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Needs of Families of Severe Traumatic Brain Injured Individuals During the Critical Care Experience

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NEEDS OF FAMILIES OF SEVERE TRAUMATIC BRAIN INJURED INDIVIDUALS
DURING THE CRITICAL CARE EXPERIENCE

By

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ABSTRACT
NEEDS OF FAMILIES
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BRAIN INJURED INDIVIDUALS DURING THE CRITICAL CARE EXPERIENCE

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Traumatic brain injury occurs without warning, disrupts the life of the individual and family, causing stress. The purpose of this descriptive study was three part: to identify the needs of families of severe traumatic brain injured (TBI) individuals during the critical care experience, to identify who met those needs, and to obtain qualitative data regarding nursing care. Family Systems Theory provided the theoretical framework to support this study.

A convenience sample from a large Midwestern teaching institution consisted of 28 family members of severe TBI individuals. The sample received by mail a demographic profile, a questionnaire (Critical Care Family Needs Inventory), and an additional qualitative section regarding nursing care and overall experience.

The research questions were answered by descriptive analysis. The top ten needs were consistent with previous family needs studies. Themes emerged from the qualitative data revealing insight into the overall system, physicians, communication, and nursing.

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Introduction

Chapter 1

Traumatic brain injury (TBI) is a major health concern. Statistics reveal that every fifteen seconds someone sustains a TBI in the United States, and every five minutes one of those individuals will die and another become permanently disabled (National Head Injury Foundation (NHIF), 1990). A survivor of a TBI can expect to face 5-10 years of intensive services with an estimated lifetime financial cost in excess of 4 million dollars related to lifelong debilitating loss of function (NHIF, 1995).

Traumatic brain injury occurs without warning and instantly disrupts the life of the individual and the family system. This event causes stress for the family and can lead to crisis. From the initial phone call announcing an injury, to a family member at the hospital the intensity of feelings increases. Feelings can range from frustration to helplessness throughout the course of the injury. Families are often shocked to find the person they knew as healthy, hours before, is now unresponsive, corpse-like, and often in a critical care setting (Mass-Chum & Ryan, 1981). Meeting the needs of the TBI adult is challenging and consumes a great deal of the health care professionals time. Meeting the needs of the families becomes an even greater challenge, as they have now become silent victims.

TBI is the result of a rapid acceleration and deceleration of the head during which time the brain is whipped back and forth, bouncing off the inside of the skull. This may leave a visible injury to the outside of the head as well as cause the brain to swell, bleed or both resulting in temporary or permanent brain damage.

Motor vehicle accidents cause 50% of all TBI with falls accounting for 21%, assaults and violence 12%, and sports and recreation 10% (NHIF, 1995).

The residual effects of TBI can be lifelong and devastating to the victim as well as the family. "The Silent Epidemic" is a phrase frequently used to describe the sequelae of TBI (NHIF, 1995). Symptoms can include physical, cognitive, and psychological-social-behavioral-emotional impairments.

Families of TBI individuals experience multiple needs during the critical care period (Engli and Kirsivali-Farmer, 1993). These needs contribute to further stress. More often than not, health care professionals direct their energies toward the needs of the victim. Although, the intention to give support to the family is ever present, the reality is that the needs of family are often placed second to the victims needs. Unmet needs may affect the families ability to cope with the critical care period (Koller, 1991). The family that is unable to cope with the event may experience a crisis. This can affect how the family interacts with and feels about the health care providers.

Nurses play a key role in assessing, and intervening with families during the critical care period. Identifying the needs of families of severe TBI individuals and knowing if those needs had been met and by whom will allow the critical care nurse to individualize the nursing interventions that will be of value and use for each individual family. Therefore, the purpose of this study is to identify the needs of families of severe TBI adults when faced with stress during the critical care experience.

Literature and Conceptual Framework

Chapter 2

Conceptual Framework

Sudden and unexpected hospitalization can cause stress in the most stable families. Patient needs are a priority for nurses, but family needs must also be recognized. If family needs related to the event are not met, unnecessary stress can occur within the family system (Hill, 1963).

Family Systems Theory

Family systems theory provides a foundation for understanding the family as an interactional unit (Koller, 1991). It is a dynamic and ongoing system. The system maintains itself around some form of equilibrium that has been established by the family over time. Equilibrium is maintained through the use of various resources and coping strategies when the family has encountered stressful events. As stressful events are received into the family system the equilibrium is disrupted. All families experience stressful events, and all have varying resources to cope with stress.

A family system is composed of many subsystems such as parent-child, marital, and sibling subsystems (Leahy & Wright, 1984). These subsystems are composed of individuals that are made up of complex physical and psychological subsystems. The family does not live in isolation, but is part of larger suprasystems that consist

of neighborhoods, organizations, and communities. (Leahy & Wright, 1984).

Family systems are not concrete. They can be defined by their boundaries, those imaginary lines that establish the limits of how far a family system can be taxed or stressed. The boundaries are both open and closed. The degree to which a family system is open, that is, influenced by outside systems will determine its self identity and integrity. A family system that is more open may be too susceptible to outside influences and therefore not strong enough to rely on its own resources.

However, a family system that is too closed may not allow itself to accept outside influences in the form of support. Boundaries are influenced by many factors including the environment, past experiences, communication, values, and the hierarchy of its members (Leahy & Wright, 1984).

The whole of the family is more than the sum of the individual family members. The whole represents and highlights the individuals who make up the family system and how they interact amongst each other as well as with the outside systems. The family as a whole is greater than the sum of its parts (Leahy & Wright, 1984). Nurses need to understand that meeting with whole families will allow for communication and observation of family members interactions that will be beneficial to the structure of care for the patients and the family members.

Boundaries will exist within family systems as well as between individual family members. When change occurs, such as a traumatic event, it will affect the family as well as its individual members. A change in one family member affects all family members to varying degrees. Each family member has different roles and functions.

Each family will be unique in its organization of those roles. For example, the traditional family, as labeled by our society, consists of a mother, father, and children. The father and mother share in the responsibilities of household management with duties assumed by each. This would include financial support and budgeting, child rearing, and daily household tasks. Disrupt this structure with a traumatic event involving either partner and stress affects all members of the family. What was perceived as comfortable and normal, may have become awkward and tense. Roles and routines have been disrupted for all family members.

A commonly encountered victim of TBI is the young single male. His family structure may include a mother, father, stepparents, stepsiblings, girlfriend and offspring of his own. This traumatic event may compound the already present family stresses and leaves family members on an emotional edge. Often times it is the traumatic event that triggers family members to lash out emotionally and place blame for the event on each other. Nurses are commonly in the position of counselor and mediator assisting the family in dealing with these many stressors.

The degree to which individuals react to the trauma and related stressors will depend upon the strength of their surrounding boundaries. It is important for the nurse to understand this phenomenon when intervening with a family system. If one family member is responding to change, other family members will be unable to respond as in the normal fashion since one member is now behaving differently (Leahy & Wright, 1984).

Family systems are in a constant state of change. Each family has, at certain stages of its development, boundaries that enable it to deal with life's usual stressors and changes. Boundaries enable the family to maintain a sense of stability. Sudden events such as TBI can alter the boundaries of a family or individual members. Needs may be difficult to identify by the family members. The nurse may be able to assist with meeting their needs to enable them to return to a stable state of change.

The final concept of family systems is that of understanding family members' behaviors from circular rather than linear causality. Linear causality is defined as one event causing another. It is heavily rooted in a framework of continuous progression of time (Leahy & Wright, 1984). For example, when the clock strikes 6:00 p.m. the family eats dinner. Event A (time) is seen as the cause of event B (dinner). Circular causality is dependent upon reciprocal relationships based upon the meaning of the relationship. For example, if a spouse takes an interest in her husband's cognitive rehabilitation sessions (event A) and the husband responds by demonstrating correct behavior while in her presence (event B), then it is likely to result in the wife continuing to take an interest and show support and her husband to continue to feel successful and willing to work harder at recovery (A causes B causes A again).

