INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700 800/521-0600

Université d'Ottawa · University of Ottawa

A COMPARISON OF FAMILY NEEDS PERCEIVED BY NURSES AND FAMILY MEMBERS OF ACUTELY BRAIN INJURED PATIENTS

by

BARBARA NEABEL

Thesis submitted to the
School of Graduate Studies and Research
in partial fulfillment of the requirements for the
degree of Master of Science in Nursing

University of Ottawa

May, 1998

Abstract

The onset of a brain injury as a result of trauma or a stroke is often sudden and occurs without warning. The deficits sustained from the injury can be devastating to the patients and their families. Recently, greater attention has been directed towards family members since they play a crucial role in the recovery of persons with brain injuries. Hence, it is important that the family members' needs be identified. There is a paucity of research that addresses the needs of families of persons with a brain injury. In addition, no studies have been found to date that focused on the nurses' perceptions of family needs in this population.

Neuman Systems Model, which is based on stress and the reaction to stress, guided the study that was conducted on two neuroscience units in Ottawa, Ontario. The model is based on stress and the reaction to stress. The following objectives were addressed: 1) to identify the needs of family members of acutely brain injured patients (Traumatic Brain Injuries (TBI) and stroke) on a neuroscience unit; 2) to determine the relationship between nurses and family members in identifying family needs of patients with acute brain injuries; 3) to determine whether the family members perceive their needs are met and by whom; and 4) to compare the needs of family members of patients with TBI and stroke.

The sample for this comparative descriptive study consisted of 22 family members paired with 22 registered nurses (RNs). Data were collected from family members of patients with acute brain injuries and the registered nurses who cared for these patients. A modified version of the Critical Care Family Needs Inventory (CCFNI) was used to elicit the participants' perceptions of family needs. Needs considered to be most important to the family members and nurses were related to the psychological variable in Neuman's Model. The results showed a low association between family members' and nurses' perceptions of family needs. Only half of the family members reported that their needs were met more than 50% of the time. Implications of the findings support a key aspect of Neuman's model, namely, verifying perceptions. It is important for nurses to verify their perceptions with family members prior to initiating interventions to meet

the family member's needs. Suggestions for future research based on the results of the study are also provided.

Acknowledgments

I would like to take this opportunity to express my sincere gratitude to a number of people who have been supportive and instrumental in my learning experience.

I would like to begin with thanking my thesis committee for their time and efforts in assisting me to complete this project. There were times I didn't think I would get to this point and I couldn't have done it without all of you! To my thesis supervisor, Dr. Cora Hinds, thank-you for your guidance and sharing your knowledge on family nursing. To Jocelyne Van Neste Kenny, thank-you for your never-ending support and encouragement as well as sharing your expertise and enthusiasm with the brain injured population. To Travis Gee, words cannot express my gratitude for your patience in helping me to develop an appreciation for statistics (and computer statistics programs!)

I am also very grateful to the family members and nurses who participated in the study. Thank-you for your time and cooperation during a difficult and uncertain period in your lives. A special thank-you to Jan Leahy, Carole St. Denis, and Hazel Matte for identifying the eligible family members. Your help was greatly appreciated.

In addition, I would like to extend my sincere appreciation to Dr. Frances Fothergill-Bourbonnais and Professor Jean Dunning. Your genuine interest and concern in both my professional and personal growth has been overwhelming. I am truly honored and indebted to both of you. I will treasure all the learning opportunities you have provided to me.

Most of all, I want to thank God, my family, and friends who have stood by me during what has been an unforgettable and challenging period in my life. It was your unconditional love, ongoing support, and numerous phone calls that gave me the strength to persevere. I thank God for each of you. You have taught me the most valuable lessons in life and what being a family truly means. It is for this reason that I dedicate my thesis to all of you.

Table of Contents

List of Figures

List of Tables

Chapter One

Introduction

Background to the Problem

There are few illnesses, diseases, or injuries that result in the devastating damage associated with brain injuries. All levels of human functioning can be affected by a brain injury and can leave an individual with physical, cognitive, behavioural and psychosocial deficits. Two of the major causes of a brain injury are strokes and trauma. In the province of Ontario, there were 17,405 hospital admissions in 1993-94 for patients 20 years and older as the result of non-traumatic intracerebral hemorrhage, non-traumatic intracranial hemorrhage, occlusion of cerebral arteries and acute but ill-defined cerebrovascular disease (Statistics Canada, 1996). During this period and for the same age group, there were 4,770 hospital admissions in Ontario for patients who had traumatic intracranial injuries and skull fractures with intracranial injuries (Statistics Canada, 1996). Furthermore, it has been estimated that every day in Ontario forty-four people will sustain a brain injury (Borsellino, 1994). Approximately 300 people a year sustain a moderate to severe brain injury within the Ottawa-Carleton region (Ottawa-Carleton Regional District Health Council, 1989).

The survival rate for those who have received a brain injury has greatly improved with the advancement in medical technology (Carson, 1993; Elliot & Smith, 1985; Frye, 1987; Miller, 1993; Rogers & Kreutzer, 1984). As a result, more of these patients are being integrated into the community and cared for by their families (Dring, 1989; Miller, 1993). Unfortunately, it has been suggested that the family is rarely prepared to face the challenge of caring for the family member with a brain injury (Casas, 1989; Frye, 1987; Miller, 1993) and they may not be able to effectively deal with the problems that arise (Livingston, 1990). Nurses are in a pivotal position to help families provide the appropriate level of care for these patients. However, before nurses can intervene, they must understand the families' needs.

There are a number of stressors experienced by family members in the initial hospitalization period following a brain injury. Since the onset of a brain injury is often sudden and occurs without warning it can cause a situational crisis for the family (Leske, 1986; Watson, 1986). Shock and denial are two common immediate reactions of family members (Miller, 1993; Rape, Bush, & Slavin, 1992), although each family member may have a unique response. Because of concerns during the acute care period in stabilizing the patient, the family member's needs may be overlooked (Daley, 1984; Drummond, 1988) or go unrecognized by health care professionals (Chesla, 1996; Testani-Dufour, Chappel-Aiken, & Gueldner, 1992). This leaves the family members to cope on their own during a period of time when their level of stress is high. Adding to an already high stress level is the uncertainty regarding length of recovery, personality and behavioural changes in the patient that can be taxing and overwhelming for the family (Bernstein, 1990; Elliot & Smith, 1985; Kreutzer, Gervasio, & Camplair, 1994; Ottawa-Carleton Regional District Health Council, 1989; Williams, 1994).

In addition, recent health care restructuring has limited the number of rehabilitation beds that are available, thus requiring some patients either to stay longer on a neuroscience unit or to be transferred to transition units or their home hospital until a rehabilitation bed becomes available. This can be frustrating for some family members as they perceive that their injured family member's rehabilitation is being delayed. The accumulation of stressors placed on the family may impede their abilities to maintain other responsibilities, for example the household and employment. This can cause additional problems for the family (Kreutzer, Gervasio et al., 1994; Mauss-Clum & Ryan, 1981) and make their adjustment to the effects of a brain injury in the relative difficult. In summary, the traumatic effects of a brain injury as well as the health care environment not only have an impact the person with the injury but also his or her family (Kay & Cavallo, 1994; Kosciulek, 1996; Richmond, Metcalf, & Winterhalter, 1987), and in some cases, may cause family members to suffer from the experience more or as much as the patient (Testani-Dufour et al., 1992).

Recently, greater attention has been directed towards family members since they play a crucial role in the recovery of patients with brain injuries (Evans et al., 1992; Evans, Hendricks, Haselkorn, Bishop, & Baldwin, 1992; Farzan, 1991; Frye, 1982; Miller, 1993; Rosenthal & Young, 1988; Testani-Dufour et al., 1992). It has been suggested that addressing and meeting the needs of the family as well as the patient in acute care settings enhances the chance for successful patient and family recovery (Elliot & Smith, 1985; Pierce & Salter, 1988; Richmond et al., 1987; Rosenthal & Young, 1988; Stroker, 1983). Current thinking is that health care professionals who acknowledge this influence will develop a stronger alliance with the family when caring for the patients (Danielson, Hamel-Bissell, & Winstead-Fry, 1993), which should help to improve both patient and family outcomes following an illness or hospitalization. Although there is a growing recognition in the nursing literature that family-centered care is an integral part of nursing practice, this ideal is often not well implemented (Friedman, 1992).

In order for neuroscience nurses to provide family nursing interventions that will buffer the effects of stressors, it is important that they understand the needs of the family members (Williams, 1994). Previous studies have identified the needs of family members of patients with brain injuries in Intensive Care Units (ICU), rehabilitation facilities, and community settings (Acorn & Roberts, 1992; Bernstein, 1990; Campbell, 1988; Casas, 1989; Engli & Kirsivali-Farmer, 1993; Grant & Bean, 1992; Johnson, 1995; Kreutzer, Serio, & Bergquist, 1994; Mathis, 1984; Mauss-Clum & Ryan, 1981; McLean, Roper-Hall, Mayer, & Main, 1991; Stroker, 1983; Wellwood, Dennis, & Warlow, 1994). However, no studies have been found to date that address the needs of family members of patients with brain injuries on a neuroscience unit. In order to ensure that family-centered care is provided while the patients and families are on neuroscience units, it is imperative that the needs of the family members be identified during this period of hospitalization. Furthermore, since nurses are the persons who interact most frequently with the family it is important to examine their perceptions of family needs which may influence the care they provide. No studies were found that dealt specifically with nurses' perceptions of family needs in the brain injured population. Two studies were found that involved nurses' perceptions of family needs of

patients with neurological conditions along with other critically ill patients in ICU (Dockter et al., 1988; Forrester, Murphy, Price, & Monaghan, 1990). Another study focused on health care professionals' perceptions of the educational needs of family members of stroke patients who were on average 16 months post-stroke (van Veenendaal, Grinspun, & Adriaanse, 1996). Further research is needed to address the current gap in the literature concerning the needs of family members of patients with brain injuries on a neuroscience unit and the nurses' perceptions of these needs.

Study Purpose and Objectives

With this background in mind, the purpose of this study was therefore to explore the perceptions of both nurses and family members of brain injured patients in identifying family needs and determining the degree to which these needs were met while the patient was on a neuroscience unit. A second purpose was to identify if there was a difference between the needs of family members of patients with strokes and those with traumatic brain injuries (TBI). The following were the specific objectives for this study:

1) to identify the needs of family members of patients with acute brain injuries (TBI and stroke) on a neuroscience unit;
2) to determine the relationship between nurses and family members in identifying family needs of patients with acute brain injuries;
3) to determine whether the family members perceive their needs are met and by whom; and
4) to compare the needs of family members of patients with TBI and stroke.

Operational Definitions

The following definitions of terms were used in this study:

Acute Brain Injury: An acute brain injury refers to those injuries causing a sudden onset of neurological dysfunction as a result of trauma or a stroke.

Family Member: The family member is considered to be the legal next-of-kin of the patient, or is related to the patient either by marriage, blood, or as a significant other. They must be 18 years or older and be able to read and comprehend English. For the purpose of this study, the first level of nursing research with patients and families,[1] nursing of individual/family member, as outlined by Robinson (1995) will be used since only one family member is the unit of interest.

Family Needs: These are the needs identified by the family members and nurses as measured by a modified version of the Critical Care Family Needs Inventory (CCFNI) (see Leske, 1986).[2]

Neuroscience Nurse: Registered nurse in either a full- or part-time position on the neuroscience unit who provides care to patients with brain injuries and interacts with their family members.

---

[1] Robinson (1995) proposed four levels of nursing research with patients and families as an attempt to develop a common language. In the first level, the unit of interest is the individual family member in the context of the family. The unit of interest in the second level is the relationship between two or more individuals in the context of the family. In the third level, the family is the unit of interest whereas the individual family members and their relationships form the background. Lastly, the unit of interest in the fourth level is the individual family members and the family system.

[2] I wish to thank J.S. Leske who gave me permission to use and modify the instrument for my thesis.

Chapter Two

Literature Review and Conceptual Model

This chapter is divided into two sections. A critical review of the literature on the needs of family members as they are perceived by family members and nursing staff is presented in the first section. The theoretical framework for the present study is then outlined in the second half of this chapter.

Review of Previous Research

A literature search using the following databases, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Healthstar, Medline and Psych Info, was done to explore the research on family and family members' needs, as well as nurses' perceptions of these needs within the brain injured population from 1975 to the present. The key words used for the search were: brain injury; head injury; stroke; family; family needs; and nursing perceptions. The reference lists of the relevant studies were also used to identify additional research studies not retrieved by the computerized literature search. The results of the literature search revealed that many studies have been done to identify the needs of family members of critically ill patients in the intensive care unit (ICU) and a smaller number have been done that examined their long-term needs. However, only a few of these studies have focused on the brain injured population, and no studies were found that examined family members' needs on neuroscience units. Likewise, there were some studies that investigated the nurses' perceptions of critical care and long-term family needs. However, none of these studies dealt specifically with family members of acute brain injured patients and none were done on neuroscience units. Therefore, the critical analysis of the literature on family members' needs will be discussed according to the perceptions of family members and nurses in ICU settings.

Family Members' Perceptions. In most cases, the onset of a severe brain injury is life threatening and requires that the patient be treated in an intensive care unit (ICU). There were

five studies found that specifically addressed the needs of family members of critically ill patients with brain injuries in the ICU (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993; Johnson, 1995; Mathis, 1984; Mauss-Clum & Ryan, 1981). The causes of the brain injuries in these studies were strokes, subarachnoid hemorrhage, anoxia, and open and closed head injuries (Engli & Kirsivali-Farmer, 1993; Johnson, 1995; Mathis, 1984; Mauss-Clum & Ryan, 1981). Mauss-Clum and Ryan (1981) further reported that family members of patients with Alzheimer's and Parkinson's disease were included in their study. No description of the neurological diagnosis was provided by Bernstein (1990). A convenience sample was used for each study and the description of the ICU was limited to the number of available beds (Engli & Kirsivali-Farmer, 1993), or that it was in a teaching hospital (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993; Mathis, 1984). The number of family members per patient who were asked to participate was provided in only two studies (Engli & Kirsivali-Farmer, 1993; Mathis, 1984) with one family member per patient being involved. The lack of information describing the settings and the number of family members per patient participating limits the generalizability of the results of these studies.

One of the earliest studies done to examine the needs of family members in the brain injured population was a retrospective study of family members of patients attending an outpatient rehabilitation program (Mauss-Clum & Ryan, 1981). Although it was not clearly stated, the family member was asked to recall the professional help that they felt they needed while the patient was in the ICU, what help they actually received, and who provided the help. Most of the patients attending the outpatient rehabilitation program were at least six months post-injury. One limitation of this design is the possibility that some family members may not remember all of the details of the ICU experience to accurately answer the questionnaire or their present circumstances may influence their responses. However, in this study family members identified five areas where help was needed. These are listed in order of importance with the corresponding percentage of family members who reported receiving help in that area: kind and clear explanations concerning the patient's condition (57%); discussion of realistic expectations (23%); emotional support (50%); financial counseling (10%); and resource counseling (3%). The majority of family members (90%)

reported that the changes in the patients' personality made their adjustment more difficult. All of the mothers in the study reported feeling frustrated during the experience whereas the wives of the patients experienced more depression and anger. Seventeen percent of the respondents identified nurses as a source of emotional support, whereas, 50% selected relatives and friends, and 43% chose physicians (Mauss-Clum & Ryan, 1981).

Three studies were conducted that compared family members of patients with acute brain injuries with family members of patients with: 1) cardiac/myocardial infarctions (MI) (Bernstein, 1990); 2) chest pain, heart failure, neck surgery, and pneumonia (Engli & Kirsivali-Farmer, 1993); and 3) coronary bypass, respiratory failure and ruptured abdominal aortic aneurysms (Mathis, 1984). The Critical Care Family Needs Inventory (CCFNI) (see Leske, 1986) which consists of 45 need statements to rank the personal needs of family members was used in each of these studies. This tool was self-administered in two studies (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993) and in Mathis' study it was used as a structured interview guide. In each study, the family members were asked to participate at least 72 hours after the patients' admission into the ICU. Mathis (1984) also included family members of patients who had been transferred out of the ICU to a general ward for less than 48 hours.

Bernstein (1990) found that 13 of the top 15 need statements were the same for the two groups of family members (brain injured versus MI/cardiac), although, the needs were ranked differently. For example, the need for honest information, the prognosis, to have explanations that are understandable and to feel there is hope was common in both groups. Differences in ranking may be related to the unpredictable outcome, the prolonged recovery and unresponsiveness of patients with brain injuries (Bernstein, 1990). Although there were no significant differences between the two groups, a significant difference was detected in the factor relating to accessibility to information. This factor was higher in the cardiac/MI group suggesting it was easier for them to obtain information. The uncertainty associated with brain injuries may have caused those family members more stress and impaired their ability to recognize their needs or ask questions (Bernstein, 1990). In response to the open-ended question concerning what the

family members greatest need was and who was best to meet this need, the family members in both groups reported their greatest need was to be given accurate information. Physicians were ranked the highest and nurses were ranked fourth in meeting this need which may be related to the public's perception that only physicians can give medical information (Bernstein, 1990).

In contrast, Engli and Kirsivali-Farmer (1993) reported a statistically significant difference in rating the degree of importance of needs between family members of patients with and without brain injuries. According to Engli and Kirsivali-Farmer (1993), the difference in the two groups may be related to the sudden onset and extent of the injury. They further reported that additional analysis showed a high similarity in the rank ordering of the needs between the two groups. In their study, five of the ten top needs were the same. These were: to be called at home about changes in the patient's condition; to know how the patient is being treated medically; to have explanations that are understandable; to know specific facts concerning the patients' progress; and to feel hospital personnel care. The need to know the prognosis and have questions answered honestly, were the two top needs of family members of patients with brain injuries. These needs were not identified in the ten top needs of family members of patients without brain injuries. Similar to Bernstein (1990), family members of patients with brain injures indicated that 53% of their needs were met by physicians while those without brain injuries reported 57% of their needs were met by physicians (Engli & Kirsivali-Farmer, 1993). Both groups of family members stated that 33% of their needs were met by nurses and 20% were met by friends, chaplains, and other relatives. These results may be related to the fact that the top ranking needs are about information, such as the patients' prognosis and medical treatment, and family members may perceive physicians and not nurses as having this information (Engli & Kirsivali-Farmer, 1993).

Mathis (1984) also reported a statistically significant difference in the rating of family needs between the two groups of family members in her study. She noted that the separation family members experience because of the unresponsiveness of the patients with brain injuries may contribute to the difference in rating of family needs. Mathis (1984) also compared the rating of family needs by the two groups of family members in her study with the results of a previous study

done by Molter (1979). No diagnosis was provided for the patients whose family members were participating in Molter's study. Similar to Mathis, the time in which the family members participated was greater than 72 hours in ICU and less than 48 hours on a general ward (Molter, 1979). When the results of these studies were compared, Mathis (1984) found that eight of the ten top needs identified were similar, although they were ranked differently. These needs were: to have questions answered honestly; to feel hospital personnel care about the patient; to know exactly what is being done for the patient; to feel there is hope; to have specific facts on the patient's progress; to have reassurance that the best care is being given; to be called at home if there are changes in the patient; and to receive information once a day. The least important needs identified by the two groups of family members in Mathis' study were: to have visiting hours changed for special conditions; to talk about negative feelings; to be encouraged to cry; and to have another person with you when visiting the relative. For each of these need statements, family members of patients with a brain injury ranked them as being more important than family members of patients without a brain injury.

The ten most important needs of family members of patients with neurologic/neurosurgical conditions as identified in these three studies are listed in Table 1. As noted in Table 1, six of the needs were the same although they were ranked in a slightly different order and centered on assurance and information needs. These needs were: to be encouraged that the patient is being given the best care possible; to have questions answered honestly; to be called at home about changes in the patient's condition; to know specific facts concerning the patient's progress; to feel that the hospital personnel care about the patient; and to know how the patient is being treated medically. The results suggest that families of patients who are critically ill with neurological conditions may share some similar needs, although the needs may be ranked differently.

Table 1

Summary of the Ten Most Important Needs Identified by Family Members of Patients with Brain Injuries from Comparative Studies using the CCFNI in the ICU

Bernstein (1990)	Engli & Kirsivali-Farmer (1993)	Mathis (1984)
1. To be encouraged that the patient is being given the best care possible	1. To know the prognosis	1. To feel that hospital personnel care about the patient
2. To have questions answered honestly	2. To have questions answered honestly	2. To be called at home about changes in the patient's condition
3. To know the prognosis	3. To be assured that the best care possible is being given to the patient	3. To know exactly what is being done for the patient
4. To be called at home about changes in the patient's condition	4. To be called at home about changes in the patient's condition	4. To be assured that the best possible care is being given to the patient
5. To feel there is hope	5. To feel that the hospital personnel care about the patient	5. To have questions answered honestly
6. To have explanations given that are understandable	6. To have a specific person to call at the hospital when unable to visit	6. To be told how the patient was being treated medically
7. To know specific facts concerning the patient's progress	7. To know how the patient is being treated medically	7. To receive information about the patient's condition at least once a day
8. To feel that the hospital personnel care about the patient	8. To have explanations that are understandable	8. To feel accepted by hospital personnel
9. To know exactly what is being done for the patient	9. To know specific facts concerning the patient's progress	9. To feel there is hope
10. To know how the patient is being treated medically	10. To see the patient frequently	10. To have specific facts concerning the patient's progress

Using a phenomenological approach, Johnson (1995) explored the experiences of all family members of a patient who had a traumatic brain injury from the time of the accident to rehabilitation. The themes that evolved from the interviews of the six family members were: helplessness and the need to hope; the need to be informed and involved; and the impact of intubation/extubation. Similar to the previous studies, the need for hope, to receive information concerning the care and treatment of the patient as well as to receive honest answers were important to the family members in this study.

A number of additional studies have been done that explored the needs of family members of patients in ICU of which eight reported to have involved patients with neurological/neurosurgical conditions along with other critically ill patients from surgical-trauma, coronary, medical, cardiovascular and thoracic surgery ICUs (Davis-Martin, 1994; Freichels, 1991; Jamerson et al., 1996; Leske, 1986; Pelletier, 1993; Price, Forrester, Murphy, & Monaghan, 1991; Rukholm, Bailey, Coutu-Wakulczyk, & Bailey, 1991; Zazpe, Margall, Otano, Perochena, & Asiain, 1997). Motor vehicle accidents and cerebral vascular diseases were identified as the cause of the neurological/neurosurgical conditions in three studies (Freichels, 1991; Leske, 1986; Pelletier, 1993). The other studies did not specify the diagnoses involved in the patients' admissions to the ICU but reported that a neurology/neurosurgery ICU was one of the settings for the study. Similar to the previous studies, the CCFNI was used to gather data about family needs for six of the studies (Davis-Martin, 1994; Freichels, 1991; Leske, 1986; Price et al., 1991; Rukholm et al., 1991; Zazpe et al., 1997). Pelletier (1993) did a secondary analysis of interview transcripts to obtain the needs of family members of patients who were organ and tissue donors. Jamerson et al. (1996) did a qualitative study to explore the experiences of family members during which some of their needs were identified. While most of the studies were conducted in the United States (Davis-Martin, 1994; Freichels, 1991; Jamerson et al., 1996; Leske, 1986; Price et al., 1991), two were carried out in Canada (Pelletier, 1993; Rukholm et al., 1991) and one in Spain (Zazpe et al., 1997).

Jamerson et al. (1996) interviewed 18 women and 2 men in their qualitative study to explore family members' experiences while patients were in ICU. Four themes were identified: hovering; information seeking; tracking; and garnering resources. In the initial hovering phase family members were reported to be unaware of their needs, however, seeking information brought them out of this phase. The information they sought centered around the patient's condition and there was a need to be informed of any changes which was similar to the findings of previous studies (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993; Johnson, 1995; Mathis, 1984). Furthermore, tracking involved being with the patient to observe, analyze and evaluate the care the patient received. The family members needed to be reassured the best care was being given which was also reported in previous studies (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993; Mathis, 1984). Personal needs, such as rest and nutrition, and pyschosocial needs, such as support from family and friends , were needs identified in the phase of garnering resources.

Similar needs were identified by Pelletier (1993) when she performed a secondary analysis of interview transcripts of seven families of patients involved in organ and tissue donations. Needs for: 1) information concerning the patient's condition and diagnosis; 2) emotional support; 3) to visit or be with the patient; and 4) to consent to organ and tissue donation, were the themes that evolved from the analysis. Most of the family members reported that unless they asked questions their need for information was unmet. They were appreciative of nurses who provided them with information and emotional support and expressed a desire to have received more support from other health care professionals.

In a descriptive study to determine the extent to which family needs were met, Zazpe et al. (1997) asked 85 family members to identify their needs 48 hours after the patient's admission into the ICU and then to rate how well that need was met. For this study, a modified version of the CCFNI was grouped into four categories: information; confidence; comfort of the ICU environment; and emotional support. The results revealed that needs related to confidence and information were the most frequently identified needs for over 90% of the family members (Zazpe et al., 1997). Examples of needs related to confidence were: being assured that the best care is

being given and to feel that hospital staff care about the patient. The need to have explanations that are understandable was an example of needs related to information.

These results are consistent with Leske (1986) who had used a consensus response obtained from 55 family members of 20 critically ill patients. This is the only study that reported using a consensus response from the family members. The three top needs identified by these family members were to feel there is hope, to have questions answered honestly and to know the prognosis (Leske, 1986). In addition, Leske compared the results of her study with Molter's (1979) and found that there were significant differences with some of the need statements for the family members. Examples of these need statements were: to have visiting hours changed for special conditions; to have a place to be alone; to be alone at any time; to be encouraged to cry; and to have the bathroom near the waiting room. The nature of the critical illness and the fact that a consensus response was used may explain the difference in Leske's and Molter's results (Leske, 1986).

Davis-Martin (1994) and Freichels (1991) studied the long-term needs of family members of patients in the ICU. While Davis-Martin utilized the time frame of greater than two weeks, Freichels compared family members' needs during the first 72 hours after admission and then again 7-10 days later. Davis-Martin's (1994) findings were consistent with previous studies on family needs of patients in the ICU for shorter periods of time. The similarity may be related to the unstable condition of the patients that requires that they stay in the ICU longer and may cause the family members to remain in a crisis state (Davis-Martin, 1994). The three greatest needs identified in Davis-Martin's study were: to feel there is hope; to feel that hospital personnel care about the patient; and to have questions answered honestly. The needs considered to be least important to the family were: to have good food available in the hospital; to have explanations of the environment before going into the ICU for the first time; and to talk to the same nurse each day (Davis-Martin, 1994). In contrast, the results of Freichels' (1991) study suggested that the family members perceived their needs to be less important during the second time period. However, at both time periods the needs related to assurance, such as to have questions answered honestly,

were highest, whereas needs related to comfort and support of the family member were considered to be least important (Freichels, 1991). It should be noted that eight of the top ten needs identified during the two time periods were identical although they were ranked in a different order.

Contrary to the other research studies, Price et al. (1991) categorized the family members who participated in their study into groups consisting of parents, spouses, siblings, adult children, and significant others. They compared the ranking of family needs across the categories and found that the needs were ranked in a similar manner, however, the group that differed the most was the spouses. In particular, the spouses ranked the need to know the prognosis and to feel there was hope higher than the other family members as a whole while the need to have someone concerned about the family's health was less important than the others. As a whole, the family members in this study identified similar needs found in other studies, although the need to feel hope was ranked lower (11th) compared to the other studies (Price et al., 1991).

In their descriptive study Rukholm et al. (1991) identified similar needs to the previous studies using a modified version of the CCFNI. The results of their study suggested that men scored lower than women on rating the importance of family needs except for men aged 69 to 85. These authors also did a regression analysis on certain demographic characteristics, knowledge, spiritual needs and worries with family needs and with situational and trait anxiety. The results revealed that spiritual needs and situational anxiety demonstrated a significant influence on family needs and accounted for 33% of the variance. The results of the analysis of variance suggested that family needs and age had a significant influence on situational anxiety and that family needs and education had a significant influence on trait anxiety. These results suggest that meeting the family's need may decrease the amount of anxiety family members have during the patient's critical care period (Rukholm et al., 1991).

A comparison of the ten most important needs of family members of critically ill patients in the ICU from the cited studies that used the CCFNI are listed in Table 2 (Davis-Martin, 1994; Freichels, 1991; Leske, 1986; Price et al., 1991; Rukholm et al., 1991). Omitted from this table is

the study by Zazpe et al. (1997) since they categorized the needs in a slightly different format. As noted in Table 2, five needs were similar which may suggest that family members of critically ill patients may have some common needs. These needs were: to feel that hospital personnel care about the patient; to have questions answered honestly; to have explanations given in terms that are understandable; to know the prognosis; and to know specific facts concerning the patient's progress. These needs are related to information and reassurance. Interestingly, the five needs identified by family members of critically ill patients were five of the ten most important needs Leske (1991b) reported in a study that combined the raw data from 27 studies conducted in 15 states over a ten year period, 1980 to 1989. All of those studies involved family members of patients admitted to the ICU and the data were collected during the first 72 hours of admission. Three of these five needs were also identified by family members of patients who were critically ill with neurological/neurosurgical conditions (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993; Mathis, 1984) which may suggest that regardless of the diagnosis some needs may be common among family members of critically ill patients. These needs were: to feel that hospital personnel care about the patient; to have questions answered honestly; and to know specific facts concerning the patient's progress.

