# TRAUMATICALLY BRAIN-INJURED MALE IN THE HOME: PERCEIVED FAMILY FUNCTION

A Research Project for the Degree of M. S. N. MICHIGAN STATE UNIVERSITY LORRAINE J. PEARL 1990 THESIS

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PERCEIVED FAMILY FUNCTION

Ву

Lorraine J. Pearl

A RESEARCH PROJECT

Submitted to

Michigan State University

College of Nursing

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE IN NURSING

1990

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Copyright by Lorraine J. Pearl 1990 Dedicated to my parents and role models, James and Irene Pearl, whose love and support have been a constant source of inspiration and encouragement to me in my pursuit of life, education, and all my goals and aspirations. To Marilyn Krueger, my second grade schoolteacher, friend, mentor, and role model, who represents the epitome of what an educator should be and for inspiring me in the pursuit of the joy of learning. Last, but not least, to the brain-injured patients and their families with whom I have had the pleasure and privilege to work with during my years in the nursing profession. ÷,

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#### ABSTRACT

#### TRAUMATICALLY BRAIN-INJURED MALE IN THE HOME: PERCEIVED FAMILY FUNCTION

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Traumatic brain injury and its sequelae places a heavy burden upon society in terms of morbidity, mortality, and expenditure of health care resources. Until recently, limited research has been directed towards the patient's biopsychosocial sequelae to head injury and even less to its impact on the patient's family. The purpose of this study is to examine the perceived level of family function in the family unit in the presence of having a traumatically brain-injured male (20 to 40 years old) at home for at least three to six months postdischarge from a rehabilitation facility. The patient's and spouse's perceived level of family function will be assessed and measured across 21 indicators as denoted in the Feetham Family Functioning Survey (1988 version). The instrument will be administered to a pilot study of ten married couples. Results will be analyzed to determine the importance of, similarities and discrepancies between the scores of the brain-injured males' and their wives' perceptions of family function. Information gained from this study will assist nurses and other health professionals to develop interventions and more judiciously allocate resources to promote optimal patient rehabilitation and family's adjustment to patient's brain injury.

#### CHAPTER ONE

#### Introduction

Traumatic brain injury (TBI) extracts an exorbitant cost in terms of human morbidity and mortality and an expenditure of billions of health care dollars annually in the United States (Bush, 1988). Over 110,000 lives are lost annually in the United States due to traumatic injuries. Trauma ranks as the fourth cause of death in adults in the United States (preceded by heart disease, cancer, and stroke) (Stevens, 1982; McGuffin, 1983; Cole, Cope, & Cervelli, 1985). McGuffin (1983) states, "head injuries account for death in 70% of the (trauma) cases and surpass all other causes in persons between the ages of 1 and 35" (p. 189). "In the United States more persons have died of brain injury than have died in all of America's wars" (Bush, 1988, p. 74). There are approximately
1,500,000 brain injuries per year and 60,000 to 70,000
of these are moderate to severe cases. According to
Bush (1988), "2,000 persons remain in a persistent
vegetative state each year" (p. 74).

Greater than 50% of head injuries are incurred in motor vehicle accidents. Alcohol intoxication is a factor in many of these road accidents (Jennett & Teasdale, 1981). Other common causes of head injury are assaults, falls, sport and work injuries, respectively (Jennett & Teasdale, 1981). Head injuries vary in degree of severity from mild concussion without brain damage to penetrating injuries (e.g., missile injuries such as gunshot wounds and lawn darts) that can result in death.

Patients with mild to severe brain injury require rehabilitation. Rehabilitation costs can be quite expensive depending on the severity of the injury. Bush (1988) claims that, "only 1 out of 15 persons who experience head injury receives rehabilitation...such is the magnitude of the funding problem" (p. 75). Family members must be included in the patient's rehabilitation program to facilitate the patient's

optimal functional recovery, reintegration into the family system and community, and to help contain costs (Jennett, 1988; Bond, 1988). The unexpected event of a serious head injury incurred by a family member causes psychosocial changes within the family unit (Bond, 1988; Jennett, 1988; Livingston & Brooks, 1988). The purpose of this project is to assess the level of function in the family unit with a traumatically braininjured male spouse at home. The perceptions of the brain-injured male and his spouse will be utilized. The perceived level of family function will be assessed and quantitatively measured by using the Feetham Family Functioning Survey (FFFS) instrument (1988) which measures 21 indicators of family function across three relationship areas as noted under Factors One, Two, and Three (see Table 8).