Individual family members construct their own reality of a situation based on personal beliefs and perceptions. It is easy for members to blame others, or see

traumatic events in a narrow (linear) perspective. Families and individual members may need assistance from external resources to move from a linear to a circular perspective. A circular perspective offers opportunity to explore relationships and allow implicit information to become explicit. According to Leahy and Wright (1984), one of the most common traps for nurses is accepting one family member's perception as the "truth" or to decide who is "right". Therapeutic communication between the nurse and the family and the individual family members will facilitate the movement to a circular perspective. This will assist the family in understanding the event and working through the stressors together for the sake of their loved one.

Summary

The family is a group of interacting personalities, intricately organized internally into positions, roles, and norms (Hill, 1963). When viewed externally it can be seen as an organized group engaged in transactions. In a society of rapid change, the family experiences daily stressors through these transactions. The family relies upon available resources to assist in daily management of these stressors. Some families are stressed beyond their boundaries of equilibrium and experience unmanageable stress. Traumatic brain injury is an example of a stressor that can propel a family to this level (Acorn & Roberts, 1992; Martin, 1994; Stavros, 1987; and Zeigler, 1987).

Literature Review

Family Needs

Many studies have been conducted regarding needs of families during the critical care event. A pioneer of this type of needs research is Nancy Molter. In 1979, Molter conducted a study to assess the needs of relatives of critically ill patients using an exploratory, descriptive design to interview 40 relatives of patients in critical care units. Patients had to have spent at least 72 hours in the critical care unit and had to be out of the Critical Care Unit and on a General Ward area for less than 48 hours. A convenience sample was used including subjects at least 18 years of age, who the investigator made contact with during visitation times. No data are available regarding the number of patients and their diagnoses for this study.

A structured interview technique was used. A list of 45 needs statements was developed by the investigator through review of the literature and a survey of 23 graduate students of nursing (Molter, 1979). One family member was chosen to identify family needs. The needs statements were read to the subjects and they were asked to respond to each need statement by rating its importance on a likert-type scale of (1) representing not important at all to (4) representing very important. Subjects were asked to identify who met each need, if indeed they were met. Molter (1979) found that hope was the primary need expressed of families.

Most of the identified needs were met more than fifty percent of the time. Nurses were the individuals who most often met these needs. At the conclusion of the interview Molter asked the subjects to identify any additional needs that were not addressed in the 45 statements. No new needs were identified.

The primary limitation of Molter's study is that only one individual family member represented the needs of the entire family. Another limitation is the use of the structured interview technique. The potential for interviewer bias is high with such technique. However, Molter felt this technique allowed for clarification and discussion of the need statements within a limited time span.

Rodgers (1983) was the first to replicate Molter's (1979) study. Rodgers intent was to describe the needs of relatives of cardiac surgery patients during the critical postoperative period. Three questions were addressed: what were the needs of relatives of cardiac surgery patients while the patient is in the Intensive Care Unit, what was the incidence of needs satisfaction, and who assisted in the fulfillment of the identified needs for these relatives? This descriptive study was conducted in a 450-bed metropolitan teaching hospital in the Northeast. A questionnaire was developed based upon Molter's interview questions. Content validity was established for the tool through review of the literature and by agreement of a panel of experts who had experience in interactions with relatives of cardiac surgery patients. Data were collected by one investigator, at least 24 hours from the time of surgery but not greater than 48 hours after transfer to the general surgical ward. The reliability was 0.93. Questionnaires were distributed in

the waiting room solarium to those who met the entrance criteria.

The sample consisted of 20 relatives of 11 cardiac patients. Ten subjects were spouses which made up 50% of the sample, and 35% were children of the patient. Subjects ranged in age from 20-81 and 75% of the total were women. Ninety percent of the questionnaires were administered on postoperative day 1 or 2.

Results of the study were consistent with Molter's 1979 study. The one need identified by all relatives as very important was to have the assurance of being called at home if there was a change in the patient's condition. The least important concern was to discuss financial matters with someone. Relatives were asked to identify the level of satisfaction of each need as having been met on the second part of the questionnaire. Forty of the 45 needs listed were identified as having been met by at least 60% of the relatives who perceived them as importance or very important. Seven of the 10 most important responses were fulfilled for all participants. The third part of the study dealt with the identification of persons contributing to the fulfillment of the relatives' needs. The majority of needs were met by nurses in 22 of the 34 items. More nurses than physicians were identified in fulfilling the top 10 needs except for the need for hope, which was satisfied by persons from all resource categories. Other relatives were also identified as a major resource for fulfilling needs. This was consistent with Molter's study.

One limitation of this study was the small sample size. Further research on larger sample sizes and sites would be necessary to generalize the findings. Another limitation was that the researcher sought out the opinion of the primary

and/or associate nurse caring for the patient as a prerequisite to the investigator approaching the family for the study. No rationale is given as to the content of discussion between the investigator and the nurse(s), but it could be inferred to have a selective or biased influence on choosing families for the study. A final limitation is the families were given the questionnaires to complete in the waiting rooms or the solarium. Outside influences could be significant if the questionnaire was not completed by one person, or the environmental stimuli was not conducive for filling out a questionnaire.

Daley (1984) assessed the perceived greatest needs of family members during the first 72-hour period of critical care or within the initial crisis period and determine whom the family perceived as the person to meet those needs. A research instrument that consisted of 46 need statements was developed based on Molter's (1979), other researchers, as well as Daley's personal experiences. The 46 need statements were subdivided into six major categories of need: a) personal b) decreased anxiety c) support and ventilation d) information e) to be with the patient and f) the need to be helpful. The needs statements were either read to the subjects by the researcher, or read by the subjects. Each response was recorded on a likert type scale. The subjects were then asked to select the person they perceived as being the most likely to meet the stated need (doctor, nurse, minister, family member, self, or other). Validity for the statements were established by faculty members of a graduate nursing program who had expert knowledge in this area. The instrument was pretested and revisions made. The sample consisted of

10 men and 30 women ages 18-65. Primarily the relationship to the patient was adult children (35%) and spouses (35%). The results of the study were categorized according to the needs groups and rank ordering by means scale was established. The need category of highest significance was that of anxiety relief in which all needs scored 3.225 or higher on a 4 point likert scale. Needs such as: to know what may be expected, to be called at home, to know if the nurses are giving the best care possible, and to be told there is hope, are similar to the findings of Molter and Rodgers (1983). Family members care least about being alone, having friends and children nearby, or having personal needs such as food or coffee available. These are consistent with the studies of Molter and Rodgers. The physician and the nurse were perceived most often as the two persons most likely to meet the needs of the family members in all three studies cited.

Limitations of this study were small sample size and method of data collection. Differences were cited in the rank ordering of needs between Molter's study (1979) and Daley's study (1984). This could have been due to the time frame of contact. Daley cited that families interviewed within 24 hours of admission had a difficult time with following direction and often omitted answering sections of the questionnaire. Daley offered the subjects two choices to respond to the study. The subjects could either read the answers independently or have the answers read to them by the researcher. This inconsistency may have had an influence in the results. Multiple family members were utilized for each patient and it is not stated how many family members per patient participated. Based on available data it would

average 1.4 family members per patient resulting in 40 subjects. The study may be biased if numerous family members participated for one patient and only 1-2 for another.

Leske (1986) wanted to identify the needs of family members of critically ill adults. In collaboration with Molter a revised tool was developed from Molter's Needs Assessment tool and was renamed the Critical Care Family Needs Inventory (CCFNI). Leske used a survey design to interview 20 male and 35 female adult family members of 20 critically ill patients in three Midwestern metropolitan hospitals. Subjects were approached within 72 hours of a patient's admission and limited to those the researcher made contact with and who fit the criteria for admission into the study.

The tool was revised by changing the order of the needs statements by using a table of random numbers. An additional open-ended item was added to identify any new needs not previously reported. A 4 point likert scale was used. Reliability was estimated using Cronbach's alpha at 0.98 which supports internal consistency. Content validity was supported through no new needs identified by relatives in either Leske's (1986) or Molter's (1979) studies. Leske approached families as a group interview and each question was read to the family and consensus was reached for an answer. This differed from the previous three studies cited. Leske's results were strikingly similar to the studies by Molter, Rodgers (1983), and Daley (1984). The need for hope was identified as number one in both Leske's and Molter's studies but remained in the top 10 ranking of importance in

studies by Rodgers and Daley.