Table 2

Summary of the Ten Most Important Needs Identified by Family Members of Critically Ill Patients in ICU using the CCFNI

Davis-Martin (1994) (two weeks)	Freichels (1991) (first 72 hours)	Freichels (1991) (7-10 days)	Leske (1986) (first 72 hours)	Price et al. (1991) (24-72 hours)	Rukholm et al. (1991) (time not provided)
1. To feel there is hope	1. To have questions answered honestly	1. To have questions answered honestly	1. To feel there is hope	1. To have questions answered honestly	1. To be assured of best care
2. To feel that hospital personnel care about the patient	2. To know specific facts concerning patient's progress	2. To be assured that the best care possible is being given	2. To have questions answered honestly	2. To be assured that the best care possible is being given	2. Honest answers
3. To have questions answered honestly	3. To be assured that the best care possible is being given	3. To know the expected outcome	3. To know the prognosis	3. To feel that hospital personnel care about the patient	3. To be called regarding changes
4. To know the prognosis	4. To be called at home about changes in the patient's condition	4. To have explanations that are understandable	4. To know specific facts concerning the patient's progress	4. To have explanations that are understandable	4. To know the prognosis
5. To be assured that the best possible care is being given	5. To feel that hospital personnel care about the patient	5. To be called at home about changes in the patient's condition	5. To have explanations that are understandable	5. To know specific facts about the patient's condition	5. To know specific progress
6. To have explanations that are understandable	6. To know the expected outcome	6. To feel there is hope	6. To receive information once a day on the patient	6. To know how the patient was being treated	6. To feel hopeful
7. To see the patient frequently	7. To have explanations given that are understandable	7. To feel that hospital personnel care about the patient	7. To be called at home about changes in the patient	7. To be called at home about changes in the patient's condition	7. To know medical treatment
8. To know specific facts concerning the patient's progress	8. To feel there is hope	8. To know specific facts concerning the patient's progress	8. To feel hospital personnel care about the patient	8. To know exactly what was being done for the patient	8. To know exact care
9. To receive information about the patient once a day	9. To receive information about the patient once a day	9. To know how the patient is being treated medically	9. To see the patient frequently	9. To know the prognosis	9. Understandable explanations
10. To feel accepted by hospital staff	10. To know exactly what is being done for the patient	10. To see the patient frequently	10. To know why things were done for the patient	10. To know why things were done for the patient	10. To know that the staff care

A fewer number of studies have been done that examined the long-term needs of family members caring for a loved one with a brain injury at home (Acorn & Roberts, 1992; Campbell, 1988; Casas, 1989; Grant & Bean, 1992; Kreutzer, Serio, et al., 1994; McLean et al., 1991; Stroker, 1983; van Veenendaal et al., 1996; Wellwood et al., 1994). Similar to the studies in critical care, the results of these studies indicate that the need for information concerning the patients' injury, the effects of the injury and outcome is important to the family members (Acorn & Roberts, 1992; Campbell, 1988; Casas, 1989; Kreutzer, Serio, et al., 1994; van Veenendaal et al., 1996; Wellwood et al., 1994). The need for hope and receiving honest answers to their questions were also identified in these studies (Acorn & Roberts, 1992; Campbell, 1988; Kreutzer, Serio, et al., 1994). Additional needs identified in the long-term studies that were not reported in the ICU studies were related to receiving information on community resources, such as support groups and respite care, and strategies to assist in the patients' care (Acorn & Roberts, 1992; Grant & Bean, 1992; Kreutzer, Serio, et al., 1994; McLean et al., 1991; Stroker, 1983; van Veenendaal et al., 1996). In summary, this review shows that family members of patients with brain injuries experience a variety of needs and that these needs change over time.

Nurses' Perceptions. A few studies have assessed family needs from both the family members' and nurses' perceptions. These studies have involved family members and nurses in coronary care units (Caplin & Sexton, 1988; Johnston, 1986), multiple ICUs consisting of neurosurgical, neurologic, medical-surgical, coronary, cardiovascular, cardiothoracic, advanced care and telemetry step-down units (Dockter et al., 1988; Forrester et al., 1990; Kleinpell & Powers, 1992; Lynn-McHale & Bellinger, 1988; O'Malley et al., 1991), and multiple ICUs with no specific diagnosis (Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; O'Neill Norris & Grove, 1986; Prowse, 1984). Jacono et al., (1990) used both an adult ICU and neonatal ICU for their study. Furthermore, there was one study that focused on health care professionals perceptions of family educational needs in patients with strokes (van Veenendaal et al., 1996). A comparison of family needs as perceived by the family members of critically ill patients and nurses were assessed in

each of these studies with the exception of one (O'Malley et al., 1991), which focused only on the critical care nurses' perception. Only two studies reported that the nurses were familiar with the family member on whom they completed a questionnaire on family needs (Forrester et al., 1990; Johnston, 1986). This allowed for a more accurate comparison to be made rather than having the nurses complete the questionnaire in relation to a general view of family needs and thus, strengthened the design of the studies (Burns & Grove, 1995). Overall, the results of the nurses' perceptions varied among the studies.

A statistically significant difference was found between family members' and nurses' perceptions of family needs for some of these studies (Forrester et al., 1990; Jacono et al., 1990; Johnston, 1986; Kleinpell & Powers, 1992; Lynn-McHale & Bellinger, 1988; O'Neill Norris & Grove, 1986). By analyzing total mean scores, Lynn-McHale and Bellinger (1988) found that the nurses were moderately accurate at identifying the extent family needs were perceived to have been met. However, at the item level family members ranked comfort needs, such as having food available and comfortable waiting rooms, and emotional support needs, such as being encouraged to cry and to have another person visit with them, lower than the nurses. Needs relating to institutional support services were the only category of needs that the nurses and family agreed in their level of satisfaction (Lynn-McHale & Bellinger, 1988). Forrester et al. (1990) found that critical care nurses were moderately accurate (50%) in identifying family needs. All of the needs that were statistically significant in their study were considered more important by the family members. More specifically, six of these needs were identified as being most important for the family members whereas four were listed as most important by the nurses. Some examples of these needs were: to have questions answered honestly; to have explanations that are understandable; to feel that hospital personnel care; and to know how the patient was being treated. Similarly, O'Neill Norris and Grove (1986) reported that the needs for hope, honest answers to questions, to know about the type of staff taking care of the patient, to feel accepted by hospital staff, and to be called at home about changes were all ranked higher by the families. Moreover, Jacono et al. (1990) noted that critical care nurses in an adult ICU and neonatal ICU

were accurate in identifying 56% of the family needs. The following are examples of some of the needs identified by the family members and nurses that had a significantly different rating: to help with the patient's physical care; to see the patient frequently; to talk about feelings; and to have visiting hours start on time. All of the needs that were statistically different were rated higher by the family with one exception, to talk about feelings (Jacono et al., 1990). Furthermore, Johnston (1986) documented that only one nurse out of 25 identified a similar pattern in prioritizing the needs of the spouse he or she was assessing. Lastly, Kleinpell and Powers (1992) found that although family members and nurses identified similar needs as important, the family had rated several of those needs higher than the nurses. There were some needs that families ranked as important but not satisfactorily met, such as to have directions as to what to do at the bedside and to have friends nearby for support (Kleinpell & Powers, 1992).

In contrast, Prowse (1984) reported that there was a general agreement between nurses and family members in identifying family needs. There was also general agreement concerning the nurses' responsibility to meet family needs, although there were two exceptions. These were: to have someone to talk to about their feelings and to have someone concerned about their health. More nurses than family members indicated that it was the nurses responsibility to meet these needs (Prowse, 1984). Likewise, in a study that examined the stresses experienced by spouses of patients who had a MI, Caplin and Sexton (1988) noted a high correlation between the nurses and the spouses in their ranking of stresses. Dockter et al. (1988) reported similar results. They developed their own questionnaire which had four categories: preparation/physical; anxiety; participation/information; and emotional support. They found that nurses and family members agreed that the categories preparation/physical and anxiety contained the greatest needs of the family members. These categories were related to details concerning the patient's condition and appearance and the families' concerns about the patient. There were five items that nurses perceived differently than the family members. The nurses thought the family members were anxious on admission, did not want to participate in patient care, were not allowed enough

time to visit, were comfortable expressing their feelings, and were uncomfortable asking questions.

O'Malley et al. (1991) studied 126 critical care nurses' perceptions of family needs from four different units. This descriptive study did not examine the family members' perceptions. The five needs perceived to be most important for the nurses were: to have questions answered honestly; to feel that hospital personnel care; to be assured that they will be called if the patient's condition changes; to have explanations that are understandable; and to talk about death. The nurses ranked cognitive needs higher than the psychological, personal and physical needs. Furthermore, the nurses reported that they could meet 85% of family needs if they had the time. The nurses identified physicians, chaplains, administration, and social services as additional people to help meet family needs. Further results suggested that nurses with a baccalaureate degree rated family needs lower than nurses with an associate degree in nursing. In addition, nurses who had 4-6 years of critical care nursing experience rated the importance of needs more accurately than nurses with less than 3 years or more than 6 years of critical care experience (O'Malley et al., 1991).

van Veenendaal et al. (1996) explored health care professionals' perceptions of the educational needs of family members caring for a loved one with a stroke. Health care professionals consisted of nurses, physiotherapists, and social workers in this study. They reported that family members desired more information concerning: the rehabilitation process; reducing the risk of a new stroke; what is done for the stroke survivor; and medication. Reducing the risk of a new stroke was information that the family desired but did not receive as noted by van Veenendaal et al., (1996).

The needs of family members of critically ill patients as perceived by nurses using a modified version of the CCFNI are compiled in Table 3. The results of these studies would suggest that nurses perceived some needs similar to family members when the needs listed in Table 3 are compared with Tables 1 and 2. Some examples of need statements that were similar in each study in the three tables were: to have questions answered honestly; to be assured the

best care possible is being given; to have explanations that are understandable; to be called at home about changes in the patient's condition; and to feel that hospital personnel care about the patient. However, there were also some differences noted in the nurses' perceptions. Specifically, the nurses tended to perceive comfort needs, such as a bathroom near the waiting room, and emotional support needs, such as to talk about feelings, as being more important to families than what the families perceived these needs to be. In addition, the need for hope was not identified as frequently in the top ten needs perceived by the nurses as compared to the family members of critically ill patients with and without brain injuries.

Table 3

Summary of the Ten Most Important Needs of Family Members of Critically Ill Patients as Identified by Nurses

Forrester et al. (1990)	Jacono et al. (1990)		Kleinpell & Powers (1992)	Lynn-McHale & Bellinger (1988)	O'Neill Norris & Grove (1986)
	ICU Nurses	NICU Nurses			
1. To have questions answered honestly	1. To have explanations that are understandable	1. To have explanations that are understandable	1. To have questions answered honestly	1. To have visiting hours changed for special conditions	1. To talk to the doctor every day
2. To be assured best care possible is being given	2. To be called at home about changes in the patient's condition	2. To be assured best care possible is being given	2. To have explanations that are understandable	2. To receive information about the patient once a day	2. To receive information about the patient once a day
3. To feel that hospital personnel cared about the patient	3. To have explanations of the environment before going in	3. To know the prognosis	3. To know the prognosis	3. To touch patient when they visit	3. To feel hospital personnel care about the patient
4. To have explanations that are understandable	4. To feel that hospital personnel cared about the patient	4. To feel there was hope	4. To know what was done for the patient	4. To be assured that the best care possible is being given	4. To have explanations that are understandable
5. To know how the patient was being treated	5. To have questions answered honestly	5. To have questions answered honestly	5. To feel that hospital personnel care	5. To feel hospital personnel care about the patient	5. To know why things were being done for the patient
6. To feel there was hope	6. To be assured best care possible is being given	6. To feel that hospital personnel cared about the patient	6. To be called about changes	6. To have explanations that are understandable	6. To be assured that the best care possible is being given
7. To be called at home about changes in the patient's condition	7. To know specific facts about the patient's condition	7. To be called at home about changes	7. To be assured that the best care possible is being given	7. To have a bathroom near the waiting room	7. To know how the patient was treated
8. To know exactly what was being done for the patient	8. To know the prognosis	8. To talk about the possibility of the patient's death	8. To feel there is hope	8. To have a waiting room near the patient	8. To have questions answered honestly
9. To know the prognosis	9. To know exactly what was being done for the patient	9. To talk about feelings	9. To receive information daily	9. To be called at home about changes in the patient's condition	9. To be told about other people who could help with problems
10. To know specific facts about the patient's condition	10. To talk about feelings	10. To know why things were being done for the patient	10. To know about the patient's progress	10. To have religious advisor visit with them	10. To see the patient frequently

Summary. The impact of a severe brain injury can be devastating to the patients and their families. It is important that the family members' needs be identified since they have a crucial role in the recovery of the patients. Previous research suggests that family members in ICU are able to identify their needs. Some of these studies included family members of patients with brain injuries. The results indicate that family members experience some similar needs, however, the uncertain outcome and condition of the patients with brain injuries may be factors which influence their family members' ranking of needs differently from other family members of patients in ICU settings. No studies have been done on an acute care neuroscience unit to determine what the family needs are in these settings. The nurses' ability to identify needs similar to the family members varied among the studies reviewed. It is important for nurses to assess family needs to ensure that the appropriate interventions are initiated. Similarly, no studies have been found that examine the nurses' perceptions of family needs of patients with brain injuries in an acute care setting. Therefore, this study will address the current gap in research. The knowledge gained can be used by neuroscience nurses to develop nursing interventions, such as support programs and informational booklets, that will best meet the families' needs. Thus, in meeting the needs of the family, the likelihood of a more successful adaptation to the injury will be heightened for both family members and patients.

Conceptual Model

Description. The Neuman Systems Model (NSM) was the conceptual framework for this study. Stress and the reaction to stress are the two major components on which the model is based (Neuman, 1995). The development of this model has been influenced by scholars from other disciplines such as: Bertalanffy; Caplan; de Chardin; Gesalt; Lazarus; Marx; and Selye (Cross, 1990; Fawcett, 1995; Lancaster, 1996; Meleis, 1991; Neuman, 1995). In earlier versions of the model, Neuman documented ten assumptions. However, in the most recent edition of her book, she reported that the assumptions may also be viewed as propositions (Neuman, 1995). Appendix A represents NSM for viewing the family. However, the model has been applied to the

individual family member for this study. A brief description of Neuman's model will be presented based on its assumptions and main concepts.

According to Neuman (1995), the **client/client system** is an open system that constantly interacts with the environment and can be either an individual, family group, or community. For the purposes of this study, client refers to the individual. The client consists of a **core structure** that contains innate basic survival factors and the following five **variables**: physiological; psychological; sociocultural; developmental; and spiritual. The **physiological variable** refers to bodily structure and functions, such as obtaining adequate rest and nutrition for the maintenance of the person's physical health. The **psychological variable** pertains to relationships, such as interactions with health care professionals and friends, and mental processes, such as attitudes and values. The **sociocultural variable** is a composite of social and cultural functions and includes the client's economic level, cultural practices, and behaviour patterns. The **developmental variable** is associated with developmental life processes and the **spiritual variable** involves the influence of spiritual beliefs within the client.

Surrounding the core structure are three concentric circles that protect it from stressors. The five variables are also part of the concentric circles and they "determine the nature and degree of system reaction or possible reaction to the stressor" (Neuman, 1995, p. 21). The outermost circle is the **flexible line of defense** that acts as a buffer, in an accordion-like manner, to the **environmental stressors**. The internal and external environments consist of stressors that can be: **intrapersonal**, arising within the individual; **interpersonal**, occurring between individuals; and **extrapersonal**, which are outside of the individual. The **normal line of defense** represents the client's usual wellness level that has evolved over time. Neuman (1995) stated that "variances from wellness or varying degrees of system instability" (p. 33) develop if stressors penetrate the normal line of defense. The potential to disrupt the normal line of defense is different for each stressor. A key aspect of Neuman's model is verifying perceptions. For example, depending on how the client cognitively appraises the stressors, whether positively or negatively, will have an influence on his or her reaction to the stressor. The

degree of reaction to the stressors as they invade the normal line of defense refers to the amount of instability within the system. **Lines of resistance** are activated when the normal line of defense has been penetrated. To support the core structure, the lines of resistance contain both "known and unknown internal and external resource factors" (Neuman, 1995, p. 30). The function of the lines of resistance is to stabilize and return the client to his or her usual state of wellness or to a higher level. **Wellness** is maintained when the five variables function harmoniously (Grant, Kinney, & Davis, 1993; Neuman, 1995). **Illness** indicates disharmony within the client system (Neuman, 1995).

In this model, the **goal of nursing** is to retain, attain, or maintain system stability as stressors impose on the system. There are three levels of **prevention as interventions** that nurses can utilize depending upon the impact or possible impact of the stressors on the client to achieve the nursing goal. Primary prevention is required when a stressor is suspected but there has been no reaction noted. Secondary prevention would be necessary when a reaction has developed in response to a stressor. Lastly, tertiary prevention interventions are used to maintain wellness after some form of treatment has been instituted. **Reconstitution** is referred to the state when the client returns and maintains stability after some form of treatment. Neuman's model is unique in that the perceptions of both the client and nurse are necessary to determine the relevant goals and interventions (Neuman, 1995).

Rationale for Selection of the Model. Neuman has been greatly influenced by general systems theory in her model (Fawcett, 1995). The identification of family members' needs lends itself to a systems approach. Systems theory provides a method for understanding the interactions between individual members within the family as well as the interactions of the family members with other systems (Artinian, 1994; Casey, 1996; Friedman, 1992; Wright & Leahey, 1994). A key concept that is characteristic of systems theory is the notion of circular causality (Casey, 1996; Friedman, 1992). Circular causality refers to the effect and influence an individual's behaviour has on another (Wright & Leahey, 1994). For example, the patient's behaviour

following a brain injury and the behaviour of health care professionals, such as nurses, can influence the family member's behaviour. Similarly, in systems theory the relationships connect the system and its parts together causing them to be interdependent (Casey, 1996) or connected (Leaf, 1993). Thus, whatever affects the system as a whole will affect each of its parts (Friedman, 1992). For example, when one member of the family is affected by an injury, such as a brain injury, the whole family is affected (Leaf, 1993). Previous studies have utilized concepts from systems theory for the purpose of assessing the family members' needs (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993; Grant & Bean, 1992; Mathis, 1984). Since the sample for this study was concerned with one family member rather than the entire family, Neuman's model was selected instead of Family Systems Theory.

In addition to the influence of general systems theory in Neuman's model, the emphasis of her model on stress and the system's reaction to stress further supports its selection for this study. Neuman (1995) reported that "employing a systems-based perspective explains how system stability is achieved in relation to stressors imposed upon it" (p. 25). As previously mentioned, the families of patients with brain injuries have a significant increase in stress as a result of the injury which may impede the families' adjustment (Kreutzer, Gervasio et al., 1994; Mauss-Clum & Ryan, 1981). Unmet needs are considered to be stressors to the family members. By examining family members' needs, some insight on the stressors that have an impact on the family members' of patients with brain injuries may be identified. Neuman's emphasis on verifying perceptions may result in appropriate nursing interventions being developed to meet the needs of family members of patients with brain injuries. Neuman's model has been used in other studies to identify family needs (Bowdler & Barrell, 1987; Decker & Young, 1991; Grant & Bean, 1992; Kahn, 1992) which further supports its use in this study. In summary, the wholistic and systemic approach that Neuman's model utilizes makes it ideal in the study of family members' needs. For these reasons, Neuman Systems Model was chosen as the conceptual model for this study.

Utilization of Neuman Systems Model in Present Study. Acute brain injuries are often sudden and unexpected. The resulting deficits can produce a crisis for the family (Elliot & Smith, 1985; Leske, 1986). It has been noted that the family can experience many crises throughout the hospital stay. Furthermore, the family are attempting to deal with something with which they may have no prior experience (Stambrook, Peters, & Moore, 1989). These factors have the potential to lead to instability within the family member or client as the normal lines of defense are penetrated by stressors. Wellness is maintained when there is a harmonious relationship between the physiological, psychological, sociocultural, developmental, and spiritual variables (Neuman, 1995). Family members are in a state of optimal wellness when their needs are met. However, if their needs are not met their level of wellness is reduced (Neuman, 1995). Three types of stressors can occur which consequently affect the family member's level of wellness by altering the harmonious relationship between the five variables as previously described. The first stressor, intra-personal, are internal factors such as thoughts or feelings that occur within the family member (Neuman, 1995) and may be directly related to the impact the illness or injury has on him or her. Intra-personal stressors are indicated by needs relating to the person's feelings or thoughts (Grant & Bean, 1992). Inter-personal stressors occur between the family member and another person (Neuman, 1995), such as health care professionals, other family members or friends. Examples of these stressors are needs related to communication with others or expectations or affection from others (Grant & Bean, 1992). Finally, needs related to financial or employment concerns are examples of extra-personal stressors that occur outside or are distal to the family member (Neuman, 1995).

For this study, the client system will refer to the family member of the patient with an acute brain injury. Both the nurses' and family members' perceptions of family needs will be taken into consideration which is consistent with Neuman's model. Neuman's conceptual model will also be used to discuss the needs of family members according to the five variables: physiological; psychological; sociocultural; developmental; and spiritual. The needs identified by families in previous studies suggested that they are related to the variables in Neuman's model (Grant &

Bean, 1992; Kahn, 1992). The unmet needs identified will be discussed according to the three types of stressors. Lastly, some examples of appropriate primary, secondary, and tertiary prevention strategies as nursing interventions will be provided to assist neuroscience nurses in their interactions with the family members of patients who have had a brain injury.

Limitations of the Neuman Systems Model. Neuman's definition of health is a limitation to her model. Although Neuman considers health to be on a continuum, wellness and illness are seen as dichotomous end points rather than polar ends (Fawcett, 1995). Further clarification is also needed concerning Neuman's views of illness as entropy, which according to general systems theory is characteristic of a closed system (Fawcett, 1995; Lancaster, 1996). This contradicts the view of the client system as an open system. The understanding of the concepts of wellness and illness would be enhanced by clarifying these issues. Likewise, the attributes Neuman used to describe the system-environment interactions, such as steady state and dynamic equilibrium, are incongruent with the constant energy exchange noted in an open system and requires clarification (Fawcett, 1995; Lancaster, 1996). However, despite these limitations, the model has been widely used in curriculum development, administration, clinical, and research settings (Neuman, 1995).

Summary. The Neuman Systems Model has been described and is shown to be an appropriate conceptual framework to guide the current study. The concepts within Neuman's model are extensive and allow the framework to be utilized in research in a variety of ways. In this particular study, only a portion of the framework will be utilized to address the research questions. The model will be used to discuss the needs of family members according to the five variables and the unmet needs will be discussed according to the three environmental stressors.

Chapter Three

Methods

This chapter will discuss the methods employed for the study. In particular, the research design, setting, sample, sample size, method of measurement, data collection procedure, data analysis plan, and the protection of human rights are described.

Research Design

A comparative descriptive research design (Burns & Grove, 1995) was used to answer the research questions for this study. A convenience sample was obtained from the neuroscience units of two hospitals in the Ottawa-Carleton region of Ontario. Data were collected from paired samples consisting of the family members of patients with acute brain injuries and the registered nurses (RNs) who cared for these patients. A modified version of the Critical Care Family Needs Inventory (CCFNI) (see Leske, 1986) was used to elicit the participants' perceptions of family needs after permission was obtained from the authors of the instrument (see Appendix B for letter of permission; and Appendix C for copy of the original version of instrument). Both descriptive and inferential statistics were used in the analysis of the data.

Setting

The setting for this study was the neuroscience units in two teaching hospitals in Ottawa, Ontario. On neuroscience units, specialized care is provided to people who have disorders and dysfunctions of the nervous system. Patients commonly seen on these units are those with strokes and TBI. Traumatic brain injuries can include those with diffuse brain injuries, which are characterized by widespread neurological dysfunction (Hickey, 1986). Diffuse injuries result in greater deficits since more than one area of the brain has been injured (DeBoskey, Hecht, & Calub, 1991; Marshall, Marshall, Vos & Chesnut, 1990). One of the assessment tools universally used with the neuroscience population is the Glasgow Coma Scale (GCS). This tool is an indicator of the patient's state of responsiveness to stimuli (Mitchell & Hodges, 1988). The tool measures

the patient's best response to three parameters of behavioural activity; eye opening, verbalization, and movement (Mitchell, 1988). The score obtained can range from 3-15 with a GCS score of 3 representing patients who are comatose and a score of 15 represents patients who are fully alert and well-oriented (Hickey, 1986).

A brief description is provided of the neuroscience units used in this study. The neuroscience unit at the one institution had 38 beds and a five bed step-down unit. The visiting hours at this hospital were from 10 a.m. to 9 p.m. The nurse/patient ratio on the neuroscience unit was 5:1 and approximately 2:1 in the step-down unit. These nurse/patient ratios were comparable to the neuroscience unit and step-down unit at the second institution which had 36 beds and an eight bed step-down unit. The visiting hours for this hospital were from 9:30 a.m. to 8:30 p.m. Visiting hours are not strictly adhered to, especially in the case of very ill patients, when efforts are made to accommodate family members who wish to stay longer (Nurse Manager on the Neuroscience Unit, personal communication, April 22, 1996). The philosophy statements for both hospitals addressed the importance of caring for family members of the patients on the unit (see Appendix D for a copy of the philosophy statements).

Sample

The target populations for this study were the family members of patients with acute brain injuries on neuroscience units and the RNs who work on those units. A convenience sampling technique was used to increase the possibility of meeting the appropriate sample size for the study. The inclusion criteria for the patients whose family members would be considered for the study were: 1) admitted with a diagnosis of an acute brain injury from trauma or vascular causes; 2) had been on the neuroscience unit for a minimum of seven days to allow the family an opportunity to begin to adjust to the admission; and 3) had a GCS $\leq$ 12.

Minor modifications were made to the inclusion criteria following a discussion with committee members. Initially, the time period the patient was to be on the unit, criterion number 2, was seven days. This was changed to five days in view of the fact that many patients were being

discharged or transferred to their home hospitals before the seventh day which resulted in many family members being missed who could have been approached to seek their willingness to participate in the study. A third criterion, having an admission GCS value of 12 or less, was discontinued because it was too restrictive. After several weeks into the data collection phase it was discovered that a GCS of 12 or less limited the number of family members of patients who had a stroke from participating in the study. Generally, patients with a stroke tend to have higher GCS values than patients with TBI because a stroke tends to cause focal injuries whereas TBI are more commonly diffuse (DeBoskey et al., 1991; Marshall et al., 1990). Focal injuries are ones that occur in only one area of the brain resulting in a deficit to that region while other areas are not affected. Diffuse injuries occur in a number of different areas in the brain resulting in more deficits (DeBoskey et al., 1991; Marshall et al., 1990). Consequently, these changes were made to increase the likelihood of obtaining the sample size needed for the study.

The exclusion criteria for the patients were that: 1) the patient was younger than 18 years of age; and 2) was admitted with a diagnosis of Subarachnoid Hemorrhage (SAH) or Arteriovenous Malformation (AVM). Patients with SAH were excluded because one of the institutions was participating in another study that involved these patients. There was the possibility that participation in the SAH study could influence the family members' responses to the questionnaire for the present study. Patients admitted with a diagnosis of AVM were excluded since this is a relatively rare condition and tends to be more common in the younger population (Hickey, 1986).

Only one member of the patient's family was asked to participate in the investigation. The inclusion criteria for the family members of the patients previously mentioned were: 1) related to the patient either by marriage, blood, or a significant other; 2) considered to be the legal next-of-kin of the patient; 3) 18 years of age or older; 4) able to speak and read English; and 5) making visits to the patient regularly, for example, every day as observed by the nursing staff.

The inclusion criteria for the nurses were that: 1) they had to be registered nurses; 2) they were employed in a full-time or regular part-time position on the neuroscience unit at either

institution; and 3) they had provided a minimum of two days care to patients whose family members had agreed to participate. The exclusion criteria as follows were: 1) nurses who were on maternity leave, extended sick time, or educational leave; and 2) nurses who were employed in a casual position on the neuroscience unit.