The availability of highly sophisticated life support technology in the treatment of critically injured patients has resulted in the survival of increasing numbers of seriously brain-injured patients (Cole, Cope, & Cervelli, 1985; McGuffin, 1983). Among the survivors of brain injury in the United States, it is estimated that 50,000 to 70,000 of these patients

have residual intellectual and behavioral deficits that prevent their return to a premorbid level of function and lifestyle (Michigan Head Injury Alliance, 1988; Dring, 1989; Warren & Peck, 1984).

### Problems for Client and Family

The families of brain-injured (BI) patients are having to assume a more active role in the rehabilitation of (BI) patients due to the rising cost of hospital care and the limitation of in-hospital days under the prospective payment system (Dring, 1989; Cole, Cope, & Cervelli, 1985). Families are often unprepared to meet the demands required to adequately care for a physically, cognitively, or behaviorally impaired brain-injured person in their home. Consequently, brain-injured patients "often lose cognitive and social skills developed during acute rehabilitation and become even more dependent on the family" (Cole, Cope, & Cervelli, 1985, p. 38). These patients can develop secondary behavioral problems and create disruption in normal patterns of family functioning due to their "impaired social perceptiveness and learning, emotional alterations,

altered sexual drive, impaired self-control and selfregulation" (Rao, Sulton, Young, & Harvey, 1986, p. 759).

The relatives of brain-injured persons may be under both physical and psychological stress due to a number of factors: the burden of the caregiver role, role overload, role fatigue, role reversal, lack of nursing skills, lack of knowledge about the patient's injury, illness, and prognosis, lack of coping skills and support systems, and financial strains on the family's economic resources (Cole, et al., 1985; Dring, 1989; Rao, et al., 1986; Elliott & Smith, 1985; Bond, 1975, 1976; Ekberg, Griffith, & Foxall, 1986; and Stress can manifest itself in the Brooks, 1984). form of physical and emotional symptoms experienced by family members (Brooks, 1984; Bond, 1976; Livingston & Brooks, 1988; Stevens, 1982; and Cole, Cope, & Cervelli, 1985). Spouse burnout syndrome has been identified in some cases in which one spouse must assume the caregiving burden of a chronically ill mate (Ekberg, Griffith, & Foxall, 1986). The 'spouse burnout syndrome' has not been evaluated in caring for a traumatically brain-injured spouse.

Normal activities of daily living are altered for the brain-injured adult as well as for his/her family. The spouse of the brain-injured adult despite the increased burden of the caregiver role may not be the most severely stressed member of the family unit (Brooks, 1984; Livingston & Brooks, 1988; Brooks, Campsie, Symington, Beatties, & McKinlay, 1986). A question arises relating to how family functioning is affected when a brain-injured adult is in the home; therefore, the research question for this study is:

What is the level of family function in a family unit containing a traumatically brain-injured male at home as perceived by the brain-injured male and his spouse?

A plausible hypothesis for this study might be that:

There will be a difference between the braininjured male's perceived level of family function and his spouse's perceived level of family function.

This research project will be a pilot study in an effort to assess the family unit's perceived level of function in the presence of having a brain-injured male at home. The FFFS (1988) will be used to obtain the

used to obtain the brain-injured male's and his spouse's perceptions of their family unit's level of function once the TBI male is in the home setting. The study will provide a convenience sample and will not attempt to measure or control for extraneous variables. Consequently, the results of the pilot study cannot be generalized to a larger population. The purpose of the pilot study is to assess the adequacy of the measurement instrument and to guide further research (Polit & Hungler, 1983).

#### DEFINITION OF CONCEPTS

## A. <u>Traumatically Brain-Injured Male:</u>

A male who has incurred a head injury as a result of distinct mechanical factors which impact on the brain and cause damage. Brain injuries are classified as either a primary or secondary type injury. The former is seldom affected by treatment; whereas, the latter is caused by a complication such as cerebral edema, hypoxia, intracranial hematoma, and hypotension, and is potentially preventable or reversible with treatment (Teasdale & Mendelow, 1984).

Brain damage occurs at varying degrees of severity. According to Jennett and Teasdale (1981), the length of the post-traumatic amnesia period which they define as the interval between injury and return to full consciousness seems to have a direct relationship to the patient's degree of brain injury resulting in possible cognitive, social, mental, and physical handicaps (see Table 3 regarding posttraumatic amnesia period scale.) Bond (1975, 1976) and Brooks (1984) note that the length of the posttraumatic amnesia period is also a good prognosticator of patient's recovery and outcome. For purposes of this study both primary and secondary BI males will be included.

Traumatic brain injury is two to three times more prevalent in males than females. The study conducted by Rimel and Jane (1983) revealed that the age distribution of 10 to 39 years accounted for 74% of the head injuries.