A limitation of Leske's study (1986) was the interview technique. The consensus method may have altered the results in that not all group members may have been comfortable with the answers or felt influenced in agreeing to the group answer. Another limitation was the small sample size. Item analysis needs to be done to determine the structure of the CCFNI. Inter-item correlation should determine whether the high alpha is due to the consistency of responses or the repetition of items.

In 1991, Price, Forrester, Murphy, and Monaghan studied the needs of families using the CCFNI with the largest sample size documented to date. This descriptive study reported the needs of 213 family members of 114 critically ill adults in a large, urban, public teaching hospital in Northeastern United States. Interviews with qualified subjects took place between 24 and 72 hours after admission to the critical care unit. The top 10 needs cited were consistent with prior studies. The one striking difference was the ranking of the need to feel there was hope. In all studies cited thus far, this need ranked in the top ten, and in 3 of 4 studies it ranked in the top five. However, in this study the need to feel there was hope was ranked 11th. Price et al. estimate the reason for this ranking difference was related to the clinical setting from which the sample was obtained. Patients in this particular study were desperately ill and had been the objects of significant surgical manipulation. The nature of the units, the clinical problems of the patients, the

relative seriousness of the prognoses, and the perceived meanings of the typical health crises were all variables that may help explain why the maintenance of hope was not identified as higher in the rankings. The rankings of the least important needs were consistent with all studies cited thus far.

The second largest descriptive study to utilize the revised CCFNI was conducted by Warren (1993). This descriptive, exploratory study assessed the needs of 94 family members of critically ill adults during the first 18-24 hours after admission to the intensive care unit and the order to which those needs were met 36-48 hours after admission of the patient. Warren added two additional instruments, the Demographic Data Questionnaire and the Needs Met Inventory (NMI). Subscales were used to divide the needs statements for further analysis: Support, Comfort, Assurance, Information, and Proximity. Seven questions listed under assurance all ranked very important/important. Having questions answered honestly and being assured that the best possible care is being given to the patient scored the highest under "usually/always met". The idea that assurance needs are the most important to the family of a critical care patient is supported by previous works (Daley, 1984; Leske, 1986; Molter, 1979; Mendonca and Warren, 1998; Rodgers, 1983; and Price et. al., 1991).

O'Neill - Norris, and Grove (1986) expanded the use of Molter's (1979) tool by assessing the needs of critical care families and the perceived needs of families as identified by critical care nurses. A comparison of the families needs to those

perceived by the nurses was also discussed. The research conducted was a descriptive survey at a major medical center in Northeast Texas. A pilot study was conducted to determine if Molter's 45 need statements reflected the psychosocial needs of family members of critically ill adults as perceived by both intensive care nurses and family members. The needs statements were given to a convenience sample of five graduate nursing students currently employed in intensive care units and five family members of critically ill adults. A Q sort methodology was used by the subjects to sort the needs. Analyzing the Q sort data was done by generating median scores therefore content validity was established. With a possible score of 5, the range of median scores for the 45-item questionnaire was 5.00 to 1.33 for the nurses, and 4.67 to 1.33 for the family members. Based on the results, the 45 needs statements were reduced to 30 using the median cutoff score of 2.30. Twenty eight items were retained as written, and two were revised. The 30 needs statements were then randomly arranged into questionnaire form.

The convenience sample of 20 nurses and 20 family members participated in the study. Six intensive care units were used and only one family member per patient was used to represent the family. The family member was contacted by one investigator during an intensive care visit at least 48 hours after the patient had been admitted to an intensive care unit. The nurses were approached individually or as a group at the end of a shift by the investigator. All subjects were given verbal and written instructions prior to completing the questionnaire.

The findings on families perceptions of their needs were similar to those of the six previous studies. O'Neill-Norris and Grove (1986) found the four most important needs identified by family members had a mean value of 4.00. The need for hope was identified as number one. The nurses perceptions of the families needs matched three of the four top needs identified by the families, but differences existed between the groups in the two needs of hope and feeling the patient was receiving the best possible care. Nurses ranked these needs lower in importance than the families. The limitations of this study are similar to those cited previously, the descriptive design, and the limited generalization beyond the sample and the geographic area studied. Needs are subjective, and limiting the family representation to one member per study could bias the data.

Four additional studies have been reported that compared the needs and/or satisfaction levels of families of critically ill adults to those perceived by the nurses in the critical care units (Forrester, Murphy, Price, and Monaghan, 1990; Kleinpell and Powers, 1992; Lynn-McHale and Bellinger, 1988; and Murphy, Forrester, Price, and Monaghan, 1992). Although two report moderate accuracy of the nurses ability to identify the needs of the families (Lynn-McHale, and Bellinger, 1988; and Forrester et al., 1990) all report significant differences in many of the perceived needs of the family as compared to the nurse. Needs identified by family as not satisfactorily being met included psychological support systems, institutional support services, and the environment. Nurses consistently perceived these areas

of need as being satisfactorily met for the family. These studies continue to support the need for further identification of family needs through accurate ongoing assessment by the critical care nurse.

Most of the literature reviewed has assessed the needs of the general critical care family. Limited research has been conducted identifying the needs of families of critically ill brain injured patients. Mauss-Clum and Ryan (1981) conducted a pilot study of family members of veterans participating in an outpatient Brain Injury Rehabilitation Unit. Patients in the study were all men and had suffered brain injury as a result of trauma, vascular insult, or disease. All had experienced critical care hospitalization related to the brain injury. Forty questionnaires were distributed with a response rate of 80%. All responders were female (19 wives and 11 mothers). Needs identified by families during the critical care experience were provision of a kind and clear explanation, a discussion of realistic expectations, emotional support, financial counseling, and resource counseling. Family members were also asked who was most helpful in providing emotional support during the critical care stay. Half of the family identified a relative or friend, while only 17% chose the nurse. Despite the limitations of this study, this was the first documented attempt to identify the needs of the families of neurologically impaired patients.

Molter (1979) stated that certain family members were not included in her study because the patient was in a special care unit and it was thought that these

family members would have special needs. Mathis (1984) therefore was the first to research the differences of needs of families with and without brain injury. Utilizing Molter's tool, Mathis conducted a comparative descriptive, structured interview study. The sample consisted of 26 family members (15 without brain injury relative, 11 with brain injury relative). One family member per patient was asked to participate. Inclusion criteria was similar to that of Molter's study.

More than half of all the families perceived eight of the needs statements to be very important. The eight were: to have questions answered honestly, to feel that hospital personnel cared about the relative, to know exactly what was being done for the relative, to feel there was hope, to have specific facts concerning the relative's progress, reassurance that the best care possible was being given the relative, to know they would be called at home if there were any changes in their relative's condition, and to receive information about the relative's condition at least once a day. These findings would suggest that at least some of the needs may be applied to all family members of critically ill patients.

Statistically significant differences were found in the perception of the degree of importance of personal needs of families with brain injury as compared to those without brain injury. However, the differences found could have been the result of a Type I error due to the large number of frequency counts from the tools. Despite the differences cited utilizing Chi Square, the Spearman rank-order correlation's suggest a strong relationship between the groups. It appears that what differed among the family members was their perception of the degree of

importance of each need statement.

Engli and Kirsivali-Farmer (1993) replicated, in part, Mathis' (1984) study. A convenience, nonprobability sample was used. Of 45 families approached only 14 participated by returning the questionnaire (6 non brain injured, 8 brain injured). Overall, five of the top 10 needs statements were the same in both groups, although ranked differently. Comparison to the Mathis study revealed similar findings of top 10 needs statements in the brain injured and nonbrain injured families. Differences being in the ordering of importance of the identified needs. The need to know the prognosis, to have questions answered honestly, and to be assured that the best possible care is being given to the patient were the top 3 needs of families with brain injury. Statistically significant differences were found similar to the Mathis study suggesting that families of brain injured patients do perceive needs differently than those of nonbrain injured patients. However, Spearman rank order correlation suggests a strong relationship between the two groups in this study and in comparison to the Mathis study.