Sample Size

Polit and Hungler (1991) reported that for studies using bivariate correlation statistics, conventional values of 0.10, 0.30, and 0.50 represented small, medium, and large effect sizes, respectively, if there were no prior estimates of effect size available. By using the computer program PC-SIZE: A Program for Sample Size Determinations, Version 2.13 (Dallal, 1986), the sample size for this study was calculated to be 32 with an alpha level of 0.05, power of 0.80, and an effect size of 0.50. Accordingly, 32 family members paired with 32 RNs were required to meet the effect size and power for the study.

Method of Measurement

The participants were asked to complete a self-administered questionnaire (see Appendix E) that was divided into two main sections: a demographic profile and a modified version of the CCFNI. The demographic data on the patients that were collected from the family members consisted of: the date of hospital admission; admitting diagnosis; number of days on the unit; age; gender; and position in the family. In addition, the patients' present GCS and whether they had any loss of consciousness was obtained from the nursing staff after consent from the family had been obtained to provide information on the severity of the patient's condition. The demographic data for the family members included: gender, age, relationship to patient, highest level of education, income range, religion, ethnicity, satisfaction with the frequency of visits with the patient, and prior hospital experience. The demographic data collected from the nurses included: gender; age; employment status; highest level of nursing education; years of nursing experience; years of neuroscience nursing experience; and whether they had any recent education on family needs.

The second section of the self administered questionnaire consisted of the modified version of the CCFNI. The initial version of the family needs inventory was developed by Molter in 1976 and was then modified by Leske and Molter in 1983 and named the Critical Care Family Needs Inventory (Leske, 1986). The data gathering instrument consisted of 45 need statements with each need statement being scored in the following format: (1) not important; (2) slightly important; (3) important; and (4) very important. At the end of the instrument an 'other' category was added for family members to identify needs not previously mentioned in the tool. The CCFNI has been widely used in other studies as previously noted in the literature review.

The psychometric properties of the CCFNI were reported based on the data gathered from 21 nurse investigators from 14 different states over a nine year period (Leske, 1991a). The results revealed that the internal consistency reliability using Chronbach's alpha was 0.92. Factor analysis was also used to test the construct validity of the tool. There were five factors identified: support, comfort, information, proximity, and assurance. The correlations between these factors were relatively low (ranging from $r = 0.07$ to 0.39). These results demonstrated that the CCFNI can measure distinct dimensions of family needs (Leske, 1991a). Moreover, Macey and Bouman (1991) tested additional psychometric properties of the CCFNI. Specifically, they examined the content validity, test-retest reliability, and the readability of the instrument. Results of their study indicated that content validity was established, however, the experts who reviewed the instrument found some redundancies among the statements. The test-retest reliability suggested that over 70% of the family members agreed on the rating of importance for 39 of the 45 need statements. Lastly, using the Gunning Fog Index, Macey and Bouman (1991) reported the readability level for the instrument was within the 'easy to read' level. Overall, the psychometric properties of the CCFNI demonstrated that it was a reliable and valid instrument.

Permission to use and modify the CCFNI for this study was provided by the authors of the instrument (see Appendix B). The first modification involved the 'other' category found at the end of the CCFNI. This open ended question was reworded to elicit the family members greatest need at the time. In addition, this question was moved to the demographic section of the

questionnaire which preceded the need statements outlined in the CCFNI. In order to avoid influencing the participants' responses on questionnaires general questions should be placed before more specific questions (Polit & Hungler, 1991). For this reason, the open ended question was moved to avoid having the family members be influenced by the need statements. The second modification entailed replacing the words 'critical care unit' with 'neuroscience unit' to make need statements number 2 and 26 more appropriate. Finally, the last modification made to the CCFNI was the addition of two columns to the questionnaire that the family members were to complete. The first column was to ascertain whether the family member's need was met and the second column was to determine who met the need. This change was similar to two previous studies (Engli & Kirsivali-Farmer, 1993; Molter, 1979). In the first study, the internal consistency of the modified instrument was calculated to be 0.78 for family members of patients who were critically ill without a brain injury and 0.94 for family members of patients with a brain injury (Engli & Kirsivali-Farmer, 1993). The internal consistency of the instrument was not reported in Molter's study.

A panel of eight nurses was asked to categorize the need statements of the CCFNI into one of the five variables and three categories of stressors as defined by Neuman (1995) before beginning the study. The panel of nurses consisted of five graduate students, two university professors from the School of Nursing at the University of Ottawa and a nurse clinician. The inter-rater reliability was calculated by determining the percentage of agreement (LoBiondo-Wood & Haber, 1994) between the nurses' responses. Although this is a simple way to calculate the inter-rater reliability, it should be noted that the results may be overestimated (Polit & Hungler, 1991). The results revealed moderate inter-rater reliabilities since the overall agreement for the classification of the needs statements was 74.7% for the five variables and 65.3% for the three stressors. The inter-rater reliabilities for each individual need statement is provided in Appendix F. There were some differences noted in the classification of the needs in this study with those reported by Kahn (1992). For example, the need to feel that the hospital personnel care about the patient was considered to be associated with the psychological variable in this study whereas

Kahn (1992) reported that it was related to the developmental variable. Likewise, to be told about chaplain services was classified as a spiritual variable in the present study while Kahn noted it to be sociocultural.

As noted in Appendix F, the majority of the need statements were considered to be related to the psychological variable (n = 34). There were three need statements related to the physiological variable and these were: to have good food available in the hospital; to have someone be concerned with your health; and to have a bathroom near the waiting room. In addition, the three needs related to the spiritual variable were: to have a pastor visit; to talk about the possibility of the patient's death; and to be told about chaplain services. The need to feel there is hope was considered to be related to both the spiritual and psychological variable. To have someone to help with financial problems was associated with the sociocultural variable. As well, three variables were associated with both the psychological and sociocultural variable. These were: to have friends nearby for support; to be told about someone to help with family problems; and to have visiting hours start on time. Nine of the need statements were considered to be extra-personal stressors and nine were intra-personal stressors. Nineteen need statements were classified as inter-personal stressors while five were both inter- and extra-personal stressors. Lastly, two needs were categorized as both intra- and inter-personal.

Pilot Study

A pilot study was done to determine the content validity of the modified measurement tool. Cronbach's alpha co-efficient was not calculated at this time because the sample size for the pilot study was small. A panel of four registered nurses knowledgeable in neuroscience nursing and issues involving the family of patients with brain injuries, and four family members were asked to complete the questionnaire and to review the tool for content validity. A convenience sampling technique was used to select the family members based on the inclusion criteria previously described. Family members were identified with the assistance of the nurse manager at hospital number one and the team leaders on the neuroscience unit and neuro observation unit at

hospital number two. One family member of a patient with a TBI did not return the questionnaire. The researcher was unable to contact the family member during a follow-up telephone call. Therefore, the total sample size for the pilot study was seven (three family members and four nurses). The demographics of the patients, their family members, and the registered nurses who participated in the pilot study are reported at this time.

There were three patients whose family members agreed to participate in the pilot study. Two of the patients were admitted with a diagnosis of a traumatic brain injury and one was admitted with a diagnosis of a stroke. Two of the patients were males and two had experienced loss of consciousness at the time of the injury. The patients' ages ranged from 41 - 90 years ($\underline{M}$ = 63.3, $\underline{SD}$ = 20.23). At the time family members consented to participate, the patients' GCS value ranged from 8 - 13 ($\underline{M}$ = 10, $\underline{SD}$ = 1.7) which represents moderate to severe brain injuries, and the length of time they were on the neuroscience units ranged from 8 - 14 days ($\underline{M}$ = 10.3, $\underline{SD}$ = 2.6). The patients held the following positions in the family: spouse (n = 2) and mother-in-law (n = 1).

All of the family members who participated in the pilot study were females (n = 3) and their ages ranged from 44 - 58 years ($\underline{M}$ = 52.6, $\underline{SD}$ = 6.2). Two of the family members were spouses of the patients and one was a daughter-in-law. All of the family members were Caucasian and had a high school education. The family members were in the following income status: $25,000 - 49,999 (n = 1) and $50,000 - 79,999 (n = 2). All of the family members were satisfied with the frequency of their visits and two had previous hospital experience.

All of the nurses who participated in the pilot study were females (n = 4). The nurses consisted of two clinical nurse educators from the neuroscience unit at hospital number one and a nurse clinician and liaison nurse from the neuroscience unit at hospital number two. Two of the nurses had a baccalaureate degree in nursing and two had a diploma in nursing. The number of years of neuroscience nursing experience ranged from 10 - 25 years ($\underline{M}$ = 20, $\underline{SD}$ = 5.9) and the number of years of nursing experience ranged from 15 - 26 years ($\underline{M}$ = 21.75, $\underline{SD}$ = 4.3). Three of the nurses (75%) had recently acquired education on family needs.

Concerning the content validity of the instrument, the family members did not identify any additional needs to add or remove from the CCFNI. Four additional needs were identified by one of the nurse respondents. These needs were: 1) to receive information on long-term care options if rehabilitation is not possible; 2) to receive information about the various stages of recovery; 3) to be able to visit the rehabilitation or long-term care institution before the patient is transferred; and 4) to receive information about rehabilitation options. These needs were added to the questionnaire used in the study to make it more specific for family members of patients with brain injuries. All of these needs were considered to be related to the psychological variable and inter-personal stressor as defined by Neuman (1995) with one exception; the need to visit the rehabilitation or long-term care institution was classified as an extra-personal stressor. Furthermore, one nurse respondent questioned whether six of the need statements were "too similar". These need statements were: 'to have visiting hours changed for special conditions' and 'to visit at any time'; 'to know how the patient is being treated medically' and 'to know exactly what is being done for the patient'; and 'to be told about other people that could help with problems' and 'to be told about someone to help with family problems'. Although these statements appear to be similar, they measure different needs and therefore no changes were made to these statements in the questionnaire. For instance, the need to visit any time implies that the family members have unrestricted visiting opportunities whereas to have visiting hours changed for special conditions indicates restricted visiting practices. In addition, to know exactly what is being done for the patient can refer to other information besides knowing how the patient is being treated medically. Finally, the need to be told about someone to help with family problems is more specific than to be told about someone to help with problems.

Data Collection Procedure

The researcher met at least once a week with the team leaders from the neuroscience unit and the neuro observation unit at hospital number two and with the Nurse Manager from the neuroscience unit at hospital number one to identify the patients and their family members who

met the inclusion criteria. Family members were approached by either the team leaders, Nurse Manager or the nurse caring for the patient to determine if they were willing to speak to the researcher concerning the study. The researcher met in a quiet room on the unit with those interested family members to explain the study and answer any of their questions. A letter of information was provided to the family member and data collection commenced after a signed consent (see Appendix G) was obtained. The family members had the option of completing the questionnaire with the researcher being present to answer any questions needing clarification, or they could complete the questionnaire at a later time and return it by mail to the researcher. A self-addressed, stamped envelope was provided to those family members who chose to complete the questionnaire at a later time. The manner in which the families were approached and the information provided to them was consistent throughout the study. Attempts were made to contact the family members if the questionnaire had not been returned two weeks later. A record was kept of the number of family members who were not willing to participate and their reason(s). This information was obtained from the nursing staff.

After the family member agreed to participate, the researcher spoke with the nurse caring for the patient on that day to determine if he or she met the inclusion criteria. If the nurse did not meet the criteria, the researcher would then speak with either the team leaders or Nurse Manager to identify nurses who had recently cared for the patient and who met the inclusion criteria. Efforts were made to enroll this nurse in the study as quickly as possible after the family member consented to participate to ensure that the family members and nurses would be completing the questionnaire during the same time period. After explaining to the nurses the purpose of the study, what their participation would involve and the risk and benefits, a letter of information (see Appendix H) was provided to them along with the self-administered questionnaire. The nurses were asked to complete the questionnaire and either mail it to the researcher in a self-addressed, stamped envelope or leave it on the unit in a specified envelope to be collected by the researcher. Consent to participate was implied by their returning the completed questionnaire anonymously. The nurses were asked not to discuss their responses to the questionnaire with

their co-workers. If the questionnaire was not returned in two weeks, a follow-up letter with a second copy of the questionnaire and a self-addressed, stamped envelop was left for the nurse in his or her mailbox on the unit as a reminder. A record was kept on the number of nurses who were not willing to participate and the reasons given.

Data Analysis

The Statistical Package for the Social Sciences for Windows (SPSS) version 6.1.3. was used to analyze the data. Data were entered twice to verify data entry. Descriptive statistics were used to analyze the demographic data collected on the patients, family members, and nurses, and the mean, standard deviations, frequencies, and percents were reported. Since the sample size was small, the t-distribution was used to calculate the 95% confidence intervals (CI) from the mean and the Z was used to calculate the CI from proportions (Diekhoff, 1992; Polit, 1996) for the demographic variables. The following formula, suggested by Fleiss (1981), was used to calculate the 95% CI from small proportions when negative values were obtained from the Z method, which results in slightly asymmetric CI.

Lower Confidence Interval

$$\frac{(2np + c_{\alpha/2} \times c_{\alpha/2} - 1) - c_{\alpha/2} \sqrt{(c_{\alpha/2} \times c_{\alpha/2} - (2 + 1/n) + 4p(nq + 1)}}{2(n + c_{\alpha/2} \times c_{\alpha/2})}$$

Upper Confidence Interval

$$\frac{(2np + c_{\alpha/2} \times c_{\alpha/2} + 1) + c_{\alpha/2} \sqrt{(c_{\alpha/2} \times c_{\alpha/2} + (2 - 1/n) + 4p(nq - 1)}}{2(n + c_{\alpha/2} \times c_{\alpha/2})}$$

where: n = sample size

p = proportion

$c_{\alpha/2}$ = 1.96 if a 95% CI is desired

q = 1 - p

For objective one, the mean value of each need statement according to the family members' ratings was calculated and ranked in descending order. This was also completed for the

nurses' ratings of family members' needs for objective number two. In addition, to determine the relationship between the nurses' and family members' ratings of needs on the CCFNI, Pearson's correlations were calculated for each family member and nurse pair. Each family member and nurse pair were correlated separately at the item level to examine the distribution of ability to perceive specific family member's needs. This was done to address the problem with level of analysis as seen in Simpson's Paradox (Yarnold, 1996). Simpson's Paradox refers to the problem of combining data from two or more groups whose means may be different thus causing misleading results by generalizing from one level of analysis to another (Yarnold, 1996).

To facilitate an understanding of Simpson's Paradox, examples of hypothetical data on the ratings of three need statements by three pairs of family members and nurses are provided in Table 4. As demonstrated in Table 4, the mean of the need statements was identical for the family member and nurse in each pair. The correlation for the combined data based on the means was approximately .98. However, the correlation for pairs 1 and 3 based on the item level or need statement was $r = -1$ and for pair 2 was $r = 1$. In this excessively simplified example, the result of the correlation based on the means was misleadingly high when the data were combined and does not reflect the individual variation between the family member and nurse pairs. According to Hedges and Olkin (1985) and Rosenthal (1984) (as cited in Yarnold, 1996), it is important to first determine whether the correlation between the variables are homogenous or heterogeneous across the samples. If the correlations across the samples are homogenous then the data may be pooled and the correlation for the combined data can be calculated. However, if the correlations are heterogeneous, as indicated by the hypothetical example, the data cannot be pooled. These steps should be taken to prevent reporting misleading results in the literature.

Table 4

A Hypothetical Example of Simpson's Paradox

	Pair 1		Pair 2		Pair 3	
	FM	RN	FM	RN	FM	RN
Need 1	1	3	7	7	7	12
Need 2	2	2	5	5	10	10
Need 3	3	1	3	3	12	7
Sample Mean	2	2	5	5	10	10
Sample Correlation	r = -1		r = 1		r = -1	

Note. FM = Family Member, RN = Registered Nurse, correlation based on the means from the three pairs was approximately .98.

In addition, it was necessary to transform the r values by using Fisher's z values to normalize the distribution and to calculate confidence intervals (Munro, 1993). This was done to complete the data analysis for objective two which sought to determine the relationship between nurses and family members in identifying the needs of the family members. Content analysis was used to analyze the open-ended question identifying additional needs of the family members. It should be noted that the qualitative data approach the problem at a higher level of aggregation since global themes may be shared, while, lower item-level responses may vary as seen in Simpson's Paradox. Furthermore, content analysis was used to code the family members' responses to the question who met their needs. A percentage of whether the needs were met or not and who met the family members' needs were calculated for objective three. The results of these analyses are discussed in the body of the text. Finally, descriptive and non-parametric statistics were used to compare the needs of family members of patients with TBI and strokes to answer objective four.

Protection of Human Rights

An informed consent was obtained from the family members. As previously mentioned, the family members were identified by the team leaders and Nurse Manager on the neuroscience units. The family members were asked by the nursing staff if they would like to speak to the researcher concerning the study prior to having any contact with the researcher. The purpose of the study as well as the benefits and risks were explained to those family members who agreed to speak to the researcher. They were told that there were no immediate benefits for participating and that there could be some discomfort for family members who might become emotional or distressed during the completion of the questionnaire. The family members were further informed that they could withdraw from the study at any time and that it would not affect the patients' care. The family members had an opportunity to ask questions prior to signing the consent form. A copy of the consent form was provided to the family members for their personal record. Likewise, a letter of information was provided to the nurses explaining the purpose of the study and procedures involved. The nurses also had an opportunity to ask questions concerning the study. The nurses' consent to participate was implied by their completing and returning the questionnaire anonymously.

Confidentiality was provided by coding the information and no names were used. The participants were instructed that the information gathered would be secured in a locked filing cabinet and that all identifying information would be destroyed by a shredding process after the study was completed. The researcher was the only person who had access to the data. Ethical approval was attained from the Research Ethics Committee and Research Ethics Board at both hospitals as well as the Nursing Research Committees at each institution (see Appendix I). The nurse managers on the neuroscience units from both hospitals had also provided letters of support for the study (see Appendix J).

Chapter Four

Results

The results of the study are presented in this chapter. The demographics and characteristics of the patients with acute brain injuries, their family members, and the registered nurses who participated in the study are described first, followed by the findings of the analyses for each of the objectives.

Characteristics of Patients

There were 22 patients whose family members agreed to participate in the study. Since there were some problems in meeting the sample size as noted in chapter three (see page 31) a decision was made to stop enrollment when the minimum number of 22 family members was obtained. Five of the patients were admitted with a diagnosis of traumatic brain injury which included subdural and epidural hematomas (n = 2) and closed head injuries (n = 3). The remaining 17 patients were admitted with the diagnosis of a stroke. Sixty-three percent of the patients were males. The patients' ages ranged from 18 - 83 years ($\underline{M}$ = 57.07, $\underline{SD}$ = 19.3, 95% *CI* = 48.5, 65.6). At the time family members consented to participate, the value of the patients' Glasgow Coma Scale (GCS) ranged from 7 - 15 ($\underline{M}$ = 12.64, $\underline{SD}$ = 2.74, 95% *CI* = 11.4, 13.9), and the length of time they were on the neuroscience units ranged from 5 - 19 days ($\underline{M}$ = 9.66, $\underline{SD}$ = 3.9, 95% *CI* = 7.9, 11.4). The patients held the following positions in the family: spouse (50%); parent (27%); child (14%); and other (9%) which represented a mother-in-law and a close friend. The patients' demographics and characteristics are summarized in Table 5.

Table 5

Patient Demographics and Characteristics (n= 22)

Variables	Mean	Standard deviation	Range	Frequency	Percentage	95% Confidence level
Diagnosis						
Traumatic Brain Injury				5	22.7	5.2 to 40.2
CVA				17	77.3	59.7 to 94.8
Gender						
Male				14	63.6	43.5 to 83.7
Female				8	36.4	16.3 to 56.5
Age (years)	57.07	19.3	18 - 83			48.5 to 65.6
Number of Days on Neuroscience Unit [a]	9.66	3.9	5 - 19			7.9 to 11.4
Present GCS	12.64	2.74	7 - 15			11.4 to 13.9
Loss of Consciousness						
Yes				6	27.3	8.6 to 45.9
No				14	63.6	43.5 to 83.7
Unknown				2	9.1	2.9 to 21
Position in Family						
Parent				6	27.2	8.6 to 45.7
Spouse				11	50.0	29.1 to 70.8
Child				3	13.6	4 to 36[b]
Other				2	9.1	2 to 31[b]

Note. [a] The sample size for this variable was 21. One patient had been on the unit for 45 days at the time the family member consented to participate. When this patient was included in the calculations, the number of days on the neuroscience unit at the time family members consented to participate ranged from 5 - 43 (M=11.18, SD = 8.11, 95% CI = 7.6, 14.8).

[b] The formula suggested by Fleiss (1981) was used to calculate the 95% CI, which results in slightly asymmetric CI.

Characteristics of Family Members

Over an eight month period of data collection, 27 family members consented to participate in the study. This represented a response rate of 79% of the total number of eligible family members who were reported to the researcher. It should be noted that the actual number of family members eligible to participate in the study is unknown to the researcher since there was some difficulty in enrolling family members as mentioned in chapter three (see p. 31). Of the seven who did not consent to participate, six were family members of patients who had traumatic brain injuries and one was a family member of a patient who had a stroke. Reasons for not participating were: family members were too upset (n=2); nursing staff were not willing to ask the family member if they would be interested in speaking to the researcher because of problems they were having with the family (n=3); family member did not believe that the patient had a brain injury (n=1); and no specific reason was provided (n=1). Of the 27 family members who consented, four did not return the questionnaire. A fifth family member was excluded because the registered nurse who consented to participate did not return the questionnaire thus causing an incomplete paired sample. Of the five family members excluded from the study, four were family members of patients who had a stroke and one was a family member of a patient with a traumatic head injury. Therefore, the final sample size was 22 (65%) of family members who were referred to the researcher. Four of the family members completed the questionnaire in the waiting room on the unit at the time they consented to participate. The remainder of the family members returned the questionnaire by mail. Seven of these family members returned the questionnaire after they were mailed a reminder letter with another copy of the questionnaire or telephone contact was made by the researcher with the family members' permission.

As can be seen in Table 6, 64% of the family members were females and 36% were males. The relationship of the family member to the patient was spouse (50%), adult child (27%), parent (14%), and other (9%) which consisted of a daughter-in-law and a friend who had power of attorney. The family members' ages ranged from 27 to 77 years ($\underline{M}$ = 51.38, $\underline{SD}$ = 14.2, 95% *CI* = 44.9, 57.8). The majority of family members were Caucasian (95%) and slightly over half (59%)

had either a college or university education. All of the family members reported being satisfied with the frequency of their visits and 54% of them had no previous hospital experience. Additional demographic characteristics of the family members are reported in Table 6.

Table 6

Family Demographics (n=22)

Variables	Mean	Standard deviation	Range	Frequency	Percentage	95% Confidence level
Gender						
Male				8	36.4	6.3 to 56.5
Female				14	63.6	43.5 to 83.7
Age (years)	51.38	14.20	27 - 77			44.9 to 57.8
Relationship to Patient						
Parent				3	13.6	4 to 36[d]
Spouse				11	50.0	29.1 to 70.8
Child				6	27.2	8.6 to 45.7
Other				2	9.1	2 to 31[d]
Level of Education [a]						
Grade school or less				1	4.5	0 to 26[d]
High school diploma				7	31.8	12.3 to 51.3
College diploma				8	36.4	16.3 to 56.5
University degree				5	22.7	5.2 to 40.2
Income Status [b]						
Less than $24,999				2	9.1	1 to 33[d]
$25,000 - 49,999				9	40.9	20.4 to 61.4
$50,000 - 74,999				7	31.8	12.3 to 51.3
Greater than $75,000				1	4.5	0 to 25[d]
Religion						
Catholic				13	59.1	38.5 to 79.6
Protestant				3	13.6	4 to 36[d]
None				6	27.3	8.6 to 45.9
Church Attendance [c]						
Not at all				2	9.1	1 to 34[d]
Rarely				4	18.2	5 to 44[d]
Fairly regularly				7	31.8	12.3 to 51.3
Regularly				5	22.7	5.2 to 40.2
Ethnicity						
White				21	95.4	86.6 to 104
Black				1	4.5	0 to 25[d]
Previous Hospital Experience						
Yes				10	45.5	24.6 to 66.3
No				12	54.5	33.6 to 75.3
Satisfied with Number of Visits						
Yes				22	100.0	87 to 100[e]

Note. [a] n =21; [b] n = 19; [c] n = 18; [d] The formula suggested by Fleiss (1981) was used to calculate the 95% CI, which results in slightly asymmetric CI. [e] The rule of three suggested by Hanley and Lippman-Hand (1983) (as cited in Braitman, 1997) was used to calculate the CI. This rule provides an approximate 95% CI from 0 to 3/N when 0/N is the point estimate.

Content analysis was used to categorize their responses to the open-ended question concerning the family members' greatest need at the time of completing the questionnaire. Five themes emerged from the analyses. The responses to this question indicated that the family members were mainly concerned about the patient. The main theme identified from their responses related to their need for information. The information they wanted consisted of: knowing the prognosis, the extent of the injury or deficits, the cause of the injury, what is happening to the patient now and what the future will hold, for example, long-term care services or rehabilitation. The family members also wanted information on the tests the patients were undergoing and the results of these tests as well as information on the medication the patient was taking. Lastly, the family members wanted information concerning additional services that would help with the patients' recovery both now and in the future such as, physiotherapy, occupational therapy, speech therapy and financial support.

The second theme that emerged concerned the type of care the patient received. The family members wanted the best care possible for their loved one and to know that he or she would be pain free and comfortable. To be with the patient and help him or her was the third theme that evolved from the family members' responses. The fourth theme was labeled hope for a complete recovery. Three family members reported that their greatest need was for the patients' full recovery. One family member had hoped that things would return back to normal once their son came out of the coma. The last theme to emerge concerned the family members themselves. Two family members reported that they were tired and needed more energy .

Characteristics of the Nurses

Twenty-six nurses, who were eligible, consented to participate which represented a response rate of 96%. One nurse, who had initially agreed to participate, declined at a later time due to an illness. The other nurses could not recall the patient and the family because time had elapsed since the admission which consequently led to the exclusion of the family member. Four additional nurses were excluded since the family members did not return the questionnaire. As

previously mentioned in chapter three, after the family member consented to participate, a registered nurse who had cared for the patient was asked to participate shortly after to ensure that the questionnaires would be completed during the same time period as the family member. Efforts were made to enroll a different nurse for each family member so that the nurse completed only one questionnaire. However, one nurse refused to participate and staffing patterns prevented the researcher from enrolling a nurse who had not completed the questionnaire and who was familiar with the family. Thus, one nurse completed two questionnaires to prevent the exclusion of another family member. The reason given by the nurse who did not want to participate was a lack of interest. Therefore, 21 nurses completed the questionnaire.

As noted in Table 7, the registered nurses who consented to participate in the study were all females with 71.4% diploma prepared. Only two of the nurses (9.5%) reported having acquired recent education on family needs which consisted of reading journal articles and attending a brain and spinal cord injury conference. Eighty percent of the nurses were employed in a full-time position. The nurses' ages ranged from 28-41 years ($\underline{M} = 34.36$, $\underline{SD} = 4.87$, 95% $CI = 32.1, 36.6$). Their nursing experience ranged from 2.5-21 years ($\underline{M} = 11.11$, $\underline{SD} = 5.2$, 95% $CI = 8.74, 13.5$) and their neuroscience nursing experience ranged from 1-19 years ($\underline{M} = 8.05$, $\underline{SD} = 4.65$, 95% $CI = 5.9, 10.2$).

Table 7

Nurses' Demographics (n=21)

Variables	Mean	Standard deviation	Range	Frequency	Percentage	95% Confidence level
Gender						
Female				21	100.0	
Age (years) [a]	34.36	4.87	28-41			32.1 to 36.6
Level of Education						
Diploma				15	71.4	50.8 to 91.9
Baccalaureate				6	28.5	7.95 to 49
Employment Status						
Full-time				17	80.9	63 to 98.7
Part-time				4	19.0	1.1 to 36.8
Number of Years Nursing Experience [b]	11.11	5.2	2.5-21			8.74 to 13.5
Number of Years of Neuroscience Nursing	8.05	4.65	1-19			5.9 to 10.2
Recent Education on Family Needs						
Yes				2	9.5	2 to 32[c]
No				19	90.4	76.9 to 103.8

Note.

[a] n = 19

[b] n = 20

[c] The formula suggested by Fleiss (1981) was used to calculate the 95% CI, which results in slightly asymmetric CI.

Content analysis was also used to categorize the nurses' responses to the open-ended question related to what they believed was the family members' greatest need. Three themes emerged from their responses. The main theme identified from the nurses' responses was the need for information. Similar to the family members, the nurses reported that receiving information on the patient's condition and progress, the implications of the injury, the expected outcomes, and available options to aid in the patient's recovery were the family members' greatest needs. The second theme that emerged from the nurses' responses was the need for the family members to understand what the long-term implications of the injury would be and how long it would take for the patient to recover. Lastly, the third theme the nurses reported as being the family members' greatest needs was for emotional support. Five of the nurses reported a need similar to the family member when comparing the responses of the paired samples.

