geographically isolated from other family members, they may need to rely heavily on health care professionals for support. Nurses should assess the family members' support systems so that they are aware which family members may require additional support from health care professionals. Nursing interventions should include developing a trusting relationship with

family members; without this trust, family members will probably be reluctant to seek support from nurses. It is also important for nurses to promote an accepting attitude toward the patients' family members. If the family members do not feel accepted by hospital personnel, they may resist seeking support and thus have greater difficulty coping with the ICU experience.

Other forms of support nurses can provide include instilling hope and allowing family members to stay with patients. Family members' hope is often sustained by the nurse's caring actions. Touching and talking to an unconscious patient demonstrates that the nurse cares and thus has hope. Also very important for family members during the ICU experience is the family members' need to be with the patient; it is essential that family members' requests to remain with the patient be given consideration by the nurses.

Family members of critically ill brain-injured patients are comforted and supported when they are reassured that their loved ones are receiving the best possible care. Although family members need reassurance, they want to receive it in multiple ways. Therefore, an effort must be made to communicate to the family member, both verbally and non-verbally, that the health professionals are providing the best possible care. It is also important to provide verbal and non-verbal communication concurrently so that the family members are able to see as well as hear that the best possible care is being provided.

Health professionals need to be aware that family members differ in their need to cry or talk about negative feelings. Although some family members deny wanting to cry or having negative feelings, other family

members reveal that it would be helpful to have someone to cry with and with whom to share negative feelings. Therefore, nurses can intervene by approaching the significant family members and asking them how this ICU experience could be made easier. Nursing interventions directed at developing a comfortable nurse/patient relationship would help family members feel at ease in ventilating such emotions, should they surface at a later time. For those family members who deny having a desire to cry or having negative feelings, it is not appropriate to encourage expression of such, since holding back emotion may be an effective coping strategy for them. However, for those family members who want to cry or express negative feelings, nurses should be available to offer support.

Related to the theme of support is the family members' need of being assured that it is all right for them to leave the hospital for a short while. When planning individualized nursing care for the patients and their family members, it is important to know that some family members find comfort in such assurance. Nurses must be sure that they convey a sense of concern for the family and their need to be away from the hospital. However, if family members feel they are being pushed away from their relative, they may feel distressed rather than comforted. Therefore, it would be appropriate for the nurse to acknowledge that, while a family member may feel "pushed away," this is not the intent of the assurance. It is also important for nurses to validate and clarify their intent with the family member.

Some family members, although not all, indicated the importance of such environmental services as a nearby waiting room, a chapel, or other place, to be alone. Family members need to be told if these services are available

through both written and verbal communication. Also, nurses can emphasize that such environmental services are necessary, especially when new ICUs are being designed. For example, the availability of a telephone would be beneficial for family members who wish to contact their support network and would be especially important for those family members geographically isolated from other family members and friends.

This study indicates that open visiting hours are very important for family members of critically ill brain-injured patients. Nurses need to support family members' desire to be with the patient in order to sustain the family members' hopes. Also, nurses need to be aware of the necessity of flexible visiting hours to allow for the family members' other commitments. If nurses listen to the needs of the family members and assess their personal situation, they can develop specific intervention strategies to meet this need.

Finally, nurses need to be aware of the inter-relationships among family members, as evidenced by family members' desire to visit together for personal support. Nurses need to be flexible about visiting regulations when a family member requests that more than two people visit at once.

Since family members use a repertoire of coping strategies to deal with the experience of having an ill relative in an ICU, it is important for nurses to assess this repertoire. With an appreciation for the strategies that will help each unique family deal with the crisis, the nurse can work with the family member to establish an effective plan to meet their needs during the ICU experience.

### **Implications for Nursing Education**

Basic nursing education programs should incorporate theory and clinical skills that enable a nurse to provide competent care to a patient's family members during a crisis period. As part of their education, nursing students need to be familiar with family nursing theory as well as theory on family coping strategies. Nurses need to develop skills to facilitate family members' verbalization of their needs during an illness crisis. Skills in assessing, planning, implementing and evaluating family members' ICU experience should be an integral part of a basic nursing program. Student nurses should be given the opportunity to implement these skills through role-playing and again in the clinical setting.

Specialty education, such as critical care nursing programs, rarely include extensive education on examining the needs of family members of critically ill patients. The results of this study indicate a need for critical care nurses to understand that family members' needs are individualized and thus an ICU experience may be perceived differently from one family member to another. Health professionals need to recognize and understand that their perception may differ from the family members' perception of what is important during the ICU experience. Critical care nurses need to be skilled at assessing the family members' perception (cognitive appraisal) of the ICU experience as well as assessing the influence of personal/demographic factors. To do this, the curriculum of a specialty education program should include theory and application of frameworks, such as Moos' (1977), to family experiences.