Limitations of this study have been identified as small sample size, selection bias related to volunteers choosing family members they perceived as being cooperative, not all needs were ranked by respondents therefore threatening the validity of the tool, and no control over consistency in the manner of which the questionnaire was completed possibly altering the meaning of the results.

Family Stress

The suddenness of critical injury, particularly severe brain injury, not only creates needs for families but also causes stress. Stressors can be identified as physical, emotional, psychological, and/or spiritual. Stressors caused by critical injury vary in intensity and duration and can have the potential effect of a lifelong burden to the family. The severity of the stress often impedes the family's ability to receive and comprehend information, and may interfere with maintenance of effective coping mechanisms (Dufour, Aiken, & Gueldner, 1992). The stressors may begin during the critical care event and may continue throughout the rehabilitation phase. New stressors may replace or compound old stressors.

Novack, Bergquist, Bennett, and Gouvier (1991) reviewed longitudinal studies that suggest family members, particularly primary care givers, experience significant stress when coping with a traumatic brain injured person at home. These studies suggest that at any one time within the first year after injury 25% of caregivers were experiencing significant stress. Relatives of TBI persons are most burdened by changes in emotional responses, subjective complaints by the injured person, and behavioral responses such as excessive talking and childishness. Although the findings of these studies are consistent, the application of these results to the United States is questionable related to the fact that the majority of the studies were conducted in European countries that do not have the rehabilitative facilities and programs that follow TBI patients found in the United States.

Novack et al. (1991) surveyed forty five family members who identified themselves as the primary caregivers for the TBI individual. Primary caregiver was defined as the person most often able to participate in family education at the rehabilitative center and likely to provide whatever care is necessary for the TBI person upon discharge home. Instruments measuring anxiety, depression, and level of disability were completed at time of admission to the rehabilitative facility, at discharge, and at 3 months post discharge. Twenty seven caregivers completed the 3 month post discharge survey which represented 60% of the original sample. Caregivers identified were 29 mothers, 3 fathers, 8 wives, 3 husbands, 1 cousin, and 1 sister. Head injuries were defined as severe in all cases related to coma status prior to admission or coma of greater than one week.

Anxiety was identified as a major problem at the time of admission but had improved by time of discharge. Anxiety remained constant at the 3 month follow-up. There was no correlation between level of anxiety and severity of disability. Although the 3 month follow-up sample was 60% of the original, the findings were considered representative of the entire sample after separate analysis to assess for responder bias. The previous studies cite higher anxiety levels for caregivers. This may be related to the lack of rehabilitative services abroad at the time of the studies.

The limitation of this study was the ability to generalize for all populations of TBI families. As cited earlier most previous works were conducted in Europe. Differences in culture and services may be significant. The study by Novack et al.

(1991) did not offer an in-depth analysis of the effectiveness of rehabilitative services on the reduction of the anxiety, however the findings did indicate a significant reduction in anxiety from admission to discharge for primary caregivers.

The impact of TBI on wives was studied by Acorn and Roberts in 1992. The analysis of twelve wives was taken from a larger sample of 100 caregivers of TBI patients in the province of British Columbia. Items on demographics, situational influences, and causes for worry regarding care of the TBI relative formed the first part of the questionnaire. The second part consisted of items addressing three needs categories: educational, psychological, and stress management. Face and content reliability were obtained. Reliability of the instrument was not reported. Latent content analysis was used to analyze comments made by the wives. Data were sorted initially into broad themes and then coded into smaller categories. The categories that emerged were role changes, emotional impact of the injury, the concept of hope, and the need for support. The needs were consistent with those cited in previous needs studies and family stress studies (Baker, 1990; Engli and Farmer, 1993; Koller, 1991; Molter, 1979; Novack et al, 1991; Warren, 1993).

In 1994 a study was conducted over a two year period of time that identified family stressors in TBI (Hall, Karzmark, Stevens, Englander, O'Hare, and Wright, 1994). Families who met the criteria for the study were identified through admission into a large comprehensive rehabilitation center. TBI patients had to be at least 15 years of age, admitted within three months of injury, and no significant secondary diagnosis of a long term condition (mental retardation). Families were

English speaking, and able to identify a primary caregiver. Families were given questionnaires at admission and requested to return it within 1 month. Families were again contacted at 6, 12, and 24 months post injury using the same questionnaires. Seventy one families completed the initial tests, 61 completed the 6 month follow-up, 63 at 1 year, and 51 at 2 years.

Seven tools were used throughout various stages of the time span. Caregivers' most common complaints about their relatives were a lack of involvement in leisure activities, fatigue, slowness, and forgetfulness (Hall et al., 1994).

Behavioral changes such as anxiety, temper outbursts, and self-centeredness were also reported by families. At the 2 year assessment, Hall et al. found stress was higher for caregivers of those with an increased risk psychosocial history, and for those without sufficient funds for services. Although caregivers reported no change in self perceived stress, the increased use of medication and substance use and decrease in employment and financial status was reported at the 2 year assessment.

Findings comparing the differences in reported stress between spouses and caregivers was significantly higher. Spouses categorized in the major crisis range was double that of caregivers at the admission time and at the 2 year interval.

Limitations to this study include inclusion criteria, culturally biased in that 92% of the study sample was Caucasian, and the continued contact over time with the same primary caregiver. Despite the limitations, the findings were consistent with the European studies.

Summary of Literature Review

Traumatic brain injury happens suddenly and without warning. Families are catapulted into an environment of wires, lines, tubes, and life saving equipment that will become the home to their loved one for days to weeks ahead. Families are defined in many ways. The significance and relationship to the victim is vital information when identifying family. Systems theory supports the interactions and reactions of one family member will effect the others (Wright and Leahy, 1984). In the chaos of events it is often recognized the families needs are secondary or sometimes forgotten. The literature documents the significant needs of the families of critical care patients with and without traumatic brain injury throughout the critical care event (Daley, 1984; Engli and Kirsivali-Farmer, 1993; Forrester, Murphy, and Monaghan, 1991; Leske, 1986; Mathis, 1984; Molter, 1979; and Warren, 1993). The needs of the families have been identified as similar yet distinct differences have been documented for the families of traumatic brain injured adults. Additionally, families are experiencing stress physically, emotionally, financially and spiritually during this traumatic time. Literature supports the stress and needs of traumatic brain injured families from the critical care time period to two years post event (Acorn and Roberts, 1992; Baker, 1990; Hall et al., 1994; Novack et al., 1991).

The early identification of needs of the family of traumatic brain injury is crucial to assisting the family in coping, decreasing stressors, and building a solid relationship with the health care team. Many health care team members will be

interacting with the family, but it is the critical care nurse who is in the position to begin facilitating that process during early interviews and interactions with the family at the bedside. Therefore, the following research questions will be studied:

1. How important are the needs of families of severe TBI individuals during the critical care experience?
2. What are the top ten needs of families of severe TBI individuals during the critical care experience?
3. Who has most often met the needs identified by families of severe TBI individuals during the critical care experience?
4. Who has most often met the top ten needs identified by families of severe TBI individuals?
5. What was described by families as helpful or useful things that were done by nurses?

Definition of Terms

Traumatic brain injured individual, a person, 15 years of age or older, who has sustained damage to the brain as a result of rapid acceleration, deceleration, or penetration caused by but not limited to the following: assault or violence, gunshot wound, motor vehicle, falls, work, or sports and recreation.

Critical care experience, the period of time from admission to discharge from the critical care unit.

Family. relative or significant other, 18 years or age or older, who visited the individual during the critical care experience on a daily or near daily basis.

Need. a personal need is a biopsychosocial requirement identified by the family member of the TBI individual during the critical care experience using the CCFNI instrument. (Molter and Leske, 1983).

Chapter 3

Method

Design

This descriptive design study assessed the needs of families of severe traumatic brain injured individuals during the critical care experience. Previous studies have collected data during the critical care experience utilizing both interview and/or questionnaire. Other studies have collected data at time intervals post critical care. This study collected data from families asking them to recall the critical care experience utilizing a demographic profile, the CCFNI (Molter and Leske, 1983), and an additional form with two open ended questions regarding nursing care. Families of severe traumatic brain injured individuals received the survey by mail if their loved one was in the critical care unit up to 18 months prior to the time of the mailing.