Objectives 1 and 2: To Identify Family Needs as Perceived by the Family Members and To Determine the Relationship with the Nurses' Perceptions

The Critical Care Family Needs Inventory (CCFNI) was used to identify the family needs as perceived by the family members and nurses, thus these two objectives are discussed together. The internal consistency reliability of the instrument for this study was calculated by using Cronbach's alpha (Polit, 1996). Since four new questions were added to the CCFNI, the internal consistency reliability was calculated twice for each sample. First, for the total instrument without the four new questions and then again, with the four questions added. The results indicated the tool has a high internal reliability in the family sample (.92 without the four new need statements and .92 with the four new need statements). Likewise, the results revealed a high internal reliability for the nurse sample (.93 without the four new need statements and .94 with the four need statements). The validity of the instrument was discussed in the previous chapter.

The mean value of each need statement according to the family members' perceptions and nurses' perceptions were calculated separately to rank order the needs. The ten top needs identified by the family members are listed in Table 8 in descending order with the corresponding

ranking as reported by the nurses. As noted in Table 8, six of the needs identified by the family members had also been identified as important by the nurses, although, the order of ranking was different. These needs were: to know the expected outcome; to know specific facts concerning the patient's progress; to feel that the hospital personnel care about the patient; to be called at home about changes in the patient's condition; to be assured that the best care possible is being given to the patient; and to have questions answered honestly. The top five needs reported by the family members were: to know the expected outcome; to feel there is hope; to know specific facts concerning the patient's progress; to receive information about the various stages of recovery; and to receive information about rehabilitation options. The top five needs identified by the nurses were: to have questions answered honestly; to be assured that the best care possible is being given to the patient; to know the expected outcome; to be called at home about changes in the patient's condition; and to have explanations that are understandable. The four remaining needs identified by the nurses as being most important to the family but are not listed in Table 8 were: to have explanations given that are understandable; to know how the patient is being treated medically; to know why things were done for the patient; and to know exactly what is being done for the patient. A complete listing of the 49 needs in rank order from most important to least important as identified by the family members with the corresponding ranking by the nurses are reported in Appendix K.

Table 8

Rank Ordering of the Ten Most Important Needs Identified by the Family Members with the Corresponding Rank Ordering Identified by the Nurses

	Family Members			Registered Nurses		
Need Statements	n	Ranking	M (SD)	n	Ranking	M (SD)
To know the expected outcome	21	1	4.00 (.00)	22	3	3.73 (.46)
To feel there is hope	22	2	3.95 (.21)	22	11	3.50 (.60)
To know specific facts concerning the patient's progress	22	3	3.91 (.29)	22	9	3.50 (.51)
*To receive information about the various stages of recovery	22	4	3.91 (.29)	22	16	3.27 (.70)
*To receive information about rehabilitation options	21	5	3.90 (.30)	22	23	3.14 (.77)
To see the patient frequently	22	6	3.86 (.35)	22	12	3.41 (.59)
To feel that the hospital personnel care about the patient	22	7	3.86 (.35)	22	6	3.59 (.59)
To be called at home about changes in the patient's condition	22	8	3.86 (.64)	22	4	3.68 (.57)
To be assured that the best care possible is being given to the patient	22	9	3.86 (.47)	22	2	3.77 (.43)
To have questions answered honestly	21	10	3.86 (.36)	21	1	3.86 (.36)

Note. *These needs statements were added to the CCFNI by the researcher.

The results concerning the order of importance of the four need statements added to the CCFNI for this study indicated that the needs were ranked as being more important among the family members than the nurses. The family members ranked the needs 'to receive information about the various stages of recovery' and 'to receive information about rehabilitation options' in the ten most important needs. They were ranked fourth and fifth, respectively, by the family members and 16 and 23 by the nurses. The need 'to receive information on long-term care options if rehabilitation is not possible' was ranked 15 by the family members and 21 by the nurses. Likewise, the need 'to be able to visit the rehabilitation or long-term care institution before the patient is transferred' was ranked 19 by the family members and 28 by the nurses.

The ten least important of the 49 needs identified by the family members with the corresponding nurses' rank ordering are reported in Table 9 in ascending order. Five of the ten needs were similar in both samples, although, they were ranked differently. These were: to have a bathroom near the waiting room; to be told about chaplain services; to have the waiting room near the patient; to be alone at any time; and to have another person with you when visiting the neuroscience unit. The five least important needs of the family members in this study were: to have visiting hours start on time; to have the waiting room near the patient; to have visiting hours changed for special conditions; to be alone at any time; and to have another person with you when visiting the neuroscience unit. The five least important family needs described by the nurses were: to have the waiting room near the patient; to be alone at any time; to have another person with you when visiting the neuroscience unit; to have a bathroom near the waiting room; and to have comfortable furniture in the waiting room. Additional needs identified by the nurses that were in the ten least important needs but were not listed in Table 9 were: to have a pastor visit; to have a place to be alone while in the hospital; to have a telephone near the waiting room; to have good food available in the hospital; and to have comfortable furniture in the waiting room.

Table 9

Rank Ordering of the Ten Least Important Needs Identified by the Family Members with the Corresponding Rank Ordering Identified by the Nurses

	Family Members			Registered Nurses		
Need Statements	n	Ranking	M (SD)	n	Ranking	M (SD)
To have a bathroom near the waiting room	22	40	2.59 (1.10)	22	48	2.09 (.53)
To be told about chaplain services	22	41	2.50 (1.26)	22	44	2.23 (.81)
To be told about someone to help with family problems	20	42	2.50 (1.19)	21	32	2.81 (.87)
To feel it is all right to cry	22	43	2.50 (1.26)	22	26	3.00 (.76)
To have someone be concerned with your health	22	44	2.45 (1.14)	20	34	2.65 (.67)
To have visiting hours start on time	21	45	2.43 (1.33)	22	35	2.64 (.79)
To have the waiting room near the patient	20	46	2.40 (1.31)	20	45	2.20 (.83)
To have visiting hours changed for special conditions	20	47	2.40 (1.35)	21	39	2.43 (.98)
To be alone at any time	22	48	2.23 (1.11)	21	46	2.19 (.75)
To have another person with you when visiting the neuroscience unit	22	49	1.95 (1.17)	20	47	2.15 (.88)

In addition to identifying family needs based on the nurses' perceptions, objective two sought to determine whether the nurses' responses to the CCFNI were congruent with the family members. Pearson Product Moment Correlation Coefficient was used to correlate the family members' ratings of need statements on the CCFNI with the nurses' ratings for each family member/nurse pair. Munro (1993) suggested the following categories for reporting the magnitude of the correlation: 0.00-0.25 (little if any); 0.26-0.49 (low); 0.50-0.69 (moderate); 0.70-0.89 (high); and 0.90-1.00 (very high). The results of the correlations between the paired samples ranged from r = -.06 to .63 and are illustrated in Figure 1. The values of the correlations were all positive with one exception (-.06). However, the magnitude of the correlations were as follows: mainly low (0.26-0.49) n = 13; moderate (0.70-0.89) n = 5; and little if any (0-0.25) n = 4. The r values were then transformed using Fisher's z to normalize the distribution and to calculate the 95% confidence intervals. The results of these calculations are presented in Appendix L. Post hoc analysis on the demographic variables of the patients, family members, and nurses with the need statements did not show any significant associations with their ability to identify family needs.

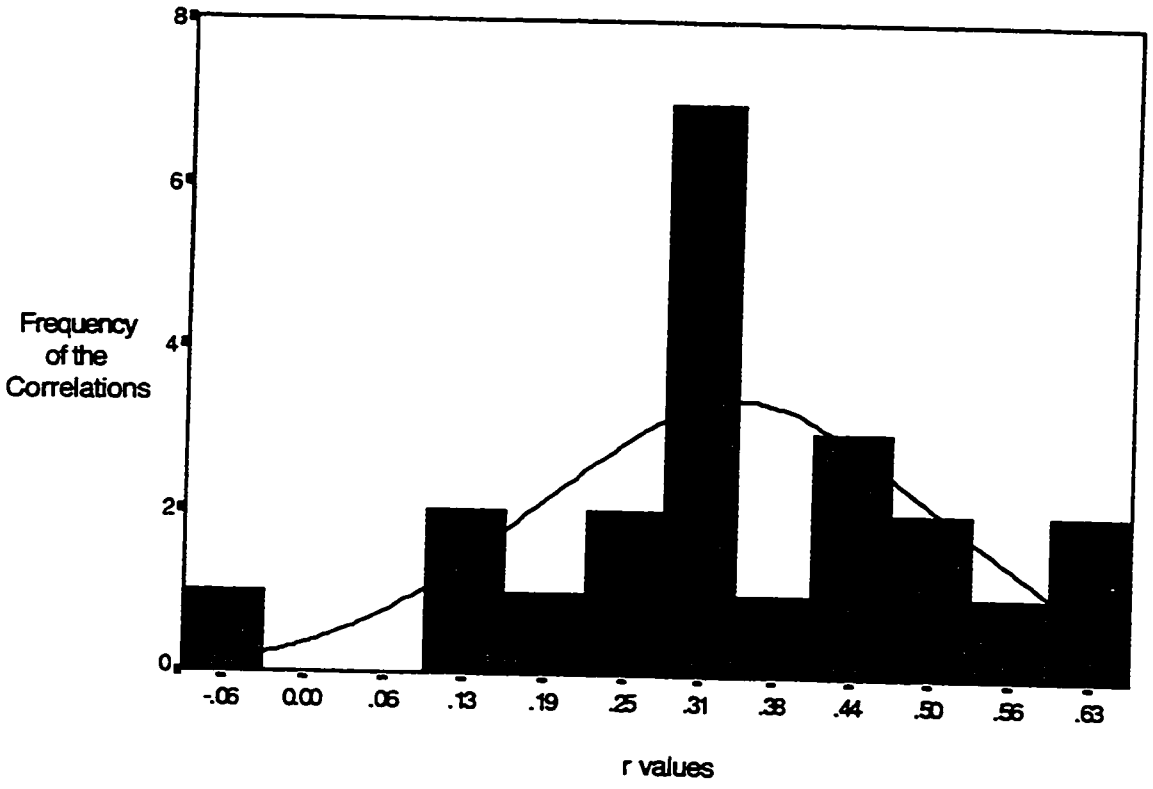


Figure 1. Histogram of the Pearson Product Moment Correlation Coefficient Value for the Paired Samples with the Normal Distribution Superimposed

Discrepancy in Needs. The mean value of each need statement obtained for the family members was subtracted from the corresponding mean value obtained by the nurses to further examine the differences in the rating of importance of the needs. The results indicated that for 20 of the 49 need statements the difference between the family members' score and the nurses' score was larger than .40 (see Appendix M). This value was selected since a difference of .40 and higher represents a moderate to high discrepancy between the family members' and nurses' responses on the CCFNI. Of the 20 need statements that had a difference of .40 or higher between the family members' and nurses' scores, only one of these needs was rated higher by the nursing staff. The need 'to feel it is all right to cry' was the only need rated higher by the nurses than the family members. There were eight additional needs that the nurses rated higher than the family members but the differences between the mean was less than .40. These were:

to have explanations of the environment before going into the neuroscience unit for the first time; to have visiting hours changed for special conditions; to talk about feelings about what has happened; to have another person with you when visiting the neuroscience unit; to have someone concerned with your health; to be assured it is all right to leave the hospital for awhile; to be told about someone to help with family problems; and to have visiting hours start on time.

Objective 3: To Determine Whether the Family Members Perceive their Needs are Met and by Whom

Each of the need statements were reported to have been met for only three family members. Overall, 30 of the needs were met more than 50% of the time for half of the family members (n=11). The needs 'to have questions answered honestly' and 'to help with the patient's physical care' were reported to have been met for more than 90% of the family members (n = 21 and 20, respectively). The need 'to have questions answered honestly' was one of the ten most important needs identified by family members in this study. Seven needs were reported to have been met for 80 - 90% of the family members. These needs were: to know exactly what is being done for the patient; to feel that the hospital personnel care about the patient; to know specific facts concerning the patient's progress; to see the patient frequently; to know why things were done for the patient; to feel accepted by the hospital staff; and to have explanations given that are understandable. The need 'to know the expected outcome' was the most important need of the family members in this study and was met for 64% (n = 14) of them. Eight of the ten most important needs were met for 68% of the family members as noted in Table 10. As well, in Table 10 there were four needs identified by the family members that were met for more than 80% of them. In contrast, six of the ten most important needs identified by the nurses were met for more than 80% of the family members.

Nineteen needs were reported to have been met less than 50% of the time for half of the family members (n=11). The least frequently met needs with the corresponding number of family members who reported the need was not met were: to talk to the doctor every day (n = 13); to visit

the rehabilitation or long-term care institution before the patient is transferred (n = 9); to have explanations of the environment before going into the neuroscience unit for the first time (n = 8); to be told about someone to help with family problems (n = 8); to have someone help with financial problems (n = 8); to receive information on long-term care options if rehabilitation is not possible (n = 7); to receive information about rehabilitation options (n = 7); and to be called at home about changes in the patient's condition (n = 7).

For each need statement, family members were asked to identify who met the need for them. Family members identified more than one person for each need statement. The person(s) listed were categorized according to profession or relationship and the frequency was calculated for each group. Eleven of the need statements, such as 'having good food available', 'a telephone near the waiting room', and 'to have visiting hours start on time', were difficult for the family members to identify a person who met this need since they were related to the hospital's environment and policies. Furthermore, there were nine need statements that some of the family members wrote on the questionnaire stating that it was too soon or that the need did not exist at this time. Some examples of these needs were: to have someone help with financial problems; to be told about other people that could help with problems; to visit the rehabilitation or long-term care institution before the patient is transferred and to receive information about rehabilitation options.

Of the remaining 29 need statements, nurses were perceived to have met the needs of family members more frequently than the other groups of professionals identified. Specifically, the family members' needs were met by the following persons in order of most helpful to least helpful: nurses (40%); physicians (18%); other (15%); all (10%); other family members (5%); physiotherapist (4%); social workers (4%); clergy (2%); and friends (2%). Nurses were reported to have met 20 of these needs more frequently than the other groups. Six of these needs were ranked in the 10 most important needs of the family members (see Table 10). These needs were: to feel there is hope; to know specific facts concerning the patient's progress; to receive information about the various stages of recovery; to feel that the hospital personnel care about

the patient; to be assured that the best care possible is being given; and to have questions answered honestly. The most important need of the family members, 'to know the expected outcome' , was met by physicians more than any other group. The third highest group came under the category of 'other' which included the family member's faith, themselves, other visitors, former patients, hospital facilities such as the coffee shop and chapel, speech therapist, occupational therapist, and pamphlets or other publications. Three needs mainly met by other family members consisted of: to have friends nearby for support; to have another person with you when visiting the neuroscience unit; and to have someone concerned with your health.

As noted in Table 10, two needs were met for a small number of family members. These were: to receive information about rehabilitation options and to be called at home about changes in the patient's condition. Some of the family members had reported that those needs were not experienced at this time or it was too soon for that need, thus, the category of 'not applicable' was selected more frequently than the other categories.

Table 10

The Frequency the Ten Most Important Needs Identified by the Family Members were Met and by Whom

Need Statements	Frequency (Percent) n=22	Met by Whom
To know the expected outcome	14 (64%)	Physicians
To feel there is hope	16 (73%)	Nurses
To know specific facts concerning the patient's progress	19 (86%)	Nurses
To receive information about the various stages of recovery	15 (68%)	Nurses
To receive information about rehabilitation options	7 (32%)	not applicable
To see the patient frequently	19 (86%)	Other
To feel that the hospital personnel care about the patient	19 (86%)	Nurses
To be called at home about changes in the patient's condition	6 (27%)	not applicable
To be assured that the best care possible is being given to the patient	17 (77%)	Nurses
To have questions answered honestly	21 (96%)	Nurses

Objective 4: To Compare the Needs of Family Members of Patients with TBI and Stroke

It should be noted that the small and unequal sample size between family members of patients who have had a stroke and those who have had a TBI limits the conclusions that can be drawn. As seen in Table 11, there was a statistically significant difference between the age of patients with a stroke and those with a TBI ($t=4.28$, $df=6.6$, $p<.001$). In general, the patients with TBI were younger ($M=33.1$, $SD=4.2$) than the patients who had a stroke ($M=64.12$, $SD=14.4$). There was also a statistically significant difference between patients with strokes and patients who had a TBI with respect to the patients' position in the family ($p<.001$ Fisher's Exact Test 2-tail). Sixty percent of the patients with a TBI were adult children of the family member who participated in the study whereas 59% of the patients with strokes were the spouse of the family member. Furthermore, the patients with a TBI had a lower GCS value ($M=10.8$, $SD = 3.11$) than patients with strokes ($M=13$, $SD=2.4$), although this was not statistically significant ($t=1.57$, $df=5.55$, $p>.05$). However, there was a significant difference noted between the two groups of patients with regards to experiencing loss of consciousness at the time of injury ($p<.001$ Fisher's Exact Test 2-tail). All of the patients who sustained a TBI had experienced loss of consciousness in contrast to only one patient with a stroke, which can be explained by the diffuse nature of TBI. No other significant differences were noted between the two groups of patients.

Table 11

Comparison of Demographics and Characteristics Between Patients with Strokes and Patients with TBI

	Strokes (n = 17)		TBI (n = 5)		
Variables	(SD)	Frequency (%)	M (SD)	Frequency (%)	p†
Gender					
Male		9 (53%)		5 (100)	NS
Female		8 (47%)			
Age (years)	64.12 (14.4)		33.1 (14.2)		<.001
Number of Days on Neuroscience Unit	9.59 (3.89)		10.0 (5.1)*		NS
Present GCS	13.2 (2.5)		10.8 (3.11)		NS
Loss of Consciousness					
Yes		1 (6%)		5 (100)	<.001
No		16 (94%)			
Unknown					
Position in Family					<.001
Parent		6 (35%)		0	
Spouse		10 (59%)		1 (20%)	
Child		0		3 (60%)	
Other		1(6%)		1 (20%)	

Note. *This result does not contain the patient who had been on the unit for 45 days when the family member consented to participate. When the outlier was included, the number of days on the neuroscience unit ranged from 5 - 45 (M = 16.6, SD = 15.4, p=NS). † Probabilities from proportions were calculated by using Fisher's Exact Test (2-tail) and from the mean by using t-test for independent samples.

As seen in Table 12, there was a statistically significant difference between family members of patients with strokes and family members of patients with TBI with respect to the relationship of the family member to the patient ($p<.05$ Fisher's Exact Test 2-tail). Sixty percent of the family members of patients with a TBI were a parent of the patient while 59% were the spouse of the patient with a stroke. A statistically significant difference was also noted between the two groups of family members with respect to previous hospital experience ($p<.05$ Fisher's Exact Test 2-tail). Fifty-nine percent of the family members of patients with a stroke had a previous hospital experience whereas none of the family members of patients with TBI had any previous experience. There were no statistically significant differences noted between the two groups of family members with respect to the remaining demographic variables as noted in Table 12. The income status, ethnicity, and age of the family members is comparable in both samples. Lastly, 71% of the family members of patients who had a stroke were females whereas 60% of the family members of patients with TBI were males.

Table 12

Comparison of Demographics Between Family Members of Patients with Strokes and Patients with TBI

	Strokes (n = 17)		TBI (n = 5)		
Variables	M (SD)	Frequency (%)	M (SD)	Frequency (%)	p[T]
Gender					
Male		5 (29%)		3 (60%)	NS
Female		12 (71%)		2 (40%)	
Age (years)	52.6 (14.9)		46.3 (10.4) [a]		NS
Relationship to Patient					
Parent		0		3 (60%)	
Spouse		10 (59%)		1 (20%)	<.05
Child		6 (35 %)		0	
Other		1 (6%)		1 (20%)	
Level of Education [b]					
Grade school or less		1 (6%)		0	
High school diploma		6 (35%)		1 (20%)	NS
College diploma		6 (35%)		2 (40%)	
University degree		3 (18%)		2 (40%)	
Income Status [c]					
Less than $24,999		2 (12%)		0	
$25,000 -49,999		7 (41%)		2 (40%)	NS
$50,000 -74,999		5 (29%)		2 (40%)	
Greater than $75,000		1 (6)		0	
Religion					
Catholic		9 (53%)		4 (80%)	
Protestant		3 (18%)		0	NS
None		5 (29%)		1 (20%)	
Church Attendance [d]					
Not at all		2 (12%)		0	
Rarely		4 (24%)		0	NS
Fairly regularly		5 (29%)		2 (40%)	
Regularly		3(16%)		2 (40%)	
Ethnicity					
White		17 (100%)		4 (80%)	NS
Black				1 (20%)	
Previous Hospital Experience					
Yes		10 (59%)		0	<.05
No		7 (41%)		5 (100%)	
Satisfied with Number of Visits					N/A
Yes		17 (100%)		5 (100%)	

Note. [a] n = 4; [b] n = 16 for family members of patients with strokes; [c] n = 16 for the family members of patients with strokes and n = 4 for family members of patients with TBI; [d] n = 14 for the family members of patients with strokes and n = 4 for family members of patients with TBI; [T] probabilities from proportions were calculated by using Fisher's Exact Test (2-tail) and from the mean by using t-test for independent samples.

An item mean was calculated for each need statement for the family members of patients with a stroke and for those of patients with TBI. The need statements were ranked in order of most important to least important. The ten top needs identified by the family members of patients with a stroke are listed in Table 13 with the corresponding ranking of family members of patients with TBI. To summarize, six of the needs were similar for both samples although they were ranked differently. The six needs were: to know the expected outcome; to receive information on long-term care options if rehabilitation is not possible; to feel there is hope; to know specific facts concerning the patient's progress; to see the patient frequently; and to feel that the hospital personnel care about the patient. The remaining four needs ranked in the top ten as identified by the family members of patients with TBI that were not listed in Table 13 were: to be told about transfer plans while they are being made; to help with the patient's physical care; to have explanations given that are understandable; and to be assured that the best care possible is being given to the patient. Nine of the ten top needs identified by the family members of patients with TBI were rated as very important by all of the family members.

It is also interesting to note in Table 13 that the family members of patients with a stroke have rated three of the four need statements added to the CCFNI within the ten most important needs. These needs were: to receive information on long-term care options if rehabilitation is not possible; to receive information about rehabilitation options; and to receive information about the various stages of recovery. The need statements were ranked first, fourth, and fifth, respectively, for these family members, whereas, the needs were ranked 29, 16, and 10, for the family members of patients with TBI. The need to be able to visit the rehabilitation or long-term care institution before the patient is transferred was ranked 18 for family members of stroke patients and 22 for those of patients with TBI.

Table 13

Rank Ordering of the Ten Most Important Needs Identified by Family Members of Patients with Strokes with the Corresponding Rank Ordering Identified by Family Members of Patients with TBI

	Strokes			TBI		
Need Statements	n	Ranking	M (SD)	n	Ranking	M (SD)
To receive information on long-term care options if rehabilitation is not possible*	17	1	4.00 (.00)	4	29	3.00 (1.41)
To be called at home about changes in the patient's condition	17	2	4.00 (.00)	5	23	3.40 (1.34)
To know the expected outcome	16	3	4.00 (.00)	5	9	4.00 (.00)
To receive information about rehabilitation options*	17	4	3.94(.24)	4	16	3.75(.50)
To receive information about the various stages of recovery*	17	5	3.94 (.24)	5	10	3.80 (.45)
To feel there is hope	17	6	3.94 (.24)	5	8	4.00 (.00)
To know specific facts concerning the patient's progress	17	7	3.88 (.33)	5	2	4.00 (.00)
To have questions answered honestly	17	8	3.88 (.33)	4	17	3.75 (.50)
To see the patient frequently	17	9	3.82 (.39)	5	1	4.00 (.00)
To feel that hospital personnel care about the patient	17	10	3.82 (.39)	5	3	4.00 (.00)

Note. * These need statements were added to the CCFNI by the researcher.

Six of the ten least important needs are the same for both groups of family members although they were ranked differently (Table 14). These are: to talk to the same nurse every day; to have visiting hours changed for special conditions; to have someone be concerned with your health; to have visiting hours start on time; to be alone at any time; and to have another person with you when visiting the neuroscience unit. The five least important needs of the family members of patients with a TBI were: to have another person with you when visiting the neuroscience unit; to feel it is all right to cry; to be alone at any time; to have the waiting room near the patient; and to have a bathroom near the waiting room. The five least important needs of the family members of patients with a stroke were: to have another person with you when visiting the neuroscience unit; to have visiting hours changed for special conditions; to have someone help with financial problems; to have a bathroom near the waiting room; and to have someone be concerned with your health. Both groups of family members reported the least important need was to have another person with you when visiting the neuroscience unit.

Table 14

Rank Ordering of the Ten Least Important Needs Identified by Family Members of Patients with Strokes with the Corresponding Rank Ordering by Family Members of Patients with TBI in Ascending Order

	Strokes			TBI		
Need Statements	n	Ranking	M (SD)	n	Ranking	M (SD)
To talk to the same nurse every day	17	40	2.71 (1.1)	4	40	2.25 (.75)
To have comfortable furniture in the waiting room	17	41	2.65 (.86)	4	37	2.60 (1.52)
To have a place to be alone while in the hospital	17	42	2.65 (.93)	5	34	3.00 (1.41)
To have visiting hours start on time	16	43	2.63 (1.31)	5	43	1.80(1.3)
To be told about chaplain services	17	44	2.53 (1.23)	5	39	2.40 (.68)
To have someone be concerned with your health	17	45	2.53 (1.12)	5	42	2.2 (1.30)
To be alone at any time	17	46	2.47 (1.12)	5	47	1.4 (.55)
To have someone help with financial problems	15	47	2.47 (1.36)	5	22	3.00 (1.41)
To have visiting hours changed for special conditions	16	48	2.44 (1.36)	5	41	2.25 (1.5)
To have another person with you when visiting the neuroscience unit	17	49	2.18 (1.24)	5	49	1.2 (.45)

Chapter Five

Discussion

The interpretations of the findings of the study are discussed in this chapter. Specifically, the findings will be summarized and discussed according to the objectives. This is followed by a discussion on the limitations of the study. In addition, the implications of the findings will be described as they relate to theory, practice, and research. The chapter will conclude with a brief summary.

Discussion of the Findings

Grant, Kinney, and Davis (1993) documented that one of the key factors to advance nursing's body of knowledge is to interpret findings of research within the context of a conceptual model or framework. With this in mind, the findings will be discussed in relation to the conceptual framework that guided the study. Each objective will be discussed separately following a brief discussion of the sample characteristics.

Sample Characteristics. In general, the patients in the study were mainly males (64%) and the average age was 57 years old. These characteristics were similar to those reported by Engli and Kirsivali-Farmer (1993) in their sample of patients with acute brain injuries. They were on the neuroscience unit an average of 11 days at the time the family members consented to participate in the study. The ratio of stroke to TBI patients for the study was approximately 4:1, which corresponded to the ratio of hospital admissions in Ontario in 1993-94 for this patient population (Statistics Canada, 1996). When the demographic data for the patients with strokes were compared to the patients with TBI, some significant differences were noted with regards to the patients' age, position in the family and loss of consciousness. The patients who sustained a TBI were on average 31 years younger than the patients who had a stroke, which is typical for these patient populations. This also explains the TBI patients' position in the family as being an adult child since they are much younger than the stroke patients who generally were the spouse of the

family member who participated. Lastly, all the patients who sustained a TBI had experienced a loss of consciousness at the time of the injury, which is very common for this population, in contrast to one patient with a stroke. These results indicate that the sample may be representative of the population.

The family members who participated were mainly females and their average age was 51. The relationship of the family members to the patients were comprised of mainly spouses, adult children and parents. These results are also comparable to the other studies that have examined family needs in that the family members who were the identified next-of-kin were mainly the spouse or parent of the patient and were females (Freichels, 1991; Mathis, 1984; Mauss-Clum & Ryan, 1981; Rukholm et al., 1991). In addition, 59% of the family members had a post-secondary education which was a higher level of education than was reported in other studies (Bernstein, 1990; O'Neill Norris & Grove, 1986; Rukholm et al., 1991). A possible explanation for the difference in the level of education may be related to the fact that the other studies were done in the United States (Freichels, 1991; Mathis, 1984; Mauss-Clum & Ryan, 1981) and may reflect variations in access to education to all levels of the population. Moreover, the higher level of education found in this study may be the result of lower cost of education in Canada.

Significant differences were found between the family members of patients who had a stroke and family members of patients who had a TBI with respect to the relationship of the family member to the patient and previous hospital experience. Sixty percent of the family members of patients with TBI were a parent of the patient whereas 59% were the spouse of the patient who had a stroke. Fifty-nine percent of the family members of patients who had a stroke had a previous hospital experience whereas none of the family members of patients with a TBI had any previous experience. This may mirror the different developmental life cycle the two groups of family members were in and account for the significant differences that were noted. No significant differences were found with regards to the other demographic variables such as, gender, age, level of income or education.