It is important for all nurses to know the common areas of concern for family members of critically ill brain-injured patients during the ICU experience. It is equally important that nurses feel competent in assessing the family members' personal situation and validating their findings with the family members. As well, nurses need to be able to develop nursing care plans individualized to the needs of these family members. Planning interventions and follow-up evaluation of the success of these interventions are also necessary skills that should be incorporated into the curricula of all basic and specialty nursing education programs.

### **Implications for Nursing Research**

Data obtained in this study also have implications for future research. The incongruity between the ratings of perceived importance and the rationale provided suggest a different method of studying this phenomenon. A qualitative research design may provide more useful knowledge because this design would eliminate the restraints of having to respond to pre-selected questions. A qualitative design would allow the researcher a greater focus on each family member's specific needs, thereby producing knowledge with greater relevance for clinical application.

This study focused on providing data on the needs of family members of critically ill brain-injured patients during the ICU experience. Further studies using a qualitative design and conducted at different time periods would add to the body of knowledge about family members' needs. A study conducted while the patient is still in the ICU--for example, between 24 to 72 hours after admission--would be beneficial since the varying time frame of this study may have affected the results. Another study could center on obtaining



information from family members about helpful interventions during the ICU experience.

One additional area of research that this investigator recommends is a study on the needs of family members of critically ill brain-injured patients diagnosed as brain dead. This group of family members was not included in this study. However, brain dead patients are being seen more frequently in ICU, and their family members presumably have urgent and unique needs.

Research relating to the above recommendations will provide much needed information about the ICU experience for family members of critically ill brain-injured patients and will provide direction for nursing practice in terms of assisting family members to cope with this sudden, unexpected event.

### **Implications for Nursing Administration**

Nursing administration need to be aware of the importance of the availability of environmental supports for family members of ICU patients. It needs to provide input into architectural design and thus ensure that aspects such as having the waiting room in close proximity to the ICU are addressed. Nursing administration needs to ensure that the ICU has open visiting hours and information related to available food and lodging and availability of a telephone.

Nursing administration needs to provide and support a family-centered philosophy in the hospital and especially in the Intensive Care Unit. It is vital for administration to implement such structural changes as appropriate forms for family assessments. Knowledgeable nurses also need to be available to spend the necessary time to do a detailed family assessment.

Nursing administration also needs to support nurses in obtaining inservice and/or continuing education about the needs of family members of ICU patients.

### **Summary**

This chapter concludes the report of a nursing research study concerned with understanding the needs of family members while an ill family member is in the ICU following an acute brain injury. It summarizes the study, highlights the major conclusions, and describes the implications this study may have for nursing practice, education, research and administration.

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## APPENDIX A

### Information Regarding a Research Study

My name is Patricia FitzGerald. I am a Registered Nurse and a student in the Master of Science in Nursing program at the University of British Columbia. I am interested in learning about the needs of family members during the time a patient is in the Intensive Care Unit.

I would like your permission to interview you and ask you questions about how important or unimportant certain needs were for you during the time your family member was in the ICU. The interview will take approximately 45 minutes and will be conducted in a quiet room on the nursing unit. The nursing staff will be informed as to your whereabouts so they can reach you quickly if necessary. You will also be free to interrupt the interview at any time to check on your loved one, or to stop the interview entirely.

If you are willing to participate in the study, please leave your phone number at the nursing station and I will contact you to arrange an interview within the next forty-eight hours, if possible. I would like to tape record the interview so that I can accurately recall what you share with me. If at any time during our conversation you wish to have something erased, it will be done in your presence. The questionnaires and tape recordings will be shared with my two professors only. After my research report is written, the tape recordings and questionnaires will be destroyed.

It is anticipated that the findings of this study will provide information to nurses to help them assist family members, like yourself, who have a loved one in the ICU. Other than having the opportunity to talk about your

## APPENDIX B

### Needs of Family Members of Critically Ill Brain-Injured Patients During the ICU Experience

#### CONSENT FORM

I agree to participate in the research study to be conducted by Patricia FitzGerald, a Master of Science in Nursing student at the University of British Columbia.

I have read the information letter explaining the study and understand that:

1. I will be asked questions about the needs I had related to my family member being a patient in the ICU.
2. the interviews will be tape recorded and will last approximately 45 minutes.
3. the information gained from the interview will be available only to Patricia and her two professors and will be destroyed after the thesis has been accepted.
4. my refusal to participate or my desire to withdraw from the study at any time will be respected and will not affect the medical or nursing care of my family member.

All my questions about the study have been answered by Patricia FitzGerald. I have received a copy of the information letter and consent form and I agree to participate in the study.