Through professional experience and contact with colleagues, it is clear that families do experience stress and can identify their needs during the critical care time frame. Families have expressed vivid memories of this experience months and years later through visits, letters, and updates to nurses, physicians, and social workers. TBI is not an injury that heals and disappears. Families live with a daily reminder.

Study Site and Subjects

For this investigation, 195 families of TBI patients were invited to participate by way of a mailed survey. All patients were from a large, midwest teaching hospital.

Input was received from the manager of the medical records department to facilitate a timely and successful turnaround regarding accessibility of the names and addresses for the study. The information required for inputting into the computer search would include Diagnostic Related Group (DRG) numbers, a specific time period, and the admitting nursing unit. The manager was contacted by phone when the study was approved. The targeted list was secured after considerable delay related to communication and systems issues.

The following DRG classifications were used to obtain the sample: # 2 (Craniotomy for Trauma greater than age 17), #3 (Craniotomy for Trauma ages 0-17), #484 (Craniotomy for Multiple Significant Trauma), # 486 (Other Operative Procedures for Multiple Significant Trauma), #487 (Other Multiple Significant Trauma), #27-30 (Traumatic Stupors and Comas less than 1 hour and greater than 1 hour), and #31-33 (Concussions), and admitted to surgical critical care within 18 months of data collection. The final list yielded 195 families.

Of the 195 surveys mailed, 121 never responded, 26 were returned undeliverable (address unknown, no forwarding address), and 48 were returned answered. Of the 48 respondents, which was a return of 24.7%, 9 were actually not brain injured and had gotten into the sample through error in selecting the sample. Each of these families wrote a note, or called the researcher to notify of the error. However, each one did want to fill it out or had filled it out when the survey was returned. Additionally, 5 returned with notes explaining why they could not participate. One had actually received the survey on the anniversary of the

death of her father but still took the time to write the researcher a note explaining why she could not fill out the survey. Twenty eight met the inclusion criteria, which was a 14.5% final response rate. A small sample size is consistent for mailed surveys according to Polit and Hunger (1995).

The criteria for acceptance into the study was one family member per patient who met the following criteria:

Family member was:

1. A minimum of 18 years of age at the time of the hospitalization
2. English speaking and reading as primary language
3. A visitor of the victim on a daily or near daily basis during the critical care experience

TBI individual was:

1. A minimum of 15 years of age at time of injury.
2. Admitted to the hospital as a result of traumatic injury to brain. This would include but is not limited to: penetrating wound, rapid acceleration/deceleration
3. injury, blunt force/hit, or fall.
4. Admitted within 18 months at time of data collection.

The sample consisted of 19 females and 9 males. Spouses (42.9%) and daughters (35.7%) made up the majority of the respondents. All could read and speak English. The levels of education varied. Over half (57.1%) had completed high school as the highest level of education, and 28.6% had either a Bachelor's or Associate's Degree. Two held technical degrees, as well as one master's and one

doctorate degree. The ages ranged from 24-73. The mean age was 49.07 years (s.d. 11.88).

The patient sample consisted of 16 males and 12 females. The causes for the TBI were 17 Motor Vehicle Accidents (MVA)(60.7%), 5 falls (17.9%), 3 recreational vehicles, 2 blunt objects, and 1 assault. The ages ranged from 15-81. The mean age was 41.39 years with a s.d. of 22.61. Over half, 53.6%, were between the ages of 15-37. Over 80% of the patients' length of stays were 10 days or less. The patients were hospitalized 9-18 months prior to the survey. The majority (60.2%) were hospitalized during the period of time commonly referred to as trauma season which is from May-August.

Instruments

Three instruments were used in the study: a Demographic Profile developed for this study, the Critical Care Family Needs Inventory (CCFNI). (Molter and Leske, 1983), and an additional sheet with questions regarding nursing care. (See Appendix A). The demographic sheet consisted of fill in the blank and checklist style questions that were used to obtain qualification criteria and statistical data for research analysis.

The second instrument used was the CCFNI (Molter and Leske, 1983). The CCFNI consists of 45 declarative statements related to specific needs that may be perceived by a family member during the time the patient was in the critical care unit. Each statement was followed by a response based on a likert scale of 1 (not important) to a 4 (very important). Additionally, the family member was asked to

identify who met that need. The additional sheet contained two open ended questions asking the family member to list what was helpful or useful that was done by a nurse and any further comments not mentioned with the tool in relation to the critical care experience.

Content validity had been established for the original tool by Molter (1979) utilizing professional nurses to compile the list of need statements and by having the structured interview guide reviewed by two intensive care nurses as well as a nurse who had a relative in an intensive care unit. Daley (1984) revised the original tool incorporating needs statements of Molter's, other researchers, and her own personal experiences. Content validity was further established by utilizing faculty of a graduate nursing program to review and edit the instrument. The faculty selected were experts in the content being studied. The instrument was pretested and revised based on the pretest results. Leske (1986) joined Molter in revising the original tool, and renamed it the CCFNI. Content validity was supported through no additional needs identified in either Leske's (1986) or Molter's (1979) studies.

Additionally, Macy and Bouman (1991) conducted an evaluation on the CCFNI. An expert panel of Masters prepared nurses with extensive critical care backgrounds examined the instrument for validity, reliability, and readability. The panel found numerous redundancies among the need statements, but overall content validity was established.

Reliability is not reported in the original tool by Molter (1979), however studies have reported impressive evidence of internal consistency (Leske, 1986; Mathis, 1984; O'Neill-Norris and Grove, 1986) ranging from .85-.98. Macy and Bouman (1991) administered the CCFNI to 51 family members of critically ill patients on two separate occasions. Test-retest scores were found to be highly correlated ($r=0.99$).

Readability was calculated at 9.0, using the Gunning Fog Index, indicating the CCFNI could be read and understood at the ninth grade reading levels. According to Polit and Hunger (1995), an acceptable reliability coefficient is greater than .70. This instrument obtained an alpha coefficient score of .871 when tested. This is acceptable. Written permission was obtained and research will be shared with Molter and Leske. (See Appendix B).

Procedure

Families were contacted by mail. Each family received an introductory letter explaining the purpose of the study, a copy of the CCFNI, the Demographic Profile, the additional page of questions, and a self-addressed returned envelope. A request of 2 weeks to complete the survey was written in the introductory letter. Informed consent was understood and written within the context of the introductory letter that by completing and returning the survey consent had been given.

Threats to internal validity existed related to the recall nature of the study. There was no means of control over the subjects. This may have effect on the

ability to defend the results against competing explanations. Maturation was another factor given the time frame of up to 18 months post critical care experience at the time of the survey. Family members may be at varying levels of emotional stress, physical stress, and psychological stress.

Threats to external validity existed related to the convenience of the sample and its size. Several surveys were returned undeliverable and address unknown. The ability to generalize was limited. The interaction of time and treatment of family and patient may have factored into the responses and of those who did not respond.

The risks to the subjects could have been emotional trauma. Bringing up past events may have caused unwanted stress as evidenced by surveys that were sent back, unanswered, yet with notes attached detailing the emotions still being felt. Fear of identification, despite the confidentiality statement by the researcher, can affect a person's response on a survey. The patient and or family may continue to utilize the facility in which the survey drew its sample and therefore may create hesitancy in the responses from the family out of being identified especially if negative responses were stated.

A statement regarding informed consent for the subjects was incorporated into the survey directions. The approval of The Human Research Review Committee of Grand Valley State University, and the appropriate hospital review committees was obtained prior to the start of the research. (See Appendix C).

Chapter 4

Data Analysis

The purpose of this research was to (a) identify the importance of needs of families of severe brain injured individuals during the critical care experience, (b) identify the top ten needs of families of severe brain injured individuals during the critical care experience, (c) identify who has met the needs of the families of severe brain injured individuals during the critical care experience, (d) identify who has met the top ten needs of families of severe brain injured individuals, and (e) describe what families identified as helpful or useful things done by nurses during the critical care experience. Data analysis was accomplished utilizing the Statistical Package for Social Sciences (SPSS) software ($p=.05$).