All of the nurses who participated were females and most were employed in a full-time position. Their average age was 34 years and they had on average 11 years of nursing experience and 8 years of neuroscience nursing experience. The average age of the nurses in this study is at the upper limits of the average age reported in other studies which have ranged from 25 -35 years (Caplin & Sexton, 1988; Dockter et al., 1988; Forrester et al., 1990; Fox & Jeffrey, 1997; Hickey & Lewandowski, 1988). Seventy-one percent were diploma prepared nurses which is higher than results reported by Statistics Canada (1993) which noted that 62% of the nurses employed in Ontario in a staff position were diploma prepared. This difference may be related to the fact that half of the nurses in the study had graduated more than 11 years ago from their college program. At the time they graduated, the emphasis placed on having a baccalaureate degree as the entry to practice may not have been stressed as much as it has been during the past decade. It may be difficult for some nurses to upgrade their nursing education by enrolling in a post-RN program because of the decline in the economy and the rising cost of education. As well, recent restructuring of the health care system may leave many nurses reluctant to give up full-time employment to return to school.

Objective 1: To Identify Family Needs as Perceived by the Family Members. The findings of the study suggested that the family members' main concerns were related to obtaining information about the patient. This was indicated by the global themes obtained by their responses to the open-ended question and the rank ordering of the need statements from the CCFNI. The family members wanted specific information related to the patient's expected outcome, progress, stages of recovery and rehabilitation options. They also wanted reassurance concerning the care given to the patient and that they would receive honest answers and be kept informed of any changes. Furthermore, they wanted to feel that the hospital personnel cared about the patient and that they could see the patient frequently. An additional need perceived to be very important to the family members was the need for hope. All of these needs were related to the psychological variable described in Neuman's model (1995). According to this model, the

psychological variable refers to mental processes, such as attitudes and values, and relationships with others, such as health care professionals and friends. Although hope is often associated with spiritual beliefs, concept analysis of the term indicated that it also has a strong cognitive component (Dufault & Martocchio, 1985; Fowler, 1995; Morse & Doberneck, 1995; Thompson, 1994) and therefore, can be related to either the spiritual or psychological variable. Kahn (1992) reported a similar classification of family needs, although there were some discrepancies. In her study involving family members of critically ill patients, the need to have questions answered honestly was categorized as a sociocultural variable and the need to feel that hospital personnel care about the patient was considered to be related to the developmental variable.

The nature of the patient's injury and his or her condition may explain why the need for information and hope is important to the family members. Often the information family members need concerning prognosis and recovery is difficult to provide because a brain injury affects each person differently (McClelland, 1988). The outcome is related to the severity and type of injury (Katz, 1992; McClelland, 1988) as well as other factors, such as the timing of surgical and medical interventions, age, prior health condition, and whether there were any other concurrent health care problems or injuries (Buchanan & Capp, 1988; Nikas, 1987). Furthermore, it is difficult to predict the extent of the patients' deficits and length of recovery following a brain injury during the early stages of hospitalization. Consequently, the family members have a number of questions that have few answers. Seeking information concerning the patient's condition and reassurance regarding his or her care as well as to be kept informed may assist the family members to regain a sense of control over their present circumstances. Seeking information may also indicate some of the cognitive processing that occurs in family members as they try to understand what is happening and to find some meaning or purpose in the situation. According to Neuman (1995) there is a strong correlation between coping and the client's perceptions and cognition. As noted earlier, depending on how the client perceives or appraises the stressor will determine his or her reaction to the stressor and subsequently his or her ability to cope with the stressor. Likewise, hope may help the family members search for meaning in their present situation. The need for

hope may also be an additional coping mechanisms employed by the family members to support them through the uncertainty they are experiencing. Koller (1991) noted that hope was one of the coping mechanisms used most frequently by family members during a critical illness. These various reasons may explain why the need for obtaining information and hope were perceived to be more important than other needs related to the psychological variable, such as to feel it is all right to cry or to be alone at any time, which were considered to be least important to the family members.

Additional needs that warrant discussion involve the physiological variable. Neuman (1995) defined this variable as referring to bodily structures and functions. The relatively low ranking of these needs by the family members would suggest that the family is least concerned about their physical needs at this time. For instance, the family members ranked the need to have a bathroom near the waiting room or to have someone concerned about their health as one of their least important needs. These results are similar to previous studies (Freichels, 1992; Leske, 1986; O' Neill Norris & Grove, 1986; Prowse, 1984). Interestingly, one of the themes that evolved from the open-ended question contradicts the relatively low ranking of the needs related to the physiological variable. The need for more energy was identified as one of the greatest needs of the family members. This need was interpreted to be related to the physiological variable since some of the family members reported that they were "tired". However, the need for energy could also be related to the psychological variable. The energy expended upon visiting the patient frequently and being concerned about his or her welfare may cause family members to neglect their self-care needs of getting adequate rest and may lead to a deterioration in their health. This may have serious implications for the family members since the maintenance of their health is important in order to endure the long recovery period associated with brain injuries. Perhaps this particular need should be added to the CCFNI since it is not currently reflected in any of the need statements. This would assist health care professionals to determine how important the need for energy is to other family members and whether this is a need that is present throughout the patient's hospitalization. However, attempts should be made to determine whether there is a

difference between physical and mental energy or whether they are interconnected. This would help to provide a better understanding on the relationship of energy with the psychological and physiological variables.

With the exception of the need to receive information about the various stages of recovery and rehabilitation options, the family members in this study identified needs similar to family members of patients who were critically ill with and without neurological conditions (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993; Johnson, 1995; Leske, 1986,1991b; Mathis, 1984; Rukholm et al., 1991; Zazpe et al., 1997). Studies that explored family needs with patients who were in ICU for longer time periods also reported similar findings (Davis-Martin, 1994; Freichels, 1991). The uncertainty about return of functions associated with brain injuries may cause family members to be experiencing similar levels of stress as those in ICU and thus have similar needs. The similarity in the relative importance of these needs for both ICU and neuroscience unit settings may also suggest that they are universal to family members and are not related to the patients' level of acuity. Leske (1992) and Serio, Kreutzer, and Gervasio (1995) did not find an association between medical diagnosis and severity, and length of time since the injury with the rating of importance of family needs. Thus, these needs of the family members should be anticipated by health care professionals regardless of the patient's condition and efforts to meet them should be incorporated into plans of care.

Unlike the families of patients in ICU, the family members in this study were also concerned about the long-term implications of the injury. This was reflected in the high ranking of the four need statements added to the questionnaire. As previously noted in chapter three (see p. 37), these statements involve needs related to the stages of recovery, rehabilitation or long-term care options, and visiting these facilities prior to transfer. The high ranking of these needs may indicate that the family members are also looking towards the future and are not focusing solely on the present circumstances. The family members' concerns related to the long-term physical, cognitive, and behavioural effects of the injury as well as the options of treatment that are available to provide the best care for their loved one may explain why they are also concerned

about the future. These findings are more in line with findings from previous studies that have examined needs of family members caring for a loved one with a brain injury (Campbell, 1988; Casas, 1989; Grant & Bean, 1992; Kreutzer, Serio, et al., 1994; McLean et al., 1991; van Veenendaal et al., 1996; Wellwood et al., 1994). These studies indicated that the family members were concerned about what the future held for their loved one. Looking towards the future may be a characteristic that is common for family members concerned about the welfare of a loved one who has a brain injury because of the long-term deficits and the substantial care that this may involve. Consequently, it may be an appropriate time to initiate interventions that will help to prepare the family members for the future when patients with brain injuries are on a neuroscience unit.

Objective 2: To Determine the Relationship Between Nurses and Family Members in Identifying Family Needs. The findings of the study indicated that the nurses perceived needs differently than the family members. In their response to the open-ended question only a few nurses were able to identify a need similar to the family member they were assessing. In particular, some of the nurses believed the family members' greatest need was for emotional support which was not reported by the family members. When the mean responses to need statements were compared, the nurses were able to identify some of the needs the family members rated most and least important. As mentioned previously, the global sharing of themes obtained from the qualitative data and comparing mean values from the whole sample tend to generalize results since these approaches are a higher level of data aggregation. However, when the family member and nurse pairs were correlated separately at the item level to address Simpson's Paradox, a range of scores were mainly obtained in the low range while some were in the moderate range. This indicates that some nurses were better than others in their ability to perceive the family members' needs. It is possible that nurses who spent more time with the family members may rate needs that are more in line with the family members. Unfortunately, this variable was not measured in the study. Interestingly, post hoc analysis between the nurses' demographic

variables and ratings of family needs were not significant. Although O'Malley et al. (1991) found that the nurses' educational preparation, length of time in nursing and length of time in critical care settings influenced their perceptions of family needs. Nurses who had a baccalaureate degree with more than 7 years experience rated family needs lower than any other combination of nurses with different levels of education and years of experience (O'Malley et al., 1991). Nurses who had 4-6 years of critical care nursing experience rated family needs higher than nurses who had less than 3 years experience and those who had more than 6 years. It was suggested that nurses with more than 6 years experience were considered to be experts and may have met family needs with little conscious awareness. Consequently, family needs were not considered a high priority by those nurses (O'Malley et al., 1991).

As previously mentioned, the nurses generally rated the importance of the need statements lower than the family members with the exception of nine needs out of 49 (see p. 58). Those particular needs were associated with the psychological variable and dealt with the family member's expression of feelings, changes with visiting hours, and having someone with them when they were visiting the patient. These findings were consistent with previous research that noted nurses had ranked most of the needs lower than the family members with the exception of those needs related to emotional support (Forrester et al., 1990; Jacono et al., 1990; Johnston, 1986; Kleinpell & Powers, 1992; Lynn-McHale & Bellinger, 1988; O'Neill Norris & Grove, 1986; Prowse, 1984). However, unlike the nurses in this study, those studies generally found that nurses were moderately accurate at identifying needs similar to the family members.

There are some possible explanations for the low association between the nurses' and family members' ratings of the family members' needs in this study. First, the statistical analysis used in the present study was slightly different than the other studies that compared nurses' responses with the family members' responses. As noted in chapter three (see p. 41-42), each family member and nurse pair was correlated separately at the item level to investigate the distribution of the nurses' ability to perceive specific family member's needs and to address the problem with level of analysis as seen in Simpson's Paradox (Yarnold, 1996). In two previous

studies (Forrester et al., 1990; Jacono et al., 1990), the mean responses of the nurses and family members were compared without taking Simpson's Paradox into consideration. Thus, their results may be misleading and they may have inadvertently not answered their research question. In particular, Forrester et al., (1990) also used paired samples to address their question. However, by comparing the group mean they generalized their results and individual differences in the ability to rank family member's needs were not identified.

Another possible explanation is the lack of educational preparation the nurses may have had on family-focused care or family nursing. Only two nurses had obtained any recent education on family needs, consequently, the majority of the nurses may be unaware of the current literature that accentuates family-centered care and the importance of assessing family members' needs. In addition, most of the nurses were diploma prepared and their average number of years of nursing experience was more than ten years. Family nursing concepts traditionally have not been an integral part of diploma nursing programs beyond providing family members with emotional support. Interestingly, recent research has suggested that the concept of support should be reconsidered in nursing since professionals are perceived by patients to be a source for providing mainly informational support (Hinds & Moyer, 1997). Perhaps this may also apply to family members since the results of this study demonstrated that they rated needs related to emotional support, such as the need to feel it is all right to cry, lower than the nurses. As well, O'Malley et al., (1991) suggested that nurses who graduated from degree programs in the early 1980s or earlier may not have received any education on family nursing. Previous authors have indicated that the lack of educational preparation may be a barrier to assist family members with their needs (Fox & Jeffrey, 1997; Hickey & Lewandowski, 1988; Vosburgh & Simpson, 1993). They suggested that nurses may feel that they do not have the necessary skills to intervene with family members which may even cause them to avoid the family. Likewise, the nurses may not consider it to be part of their role to care for the family members as well as the patient. Their focus of attention may only be on the care provided to the patient and not the family members as noted in a

previous study (Jacono et al., 1990). Unfortunately, the nurses' perceptions on family nursing were not sought in this study, but, should be pursued in future studies.

Lastly, the current health care restructuring may have limited the amount of time the nurses spent with the family members because of the impact of downsizing on nursing staff. Consequently, the nurses may have had limited contact with the family member to properly assess their needs. A number of the family members had commented to the researcher that they did not see the nurses that often since the nurses seemed to be busy. Workload and time constraints were major barriers noted by Fox and Jeffrey (1997) that limited the amount of time nurses spent with family members in their study, which focused on the role of nurses with families of patients in ICU. Artinian (1991) also reported that lack of time to develop working relationships with the family was a barrier perceived by nurses.

Concerning the four new need statements added to the CCFNI for this study, the findings indicated that the nurses rated these needs lower than the family members. These needs were to: receive information on long-term care options if rehabilitation was not possible; receive information on rehabilitation options; receive information on the various stages of recovery; and visit the long-term care or rehabilitation facility before the patient is discharged. It is interesting to note that one of the themes from the nurses' responses to the open-ended question was for the family members to understand the long-term implications of the injury. However, this was not reflected in the nurses' responses on the CCFNI. This finding may suggest that the nurses have underestimated the importance of these needs to the family members. It may be that the nurses believed it is too soon to begin to inform the family members about rehabilitation or long-term care options since it is difficult to know how the patient may progress after sustaining a brain injury. The nurses may believe that providing the family members with such information too soon may give them false hope, especially if the patient does not progress as well as the professionals have hoped. O'Neill Norris and Grove (1986) reported that nurses are more objective than family members and are concerned about giving family members false hope. In contrast, Thomas (1987) suggested that health care professionals are no more objective than those within the family and

that their views merely represent another reality. This reinforces the importance of verifying the nurse's perceptions with the family member as documented in Neuman Systems Model (Neuman, 1995). Furthermore, the difference in the nurses' ratings of the four new needs may suggest that nurses and other health care professionals have underestimated the resiliency of family members who are faced with uncertainty and their ability to handle uncomfortable information. As indicated by the high ranking of these needs by the family members, they want to receive this type of information. Family members may be more ready to receive unsettling information than what nurses and other health care professionals believe.

Objective 3: To Determine Whether the Family Members Perceive their Needs are Met and by Whom. Family members are reported to be in a state of optimal wellness when their needs are met, however, if their needs are not met their level of wellness is reduced (Neuman, 1995). Consequently, unmet needs can be considered as stressors to the family members. The findings of the study indicate that each of the need statements were reported to have been met for three family members. Most of the needs, including eight of the ten most important needs of the family members, were met more than 50% of the time. The needs that were met more frequently in this study were related to the psychological variable. This is not surprising since most of the needs of the CCFNI were categorized under this variable for the study. Because most of the needs were related to the psychological variable, a tool should be developed that more accurately reflects the other variables outlined in Neuman's model. Some examples of the needs that were met more frequently were: to have questions answered honestly; to help with the patient's physical care; to know specific facts concerning the patient's progress; to see the patient frequently; and to feel that the hospital personnel care about the patient. These findings were consistent with the results of previous studies (Engli & Kirsivali-Farmer, 1993; Mauss-Clum & Ryan, 1981; Molter, 1979). Molter (1979) reported similar needs being met for more than 50% of the family members in her study. Likewise, Engli and Kirsivali-Farmer (1993) reported that 78.5% of the family members stated their needs were met.

Overall, there were 19 needs that were met less than 50% of the time for half of the family members (n = 11). Most of the needs which were not met were classified as inter-personal stressors, followed by extra-personal, and lastly, intra-personal stressors. Inter-personal stressors were defined as occurring between the family member and another person (Neuman, 1995). Examples of these stressors were: to have directions as to what to do at the bedside; to be called at home about changes in the patient's condition; to talk to the doctor every day; and to receive information about rehabilitation options. Seven of the unmet needs were categorized to be extra-personal stressors which were defined as occurring outside of the family member (Neuman, 1995). An example of this stressor for the family members was to have someone help with financial problems. Mauss-Clum & Ryan (1981) also reported that the need for financial counseling was important to the family members in their study, however this need was only met for 10% of them. To talk about the possibility of the patient's death was deemed to be an intra- and inter-personal stressor that the family members experienced.

Inter-personal stressors were identified more frequently than the other two categories of stressors which may suggest that they are more pertinent to the family members of patients with brain injuries during the acute care phase of recovery. Grant and Bean (1992) noted that caregivers of head-injured adults reported more extra-personal stressors in their study, such as respite care and financial support. However, they examined needs of family members caring for a loved one with a brain injury at home. Subsequently, the stressors the family members experience may be more external to the family member and related to frustrations or concerns about lack of community resources. They have also had a longer time to live with the experience of having a family member with a brain injury whereas the family members in the present study were just beginning this process of learning to live or cope with an injured family member. These family members in effect are dealing with a situation with which they may have had no prior experience. The needs, which are most important to the family members, involve seeking information about the patient's condition, outcome, and progress. Consequently, they have numerous interactions with a variety of health care professionals. This may explain why inter-

personal stressors were reported more frequently. It may be that as time passes, the stressors may change to become more extra-personal in nature as Grant and Bean (1992) found in their study.

As noted in chapter four (see p. 60), there were some needs that the family members thought were too soon or not needed for them at the time they completed the questionnaire. This may explain why some of the needs were not perceived nor reported as met by family members. Two examples of these needs were: to receive information about the various stages of recovery and to be called at home about changes in the patient's condition. These needs were rated as very important by the family members but were not met for many of them because the family members felt it was too soon or not needed at that time. This section of the instrument should be changed in future studies to reflect the variations of answers concerning whether the need was met, such as met, partially met, not met, or too soon. In addition, some of the needs that were reported not met were also considered to be unimportant to the family. Thus, whether or not these needs are met may not be clinically significant if they were seen to be unimportant to the family members. These findings reinforce the importance of doing individual family assessments to identify potential stressors since a need which may be important to one family member may be unimportant for another. Hence, every effort should be made to target interventions to meet the identified needs of family members.

The family members reported that nurses were considered to have met their needs more than any other group of individuals. More specifically, the nurses were reported to have met six of the family members ten most important needs. Molter (1979) also noted that nurses were identified to have met the needs of family members more frequently in her study, however, needs that were considered to be most important to the family members were met more frequently by physicians. The role of nursing has advanced since Molter's study in that nurses have more responsibilities and function more autonomously. This may explain why they were reported to have met some of the most important needs of the family members compared to Molter's study. Other studies reported physicians as being the most likely person to meet the most important

needs of the family members (Bernstein, 1990; Daley, 1984; Engli & Kirsivali-Farmer, 1993; Molter, 1979) since the needs were related to specific informational needs. It should be noted that all of those studies were done in the ICU within the first 72 hours of the patients' admission. The family members may perceive the physicians as being the best source to provide answers to their questions concerning the patients' prognosis and medical treatment (Bernstein, 1990; Engli & Kirsivali-Farmer, 1993) at that time. As the length of hospitalization increases, family members may perceive nurses as meeting their needs since they spend more time with the patient and are aware of the patient's condition. However, the family members were aware that the researcher was a nurse and this may have inadvertently biased their responses to select the nurse category more frequently. The fact the family members reported their needs were met by a number of different sources supports the need for an interdisciplinary approach when caring for the patients with brain injuries and their family members.

It is interesting to note, however, that six of the needs rated most important by the nurses were met for more than 80% of the family members, whereas, only four needs that were rated most important by the family members were met this frequently. This result raises some questions since the family members had reported nurses as meeting their needs more frequently than others. The order in which the family members needs are met may not be based on how important the need is to the family members at that time, but that overtime nurses are meeting their needs. This may suggest that the nurses are performing activities based on their perceptions of what the family members need. Fox and Jeffrey (1997) reported similar findings. The nurses may be providing care based on their nursing experience of caring for patients with brain injuries and their family rather than the presenting need. However, if family needs are not assessed on an individual basis then some needs may go unmet for the family members. This is important since unmet needs over time may invade the family member's lines of defense and his or her state of wellness may be altered. Daley (1984) noted that the assessment is not complete if the family member's perception is not included in the process. Consequently, wholistic nursing care may

not be provided unless the family member is involved in determining relevant goals and interventions (Neuman, 1995).

The nurses' approach to care in this study may reflect values and beliefs associated with a modernist perspective rather than a postmodern perspective. According to Anderson (1996), the modernist tradition fosters a hierarchical, expert-nonexpert relationship between health care professionals and patients and their families whereas the postmodernist philosophical perspective promotes a collaborative relationship which leads to a greater satisfaction in care for all who are involved. This shift in philosophy is inherent in the present healthcare reform taking place in Ontario and Canada as people are seeking or are being forced to take a more active role in decision-making concerning the care that is provided (Anderson, 1996). The postmodernist approach is more in keeping with Neuman's model since she believes that nurses and clients should work collaboratively in developing relevant goals and interventions to meet the needs of the client. Tomlinson and Anderson (1995) reported that nursing care is to be provided in collaboration with the family member, thus empowering him or her to make decisions and become partners in health care.

Objective 4: To Compare the Needs of Family Members of Patients with TBI and Stroke.

The findings of the study indicate that family members of patients who have had a stroke perceive their needs in a somewhat different way than those of patients who sustained a TBI. However, these findings should be interpreted with caution since the sample size is small and unequal between the two groups of family members. As noted previously in chapter four (see p. 68), six of the ten most important needs were the same for family members of patients with strokes and family members of patients with TBI, although they were ranked differently. Although there were some similarities in the ranking of the need statements, the ten needs rated most important by family members of patients with a stroke indicated that they are more concerned about the long-term implications of the injury than family members of patients with a TBI. For example, the most important need for family members of patients with strokes was to receive information on

long-term care options if rehabilitation is not possible. In addition, these family members ranked the need to receive information about rehabilitation options as the fourth most important need. In contrast, the family members of patients with a TBI ranked these two needs as 29 and 16, respectively. The overall ranking of the need statements by family members of patients with a TBI indicates they are more concerned about present events, such as being close to the patient and knowing specific facts concerning his or her progress.

Several explanations may be offered for the differences in family members' ratings of the needs. Patients who sustained a TBI were on average 30 years younger than those who had a stroke. As a result, the family member who participated in the study for these patients was mainly a parent which puts them at different developmental stages and life experiences. These factors may have impacted upon the family members' perceptions of the injury or illness. Family members of patients who acquired a traumatic brain injury may have a more difficult time adapting to the injury since the patient is younger and considered to be in the prime of life. They also may not be ready psychologically to focus on the long-term sequellae of the injury. Furthermore, traumatic brain injuries generally cause diffuse injuries resulting in more severe deficits (DeBoskey et al., 1991; Marshall et al., 1990) of which the permanent extent may not be known until later. Consequently, it may be difficult for family members to consider long-term care plans in the early stages of acute care since the outcome is unknown and difficult to predict. Unlike the family members of patients with strokes, the family members of patients with TBI had no prior hospital experience. The hospitalization experience in itself may be foreign to them and they may not know what to expect. The lack of this experience, along with the patient's present condition and unknown outcome, may explain why the family members of patients with a TBI focus on the present circumstances and thus, rated the needs slightly different than family members of patients with strokes.

Study Limitations

There were some limitations identified in this study related to the design, external validity, statistical power and measurement. The study was descriptive, therefore, cause and effect relationships cannot be made (Polit & Hungler, 1991). In addition, the environment in which the participants completed the questionnaire was not controlled. Only four family members completed the questionnaire in the waiting room on the unit. The remaining family members returned the questionnaire by mail to the researcher. There is the possibility that more than one family member may have participated in completing the questionnaire in the home setting before returning it to the researcher. Likewise, the nurses were asked not to discuss their responses with each other, however, there was no guarantee that this occurred. Moreover, the current restructuring and downsizing of staff within the hospitals may have limited the amount of time the nurses spent with the family members to assess their needs. The researcher had hoped that by caring for the patient a minimum of two days would have increased the opportunity for the nurse to interact with the family member for more in depth assessment, thus overcoming this limitation. However, the length of time spent with the family member was not measured in the study and may be a confounding factor. Due to the flexible time frame in which the nurses and family members completed the questionnaire, their ability to recall family needs may have been altered.

Selection bias may have decreased the representativeness of the sample (LoBiondo-Wood & Haber, 1994; Polit & Hungler, 1991). The family members were screened by the team leaders and the nurse manager according to the inclusion and exclusion criteria. However, they may have inadvertently selected family members as suitable based on other criteria since they reported not having asked three family members because of "problems" with the family. The needs of these family members may be quite different from those who participated in the study. In addition, the family members who were willing to take part in the study may have different characteristics than those who refused, such as, better coping skills or more social support. The reasons given for refusing to participate were that some family members were too upset and one did not believe the patient had a brain injury. These family members may have different needs or

report fewer needs as being met. Likewise, the nurses who participated may have different characteristics than those who did not have the opportunity to participate given the design of the study. The variable concerning the nurses' perceptions on family nursing was not measured and may be another confounding factor.

With regards to the external validity, a non-probability sampling technique was used which decreases the generalizability of the results. However, this limitation was offset by utilizing two sites, which were fairly comparable in size, staffing, visiting policies, and care of patients, which may help increase the generalizability of the results to the target population (Burns & Grove, 1995; Polit & Hungler, 1991). To minimize the experimenter effect, the family members and nurses were approached in a similar manner by the researcher.

The results of the study are also limited because of the statistical power. Prior to commencing the study, the sample size was calculated to be 32 with alpha set a priori at $p<.05$ and power of .80. Unfortunately, the goal of enrolling 32 pairs was not met for a variety of reasons. As mentioned earlier in chapter three (see p. 31), there were problems enrolling the family members. Although changes were made to the inclusion criteria, such as discontinuing the GCS value criterion to boost enrollment, the enrollment was slow, and a decision was made to discontinue the enrollment when a minimum of 22 pairs was met. Thus, the statistical power was lower than initially anticipated. Using a formula suggested by Polit (1996), the power was recalculated to be .60 (alpha = .05).

Lastly, the modifications made to the measurement instrument and the classification of the need statements according to the five variables and three stressors defined in Neuman's Systems Model (Neuman, 1995) are also limitations. Concerning the modifications made to the CCFNI, a more accurate portrayal of whether the need was met may have been obtained by using the following categories: met; partially met; not met; or too soon to tell, instead of the 'yes' or 'no' response. As reported earlier in chapter four (see p. 62), there were some need statements that the family members wrote on the questionnaire stating it was too soon for that particular need, for example, the need to visit the rehabilitation or long-term care institution before the patient is

transferred. Moreover, the inter-rater reliabilities for categorizing the needs statements according to Neuman's model was moderate (74.7% for the five variables and 65.3% for the three stressors). The discrepancy noted in the classification of the needs may cause some difficulty in replicating the study. Furthermore, other health care professionals familiar with the model may classify the need statements under a different variable and/or stressor as seen in the study by Kahn (1992).

Implications of the Findings

Several implications of the findings can be drawn from this study as they relate to theory, practice and future research. The discussion will begin with the implications related to theory, followed by those relevant to practice, with an emphasis on the role of the advanced practice nurse (APN) , and research.

Implications for Theory. The findings of this study reinforce the importance of confirming the nurse's perceptions of family needs with the family member prior to initiating any interventions to ensure that the interventions are appropriately targeted to meet the family members' needs. As noted in the study, a low association was found between the nurses' and family members' ratings of family needs. From the perspective of Neuman's model, the perceptions of both the family member and nurse are critical to gathering data, setting goals, and planning interventions (Neuman, 1995) that will help address the family members' needs. This approach would not only ensure family members' needs are met, it would save time. Furthermore, the findings of the study provide some examples of possible stressors family members experience and which nurses should include in their assessment. As seen in the schematic representation of Neuman Systems Model (Figure 2), examples of the inter-personal stressors were to receive information on rehabilitation options, to have directions as to what to do at the bedside and to be called at home about changes in the patient's condition. An example of an extra-personal stressors was to have someone help with financial problems. To talk about the possibility of the patient's death was an example of an intra- and inter-personal stressor in the study.