Traumatic brain injury can render a plethora of stressors upon the patient and his/her family system. Goliszek (1987) defines stressor as "the event or situation that puts us on alert and gets us ready to

respond" (p. 16). The stressors that the brain-injured patient and family unit are subjected to are experienced by the family system as: 1) major life event stressors (major changes in family life or loss of a family member); 2) minor life event stressors (daily stresses involved in maintaining the family); 3) cultural stressors (especially those related to socioeconomic conditions); and 4) environmental stressors (Tomlinson, 1986, p. 79). These stresses result from situational demands (social and physical) created by environmental constraints exceeding available resources (Lazarus & Folkman, 1984).

The brain-injured patient and his/her family system may have difficulty identifying their specific stressors because they are either unable (due to patient's potentially altered cognitive, social, and physical abilities and behaviors) or unwilling to do so (due to patient's handicaps and family's lack of knowledge of patient's illness, prognosis, realistic rehabilitation goals, lack of socioeconomic resources, desire for a more favorable functional recovery of patient and resumption of his/her family roles and responsibilities, et cetera). The inability to

identify stressors upon the family unit (e.g., increased financial strains; burden of caregiver role; altered family roles, rules, responsibilities, communication patterns; lack of available resources (financial, social, educational, medical support systems)) to meet demands of caring for a brain-injured patient at home can contribute to an increased amount of stress and stressful reactions in the family system (Lezak, 1986, 1988; McCubbin & Figley, 1983). Consequently, the level of family function may be affected.

McCubbin and McCubbin (1987) define stressor as "a life event or transition...impacting upon or within the family unit which produces, or has the potential of producing change in the family social system" (pp. 4-5). They indicate that change, such as an altered state of health in a family member (e.g., traumatic brain injury in male) can have several ramifications on the family system with respect to its "boundaries, goals, patterns of interactions, or values" (Ibid., p. 5). It is the family's cognitive appraisal of the severity of the stressor (traumatically brain-injured male spouse/parent) or transition and their available

resources to cope with and meet the demands of the stressor that will determine the family's ability to maintain its stability and prevent disruption of the family system (McCubbin & McCubbin, 1987). To be eligible for the study a subject must be: 1) male, 2) incurred a mild to severe traumatic brain injury, 3) experienced some degree of psychosocial or physical sequelae in response to the head injury, 4) attained the age of 20 to 40 years old, 5) been living in the home with spouse and at least one child for at least three to six months post discharge from a rehabilitation facility, 6) able to verbalize, 7) alert and oriented to time, person, and place, and 8) able to read and write in English.

#### B. <u>Spouse:</u>

Spouse is either the male or female component of a legally bound marital dyad. For the purpose of this study, the spouse is the female married to a TBI male as defined by the eligibility criteria.

### C. <u>Family:</u>

Taylor (1988) defines the family as "not a homogeneous unit but a network of dyads, alliances, and subsets" (p. 5). Taylor (1988) elaborates four

characteristics of family relationships that comprise family dynamics as noted by Carmichael:

- Affinity which describes the closeness (cohesion) or lack of closeness (disengagement) and includes emotional and physical bonds,
- 2. Intimacy is a form of sharing,
- Reciprocity describes the give and take within the family unit,
- 4. Continuity which is an important characteristic of family dynamics and is consistent with the Ransom and Vandervoort (1973) definition of family as "a significant group of intimates with a history and a future"

(Taylor, 1988, p. 5).

Whaley and Wong (1989) propose Mauksch's (1974) definition of family as being one of the most complete and describes family as "the coexistence of more than one human being involving continuous, presumably permanent, sharing of living facilities, a perception of reciprocal obligations, a sense of commonness, and sharing of certain obligations toward each other and toward others" (p. 56). Whaley and Wong (1989) define family as "the relationships between dependent children and one or more protective adults and...implies relationships with other dependent selves, that is, siblings" (p. 56).

Miller (1980) defines the family as a "social system since it is a structural complex of elements among which there are patterned relationships" (p. 5). The family social system possesses distinct properties of wholeness, nonsummativity (interrelatedness of system parts), and equifinality. Equifinality implies that there is a circular causality among members of the family unit since the behavior of one member affects the first member, and so forth (Miller & Janoski, 1980). Terkelson (1980) defines the family as "a small social system of individuals related to each other...and members enter through birth, adoption, or marriage, and leave only by death" (p. 23).

For purposes of this study the family will be defined as a social system consisting of the traditional nuclear family headed by two legally married adults who have one or more children and at least one child is residing at home. The presence of a

child/children in the home creates added demands on the family system of the brain-injured male. This project is not setting any restriction on the age of the child residing at home.