Data analysis began with identification of the importance of needs of families of severe TBI individuals during the critical care experience. Rank ordering of the 45 need statements was based upon the importance of the needs. Ranking of the need statements is ordered by the median, however to finalize the ranking the statistical mean was used in order to compare results with previous studies. Of the 45 needs listed, 70% had a mean of 3.00 or greater, meaning the family members perceived 31 needs as important to very important. Identification of the top ten needs of families of severe TBI individuals are listed in Table 1.

Table 1

Top Ten Needs of Families of Severe TBI Individuals during the Critical Care Experience

<u>Need</u>	<u>Frequency</u>	<u>Item Mean</u>	<u>SD</u>
assured best care	28	4.00	.00
call re changes in pt.	21	3.95	.22
know the prognosis	19	3.95	.23
staff care about pt.	27	3.93	.27
talk to MD daily	27	3.93	.27
see the pt frequently	27	3.93	.27
facts re progress	27	3.93	.27
why things were done	28	3.89	.31
hope	27	3.89	.32
how pt treated medically	18	3.89	.32

Identification of who had most often met the needs of families of severe TBI individuals was analyzed at the nominal level . Eight categories of choice of who met the 45 needs most often were counted for frequency and a percentage was

calculated. This section of the questionnaire reported a large amount of missing data. Of the people who responded to the questions, the most frequent responses were that needs were being met by the nurse, physician, or the medical social worker. In some cases respondents answered with more than one person met that need. Thus additional categories were added to account for 2 sources, and 3-4 sources that were identified as meeting the need. Identification of who had most often met the top ten needs identified by families of severe TBI were counted for frequency. See table 2.

An additional sheet containing two questions was attached to the study. The additional questions "Tell me one or two things that were done by the nurses that were helpful or useful during the critical care experience", and "Tell me anything else about your critical care experience", represented qualitative research. The purpose was to draw out any additional information the family member wanted to share about the experience. Of the 28 respondents, 24 family members shared their thoughts feelings, and even a newspaper clipping regarding their experiences. The data was arranged into themes: the overall system, communication, nursing, and physician. The qualitative data is incorporated into chapter 5, and adds richness to the understanding of the families experiences.

Table 2

Top Ten Needs of Families of Severe TBI Individuals/Who Met Need

<u>Need</u>	<u>%</u>	<u>Who Met Need</u>
assured best care	25.0%	MD
call re changes in pt	17.9%	Nurse
know the prognosis	50.0%	MD
staff care re pt	28.6%	Nurse
talk to MD daily	57.1%	MD
see pt frequently	17.9%	Nurse
facts re progress	21.4%	MD
why things were done	42.9%	Nurse
hope	32.1%	2 sources
how pt treated medically	28.6%	MD

Discussion and Implications

Chapter 5

Discussion

The general purpose of this study was to identify the importance of needs of families of severe TBI and identify who met those needs while in the critical care environment. Little has been documented in this specific area (Engli, Kirsivali-Farmer, 1993; Mathis, 1984; Mauss-Clum, and Ryan, 1981). Multiple studies exist identifying the needs of critical care families (Daly, 1984; Leske, 1986; Mendonca and Warren, 1998; Molter, 1979; Warren, 1993) as was discussed in depth in chapter 2. Additionally, this study asked families to recall the critical care event up to 18 months from the time of injury.

System's theory supports the premise that families are in constant change. Stressful events such as severe TBI can alter the boundaries of equilibrium. Families construct their own memories of the events. This was evident in the vivid recall of needs, the importance of those needs, and who met those needs by those who participated in the study. Despite the time lapse of up to 18 months, families could recall names, dates, and conversations as evidenced by the anecdotal sheet of the survey.

The 45 needs statements in this study were primarily reported as important to very important by those who participated. The majority of the top ten needs were identified as very important by those who participated. The most important need

identified in this study, to be assured the best care, reported unanimous agreement as perceiving it to be very important.

The needs statements that ranked in the top ten of importance were consistent with the majority of the studies cited. Differences in absolute ranking within the top ten did exist. Interestingly, the need for hope, ranked high in the studies of the general critical care population (Leske, 1986; Mathis, 1984; Molter, 1979; O'Neill-Norris and Grove, 1986;) with the exception of one study by Price, Forrester, Murphy, and Monaghan, 1991). The Price study cited the need for hope as 11th, and attributed it to the severity of injury and illness of the population studied. In contrast, the need for hope, in this study and Mathis (1984) brain injury study both ranked the need for hope as 9th. The Engli (1993) study did not cite this need in the top ten. This sharp contrast in the need for hope between these two groups of families (with and without brain injury) is not consistent with practice as this researcher has experienced. Generally, the families are seeking hope, reassurance, continual updates of condition. Differences in demographics, sample sizes, and methodology may have had impact in the findings.

The second significant difference between this study and all studies cited was the need to talk to the physician daily. This study ranked it as fifth in the top ten. This need only appeared on the top ten list of the study by Daley (1984). All other studies cited it between 11th and 20th. Conclusions may be drawn regarding the methodology, timing, and severity of injuries. However, one mustn't forget the influence of communication at the bedside. Trust and rapport are essential

elements to building a relationship with families. It may be assumed that it is an expectation of the families to have verbal contact with the doctor daily given the type of institution in which the research was conducted. Additionally, the families may have misinterpreted who the "doctor" was that they expected to have contact with daily. In a large teaching institution such as the research site, patients are seen by a multitude of doctors daily. Lack of knowledge of who the doctor was may have resulted in the need to talk to the MD daily.

Other influences may have been inconsistency in staff caring for the patient and family, staffing patterns that suggested nurses did not have the time to spend communicating and assessing the needs of the families, and novice staff that may be preoccupied with the technical aspect of care instead of a holistic approach to care.

Meeting the needs of families of severe TBI patients is not an easy task. Much of the time spent by the health care team is focused on the patient. Needs are being met by members of the health care team as well as relatives and friends. The needs were met by the MD or the nurse in 9 out of the top 10 needs of those who responded. The needs that were concerned with information giving (prognosis, treatment, progress) were met by the MD the majority of the time. This is consistent with the study by Engli and Kirsivali-Farmer (1993). Care issues, such as assurance of best care, changes in patient condition, and that the staff care were met by the nurses the majority of the time in the studies by Molter (1979) and Rodgers (1983). This study differed in findings in that the assurance of

best care was met by the MD 25% of the time. The nurse met this need 17.9% of the time. It is important to note that of the 28 respondents, 9 did not answer this question.

Family systems theory supports the need for ongoing communication between the nurse and the family. This study reflected the importance of the needs of families as very important to important. Accurate needs assessments of the family is necessary to establish a holistic view and to maintain equilibrium. Boundaries exist within the family members and the family as a whole to protect and maintain stability. The nurse is in a position to assist with meeting the needs of families and enabling them to cope with the present stressors.

An additional information sheet was enclosed asking the family member to respond to two open ended statements. The first statement asked the family member to list one or two things that were done by the nurses that were helpful or useful during the critical care experience. The second statement asked for any additional comments regarding the critical care experience.

The responses had a significant impact on the researcher. The vividness and detailed memories that were captured on paper by the families literally took the reader back in time to the events and the surroundings. Nurses can not ignore the messages that were sent regarding care issues. Statements were categorized into themes: the overall system, communication, physician, and nursing. Each contains positive and negative feedback.

The overall system related to the hospital in general. Families cited thankfulness for allowing open visitation. One member wrote, "I live 2 ½ hours away and am self employed, I would have had to close my business". Another stated, "I could come and go as I pleased". Encouragement and support by staff in general was cited several times. One family member wrote, " everyone we came in contact with from doctors, nurses, clergy to social work and even housekeeping were very caring and warm".

Families cited the system provided them with material things, such as "toothbrush, toothpaste, and comb", "a lazy boy chair that laid down so I could sleep in the room with my husband", "parking passes, meal ticket to buy food at staff prices, and information about a hotel that we could stay at with a cut price near the hospital". Systems theory states that equilibrium is maintained through the use of various resources when encountering a stressful event such as a critical care environment.