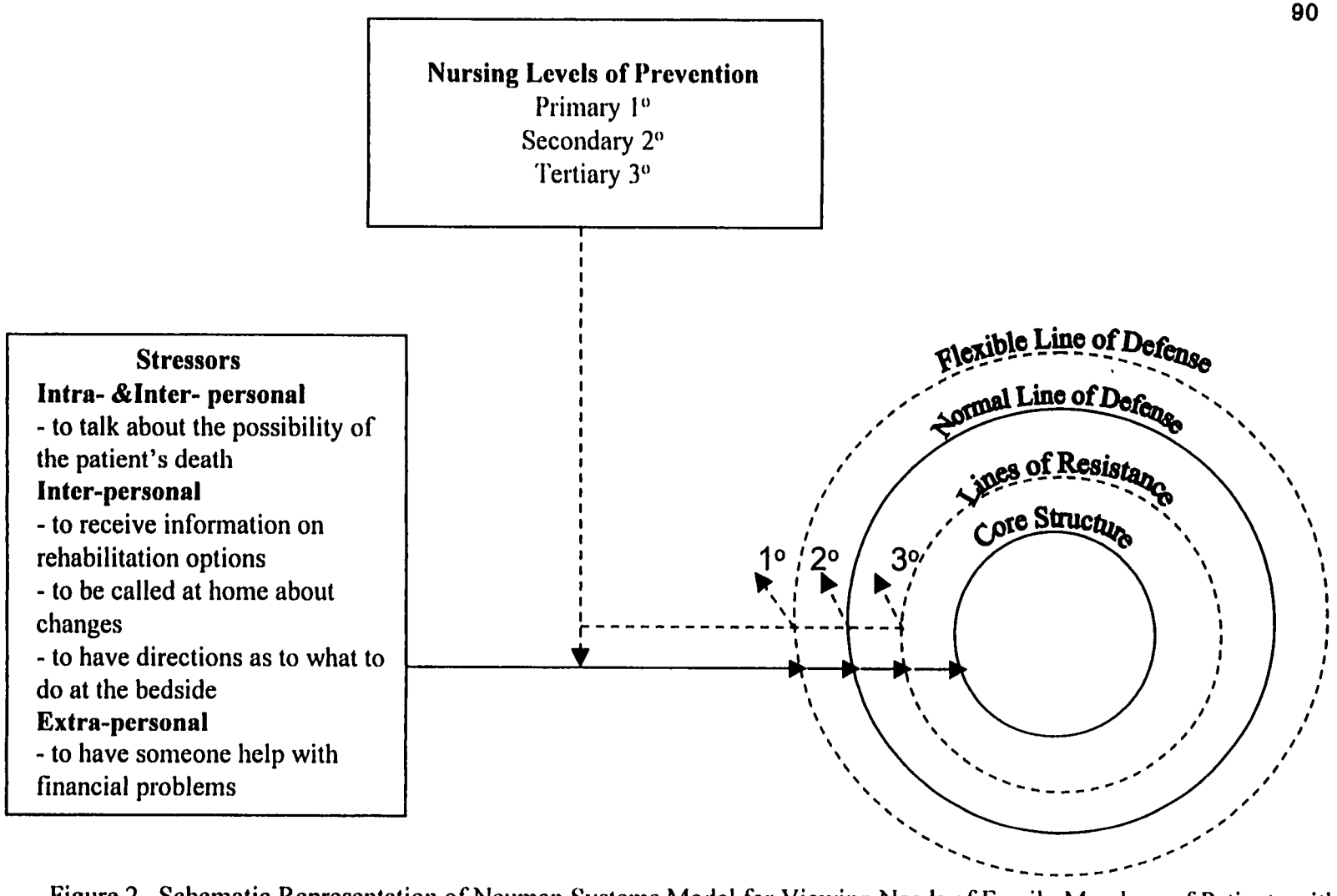


Figure 2. Schematic Representation of Neuman Systems Model for Viewing Needs of Family Members of Patients with Acute Brain Injuries

There were some difficulties in classifying need statements into one of the five variables in this study. According to Neuman (1995), wellness is maintained when there is a harmonious relationship between the physiological, psychological, sociocultural, developmental, and spiritual variables. Although previous studies indicated that family needs can be classified according to the variables (Grant & Bean, 1992; Kahn, 1992), most of the needs in this study were related to the psychological variable as categorized by a panel of expert nurses. Very few needs were judged to be related to the other variables. In fact, the panel did not categorize any needs with the developmental variable. Conversely, using a panel of graduate students, Kahn (1992) was able to sort the need statements of the CCFNI into the four variables defined by an earlier version of Neuman's model (1982). The spiritual variable had not been defined in this version of the model. However, there were some differences in the classification of needs between this study and Kahn's (1992). For example, the need to have questions answered honestly was considered to be related to the psychological variable in this study whereas Kahn (1992) classified it as a sociocultural variable. In addition, the needs to be encouraged to cry and to be alone at any time were also classified as psychological variables in the present study while Kahn reported them to be categorized under the sociocultural variable. The classification of the needs into one of the three stressors (intra, inter, extra) was similar to Grant and Bean's (1992). Reed (1993) has noted that there is difficulty operationalizing abstract terms associated with conceptual frameworks. This may explain the difficulty experienced in attempting to classify the needs according to one of the five variables in this study as well as the differences noted in the categorization in Kahn's (1992) study. Further efforts are needed to develop operational definitions which could then be tested in future studies.

It should be noted that the instrument used in the study was not based on Neuman Systems Model. The theoretical underpinnings of the Critical Care Family Needs Inventory was derived from both crisis and human need perspectives (Leske, 1991a). The researcher was unaware of an instrument based on Neuman Systems Model that demonstrated good reliability and validity that would be appropriate for this study. Thus, the CCFNI was selected since it was

reported to be a valid and reliable instrument (see p. 34). Consequently, the CCFNI may not accurately reflect Neuman Systems Model which may further explain why most of the needs were considered to be related to the psychological variable. Therefore, the development of an instrument that would more accurately capture the variables outlined in Neuman's model may assist future researchers concerned with family members' needs of the brain injured population. The data gathered from such an instrument would provide valuable information on the needs of the family members and the impact the illness or hospitalization may have on them. Furthermore, the information could be used to identify and test family nursing interventions that are theory-based.

Implications for Practice. The findings of this study indicated that the family members perceive their needs differently from the perceptions of the nurses. They also reported that nurses were meeting more of their needs. In addition, there were some needs related to the psychological variable that the family members perceived to be more important than others. There were also potential stressors identified which could have affected the family member's core structure had they invaded the flexible and normal lines of defense, and the lines of resistance. These findings have important implications for both general staff nurses and advanced practice nurses (APNs) such as a clinical nurse specialist (CNS) working with family members of patients with brain injuries. Utilizing Neuman's model, nurses could intervene at any of the three levels of prevention (1°, 2°, or 3°) to assist family members maintain their level of wellness. These levels of prevention may be used alone or simultaneously as the need indicated. As an example to demonstrate the application of the levels of prevention, each preventive strategy will be discussed as it relates to the need to receive information about the various stages of recovery. This particular need was rated more important by family members than by nurses. Failure on the part of nurses to recognize and intervene to meet this need has the potential to bring about a stress reaction. This points to the importance of ongoing assessments of patients and family members.

Interventions at the primary level of prevention are initiated when a family need is either suspected or identified. Interventions at this level reduce the possibility of the stressor occurring or strengthens the family members' flexible line of defense (Neuman, 1995). Thus, by anticipating the family members' need to receive information about the various stages of recovery, nurses can intervene to reduce the risk of this need becoming a stressor or unmet need. This can be done by providing family members with both verbal and written information about the stages of recovery following a brain injury in the form of educational sessions or booklets. While the effectiveness of these programs has not always been shown, some studies have demonstrated positive responses from family members who have participated in educational programs (Acorn, 1995; Chavez & Faber, 1987; Daley, Kleinpell, Lawringer, & Casey, 1994; Evans, Matlock, Bishop, Stranahan, & Pederson, 1988; Kernich & Robb, 1988; Mackay, 1994; Sanguinetti & Catanzaro, 1987). Advanced Practice Nurses could play key roles in developing these booklets and/or programs for the family members.

Interventions at the secondary level of prevention are initiated when a reaction to a stressor has occurred or a need has been identified as unmet. The goal of nursing at this level is to provide appropriate interventions in order to help the family members regain a sense of stability or wellness (Neuman, 1995). This is achieved through ongoing family assessments, verifying the findings with the family members, and then initiating the appropriate interventions. For example, if the need for information about the various stages of recovery is not met, nurses can intervene by providing clear answers to the family members' questions (Bueno & Sengin, 1995) regarding the stages of recovery. An educational program or booklet that provides information on brain injuries and the stages of recovery may be appropriate if this intervention has not been initiated at the primary level of prevention. As well, nurses could provide suggestions of activities family members could do with the patient that are appropriate for his or her stage of recovery. This may help to reinforce the information given to the family members about the stages of recovery.

Tertiary prevention as interventions are started when interventions related to unmet needs have been initiated. The goal of interventions at this level is to maintain the client system or

reconstitution (Neuman, 1995). For instance, following the implementation of interventions to meet the family members' need for information about the various stages of recovery, nurses can continue to reinforce information and provide reassurance on an ongoing basis about how different aspects of care relate to the stages or recovery. Advanced Practice Nurses working with these family members could also initiate support groups which would give family members a forum to share their experiences as well as ventilate their fears and concerns relating to the uncertainty pertaining to the stages of recovery. By continuing to address the family members' need for information on the stages of recovery, nurses are offering relevant interventions at the tertiary level of prevention.

While the interventions so far have been directed towards the family members, the study results also have implications for the nurses. Advanced Practice Nurses could play a role in educating other nurses on the needs of the family members and the importance of verifying their perceptions with the family members to ensure that needs will be met. The importance of family-focused care could also be shared with the nurses at that time. The APN could develop a family nursing course to be taught to the nursing staff that outlines family theory and interventions to meet the family members' needs. As well, APNs could act as a role model for the nursing staff through their interactions with family members and by demonstrating the implementation of family theory in their practice. Previous authors (Artinian, 1991; Fox & Jeffrey, 1997) have suggested that some barriers to family-focused care were workload and time constraints. In order to help alleviate these concerns, APNs could share recent research findings which indicates that nurses' interactions with family members can in itself be an intervention (Robinson, 1996). With this in mind, nurses can show sensitivity to needs of family members by engaging in the following behaviours: being active and curious listeners; demonstrating compassion; being nonjudgmental; acknowledging family strengths; and collaborating with the family (Robinson, 1996).

In addition to educating nursing staff, APNs could also play key roles in meeting family needs by influencing policy and clinical changes (Norton & Grady, 1996). Advanced Practice

Nurses could influence policy and clinical changes by taking the necessary steps to ensure that ongoing family assessments are done by recommending and adopting the use of a family assessment tool on the unit. The CCFNI could be used by nurses (Halm, 1992) to assist with the identification of the family members' needs when patients with brain injuries are admitted to the unit. Furthermore, this tool would enable the nurses to verify their perceptions with the family members, thus ensuring appropriate interventions are initiated and carried out. Clearly, there is a role for nurses in meeting the needs of the family members of patients with brain injuries.

Implications for Future Research. The findings of this study indicate that the needs most important to the family members following a brain injury were related to the psychological variable. However, there may well be needs related to the other variables defined by Neuman (1995) that were not identified in this study. As noted previously, the development of an instrument based on the Neuman Systems Model that targeted family members of patients with brain injuries could assist in more accurate identification of these needs. A future study using a qualitative approach may help to identify additional information about stressors or needs of family members of patients with brain injuries. This information would help to provide a richer understanding of family needs in this population which could then be used in the development of a more specific instrument. Furthermore, the qualitative data gathered may also lead to the generation of a formal theory on the needs of family members of patients who have acquired a brain injury.

While collecting the data, the researcher noted that some family members of patients with TBI were not asked to participate in the study because there were some underlying problems between the family and hospital staff. It is possible that these family members had needs that were not being met and which lead to confrontations with nursing staff. Future studies should be conducted to determine if an association exists between family needs that are being met and satisfaction with care. A possible hypothesis would be: family members whose needs are met in the order of importance that the needs were rated will report a higher level of satisfaction with care. Other studies should examine the relationship between family needs being met and family

adjustment following a brain injury in a family member. An example of a hypothesis to be tested for that study could be that there is a positive association between family members' needs being met and family adjustment following a brain injury in a family member. The results of these studies may provide valuable information about family resiliency as well as increase our understanding of how family members adapt to a brain injury in a family member. The results would have important implications for nursing practice and could help in the development of nursing interventions to strengthen the family system.

Although there is a growing recognition in the nursing literature concerning family-centered care and family nursing, the findings of this study suggest that it remains an ideal practice rather than a reality. Future studies should be conducted to explore nurses' perceptions of family nursing in the context of caring for patients with brain injuries and factors which promote and hinder the practice in that setting. As well, future research should be directed towards identifying factors that led to some nurses being able to assess family needs better than other nurses as indicated by the findings of this study. The information obtained would assist APNs in the development of family-focused nursing education programs in hospital settings.

Lastly, future studies should concentrate on developing and testing nursing assessments and interventions that consider both the nurse's and family member's perspective and that are designed to meet the needs of family members of patients with brain injuries. For instance, a standardized family assessment and intervention protocol similar to the one developed by Mikhail (1988) could be developed specifically for family members of patients with brain injuries. The instrument could then be tested and the results may provide nurses with research-based assessments and interventions which may help to promote family nursing care.

Conclusion

This descriptive study examined the perceptions of both nurses and family members of patients with brain injuries in identifying family members' needs as well as determining the extent to which these needs were met while the patients were on a neuroscience unit. The study also

attempted to identify if there was a difference between the needs of family members of patients with strokes and those with traumatic brain injuries. Although the nurses were able to identify some of the needs the family members rated to be the most and least important, further analysis revealed that with one exception there was a positive but mainly a low association (r=-.06 to r=.63) between family members' and nurses' ratings of these needs. Some nurses were able to assess the family member's needs better than other nurses. Family members also reported that most of their needs were met and that nurses met the needs more frequently than any other category of individuals. However, the order in which the needs were met may have been based on the nurses perceptions of what the family members needed. Most of the needs which were not met were classified as inter-personal stressors. In addition, the ten needs rated most important by family members of patients with a stroke showed that they were more concerned about the long-term implications of the injury than family members of patients with a TBI. In general, the needs that were perceived to be most important to the family members were associated with the psychological variable.

The implications of the findings were discussed as they relate to theory, nursing practice, and future research. The findings support a key aspect of the Neuman Systems Model, that is the importance of nurses reviewing their perceptions of family needs with the family members before intervening. This step will help to ensure that appropriate interventions are initiated and will further help to promote family-focused care. With the changing health care environment, more responsibility will be placed upon the family for the care of an ill family member (Grossman & Gottlieb, 1995). The family must therefore be assisted to prepare for this challenge. Nurses can play a key role in assisting family members to assume this role by assessing their needs and initiating appropriate interventions to best meet these needs in collaboration with the family members.

References

Acorn, S. (1995). Assisting families of head-injured survivors through a family support programme. Journal of Advance Nursing, 21, 872-77.

Acorn, S. & Roberts, E. (1992). Head injury: Impact on the wives. Journal of Neuroscience Nursing, 24(6), 324-28.

Anderson, H. (1996). A reflection on client-professional collaboration. Family, Systems & Health, 14(2), 193-206.

Artinian, N.T. (1991). Strengthening nurse-family relationships in critical care. AACN: Clinical Issues, 2(2), 269-275.

Artinian, N. T. (1994). Selecting a model to guide family assessment. Dimensions of Critical Care Nursing, 14(1), 4-16.

Bernstein, L. P. (1990). Family-centered care of the critically ill neurologic patient. Critical Care Nursing Clinics of North America, 2(1), 41-50.

Beuno, M.M., & Sengin, K.K. (1995). The Neuman systems model for critical care nursing: A framework for practice. In B. Neuman (Ed.), The Neuman systems model (3rd. ed. , pp. 275-91). Norwalk, CT: Appleton & Lange.

Borsellino, M. (1994, April 19). A fine mess. The Medical Post, 50.

Bowdler, J. E. & Barrell, L. M. (1987). Health needs of homeless persons. Public Health Nursing, 4(3), 135-40.

Braitman, L. (1997). Confidence interval estimates and significance tests for percentages . In B.H. Munro (Eds.), Statistical methods for health care research (3rd. ed., pp. 84-85). Philadelphia, PA: J.B. Lippincott Company.

Buchanan, K. M., & Capp, R. E. (1988). Head injury and the family. Saskatoon, SK: University Hospital.

Burns, N. & Grove, S. K. (1995). Understanding nursing research. Toronto, ON: W. B. Saunders Company.

Campbell, C. H. (1988). Needs of relatives and helpfulness of support groups in severe head injury. Rehabilitation Nursing, 13(6), 320-25.

Caplin, M.S., & Sexton, D.L. (1988). Stresses experienced by spouses of patients in a coronary care unit with a myocardial infarction. Focus on Critical Care, 15(5), 31-40.

Carson, P. (1993). Investing in the comeback: Parent's experience following traumatic brain injury. Journal of Neuroscience Nursing, 25(3), 165-73.

Casas, M. S. (1989). Experience in coping with stroke: A survey of caregivers. Journal of Rehabilitation, 55(4), 37-43.

Casey, B. A. (1996). The family as a system. In P. J. Bomar (Ed.), Nursing and family health promotion: Concepts, Assessment, and Interventions (2nd ed., pp. 49-59). Toronto, ON: W. B. Saunders Company.

Chavez, C.W., & Faber, L. (1987). Effect of an education-orientation program on family members who visit their significant other in the intensive care unit. Heart & Lung, 16(1), 92-99.

Chesla, C.A. (1996). Reconciling technologic and family care in critical-care nursing. Image: Journal of Nursing Scholarship, 28(3), 199-203.

Cross, J. R. (1990). Betty Neuman. In J. B. George (ed.), Nursing theories: The base for professional nursing practice (3rd. ed. , pp. 259-78). Norwalk, CT: Appleton & Lange.

Daley, L. (1984). The perceived immediate needs of families with relatives in the intensive care setting. Heart & Lung, 13(3), 231-37.

Daley, K., Kleinpell, R.M., Lawinger, S., & Casey, G. (1994). The effect of two nursing interventions on families of ICU patients. Clinical Nursing Research, 3(4), 414-22.

Dallal, G.E. (1986). PC-SIZE: A Program for Sample Size Determinations (Version 2.13) [Computer software] Andover, MA: Author

Danielson, C. B., Hamel-Bissell, B., & Winstead-Fry, P. (1993). The family: A dynamic influence on health and illness. In C. B. Danielson, B. Hamel-Bissell, & P. Winstead-Fry (Eds.), Families, health, & illness: Perspectives on coping and intervention (pp. 3-19). St. Louis, MO: Mosby-Year Book.

Davis-Martin, S. (1994). Perceived needs of families of long-term critical care patients: A brief report. Heart & Lung, 23(6), 515-18.

DeBoskey, D. S., Hecht, J. S., & Calub, C. J. (1991). Educating families of the head injured: A guide to medical, cognitive, and social issues. Gaithersburg, MD: Aspen Publishers, Inc.

Decker, S.D., & Young, E. (1991). Self-perceived needs of primary caregivers of home-hospice clients. Journal of Community Health Nursing, 8(3), 147-54.

Diekhoff, G. (1992). Statistics for the social and behavioral sciences: Univariate, bivariate, multivariate. Dubuque, IA: Wm. C. Brown Publishers.

Dockter, B., Black, D.R., Hovell, M.F., Engleberg, D., Amick, T., Neimier, P., & Sheets, N. (1988). Families and intensive care nurses: Comparison of perceptions. Patient Education and Counseling, 12, 29-36.

Dring, R. (1989). The informal caregiver responsible for home care of the individual with cognitive dysfunction following brain injury. Journal of Neuroscience Nursing, 21(1), 42-45.

Drummond, A.E.R. (1988). Stroke: The impact on the family. British Journal of Occupational Therapy, 51(6), 193-94.

Dufault, K. & Martocchio, B. C. (1985). Hope: Its spheres and dimensions. Nursing Clinics of North America, 20(2), 379-91.

Elliot, J. & Smith, D. R. (1985). Meeting family needs following severe head injury: A multidisciplinary approach. Journal of Neurosurgical Nursing, 17(2), 111-13.

Engli, M. & Kirsivali-Farmer, K. (1993). Needs of family members of critically ill patients with and without acute brain injury. Journal of Neuroscience Nursing, 25(2), 78-85.

Evans, R. L. , Griffith, J. , Haselkorn, J. K. , Hendricks, R. D. , Baldwin, D. , & Bishop, D. S. (1992). Poststroke family function: An evaluation of the family's role in rehabilitation. Rehabilitation Nursing, 17(3), 127-31.

Evans, R.L., Hendricks, R.D., Haselkorn, J.K., Bishop, D.S., & Baldwin, D. (1992). The family's role in stroke rehabilitation. American Journal of Physical Medicine and Rehabilitation, 71(3), 135-39.

Evans, R.L., Matlock, A.L., Bishop, D.S., Stranahan, S., & Pederson, C. (1988). Family intervention after stroke: Does counseling or education help? Stroke, 19(10), 1243-49.

Farzan, D.T. (1991). Reintegration for stroke survivors: Home and community considerations. Nursing Clinics of North America, 26(4), 1037-48.

Fawcett, J. (1995). Neuman's systems model. In M. Fithian (ed.), Analysis and evaluation of conceptual models of nursing (3rd. ed. , pp. 217-75). Philadelphia: F. A. Davis Company.

Fleiss, J.L. (1981). An introduction to applied probability. Statistical methods for rates and proportions (2nd ed., pp. 1-18). New York, NY: John Wiley & Sons.

Forrester, D.A., Murphy, P.A., Price, D.M., & Monaghan, J.F. (1990). Critical care family needs: Nurse-family member confederate pairs. Heart & Lung, 19(6), 655-61.

Fowler, S. B. (1995). Hope: Implications for neuroscience nursing. Journal of Neuroscience Nursing, 27(5), 298-304.

Fox, S., & Jeffrey, J. (1997). The role of the nurse with families of patients in ICU: The nurses' perspective. Canadian Journal of Cardiovascular Nursing, 8(1), 17-23

Freichels, T.A. (1991). Needs of family members of patients in the intensive care unit over time. Critical Care Nursing Quarterly, 14(3), 16-29.

Friedman, M. M. (1992). Systems theory. In B. E. Norwitz & S. Holmes (Eds.), Family nursing theory and practice (3rd. ed. , pp. 113-25). Norwalk, CT: Appleton & Lange.

Frye, B. A. (1982). Brain injury and family education needs. Rehabilitation Nursing, 7(4), 27-28.

Frye, B. A. (1987). Head injury and the family: Related literature. Rehabilitation Nursing, 12(3), 135-6.

Grant, J. S., & Bean, C. A. (1992). Self-identified needs of informal caregivers of head-injured adults. Family Community Health, 15(2), 49-58.

Grant, J. S. , Kinney, M. R. & Davis, L. L. (1993). Using conceptual frameworks or models to guide nursing research. Journal of Neuroscience Nursing, 25(1), 52-56.

Grossman, M., & Gottlieb, L.N. (1995). Changes in acute care: Questions in need of answers. Canadian Journal of Nursing Research, 27(4), 5-7.

Halm, M.A. (1992). Support and reassurance needs: Strategies for practice. Critical Care Nursing Clinics of North America, 4(4), 633-43.

Hickey, J.V. (1986). The clinical practice of neurological and neurosurgical nursing (2nd. ed.), Philadelphia, PA: J.D. Lippincott Company.

Hickey, M., & Lewandowski, L. (1988). Critical care nurses' role with families: A descriptive study. Heart & Lung, 17(6), 670-76.

Hinds, C., & Moyer, A. (1997). Support as experienced by patients with cancer during radiotherapy treatments. Journal of Advanced Nursing, 26, 371-79.

Jacono, J., Hicks, G., Antonioni, C., O'Brien, K., & Rasi, M. (1990). Comparison of perceived needs of family members between registered nurses and family members of critically ill patients in intensive care and neonatal intensive care units. Heart & Lung, 19(6), 72-78.

Jamerson, P.A., Scheibmeir, M., Bott, M.J., Crighton, F., Hinton, R.H., & Cobb, A.K. (1996). The experiences of families with a relative in the intensive care unit. Heart & Lung, 25(6), 467-74.

Johnson, B.P. (1995). One family's experience with head injury: A phenomenology study. Journal of Neuroscience Nursing, 27(2), 113-18.

Johnston, K. (1986). A comparison of the nurse's perception of the priority needs of the spouse as they relate to those identified by the spouse. Heart & Lung, 15(3), 305-6.

Kahn, E. C. (1992). A comparison of family needs based on the presence or absence of DNR orders. Dimensions of Critical Care Nursing, 11(5), 286-292.

Katz, D. I. (1992). Neuropathology and neurobehavioral recovery from closed head injury. Journal of Head Trauma Rehabilitation, 7(2), 1-15.

Kay, T. & Cavallo, M. M. (1994). The family system: Impact, assessment, and intervention. In J. M. Silver, S. C. Yudofsky, R. E. Hales (Eds.), Neuropsychiatry of traumatic brain injury (pp. 533-567). Washington, DC: American Psychiatric Press Inc.

Kernich, C.A., & Robb, G. (1988). Development of a stroke family support and education program. Journal of Neuroscience Nursing, 20(3), 193-97.

Kleinpell, R. M. & Powers, M. J. (1992). Needs of family members of intensive care unit patients. Applied Nursing Research, 5(1), 2-8.

Koller, P.A. (1991). Family needs and coping strategies during illness crisis. AACN: Clinical Issues, 2(2), 338-45.

Kosciulek, J.F. (1996). The circumplex model and head injury family types: A test of the balanced versus extreme hypotheses. Journal of Rehabilitation, 62(2), 49-54.

Kreutzer, J.S., Gervasio, A.H., & Camplair, P.S. (1994). Primary caregivers' psychological status and family functioning after traumatic brain injury. Brain Injury, 8(3), 197-210.

Kreutzer, J. S. , Serio, C. D. , & Bergquist, S. (1994). Family needs after brain injury: A quantitative analysis. Journal of Head Trauma Rehabilitation, 9(3), 104-15.

Lancaster, D.R. (1996). Neuman's systems model. In J.J. Fitzpatrick & A.L. Whall (Eds.), Conceptual models of nursing analysis and application, (3rd. ed., pp. 199-223). Stamford, CT: Appleton & Lange.

Leaf, L. E. (1993). Traumatic brain injury: Affecting family recovery. Brain Injury, 7(6), 543-46.

Leske, J. S. (1986). Needs of relatives of critically ill patients: A follow-up. Heart & Lung, 15(2), 189-93.

Leske, J. S. (1991a). Internal psychometric properties of the critical care family needs inventory. Heart & Lung, 20(3), 236-44.

Leske, J.S. (1991b). Overview of family needs after critical illness: From assessment to intervention. AACN: Clinical Issues, 2(2), 220-26.

Leske, J.S. (1992). Comparison ratings of need importance after critical illness from family members with varied demographic characteristics. Critical Care Nursing Clinics of North America, 4(4), 607-13.

Livingston, M.G. (1990). Effects on the family system. In M. Rosenthal, E.R. Griffith, M.R. Bond, & J.D. Miller (Eds.), Rehabilitation of the adult and child with Traumatic Brain Injury (2nd ed., pp. 225-35). Philadelphia, PA: F.A. Davis Company.

LoBiondo-Wood, G., & Haber, J. (1994). Nursing research: Methods, critical appraisal, and utilization (3rd ed.), St. Louis, MO: Mosby-Year Book Inc.

Lynn-McHale, D. J. & Bellinger, A. (1988). Need satisfaction levels of family members of critical care patients and accuracy of nurses' perceptions. Heart & Lung, 17(4), 447-53.

Macey, B.A., & Bouman, C.C. (1991). An evaluation of validity, reliability, and readability of the critical care family needs inventory. Heart & Lung, 20(4), 398-403.

Mackay, L.E. (1994). Benefits of a formalized traumatic brain injury program within a trauma center. Journal of Head Trauma Rehabilitation, 9(1), 11-19.

Marshall, S. B., Marshall, L. F., Vos, H. R., & Chesnut, R. M. (1990). Neuroscience critical care: Pathophysiology and patient management. Philadelphia, PA: W. B. Saunders Company.

Mathis, M. (1984). Personal needs of family members of critically ill patients with and without acute brain injury. Journal of Neurosurgical Nursing, 16(1), 36-44.

Mauss-Clum, N. & Ryan, M. (1981). Brain injury and the family. Journal of Neurosurgical Nursing, 13(4), 165-69.

McClelland, R. J. (1988). Psychosocial sequelae of head injury: Anatomy of a relationship. British Journal of Psychiatry, 153, 141-146.

McLean, J. , Roper-Hall, A. , Mayer, P. & Main, A. (1991). Service needs of stroke survivors and their informal carers: A pilot study. Journal of Advanced Nursing, 16, 559-64.

Meleis, A. I. (1991). On nursing clients. In D. Carroll, A. Stonehouse, V. Barishek (Eds.), Theoretical nursing: Development & progress (2nd. ed. , pp. 293-310). Philadelphia: J. B. Lippincott Company.

Mikhail, J.N. (1988). Developing a family assessment and intervention protocol. Critical Care Nurse, 8(3), 114-18.

Miller, L. (1993). Family therapy of brain injury: Syndromes, strategies, and solutions. The American Journal of Family Therapy, 21(2), 111-21.