SIGNED: \_\_\_\_\_

DATE: \_\_\_\_\_



## APPENDIX C

### Interview Structure

Subject Number \_\_\_\_\_ Date of Patient's Trauma \_\_\_\_\_

Date of Admission to ICU \_\_\_\_\_

Date of Subject's Initial Visit to ICU \_\_\_\_\_

Date and Time of Interview \_\_\_\_\_

Relationship to Patient \_\_\_\_\_

### GENERAL DEMOGRAPHIC QUESTIONS

Where is your home? \_\_\_\_\_

Do you usually live with the patient? \_\_\_\_\_

Who are you staying with now? \_\_\_\_\_

Where are you staying now? \_\_\_\_\_

Are you familiar with this city? \_\_\_\_\_

Do you have relatives or friends nearby? \_\_\_\_\_

Have you ever had a close relative or friend as a patient in an ICU in the past? If yes, could you briefly explain the circumstances?

### FIXED ALTERNATIVE QUESTIONS

The 20 need statements will be read aloud although the subject will be able to look at the questions and possible answers.

Think about how you felt, during the time you spent visiting your loved one in the ICU. Now rate the following need statements as not important (1) to very important (4).

| (1)<br>NOT<br>IMPORTANT | (2)<br>SLIGHTLY<br>IMPORTANT | (3)<br>IMPORTANT | (4)<br>VERY<br>IMPORTANT |
|-------------------------|------------------------------|------------------|--------------------------|
|-------------------------|------------------------------|------------------|--------------------------|

1. To have had explanations of the environment before going into the ICU for the first time.
2. To have had a waiting room near the patient.
3. To have had a place to be alone while in the hospital.
4. To have had more than one or two people able to visit the patient at the same time.
5. To have had directions as to what to do at the bedside.
6. To have been able to visit at any time.
7. To have been given information every day about the patient.
8. To have been reassured that the best possible care was being given to the patient.
9. To have had explanations given in terms that were understandable.
10. To have had questions answered honestly.
11. To have known exactly what was being done for the patient.
12. To have been told about how the patient was going to be treated medically.
13. To have known the prognosis.
14. To have been assured that it was alright to leave the hospital for a short while.
15. To have known that I would have been called at home about changes in the patient's condition.
16. To have felt accepted by hospital personnel.

17. To have talked to someone about negative feelings such as anger or guilt.
18. To have been encouraged to cry.
19. To have felt that hospital personnel care about the patient.
20. To have felt there was hope.

An open-ended question will be asked after every need statement: Why was that important/not important to you?

**Final Question:** In addition to the needs I have asked about, what other needs were important for you at that time?

## APPENDIX D

Summary Statistics

## FREQUENCY OF RESPONSES TO NEED STATEMENTS

| NEEDS   | CATEGORIES OF IMPORTANCE |                  |                              |                         |
|---|--------------------------|------------------|------------------------------|-------------------------|
|   | Very<br>Important<br>(4) | Important<br>(3) | Slightly<br>Important<br>(2) | Not<br>Important<br>(1) |
| 1. To have been given information every day about the patient.                            | 15                       | 0                | 0                            | 0                       |
| 2. To have been able to visit at any time.  | 14                       | 1                | 0                            | 0                       |
| 3. To have had questions answered honestly.   | 14                       | 1                | 0                            | 0                       |
| 4. To have felt there was hope.   | 14                       | 1                | 0                            | 0                       |
| 5. To have known that I would be called at home about changes in the patient's condition. | 13                       | 2                | 0                            | 0                       |
| 6. To have been re-assured that the best possible care was being given to the patient.    | 13                       | 1                | 1                            | 0                       |
| 7. To have known the prognosis.   | 12                       | 3                | 0                            | 0                       |
| 8. To have known exactly what was being done for the patient.                             | 11                       | 3                | 1                            | 0                       |

| NEEDS |   | (4) | (3) | (2) | (1) |
|-------|---|-----|-----|-----|-----|
| 9.    | To have been told about how the patient was going to be treated medically.                | 11  | 3   | 1   | 0   |
| 10.   | To have felt accepted by hospital personnel.  | 11  | 3   | 1   | 0   |
| 11.   | To have felt that hospital personnel care about the patient.                              | 10  | 5   | 0   | 0   |
| 12.   | To have had explanations given in terms that were understandable.                         | 11  | 3   | 0   | 1   |
| 13.   | To have had a waiting room near the patient.  | 11  | 1   | 3   | 0   |
| 14.   | To have had directions about what to do at the bedside.                                   | 6   | 7   | 0   | 2   |
| 15.   | To have talked to someone about negative feelings such as anger or guilt.                 | 5   | 5   | 2   | 3   |
| 16.   | To have had explanations of the environment before going into the ICU for the first time. | 5   | 5   | 1   | 4   |
| 17.   | To have been assured that it was alright to leave the hospital for a short while.         | 3   | 5   | 2   | 5   |
| 18.   | To have been encouraged to cry.   | 3   | 5   | 2   | 5   |

| NEEDS   | (4) | (3) | (2) | (1) |
|---|-----|-----|-----|-----|
| 19. To have had a place to be alone while in the hospital.                  | 3   | 4   | 3   | 5   |
| 20. To have had more than one or two people able to visit at the same time. | 3   | 2   | 0   | 10  |