The system was distressing and displeasing to some as well. "Critical care is frightening, my son will be 21 forever" was written. Another wrote, "in any hospital experience it would be helpful to know the environment (what buttons do what, where elevators are, where nurses station is, who to call when)and put this in writing would be helpful". Early discharges were cited in detail by two families. One describes "I had to beg to keep her in the hospital for an 8th day. My daughter is larger than me, I had to help her walk, shower. Someone needs to care about the ability of the caregiver once the patient leaves the hospital". Another

describes an unexpected discharge. "I had left the hospital for a few hours to shower and get a change of clothes, my daughter was to stay another night; when I returned arrangements had been made for her discharge. How can a minor with a CHI, small bleed, and a skull fracture be sent home 12 hours after extubation?". "I was never asked if I could care for her at home". "The social worker called the next day and thought she had been discharged to a rehabilitation hospital".

Communication was a common theme. Overall praise was given to nursing and medical staff for answering questions, giving information, and introducing caregivers. However, communication issues were also cited as a concern.

One mother was distressed because her daughter had vomited twice during the night and could not summon help. "she put her call light on but because her jaw was wired shut she could not talk and the staff answered the light but did not come in when she could not answer them, the buzzers need to be clearly marked". A spouse stated she was "incredibly afraid" when she arrived at the hospital and the first person to greet her was a clergy person. "Of course we thought the worse....a nurse would have been much better".

Physicians became a third theme. Comments were distributed equally. Citations of "excellent", "a woman doctor cried with us", "I was included in rounds everyday" to "I never saw the doctor", "they were never available", and "they all had an attitude".

Nursing received the most feedback. The majority of the comments were positive. Nurses were described as nice, kind, compassionate, warm, cheerful.

efficient, patient, caring, and trusting. Nurses were also cited as information givers, offering assurance, explainers, and professional. The few negative comments were insightful. One family member wrote about the inconsistency in care, "a nurse may have a certain way of handling things that I might feel comfortable with one day and the next day a different nurse is assigned who I don't feel quite as comfortable". Other descriptors were cold, scattered, poor technique, and incompetent.

The four themes that emerged and the commentary that was cited supports the importance of the needs of families of severe TBI patients. Many of the comments are directly cited in the top 10 needs list such as assurance, communication, and caring staff. The needs are being met by physicians and nurses the majority of the time according to research and the feedback documented in this study.

Limitations

The following limitations need to be considered when interpreting these findings. The sample size was small. A return rate of 15% is considerably low, therefore the findings can not be generalized. The errors in sample selection, system issues, and delayed retrieval of final sample extended the time frame for families from 8 months to 18 months from time of injury. The passage of time for families has the potential of life changes, memory lapse, and other events influencing the survey.

The question of denial by the family of their loved one having suffered a head injury is debatable related to the fact that the patient list was pulled by DRG classification of brain injury diagnostics on admission to the intensive care unit. This may account for families returning the survey unanswered or not participating at all. Some responses, phone and written, stated repeatedly that the family member had not had a head injury but had merely suffered trauma.

Another potential limitation was the DRG system. The pool of classification that contributed the names was quite varied from concussion to severe brain trauma despite the fact that each of the patients was admitted to the intensive care unit. This may have had an impact on findings and participation of this study.

Additionally, the responses were not all completed. Inconsistency in filling out the CCFNI accurately and completely, especially the section of "who met the need" left a wide margin of error. Content validity of the tool is threatened when the questionnaire is not completely filled out.

Implications for Education/Practice/Research

Although the results of this study have limited generalization, implications for nursing education, practice, and research exist. Nursing education needs to focus on the consistent identified needs of families of critical care patients such as information, reassurance, and communication. Nursing assessments of the family system become a key component to providing holistic nursing care. The needs can become a focus for teaching nursing process and determining interventions to meet

those needs as important elements of care.

As society continues to change, nursing curricula must also change. Education in cultural diversity with emphasis on family system theory might provide continued support for meeting the needs of the diverse family. Role modeling by experienced nurses and faculty should convey genuineness toward the family. How to effectively and therapeutically communicate with family, especially during the critical care period, needs to be emphasized and practiced. Basic nursing skills such as communication, dignity, and respect were equated with competency by family members in the study by Jamerson et al. (1996).

Implications for nursing practice are essential for broadening the scope of critical care nursing. Over 20 years of research has demonstrated unequivocally that family needs are very important and must be incorporated into everyday practice. Emphasis needs to move in the direction of implementation of nursing interventions that meet the documented needs of assurance, information, and communication. Family members have cited the need for information and daily contacts as consistently important. It is essential that families receive information daily in a clear, honest, caring manner. It might be helpful if nurses used a variety of communication delivery systems such as verbal and written.

Ongoing assessment by the nurse may determine the level of stress and comprehension of the family. Educational inservices for nurses to teach family system theory and nursing process can only strengthen the nursing impact at the bedside. Involvement of the nurse as well as the family in daily rounds allows for

input and education and may relieve some of the need for information and contact with physicians the family is experiencing.

Attention needs to be drawn to the mission statements of the institutions. If the mission statement embraces the concept of holistic care, the patient and family rights to know, satisfaction of needs, then the institution must be held accountable to meeting the needs of families. Critical pathways are an integrated tool that facilitates the movement through a system of care components. This is one way to daily check is needs are being assessed and implemented.

Implications for research include replication with a larger sample size. Comparison studies of families of severe TBI while in the critical care at present with this retrospective study may demonstrate a difference in perceived family needs.

The CCFNI tool, a classic, needs to be refined. The repetitiveness of the needs, the length of the tool, and the fact that most all needs were cited as important or very important may not truly capture the priorities of needs for the family. In asking who met the need it is assumed that the need was met, further research could ask was this need met and by whom. Assessment of stress of family during the critical care time and at designated time intervals post injury may show the longevity of effects of severe brain injury on caregivers.

The direction that nursing research must go is implementation and measurement of nursing interventions. Assurance needs and information needs can be met through a variety of communication interventions including verbal and written.

Intervening at the critical care experience is beneficial as the literature has shown. however impact may be better facilitated and more useful at the rehabilitative level. This premise would support the longitudinal studies by Hall, et. al (1994) and Novak, et. al (1991).

Recognizing and meeting family needs is an important part of holistic care in the critical care unit. Over the twenty years that needs assessments have been studied, several points remain constant. Families will always have needs and those needs must be addressed. Early and ongoing assessment of the family will provide the information necessary to develop a plan of care that will incorporate the needs of the patient as well as the family.

Across the nation institutions are experiencing budget cuts, nursing shortages and increased patient acuity. These changes have significant impact on staff as well as patients and families. Critical care nurses are in a position of autonomy and independence that allows for significant impact in the lives of patients and families through bedside interventions. Despite the impact of staffing ratios, and financial deficits, the overwhelming evidence that supports meeting the needs of families can not be ignored or denied. Nurses must continue to speak as the patient, and ultimately the family advocate. If the mission of the institution is to provide the best quality care, the need to support the family system can not be denied. Nursing can and will continue to pave the way for holistic, safe, and individualized care.

APPENDIX A

Dear Family of _____,

My name is Vicki Meyers. I am a critical care nurse and a student at Grand Valley State University completing my Master's degree in Nursing. As part of my education I am conducting a research study titled "Needs of Families of Severe Brain Injured Individuals during the Critical Care Experience". Your family is one of ___ families invited to participate in this study.

As a nurse who has cared for many patients with brain injuries it is important to me to take care of the families needs as well as the patients needs. The critical care experience is frightening and overwhelming to families. This study will provide our health care team with valuable information that may allow us to provide higher quality care during the critical care experience. I do not know the outcome of the injury to your loved one, however your answers, if you are willing to provide them, will help me greatly in this project.

Your family was selected to participate because you have had a loved one in the Critical Care Unit over the past 1 ½ years as a result of a severe brain injury. The enclosed survey should take you less than 30 minutes to complete. Your responses will be kept confidential to the extent permitted by law.