Mitchell, P.H. (1988). Consciousness: An overview. In P.H. Mitchell, L.C. Hodges, M. Muwaswes, & C.A. Walleck (Eds.), AANN's neuroscience nursing phenomena and practice: Human responses to neurologic health (pp. 57-66). Norwalk, CT: Appleton & Lange.

Mitchell, P.H., & Hodges, L.C. (1988). Human responses: The phenomena of neuroscience nursing. In P.H. Mitchell, L.C. Hodges, M. Muwaswes, & C.A. Walleck (Eds.), AANN's neuroscience nursing phenomena and practice: Human responses to neurologic health problems (pp. 9-17). Norwalk, CT: Appleton & Lange.

Molter, N. C. (1979). Needs of relatives of critically ill patients: A descriptive study. Heart & Lung, 8(2), 332-39.

Morse, J. M. & Doberneck, B. (1995). Delineating the concept of hope. IMAGE: Journal of Nursing Scholarship, 27(4), 277-85

Munro, B.H. (1993). Correlation. In B.H. Munro & E.B. Page (Eds.), Statistical methods for health care research (2nd ed., pp. 173-87). Philadelphia, PA: J.B. Lippincott Company.

Neuman, B. (1995). The Neuman systems model. In B. Neuman (Ed.), The Neuman systems model (3rd. ed. , pp. 3-63). Norwalk, CT: Appleton & Lange.

Nikas, D. L. (1987). Prognostic indicators in patients with severe head injury. Critical Care Nursing Quarterly, 10(3), 25-34.

Norton, S.F., & Grady, E.M. (1996). Change agent skills. In A.B. Hamric, J.A. Spross, & C.M. Hanson (Eds.), Advanced nursing practice: An integrative approach (pp. 249-272). Philadelphia, PA: W.B. Saunders Company.

O'Malley, P., Favaloro, R., Anderson, B., Anderson, M.L., Siewe, S., Benson-Landau, M., Deane, D., Feeney, J., Gmeiner, J., Keefer, N., Mains, J., & Riddle, K. (1991). Critical care nurse perceptions of family needs. Heart & Lung, 20(2), 189-201.

O'Neill Norris, L. & Grove, S. K. (1986). Investigation of selected psychosocial needs of family members of critically ill adult patients. Heart & Lung, 15(2), 194-99.

Ottawa-Carleton Regional District Health Council. (1989). Head injury rehabilitation services in Ottawa-Carleton: Report of the continuing care board's sub-committee on head injury services. Ottawa: Author.

Pelletier, M.L. (1993). The needs of family members of organ and tissue donors. Heart & Lung, 22(2), 151-57.

Pierce, L. L. & Salter, J. P. (1988). Stroke support group: A reality. Rehabilitation Nursing, 13(4), 189-90, 197.

Polit, D. F. & Hungler, B. P. (1991). Nursing research: Principles and methods (4th ed.). Philadelphia, PA: J. B. Lippincott Company.

Polit, D.F. (1996). Data analysis & statistics for nursing research. Stamford, CT: Appleton & Lange.

Price, D.M., Forrester, A., Murphy, P.A., & Monaghan, J.F. (1991). Critical care family needs in an urban teaching medical center. Heart & Lung, 20(2), 183-88.

Prowse, M. D. (1984). Needs of family members of patients as perceived by family members and nurses in an intensive care unit: An exploratory study. Heart & Lung, 13(3), 310-11.

Rape, R.N., Bush, J.P,. & Slavin, L.A. (1992). Toward a conceptualization of the family's adaptation to a member's head injury: A critique of developmental stage models. Rehabilitation Psychology, 37(1), 3-22

Reed, K.S. (1993). Adapting the Neuman systems model for family nursing. Nursing Science Quarterly, 6(2), 93-97.

Reed, K. S. (1989). Family theory related to the Neuman systems model. In B. Neuman (Ed.), The Neuman systems model (2nd. ed. , pp. 385-95). Norwalk, CT: Appleton & Lange.

Richmond, T. S. , Metcalf, J. A. , & Winterhalter, J. (1987). Support group for families of acute neurological patients. Journal of Neuroscience Nursing, 19(1), 40-43.

Robinson, C.A. (1995). Unifying distinctions for nursing research with persons and families. Journal of Family Nursing, 1(1), 8-28.

Robinson, C.A. (1996). Health care relationships revisited. Journal of Family Nursing, 2(2), 152-73.

Rogers, P. M. & Kreutzer, J. S. (1984). Family crises following head injury: A network intervention strategy. Journal of Neurosurgical Nursing, 16(6), 343-46.

Rosenthal, M., & Young, T. (1988). Effective family intervention after traumatic brain injury: Theory and practice. Journal of Head Trauma Rehabilitation, 3(4), 42-50.

Rukholm, E., Bailey, P., Coutu-Wakulczyk, G., & Bailey, W.B. (1991). Needs and anxiety levels in relatives of intensive care unit patients. Journal of Advanced Nursing, 16, 920-28.

Sanguinetti, M., & Catanzaro, M. (1987). A comparison of discharge teaching on the consequences of brain injury. Journal of Neuroscience Nursing, 19(5), 271-75.

Serio, C.D., Kreutzer, J., Gervasio, A.H. (1995). Predicting family needs after brain injury: Implications for intervention. Journal of Head Trauma Rehabilitation, 10(2), 32-45.

Stambrook, M. , Peters, L. C. , & Moore, A. D. (1989). Issues in the rehabilitation of severe traumatic brain injury: A focus on the neuropsychologist's role. Canadian Journal of Rehabilitation, 3(2), 87-98.

Statistics Canada. (1993). Nursing in Canada 1993 registered nurses. (Catalogue 83-243). Ottawa, ON: Author.

Statistics Canada. (1996). Statistics Canada shelf tables for hospital morbidity in 1993-94. (pp. 375-79, 696-700, 738-41). Ottawa, ON: Author.

Stroker, R. (1983). Impact of disability on families of stroke clients. Journal of Neurosurgical Nursing, 15(6), 360-65.

Testani-Dufour, L. , Chappel-Aiken, L. , & Gueldner, S. (1992). Traumatic brain injury: A family experience. Journal of Neuroscience Nursing, 24(6), 317-23.

Thomas, R. (1987). Methodological issues and problems in family health care research. Journal of Marriage and the Family, 49, 65-70.

Thompson, M. (1994). Nurturing hope: A vital ingredient in nursing. Journal of Christian Nursing, 11(1), 10-17.

Tomlinson, P.A., & Anderson, K.H. (1995). Family health and the Neuman systems model. In B. Neuman (Ed.), The Neuman systems model (3rd. ed. , pp. 133-43). Norwalk, CT: Appleton & Lange.

van Veenendaal, H., Grinspun, D.R., & Adriaanse, H.P. (1996). Educational needs of stroke survivors and their family members, as perceived by themselves and by health professionals. Patient Education and Counseling, 28, 265-76.

Vosburgh, D., & Simpson, P. (1993). Linking family theory and practice: A family nursing program. IMAGE: Journal of Nursing Scholarship, 25(3), 231-35

Watson, P. G. (1986). Stroke in the family: Theoretical considerations. Rehabilitation Nursing, 11(5), 15-17.

Wellwood, I. , Dennis, M. S. , & Warlow, C. P. (1994). Perceptions and knowledge of stroke among surviving patients with stroke and their carers. Age and Aging, 23, 293-98.

Williams, A. (1994). What bothers caregivers of stroke victims? Journal of Neuroscience Nursing, 26(3), 155-61.

Wright, L.M., & Leahey, M. (1994). Theoretical foundations of the Calgary family assessment and intervention models. Nurses and families: A guide to family assessment and intervention, (2nd. ed., pp. 15-36), Philadelphia, PA: F.A. Davis Company.

Yarnold, P.R. (1996). Characterizing and circumventing Simpson's paradox for ordered bivariate data. Educational and Psychological Measurement, 56(3), 430-442.

Zazpe, C., Margall, M.A., Otano, C., Perochena, M.P., & Asiain, M.C. (1997). Meeting needs of family members of critically ill patients in a Spanish intensive care unit. Intensive and Critical Care Nursing, 13, 12-16.

Appendix A

Illustration of the Neuman Systems Model

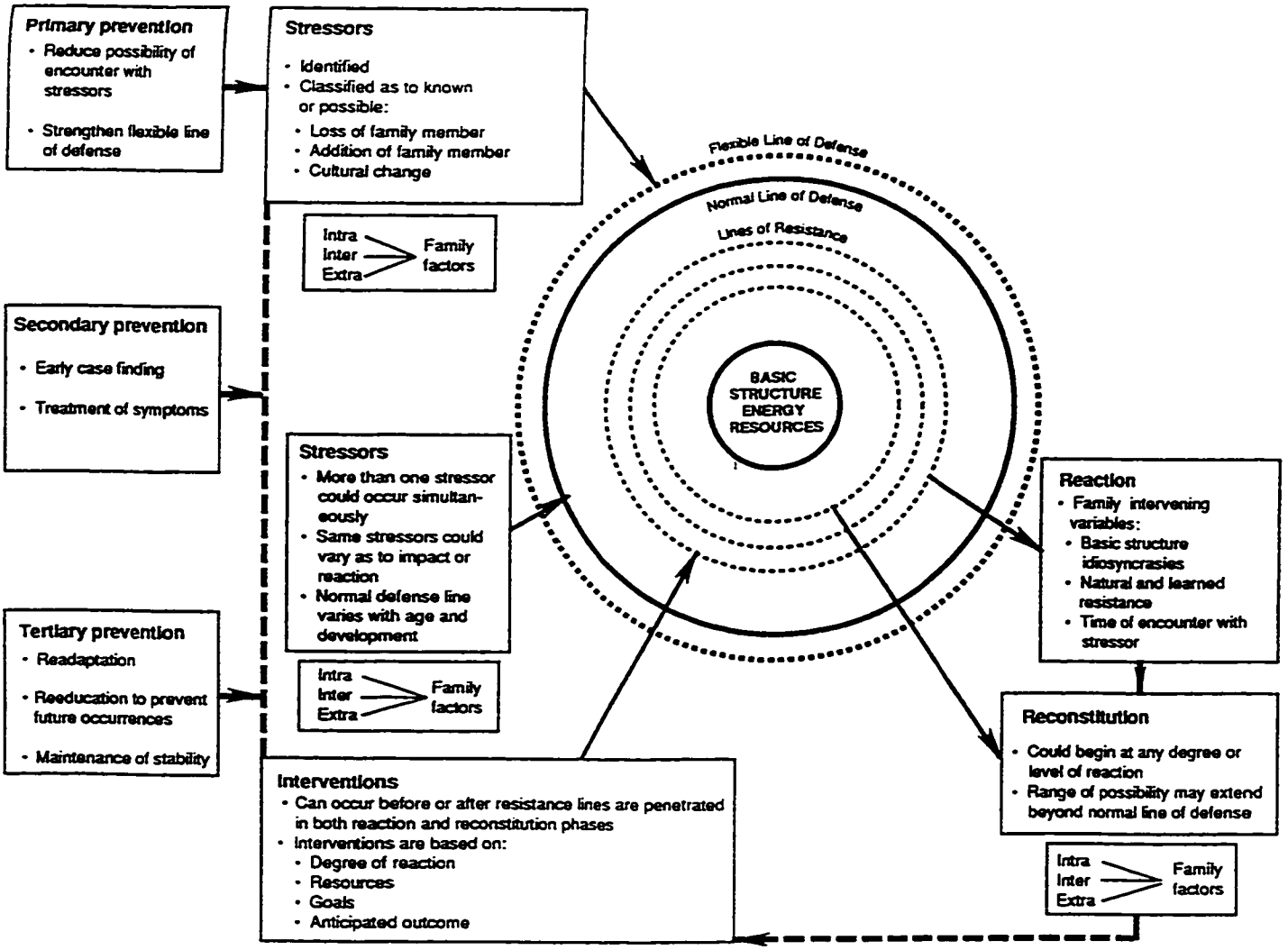


Figure 3. Neuman Systems Model for Viewing Family Problems

Note. From Reed, K. S. (1989). Family theory related to the Neuman systems model. In B. Neuman (Ed.), The Neuman systems model (2nd. ed. , pp. 387). Norwalk, CT: Appleton & Lange. Reprinted with permission.

Appendix A con't

A P P L E T O N & L A N G E

Simon & Schuster
International and Business & Professional Group
107 Elm Street, P.O. Box 120041
Stamford, CT 06912-0041
203-406-4500

6/10/97

Dear Requestor: Barbara Neabel -

Thank you for your inquiry regarding obtaining permission to reproduce material owned by Appleton & Lange division of Simon & Schuster Publishing.

Permission is granted subject to your research confirming that the material in question is original to our text. Permission is granted on a non-exclusive, one-time only or life of an edition basis, with distribution rights throughout the world. The permission is subject to the use of a credit line that must include the name of the author, title of the book, edition, copyright holder (Appleton & Lange), and year of publication. The credit line must appear on the same page where our text or illustration will appear.

Also, since permission granted is subject to author approval, write to: See Below

Fee for this project is ~~0~~

If you have any other questions, please let me know.

Sincerely,

Christine Dembski

Christine Dembski
Permissions Dept.

Betty Neuman, RN
Box 488
Beverly, OH 45715

Encl.

Permission is given to use Neuman Sick. Copyrighted material with proper credit line & payment of $50.00 upon first publication. Kindly use Beverly, OH address above. Betty Neuman 7/5/97.

Appendix B

Permission to Modify the CCFNI

5333 W. River Trail
Mequon, WI 53092

Barb Neabel
Apt #911
20470 South Vale Cresent
Ottawa, CANADA
K1B4L9

March 26, 1996

Dear Barb,

You have my permission to use or modify the copyrighted Critical Care Family Needs Inventory as long as credit is referenced in your work. The reliability and validity information is available in Leske, J.S. "Selected Psychometric Properties of the Critical Care Family Needs Inventory" unpublished doctoral dissertation, University of Wisconsin-Milwaukee, 1988 and Leske, J.S. (1991). Internal psychometric properties of the Critical Care Family Needs Inventory, Heart & Lung, 20, 236-244.

If I can be of any further help, please do not hesitate to write. Best wishes for a successful research endeavor.

Sincerely,

Jane Leske

Jane S. Leske PhD, RN

Appendix C

Critical Care Family Needs Inventory

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

Appendix C con't

	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
17. To be assured that the best care possible is being given to the patient	_____	_____	_____	_____
18. To have a place to be alone while in the hospital	_____	_____	_____	_____
19. To know exactly what is being done for the patient	_____	_____	_____	_____
20. To have comfortable furniture in the waiting room	_____	_____	_____	_____
21. To feel accepted by the hospital staff	_____	_____	_____	_____
22. To have someone to help with financial problems	_____	_____	_____	_____
23. To have a telephone near the waiting room	_____	_____	_____	_____
24. To have a pastor visit	_____	_____	_____	_____
25. To talk about the possibility of the patient's death	_____	_____	_____	_____
26. To have another person with you when visiting the critical care unit	_____	_____	_____	_____
27. To have someone be concerned with your health	_____	_____	_____	_____
28. To be assured it is alright to leave the hospital for awhile	_____	_____	_____	_____
29. To talk to the same nurse every day	_____	_____	_____	_____
30. To feel it is alright to cry	_____	_____	_____	_____
31. To be told about other people that could help with problems	_____	_____	_____	_

FAMNDS\LES3
September 12, 1991

Appendix C con't

		Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
32.	To have a bathroom near the waiting room	_____	_____	_____	_____
33.	To be alone at any time	_____	_____	_____	_____
34.	To be told about someone to help with family problems	_____	_____	_____	_____
35.	To have explanations given that are understandable	_____	_____	_____	_____
36.	To have visiting hours start on time	_____	_____	_____	_____
37.	To be told about chaplain services	_____	_____	_____	_____
38.	To help with the patient's physical care	_____	_____	_____	_____
39.	To be told about transfer plans while they are being made	_____	_____	_____	_____
40.	To be called at home about changes in the patient's condition	_____	_____	_____	_____
41.	To receive information about the patient at least once a day	_____	_____	_____	_____
42.	To feel that the hosptial personnel care about the patient	_____	_____	_____	_____
43.	To know specific facts concerning the patient's progress	_____	_____	_____	_____
44.	To see the patient frequently	_____	_____	_____	_____
45.	To have the waiting room near the patient	_____	_____	_____	_____
46.	Other:	_____	_____	_____	_____

Appendix D

Philosophy Statements from the Hospitals

NEUROSCIENCES

Philosophy of Practice

The Neuroscience Unit of the Ottawa Civic Hospital is committed to providing optimal care to our patients and their families. Out specialized team will promote the highest standard of current clinical practice and be involved in innovative therapy based upon the principles of collaborative practice, education and research. We strive to assist our patients to achieve their optimal recovery, while maintaining their dignity by respecting their individual needs and differences.

November 1995

Appendix D con't

6 NORTH WEST

Statement of Philosophy

The Nursing staff on 6 North West is dedicated to the promotion of the well-being of primarily the neurologically impaired individuals. Nursing contributes a preventative, educational, restorative service which assists individuals/families with their hospitalization. In the event that life can no longer be sustained, nursing strives to assure a peaceful death.

Statement of Principal Function

To provide nursing care primarily to neurologicaliy impaired patients according to established standards of practice. To promote maximum recovery of function through co-ordination of the multi-disciplinary health care team. To provide educational and emotional support to patients and significant others.

Statement of Purpose

To provide nursing care primarily to neurogically impaired patients; which includes observation, care and council of the patient and their significant others.

M. Taylor-Greenly
Revised: November 3, 1994
...\taylor\state.6nw

Appendix E

Study Questionnaires
Nursing Staff Questionnaire

Code number: _____

(please leave blank)

Date: _____

Part A

Please check (√) the appropriate answer.

1. Gender: M_____ F _____

2. Age: _____ years

3. Highest level of nursing education

   Diploma _____

   Baccalaureate _____

   Master _____

4. Employment Status

   Full-time _____

   Part-time _____

5. Number of years of nursing experience: _____ years

6. Number of years of neuroscience nursing experience: _____ years

7. Have you received any recent education on family needs in the acute brain injured population?

   Yes _____ Please briefly describe when and what was learned.

_____

_____

_____

_____

   No _____

Appendix E con't

8. Name of the patient you have cared for _____

9. What do you think is the greatest need that his or her family members has at this time?

_____

_____

_____

_____

_____

_____

_____

_____

Part B

Critical Care Family Needs Inventory

Please check (√) how IMPORTANT you believe each of the following needs are to the family members of patients with traumatic brain injuries.

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
10.	To know the expected outcome	_____	_____	_____	_____
11.	To have explanations of the environment before going into the neuroscience unit for the first time	_____	_____	_____	_____
12.	To talk to the doctor every day	_____	_____	_____	_____
13.	To have a specific person to call at the hospital when unable to visit	_____	_____	_____	_____
14.	To have questions answered honestly	_____	_____	_____	_____
15.	To have visiting hours changed for special conditions	_____	_____	_____	_____
16.	To talk about feelings about what has happened	_____	_____	_____	_____

Appendix E con't

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
17.	To have good food available in the hospital	_____	_____	_____	_____
18.	To have directions as to what to do at the bedside	_____	_____	_____	_____
19.	To visit at any time	_____	_____	_____	_____
20.	To know which staff members could give what type of information	_____	_____	_____	_____
21.	To have friends nearby for support	_____	_____	_____	_____
22.	To know why things were done for the patient	_____	_____	_____	_____
23.	To feel there is hope	_____	_____	_____	_____
24.	To know about the types of staff members taking care of the patient	_____	_____	_____	_____
25.	To know how the patient is being treated medically	_____	_____	_____	_____
26.	To be assured that the best care possible is being given to the patient	_____	_____	_____	_____
27.	To have a place to be alone while in the hospital	_____	_____	_____	_____
28.	To know exactly what is being done for the patient	_____	_____	_____	_____
29.	To have comfortable furniture in the waiting room	_____	_____	_____	_____
30.	To feel accepted by the hospital staff	_____	_____	_____	_____
31.	To have someone to help with financial problems	_____	_____	_____	_____
32.	To have a telephone near the waiting room	_____	_____	_____	_____

Appendix E con't

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
33.	To have a pastor visit	____	____	____	____
34.	To talk about the possibility of the patient's death	____	____	____	____
35.	To have another person with you when visiting the neuroscience unit	____	____	____	____
36.	To have someone be concerned with your health	____	____	____	____
37.	To be assured it is all right to leave the hospital for awhile	____	____	____	____
38.	To talk to the same nurse every day	____	____	____	____
39.	To feel it is all right to cry	____	____	____	____
40.	To be told about other people that could help with problems	____	____	____	____
41.	To have a bathroom near the waiting room	____	____	____	____
42.	To be alone at any time	____	____	____	____
43.	To be told about someone to help with family problems	____	____	____	____
44.	To have explanations given that are understandable	____	____	____	____
45.	To have visiting hours start on time	____	____	____	____
46.	To be told about chaplain services	____	____	____	____
47.	To help with the patient's physical care	____	____	____	____
48.	To be told about transfer plans while they are being made	____	____	____	____
49.	To be called at home about changes in the patient's condition	____	____	____	____

Appendix E con't

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
50.	To receive information about the patient at least once a day	_____	_____	_____	_____
51.	To feel that the hospital personnel care about the patient	_____	_____	_____	_____
52.	To know specific facts concerning the patient's progress	_____	_____	_____	_____
53.	To see the patient frequently	_____	_____	_____	_____
54.	To have the waiting room near the patient	_____	_____	_____	_____
55.	To receive information on long-term care options if rehabilitation is not possible	_____	_____	_____	_____
56.	To receive information about the various stages of recovery	_____	_____	_____	_____
57.	To be able to visit the rehabilitation or long-term care institution before the patient is transferred	_____	_____	_____	_____
58.	To receive information about rehabilitation options	_____	_____	_____	_____

Appendix E con't

Family Member Questionnaire

Code Number: _____

(please leave blank)

Date: _____

Part A: Patient Information

Please answer the following questions concerning your family member.

1. Date of Hospital Admission: _____
2. Admitting diagnosis: _____
3. Number of days on this unit: _____ days
4. Gender: M_____ F_____
5. Age: _____ years
6. Please check (√) the patient's position in the family.

   Husband _____

   Wife _____

   Father _____

   Mother _____

   Son _____

   Daughter _____

   Grandparent _____

   Other, please explain _____

Appendix E con't

Part B

Family Member Information

7. Gender: M_____ F_____

8. Age: _____ years

9. What is your relationship to the patient? _____

10. Please check (√) your highest level of education.

    grade school or less _____

    high school diploma _____

    CEGEP _____

    college diploma _____

    university degree _____

11. Please check (√) the range of your family income.

    less than $24,999 _____

    $25,000-49,999 _____

    $50,000-74,999 _____

    greater than $75,000 _____

12. Are you affiliated with any religious group?

    Yes _____ if yes, what group are you affiliated with ?_____

    No _____

    Do you attend regularly _____

        fairly regularly _____

        rarely _____

        not at all _____

13. What ethnic group do you identify with? _____

Appendix E con't

14. Are you satisfied with the number of times you can visit?

Yes _____

No _____ please explain why

_____

_____

_____

15. Have you had a similar hospital experience like this one?

Yes _____

No ____

16. What is your greatest need at this time?

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Appendix E con't

Part C

Critical Care Family Needs Inventory

Please check (√) how IMPORTANT each of the following needs are to you and if the need was met.

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Was this need met? yes/no	Who met this need for you?
17.	To know the expected outcome	_____	_____	_____	_____	Y___N___	_____
18.	To have explanations of the environment before going into the neuroscience unit for the first time	_____	_____	_____	_____	Y___N___	_____
19.	To talk to the doctor every day	_____	_____	_____	_____	Y___N___	_____
20.	To have a specific person to call at the hospital when unable to visit	_____	_____	_____	_____	Y___N___	_____
21.	To have questions answered honestly.	_____	_____	_____	_____	Y___N___	_____
22.	To have visiting hours changed for special conditions	_____	_____	_____	_____	Y___N___	_____
23.	To talk about feelings about what has happened	_____	_____	_____	_____	Y___N___	_____
24.	To have good food available in the hospital	_____	_____	_____	_____	Y___N___	_____

Appendix E con't

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Was this need met? yes/no	Who met this need for you?
25.	To have directions as to what to do at the bedside	_____	_____	_____	_____	Y___N___	_____
26.	To visit at any time	_____	_____	_____	_____	Y___N___	_____
27.	To know which staff members could give what type of information	_____	_____	_____	_____	Y___N___	_____
28.	To have friends nearby for support	_____	_____	_____	_____	Y___N___	_____
29.	To know why things were done for the patient	_____	_____	_____	_____	Y___N___	_____
30.	To feel there is hope	_____	_____	_____	_____	Y___N___	_____
31.	To know about the types of staff members taking care of the patient	_____	_____	_____	_____	Y___N___	_____
32.	To know how the patient is being treated medically	_____	_____	_____	_____	Y___N___	_____
33.	To be assured that the best care possible is being given to the patient	_____	_____	_____	_____	Y___N___	_____
34.	To have a place to be alone while in the hospital	_____	_____	_____	_____	Y___N___	_____

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Was this need met? yes/no	Who met this need for you?
35.	To know exactly what is being done for the patient	_____	_____	_____	_____	Y___N___	_____
36.	To have comfortable furniture in the waiting room	_____	_____	_____	_____	Y___N___	_____
37.	To feel accepted by the hospital staff	_____	_____	_____	_____	Y___N___	_____
38.	To have someone to help with financial problems	_____	_____	_____	_____	Y___N___	_____
39.	To have a telephone near the waiting room	_____	_____	_____	_____	Y___N___	_____
40.	To have a pastor visit	_____	_____	_____	_____	Y___N___	_____
41.	To talk about the possibility of the patient's death	_____	_____	_____	_____	Y___N___	_____
42.	To have another person with you when visiting the neuroscience unit	_____	_____	_____	_____	Y___N___	_____
43.	To have someone be concerned with your health	_____	_____	_____	_____	Y___N___	_____
44.	To be assured it is all right to leave the hospital for awhile	_____	_____	_____	_____	Y___N___	_____

Appendix E con't

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Was this need met? yes/no	Who met this need for you?
45.	To talk to the same nurse every day	_____	_____	_____	_____	Y___N___	_____
46.	To feel it is all right to cry	_____	_____	_____	_____	Y___N___	_____
47.	To be told about other people that could help with problems	_____	_____	_____	_____	Y___N___	_____
48.	To have a bathroom near the waiting room	_____	_____	_____	_____	Y___N___	_____
49.	To be alone at any time	_____	_____	_____	_____	Y___N___	_____
50.	To be told about someone to help with family problems	_____	_____	_____	_____	Y___N___	_____
51.	To have explanations given that are understandable	_____	_____	_____	_____	Y___N___	_____
52.	To have visiting hours start on time	_____	_____	_____	_____	Y___N___	_____
53.	To be told about chaplain services	_____	_____	_____	_____	Y___N___	_____
54.	To help with the patient's physical care	_____	_____	_____	_____	Y___N___	_____
55.	To be told about transfer plans while they are being made	_____	_____	_____	_____	Y___N___	_____

Appendix E con't

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Was this need met? yes/no	Who met this need for you?
56.	To be called at home about changes in the patient's condition	_____	_____	_____	_____	Y__ N___	_____
57.	To receive information about the patient at least once a day	_____	_____	_____	_____	Y___N___	_____
58.	To feel that the hospital personnel care about the patient	_____	_____	_____	_____	Y___N___	_____
59.	To know specific facts concerning the patient's progress	_____	_____	_____	_____	Y___N___	_____
60.	To see the patient frequently	_____	_____	_____	_____	Y___N___	_____
61.	To have the waiting room near the patient	_____	_____	_____	_____	Y___N___	_____
62.	To receive information on long-term care options if rehabilitation is not possible	_____	_____	_____	_____	Y___N___	_____
63.	To receive information about the various stages of recovery	_____	_____	_____	_____	Y___N___	_____

Appendix E con't

	Need Statement	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Was this need met? yes/no	Who met this need for you?
64.	To be able to visit the rehabilitation or long-term care institution before the patient is transferred					Y N	
65.	To receive information about rehabilitation options					Y N	

Appendix F

Inter-rater Reliability on the Classification of the Need Statements Utilizing Neuman's Framework

	Need Statement	Variable	Stressor
1.	To know the expected outcome	Psychological (100%)	Intra-personal (62.5%)
2.	To have explanations of the environment before going into the neuroscience unit for the first time	Psychological (100%)	Extra-personal (62.5%)
3.	To talk to the doctor every day	Psychological (100%)	Inter-personal (75%)
4.	To have a specific person to call at the hospital when unable to visit	Psychological (75%)	Inter-personal (62.5%)
5.	To have questions answered honestly	Psychological (100%)	Inter-personal (62.5)
6.	To have visiting hours changed for special conditions	Psychological (50%)	Extra-personal (75%)
7.	To talk about feelings about what has happened	Psychological (87.5%)	Intra-personal (50%)
8.	To have good food available in the hospital	Physiological (75%)	Extra-personal (62.5%)
9.	To have directions as to what to do at the bedside	Psychological (62.5%)	Inter-personal (75%)
10.	To visit at any time	Psychological (62.5%)	Extra-personal (50%)
11.	To know which staff members could give what type of information	Psychological (62.5%)	Inter-personal (75%)
12.	To have friends nearby for support	Psychological/Socio cultural (50% each)	Inter-personal (87.5%)
13.	To know why things were done for the patient	Psychological (100%)	Inter-personal (62.5)
14.	To feel there is hope	Spiritual/Psychological (50% each)	Intra-personal (100%)
15.	To know about the types of staff members taking care of the patient	Psychological (62.5%)	Inter-personal/Extra-personal (50% each)
16.	To know how the patient is being treated medically	Psychological (62.5%)	Inter-personal (50%)

Appendix F con't

	Need Statement	Variable	Stressor
17.	To be assured that the best care possible is being given to the patient	Psychological (87.5%)	Intra-personal (50%)
18.	To have a place to be alone while in the hospital	Psychological (62.5%)	Intra-personal (75%)
19.	To know exactly what is being done for the patient	Psychological (87.5%)	Intra-personal (62.5%)
20.	To have comfortable furniture in the waiting room	Psychological (87.5%)	Intra-personal (50%)
21.	To feel accepted by the hospital staff	Psychological (62.5%)	Inter-personal (62.5%)
22.	To have someone to help with financial problems	Sociocultural (62.5%)	Extra-personal (62.5%)
23.	To have a telephone near the waiting room	Psychological (50%)	Extra-personal (62.5%)
24.	To have a pastor visit	Spiritual (100%)	Inter-personal (75%)
25.	To talk about the possibility of the patient's death	Spiritual (50%)	Inter-personal/Extra-personal (50% each)
26.	To have another person with you when visiting the neuroscience unit	Psychological (62.5%)	Inter-personal (87.5%)
27.	To have someone be concerned with your health	Physiological (62.5%)	Inter-personal (87.5)
28.	To be assured it is all right to leave the hospital for awhile	Psychological (87.5%)	Inter-personal/Intra-personal (50% each)
29.	To talk to the same nurse every day	Psychological (100%)	Inter-personal (87.5%)
30.	To feel it is all right to cry	Psychological (87.5%)	Intra-personal (75%)
31.	To be told about other people that could help with problems	Psychological (75%)	Inter-personal/Extra-personal (50% each)
32.	To have a bathroom near the waiting room	Physiological (87.5%)	Extra-personal (62.5%)
33.	To be alone at any time	Psychological (75%)	Intra-personal (87.5%)
34.	To be told about someone to help with family problems	Psychological/Socio-cultural (50% each)	Inter-personal/Extra-personal (50% each)

Appendix F con't

	Need Statement	Variable	Stressor
35.	To have explanations given that are understandable	Psychological (50%)	Inter-personal (50%)
36.	To have visiting hours start on time	Psychological/Socio-cultural (37.5% each)	Extra-personal (62.5%)
37.	To be told about chaplain services	Spiritual (87.5%)	Inter-personal (62.5%)
38.	To help with the patient's physical care	Psychological (50%)	Inter-personal/Extra-personal (50% each)
39.	To be told about transfer plans while they are being made	Psychological (62.5%)	Inter-personal (62.5%)
40.	To be called at home about changes in the patient's condition	Psychological (100%)	Inter-personal (75%)
41.	To receive information about the patient at least once a day	Psychological (100%)	Inter-personal (87.5%)
42.	To feel that the hospital personnel care about the patient	Psychological (100%)	Inter-personal (62.5%)
43.	To know specific facts concerning the patient's progress	Psychological (100%)	Inter-personal (62.5%)
44.	To see the patient frequently	Psychological (75%)	Inter-personal/Intra-personal (50% each)
45.	To have the waiting room near the patient	Psychological (62.5%)	Extra-personal (62.5%)

Appendix G

Letter of Information and Consent Form for Family Members

TITLE OF THE PROJECT: A Comparison of Family Needs Perceived by Nurses and Family Members of Acutely Brain Injured Patients.