Although no risks are anticipated I recognize you may relive some difficult memories. Your memory and thus your time in answering these questions may help other families. By completing and returning the survey in the self addressed stamped envelope, you are giving your consent for participation to use this information in my study. If you have any questions about this study you may contact me at (616) 391-3460 or you may contact Paul Huizinga, chairperson of Human Research Review Committee at Grand Valley State University (616) 895-2472. If you have any questions regarding your rights as a participant in this study, you may call the Human Right's Committee representative, Linda Pool, at (616) 391-1291/1299.

Please return this form, even if you feel you can not fill it out, by **May 7, 1999**. Thank you for your assistance.

Yours Truly,

Vicki Meyers RN

Thank you for sharing this information with me.

Please place an X or check mark next to the proper response.

Your Relationship to the patient at the time of the critical care experience:

- 1. ___ Spouse
- 2. ___ Son
- 3. ___ Daughter
- 4. ___ Daughter-in-law
- 5. ___ Other (please write in relationship) _____
- 6. ___ Mother
- 7. ___ Father
- 8. ___ Son-in-law
- 9. ___ Significant Other

Your gender:

- 1. ___ Male
- 2. ___ Female

Is English your primary language?

- 1. ___ Yes
- 2. ___ No

Can you read English?

- 1. ___ Yes
- 2. ___ No

Your Highest Educational Level

- 1. ___ Grade school
- 2. ___ Completed high school
- 3. ___ Technical/Apprenticeship
- 4. ___ Associate degree
- 5. ___ Baccalaureate degree
- 6. ___ Masters degree
- 7. ___ Doctoral degree

How old were YOU at the time of the injury? _____

How old was your loved one at the time of the injury? _____

When was your loved one in the critical care unit? (example: March 1998) _____

How many days was your loved in the critical care _____

Did you visit your loved one daily or near daily while in the critical care unit?

- 1. ___ Yes
- 2. ___ No

What caused the brain injury in your loved one? (example: car accident)

Please check how **IMPORTANT** each of the following needs was to you during the **CRITICAL CARE EXPERIENCE**

In the **LAST** column please indicate who best met that need for you during the **CRITICAL CARE EXPERIENCE**

N=Nurse D=Doctor M=Medical Social Worker C=Clergy F=Family O=Other

	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Who Met This Need?
To know the prognosis					
To have explanations of the environment before going into the critical care unit for the first time					
To talk to the doctor everyday					
To have a specific person to call at the hospital when unable to visit					
To have questions answered honestly					
To have visiting hours changed for specific conditions					
To talk about negative feelings such as guilt or anger					
To have good food available in the hospital					
To have directions as what to do at the bedside					
To visit at any time					
To know which staff members could give what type of information					
To have friends nearby for support					
To know why things were done for the patient					
To feel there is hope					
To know about the types of staff members taking care of the patient					

Key: N=Nurse D=Doctor M=Medical Social Worker C=Clergy F=Family O=Other

code ____

	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Who Met This Need?
To know how the patient is being treated medically					
To be assured that the best care possible is being given to the patient					
To have a place to be alone while in the hospital					
To know exactly what is being done for the patient					
To have comfortable furniture in the waiting room					
To feel accepted by the hospital staff					
To have someone to help with financial problems					
To have a telephone near the waiting room					
To have a pastor visit					
To talk about the possibility of the patient's death					
To have another person with the relative when visiting the critical care unit					
To have someone be concerned with the relative's health					
To be assured it is alright to leave the hospital for awhile					
To talk to the same nurse everyday					
To be encouraged to cry					
To be told about other people that could help with problems					
To have a bathroom near the waiting room					

Key: N=Nurse D=Doctor M=Medical Social Worker C=Clergy O=Other

code _____

	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)	Who Met This Need?
To be alone at any time					
To be told about someone to help with family problems					
To have explanations given that are understandable					
To have visiting hours start on time					
To be told about chaplain services					
To help with the patient's physical care					
To be told about transfer plans while they are being made					
To be called at home about changes in the patient's condition					
To receive information about the patient once a day					
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 have the waiting room nearby					
Please list any needs not mentioned and check important and needs met					

Code# _____

Please list one or two things that were done by nurses that were helpful or useful during the critical care experience.

Please feel free to tell me anything else about your critical care experience.

APPENDIX B

Nancy Molter
16307 Halifax
San Antonio, TX 78247
April 30, 1995

Victoria Meyers
843 Covell Ave NW
Grand Rapids MI, 49504-3809

Dear Victoria,

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

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

Good Luck in your studies. I would appreciate a copy of your results.

Sincerely,


Nancy Molter

APPENDIX C



Spectrum Health

Downtown Campus

100 MICHIGAN STREET NE GRAND RAPIDS MI 49503-2500
616 391 1774 FAX 391 2745 www.spectrum-health.org

October 21, 1998

Victoria L Meyers, BSN, RN
843 Covell Rd NW
Grand Rapids, MI 49504

Dear Vicki,

The Nursing Research Committee has completed the review of your research proposal *Needs of Families of Severe Brain Injured Individual During the Critical Care Experience* at the October 20, 1998 committee meeting. I am pleased to inform you that your proposal has received approval from our committee. The committee did have two recommendations: are there other demographic questions to include that would serve to describe the sample, ie, did the person completing the survey have any previous experiences with critical care, etc; and what is the current status of the BI person at the time the person is completing the survey. Also, you might consider adding a statistical test to determine the rank ordering of the needs as you compare these to other studies. These are suggestions for you and your committee. You are now ready to proceed to the Hospital Research and Human Subjects Committee. Contact Linda Pool at the Cook Institute for those arrangements.

As per Nursing Research Committee policy, you will be assigned a sponsor who will serve as resource to you during this study. I will serve in that capacity for your study. Mike Desrocher, MSN, RN will serve in that capacity. Please contact him at 45283 when you are ready to begin data collection, and keep him informed of your progress during the study.

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

Please feel free to call me if you have any questions or need further clarification.
I can be reached at 391-1625.

Sincerely,

A solid black rectangular box redacting the signature of Linda D. Urden.

Linda D. Urden, DNSc, RN, CNA
Director, Quality, Research & Advanced Practice
Chairperson, Nursing Research Committee

c: Linda Pool, Research Office
Mike DesRocher, Neuroscience CNS
Dr Linda Bond, KSON, GVSU



Spectrum Health

Downtown Campus

100 MICHIGAN STREET NE GRAND RAPIDS MI 49503-2500
616 391 1774 FAX 391 2745 www.spectrum-health.org

November 6, 1998

Victoria L. Meyers, BSN, RN
843 Covell Rd., NW
Grand Rapids, MI 49504

Dear Ms. Meyers:

By means of the expedited review process your project, "Needs of the Families of Severe Brain Injured Individuals During the Critical Care Experience", was given approval by the Spectrum Health - Downtown Campus Research and Human Rights Committee. An attempt was made to leave a phone message at the number listed on your informed consent. However, there was concern that it may not reach you since your name was not listed on the voice mail recording.

Please be advised this does not include any budgetary items. Should you require funds from the Research and Human Rights Committee at any time, you will need to present the entire project to them. The Spectrum Health Downtown Campus number assigned to your study is #98-120.

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

The Research and Human Rights Committee and the F.D.A. requires you submit in writing, a progress report to the committee by **October 1, 1999**, and you will need reapproval should your study be ongoing at that time. Enclosed are some guidelines, entitled "Protocol Points", for your convenience in working with your study.

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

Sincerely,

Jeffrey Jones, M.D.
Chairman, Spectrum Health - Downtown Campus Research and Human Rights Committee

JJ/jfn

c: Mike Desrocher, MSN, RN
File



GRAND VALLEY
STATE UNIVERSITY

1 CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

November 11, 1998

Victoria Lynne Meyers
843 Covell NW
Grand Rapids, MI 49504

Dear Victoria:

The Human Research Review Committee of Grand Valley State University is charged to examine proposals with respect to protection of human subjects. The Committee has considered your proposal, "*Needs of Families of Severe Traumatic Brain Injured Individuals During the Critical Care Experience*", and is satisfied that you have complied with the intent of the regulations published in the Federal Register 46 (16): 8386-8392, January 26, 1981.

Sincerely,

Paul Huizenga, Chair
Human Research Review Committee

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