Purpose

You are invited to participate in a research project to study the needs of family members similar to yourself of patients with brain injuries. This study is being conducted by Barbara Neabel, RN, a full time Master of Science in Nursing student from the University of Ottawa. The information provided may help nurses to identify family needs and develop ways to meet those needs.

What is Involved

Your participation in the study would involve completing a questionnaire which is divided into three sections. The first section involves questions about your affected family member. The second section is about yourself. The last section is a questionnaire on family needs. This section involves 45 need statements and ask whether each need was met or not, and who met the need. You are asked to select one of four responses for each need statement that ranges from not important (1) to very important (4). It will take approximately 45 minutes to complete the questionnaire. The nurses that participate in the study will complete a similar questionnaire on family needs and questions about themselves. As well, information on your affected family member's present level of awareness and the length of his/her loss of consciousness will be obtained from the nursing staff.

Risk and Benefits

Although you will not directly benefit from the study, your participation may benefit others who will go through a similar experience. There are no foreseeable risks or harm involved by participating in the study. You are free to ask any questions about the study or about being a participant and you may call one of the following if you have further questions: Barbara Neabel,

Appendix G con't

RN, at (XXX) XXX-XXXX; Dr. Hinds at XXX-XXXX Ext. XXXX; or Mrs. Matte, RN, at XXX-XXXX Ext. XXXX. You will receive a copy of this letter of information and the consent form.

Voluntary Participation

Your participation in this study is voluntary. You have the right to withdraw at any time. Your withdrawal will in no way affect the care of your family member and your relationship with the health care professionals involved in his/her care.

Confidentiality

The data from the study will be coded so it will not be linked to your name. Your identity will not be revealed, nor the information you provide communicated to anyone, although the general results of the study will be published. The data will be collected by Ms. Neabel, RN, and stored in a locked filing cabinet. Only the researcher and the Research Ethics Committee of the Civic Hospital will have access to the data.

Appendix G con't

Informed Consent

The purposes and procedures involved in this study on family needs have been explained to me by the investigator, Ms. Neabel, RN. I understand the purpose and procedures of this study. Any questions I have asked have been answered to my satisfaction. I am willing to participate in this study.

_____

Name of Participant (please print)

_____ _____

Date Signature of Participant

I have explained this study to the participant and to the best of my knowledge the participant understands the nature of the study and the risks and benefits involved in this study.

_____ _____

Date Signature of Investigator

Appendix H

Letter of Information for Nurses

TITLE OF THE PROJECT: A Comparison of Family Needs Perceived by Nurses and Family Members of Acutely Brain Injured Patients.

Purpose

You are invited to participate in a research project to study the family's and nurses' perceptions of family needs of acutely brain injured patients. This study is being conducted by Barbara Neabel, RN, a full time Master of Science in Nursing student from the University of Ottawa. The information that you provide, based on your nursing experience of caring for family members of brain injured patients, may help nurses to identify family needs and develop ways to meet those needs.

What is Involved

Your participation in the study would involve completing an anonymous questionnaire that is divided into two sections. The first section involves questions about yourself and your nursing experience. The second section involves a questionnaire on family needs. You are asked to select one of four responses for each need statement that ranges from not important (1) to very important (4). To complete the questionnaire will take approximately 30 minutes. You are asked not to discuss your responses with your co-workers. You can either return the questionnaire in the self-addressed envelope that is provided or you can leave the questionnaire in an envelope placed on the unit. The family members that participate in the study will complete a similar questionnaire on family needs and a demographic data sheet.

Risk and Benefits

There are no benefits or foreseeable risks involved by participating in the study. You are free to ask any questions about the study or about being a participant and you may call one of the following if you have further questions: Barbara Neabel, RN, at (XXX) XXX-XXXX; Dr. Hinds at XXX-XXXX Ext. XXXX; or Mrs. Matte, RN, at XXX-XXXX Ext. XXXX.

Appendix H con't

Voluntary Participation

Your participation in this study is voluntary. You have the right to withdraw at any time.

Confidentiality

The data from the study will be coded so it cannot be linked to your name. Your identity will not be revealed, nor the information you provide communicated to anyone, although the general results of the study will be published. The data will be collected by Ms. Neabel, RN, and stored in a locked filing cabinet. Only the researcher and the Research Ethics Committee of the Civic Hospital will have access to the data.

Informed Consent

The purposes and procedures involved in this study on family needs have been explained to me by the investigator, Ms. Neabel, RN. I understand the purpose and procedures of this study. Any questions I have asked have been answered to my satisfaction. I am willing to participate in this study. Your consent to participate in the study will be implied by completing the questionnaire.

CIVIC
OTTAWA

September 3, 1996

Barbara Neabel, RN, BSN, MScN student
University of Ottawa
Faculty of Health Sciences
School of Nursing
Ottawa, Ontario

Dear Ms Neabel

Re: A Comparison of Family Needs Perceived by Nurses and Family Members of Acutely Brain Injured Patients

I am pleased to inform you that your research proposal has been granted final approval by the Research Committee. This is a very interesting proposal and should improve our understanding of family support.

When you submit your proposal to the Hospital Research Ethics Committee, please note the following requirements:

1. Consent Form: Identify yourself as an RN. Add Dr. Cora Hinds and Hazel Matte's names as contacts. Remove the term "interview" since you are not doing an interview. There are two typos; "The nurses who participate..." The Research Ethics....

2. Sample size; The discussion regarding effect size requires more clarity.

3. Sample selection; Clarify how you will chose the one family member to participate, eg. There could be a father and a mother of an adult child - neither is caregiver.

4. Procedure; You cannot take information off a chart or ask nurses to do so for patients who have refused consent. For those who consent to participate in the study, it must be made clear that you want access to that information.

5. Appendix G. Time involved should be changed to 30-45 minutes. Add RN after your name.

6. Spelling. Table 7 pg 71. Intra-familial

.../2

You may find your study will be strengthened by considering the following comments and suggestions of the reviewers:

1. Consider the literature base on family and professional caregivers perception of quality care. ie. Meeting the needs of patients and families.

2. Reviewers expressed concern that you have not set a sufficiently long time frame for data collection.

3. You should consider building in more explicit follow up for staff in order to achieve your required response rate.

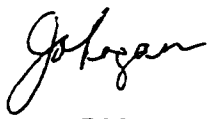
Research assistants who are engaging in nursing activities as part of the protocol must hold current certificates of registration and present them annually to the Department of Clinical Services Research & Professional Development. They must perform all nursing activities according to the Nursing policies and procedures of the Division of Patient Services and sign a statement of confidentiality (available from OCH Human Resources).

Divisional nursing policy requires investigators to complete appropriate research progress reports and submit a report of findings upon completion of the project to the Department of Clinical Services Research and Professional Development. If requested, you are expected to provide further feedback to nursing staff who have participated in the research.

Please send your proposal and appropriate application forms to the hospital Research Ethics Committee for review. For information about applying to this committee, call 761-4395. Please **do not begin your study** until you have received final approval from the Research Ethics Committee.

Best wishes for successful completion of the study. If you have any further questions or require any other assistance, do not hesitate to call.

Sincerely



Jo Logan, RN, PhD
Director - Clinical Services
Research & Professional Development

Loeb Research Institute
Ottawa Civic Hospital
1053 Carling Avenue
Ottawa, Ontario
K1Y 4E9

October 10, 1996

Ms. Barbara Neabel
2470 Southvale Crescent
Apt. 911
Ottawa, Ontario
K1B 4L9

Dear Ms. Neabel:

RE: Protocol # : 1996221-01H **A Comparison of Family Needs Perceived by Nurses and Family Members of Acutely Brain Injured Patients**

Protocol approval valid until: October 10, 1997

Thank you for your letter of October 4, 1996 with the additional information requested, a revised advertisement, and the revised consent forms. These changes have been reviewed, and the study is now approved. No changes, amendments or addenda may be made in the protocol or the consent form without the Research Ethics Committee review and approval.

The validation date should be indicated on the bottom of all consent forms and information sheets (see copy attached). Approximately one month prior to that time, a single renewal form should be sent to Research Services.

Medical Research Council guidelines require a greater involvement of the Research Ethics Committee in studies over the course of their execution. You must maintain as part of your records copies of the signed consent form. As well, you must inform the Committee of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the Committee review, either of which may impinge on the ethics of continuing the study. The REC will review the new information to determine if the protocol should be modified, discontinued, or should continue as originally approved.

Yours sincerely,

Raphael Saginur, M.D.
Chairman
Research Ethics Committee

Conseil d'éthique en recherches
737-8930

Research Ethics Board
APPROVAL 1996

HÔPITAL GÉNÉRAL D'OTTAWA OTTAWA GENERAL HOSPITAL

September 19, 1996

Ms. Barb Neabel
University of Ottawa
Department of Nursing

Dear Ms. Neabel:

RE: OGH-96-70 A Comparison of Family Needs Perceived by Nurses and Family Members of Acutely Brain Injured Patients

The Research Ethics Board has reviewed your response to a letter of concerns that you submitted on the above protocol.

I am pleased to inform you that the REB finds these revisions and the revised Patient Information Sheets dated September 19, 1996 to be acceptable with respect to the ethics of research with human subjects and has therefore approved this protocol from **September 1996 to September 1997**.

The new guidelines of the Medical Research Council require a greater involvement of the REB in studies over the course of their execution. You must maintain, as part of your records, copies of the signed consent form. As well, you must inform the REB of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the REB review, either of which may impinge on the ethics of continuing the study. The REB will review the new information to determine if the protocol would be modified, discontinued, or should continue as originally approved.

Yours sincerely,

Mike Tierney, M.Sc.
Acting Chairman
Research Ethics Board

MT/ram

HÔPITAL GÉNÉRAL D'OTTAWA OTTAWA GENERAL HOSPITAL

June 17, 1997

Barbara Neabel
MScN Candidate
University of Ottawa

Dear Barbara:

The Nursing Research Committee and the Nursing Department are pleased to inform you that we strongly endorse your research proposal, examining the learning needs of family members of patients with acute brain injuries. We wish you good luck with your thesis.

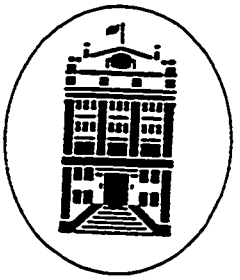
Sincerely,

Sue Malone-Tucker
Co-Chair
Nursing Research Committee

Wendy Fortier
Nursing Director
Critical and Ambulatory Care

Appendix J

Letters of Support from the Nursing Managers



Ottawa Civic Hospital

1053 Carling Ave.,
Ottawa. Ontario
Canada K1Y 4E9
(613) 761-4000

August 7, 1996

Dr. R. Saginur
Chairperson
Research Ethics Committee
Ottawa Civic Hospital

Dear Dr. Saginur:

Please accept this letter in support of the proposed nursing research project, "A Comparison of Family Needs Perceived by Nurses and Family Members of Acutely Brain Injured Patients", to be conducted by Barbara Neabel, R.N., B.S.N., M.Sc.N. Student, University of Ottawa.

I support the research proposal and the participation of nursing staff, patients and families on F7. I do not feel this proposal would impinge of nursing time related to nursing care as staff participation is voluntary. I am willing to screen families for inclusion in the study, to support the process.

Please contact me if I can be of further assistance.

Yours truly,

Hazel Matte
Clinical Services Manager
Neurosciences, F7
Ottawa Civic Hospital

Appendix J con't

HÔPITAL GÉNÉRAL D'OTTAWA OTTAWA GENERAL HOSPITAL

July 4, 1996

Mr. Mike Tierney
Acting Chairman
Research Ethics Board
Ottawa General Hospital
Suite O-24, Second Floor

Dear Mike:

I have met with Barbara Neabel to review her thesis proposal, "A Comparison of Family Needs Perceived by Nurses and Family Members of Acutely Brain Injured Patients". I would like to support her efforts in this endeavour and feel that there will be very little impact on the nursing staff in Neuro Obs or on 6 North West.

I am prepared, along with the Team Leaders in the units involved to assist with identifying potential patients and families for Barbara's study.

Thank you very much for your consideration and interest.

Sincerely,

Maureen Taylor-Greenly

Maureen Taylor-Greenly
Nursing Unit Manager, Neurosciences

Appendix K

A Comparison of the Rank Ordering of Family Needs Between Family Members and Registered Nurses

	Family Members			Registered Nurses		
Need Statements	n	Ranking	M (SD)	n	Ranking	M (SD)
To know the expected outcome	21	1	4.00 (.00)	22	3	3.73 (.46)
To feel there is hope	22	2	3.95 (.21)	22	11	3.50 (.60)
To know specific facts concerning the patient's progress	22	3	3.91 (.29)	22	9	3.50 (.51)
To receive information about the various stages of recovery	22	4	3.91 (.29)	22	16	3.27 (.70)
To receive information about rehabilitation options	21	5	3.90 (.30)	22	23	3.14 (.77)
To see the patient frequently	22	6	3.86 (.35)	22	12	3.41 (.59)
To feel that the hospital personnel care about the patient	22	7	3.86 (.35)	22	6	3.59 (.59)
To be called at home about changes in the patient's condition	22	8	3.86 (.64)	22	4	3.68 (.57)
To be assured that the best care possible is being given to the patient	22	9	3.86 (.47)	22	2	3.77 (.43)
To have questions answered honestly	21	10	3.86 (.36)	21	1	3.86 (.36)
To have explanations given that are understandable	22	11	3.82 (.39)	22	5	3.64 (.49)
To know exactly what is being done for the patient	22	12	3.82 (.39)	22	10	3.50 (.51)
To know how the patient is being treated medically	22	13	3.82 (.39)	21	7	3.52 (.51)

Appendix K con't

Need Statements	Family Members			Registered Nurses		
	n	Ranking	M (SD)	n	Ranking	M (SD)
To receive information about the patient at least once a day	22	14	3.82 (.39)	22	13	3.41 (.59)
To receive information on long-term care options if rehabilitation is not possible	21	15	3.81 (.68)	21	21	3.14 (.85)
To be told about transfer plans while they are being made	20	16	3.80 (.41)	22	20	3.18 (.85)
To know why things were done for the patient	22	17	3.73 (.46)	22	8	3.50 (.51)
To know about the types of staff members taking care of the patient	21	18	3.62 (.59)	22	19	3.23 (.61)
To be able to visit the rehabilitation or long-term care institution before the patient is transferred	21	19	3.62 (.59)	21	28	2.95 (.92)
To know which staff members could give what type of information	22	20	3.59 (.50)	22	14	3.32 (.65)
To feel accepted by the hospital staff	22	21	3.55 (.60)	22	30	2.82 (.73)
To visit at any time	21	22	3.52 (.75)	21	37	2.48 (.81)
To help with the patient's physical care	22	23	3.36 (.95)	21	31	2.81 (.60)
To have friends nearby for support	22	24	3.27 (.88)	22	15	3.27 (.63)
To talk about the possibility of the patient's death	20	25	3.20 (1.06)	21	29	2.90 (.94)

Appendix K con't

Need Statements	Family Members			Registered Nurses		
	n	Ranking	M (SD)	n	Ranking	M (SD)
To have a specific person to call at the hospital when unable to visit	20	26	3.10 (1.07)	21	33	2.81 (.81)
To talk about feelings about what has happened	21	27	3.10 (1.18)	21	17	3.24 (.62)
To have good food available in the hospital	21	28	3.10 (1.09)	22	40	2.41 (1.05)
To be told about other people that could help with problems	22	29	3.09 (.92)	22	22	3.14 (.64)
To have a telephone near the waiting room	22	30	3.00 (.98)	21	41	2.33 (.73)
To have directions as to what to do at the bedside	22	31	3.00 (1.11)	22	27	3.00 (.76)
To be assured it is all right to leave the hospital for awhile	22	32	2.95 (1.17)	22	18	3.23 (.81)
To have a pastor visit	22	33	2.95 (1.21)	21	43	2.24 (.83)
To have explanations of the environment before going into the neuroscience unit for the first time	19	34	2.95 (.97)	21	25	3.00 (.71)
To talk to the doctor every day	22	35	2.73 (1.16)	21	24	3.00 (.89)
To have a place to be alone while in the hospital	22	36	2.73 (1.03)	22	42	2.32 (.78)
To have comfortable furniture in the waiting room	22	37	2.64 (1.00)	20	49	1.90 (.79)
To talk to the same nurse every day	21	38	2.62 (1.16)	22	38	2.45 (.67)
To have someone to help with financial problems	20	39	2.60 (1.35)	21	36	2.48 (.87)

Appendix K con't

	Family Members			Registered Nurses		
Need Statements	n	Ranking	M (SD)	n	Ranking	M (SD)
To have a bathroom near the waiting room	22	40	2.59 (1.10)	22	48	2.09 (.53)
To be told about chaplain services	22	41	2.50 (1.26)	22	44	2.23 (.81)
To be told about someone to help with family problems	20	42	2.50 (1.19)	21	32	2.81 (.87)
To feel it is all right to cry	22	43	2.50 (1.26)	22	26	3.00 (.76)
To have someone be concerned with your health	22	44	2.45 (1.14)	20	34	2.65 (.67)
To have visiting hours start on time	21	45	2.43 (1.33)	22	35	2.64 (.79)
To have the waiting room near the patient	20	46	2.40 (1.31)	20	45	2.20 (.83)
To have visiting hours changed for special conditions	20	47	2.40 (1.35)	21	39	2.43 (.98)
To be alone at any time	22	48	2.23 (1.11)	21	46	2.19 (.75)
To have another person with you when visiting the neuroscience unit	22	49	1.95 (1.17)	20	47	2.15 (.88)

Appendix L

A Correlation of Family Needs Between Family Members and Nurses

Paired Sample Number	n	r	z_r	95 % CI on r
1	42	- .06	- .06	-.355 to .250*
2	46	.33	.343	.045 to .565
3	45	.14	.141	-.15 to .415*
4	46	.30	.310	.010 to .545
5	47	.42	.448	.150 to .630
6	47	.25	.255	-.040 to .50*
7	49	.54	.604	.305 to .71
8	36	.33	.343	.00 to .595
9	48	.36	.377	.085 to .585
10	48	.12	.121	-.170 to .390*
11	49	.30	.310	.020 to .535
12	49	.33	.343	.055 to .560
13	48	.26	.266	-.025 to .505*
14	49	.29	.299	.010 to .530
15	49	.48	.523	.230 to .670
16	49	.51	.563	.265 to .690
17	49	.41	.436	.145 to .620
18	46	.63	.741	.415 to .775
19	42	.32	.332	.020 to .570
20	45	.62	.725	.40 to .775
21	49	.41	.436	.145 to .62
22	48	.21	.213	-.08 to .465*

Note.

r = Pearson Product-Moment Correlation Coefficient

z_r = transformation of r using Fisher's z values

n = number of valid need statements for the paired participants

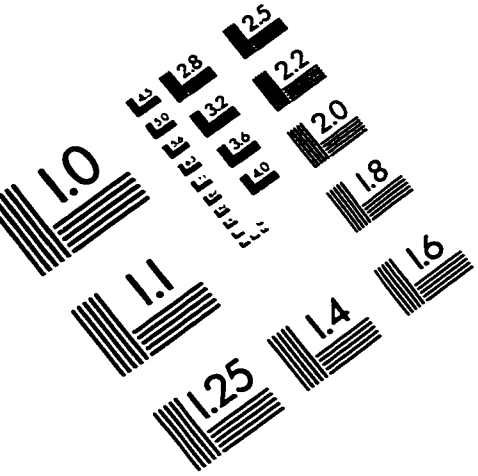
* These results are not significant.

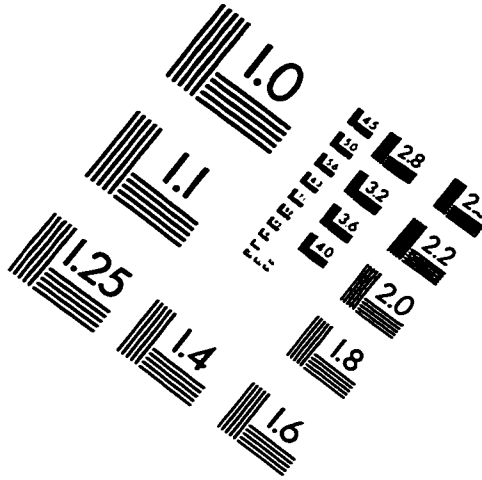
Appendix M

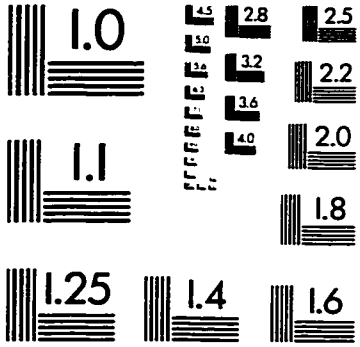
Need Statements that Represent a Moderate to High Discrepancy Between Nurses' and Family Members' Mean Value

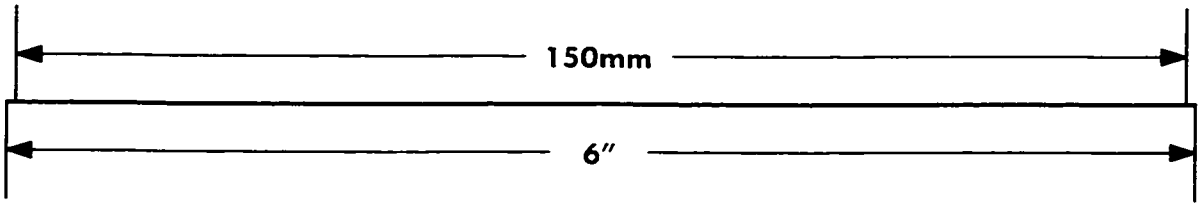
Need Statements	Nurses' Mean Value	Family Members' Mean Value	Difference	Difference Squared
To have good food available in the hospital	2.41	3.10	-.69	.48
To visit at any time	2.48	3.52	-1.04	1.08
To feel there is hope	3.50	3.95	-.45	.20
To know about the types of staff members taking care of the patient	3.23	3.62	-.39	.15
To have a place to be alone while in the hospital	2.32	2.73	-.41	.17
To have comfortable furniture in the waiting room	1.90	2.64	-.74	.55
To feel accepted by hospital staff	2.82	3.55	-.73	.53
To have a telephone near the waiting room	2.33	3.00	-.67	.45
To have a pastor visit	2.24	2.95	-.71	.50
To feel it is all right to cry	3.00	2.50	.50	.25
To have a bathroom near the waiting room	2.09	2.59	-.50	.25
To help with the patient's physical care	2.81	3.36	-.55	.30
To be told about transfer plans while they are being made	3.18	3.80	-.62	.38
To receive information about the patient at least once a day	3.41	3.82	-.41	.17
To know specific facts concerning the patient's progress	3.50	3.91	-.41	.17
To see the patient frequently	3.41	3.86	-.45	.20
To receive information on long-term care options if rehabilitation is not possible	3.14	3.81	-.67	.45
To receive information about the various stages of recovery	3.27	3.91	-.64	.41
To be able to visit the rehabilitation or long-term care institution before the patient is transferred	2.95	3.62	-.67	.45
To receive information about rehabilitation options	3.14	3.90	-.76	.58

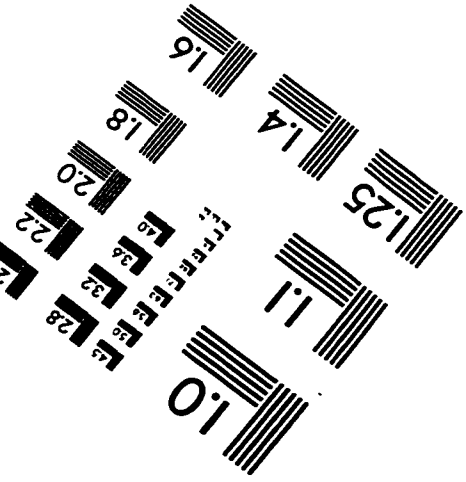
IMAGE EVALUATION
TEST TARGET (QA-3)

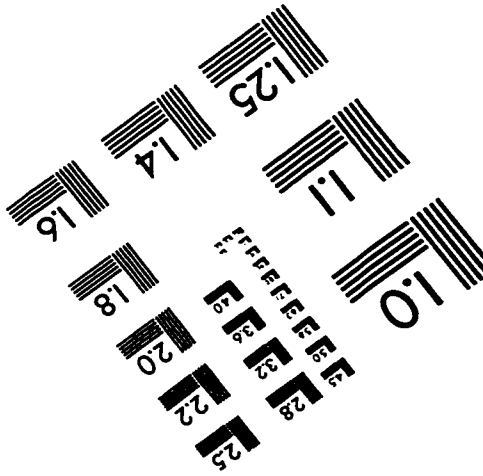












APPLIED IMAGE, Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989