#### D. <u>Family Functioning:</u>

Smith and Miller (1987) define family functioning in terms of physical, affectional, and social responsibilities. These three family obligations are actually components of the family's two major functions which they describe as instrumental and expressive functions. According to Smith and Miller (1987), instrumental functions include individual and family developmental tasks, definition of roles in the family and social structure, and socialization of children to "acquire knowledge and develop the skills, attitudes, and competence that enable them to function in society" (p. 13). Expressive family functions include establishing lines of communication; formulating rules of behavior for the individual in the family and in society; instilling beliefs, values, and norms in the individual; and developing a loving, caring relationship among family members (Smith & Miller, 1987). Smith and Miller (1987) state that:

... the family is a prime source of the belief systems, value systems, and norms that determine an individual's understanding of the nature and meaning of the world, his or her place in it, and how to reach his or her goals and aspirations (p. 13).

Taylor (1988) defines family functioning as the ability of the family: 1) to provide support to each other (including physical, emotional, and social support); 2) to establish autonomy and independence for each person in the system which facilitates personal growth; 3) to create rules that determine how individuals behave within the family system and society; 4) to adapt to change in their internal and external environments; and 5) to communicate with each other through verbal and nonverbal methods.

Smilkstein (1978) defines family functioning as "the process of nurturing that promotes emotional and physical growth and maturation of all members" (p. 1232).

Feetham defines family functioning as "those activities and relationships among and between persons

and the environment which in combination enable the family to maintain itself as an open system" (Roberts & Feetham, 1982, p. 231). She developed the FFFS (1988) which measures 21 specific indicators of the construct of family function across three relationship systems as noted by Factors One, Two, And Three.

Family systems that contain a brain-injured parent at home may be confronted with several new stresses on their unit such as: 1) increased demands on the parental role of the uninjured parent, 2) altered communication patterns between the marital dyad and between each parent-child dyad, 3) restructuring of each family member's role(s) and responsibilities within the family system, 4) reformulation of the family system's rules, values, norms, expectations, and goals for each member and the entire family unit. These new demands on the family system may necessitate change(s) in the unit's family functions. For example, it may no longer be feasible for the family to send a school age child/children to a parochial school or to finance older children's college education. The family budget may sustain further cutbacks if the working wife has to partially or completely eliminate outside

employment so she can meet the patient's care requirements as well as assuming her additional family roles/responsibilities created by BI male's injury. McCubbin and Figley (1983) note that the strength of the family unit's "bonds of coherence and unity (common interests, economic interdependence, and affection) running through the family life" (p. 9) will permit the family to restructure itself and adapt to the change(s) in its system created by having a BI male at home. This reflects the family unit's degree of family integration.

Family adaptability is the "family's capacity to meet obstacles and shift its course of action" (Ibid., p. 10). The family's available repertoire of resources, ability to effectively mobilize resources, and ability to utilize coping skills will enable the family to respond to the new demands placed on it's system in response to new stresses. If the family was a closed system with limited resources prior to the BI male's injury, it may not have the ability to effectively adapt and restructure in response to its new demands and a crisis situation may result for the family. Given such a scenario, a closed family system with limited resources could potentially disrupt in response to this stress. Open family systems with adequate resources (e.g., social, cultural, religious, economic, educational, and medical resources) would be in a better position to restructure itself and adapt to the additional demands caused by the husband's illness (McCubbin & Figley, 1983).

The degree of cohesion is reflective of the degree of family integration or "the emotional bonding that family members have toward one another and the degree of individual autonomy they experience" (Olson & McCubbin, 1982, p. 49). Cohesion includes the concepts of "emotional bonding, boundaries, coalitions, time, space, friends, independence, decision making, interests, and recreation" (Ibid., p. 49). All of these concepts may be altered to varying degrees in family systems containing a BI male depending on the type and severity of his residual deficits. The recreational activities of each spouse and child may be limited due to the patient's care needs, family's embarrassment of patient's impaired social behavior, mental, and/or physical disabilities, or fear of patient by family friends and relatives. New

subsystems and coalitions may develop in the family if the father has been severely impaired by the head injury. Significant cognitive impairment of the male spouse may permanently alter his decision making roles as a parent and as the head of the household.

The concept of family functioning will be operationalized in this project by utilizing: a) the FFFS (1988) to assess a family system's level of function as perceived by the brain-injured male and his spouse across three relationship areas (see Table 8), b) family systems theory in the context of the BI male's family unit, and c) Imogene King's nursing theory to assess the interactions between BI male and his spouse in the context of their family system and each subject's perceptions of their family unit's level of family function. (The project's theoretical frameworks will be discussed in Chapter Two).

#### <u>Assumptions</u>

This descriptive, retrospective study dealing with a specific segment of the brain-injured population will include the following assumptions: 1) the level of family functioning in families caring for a chronically
ill spouse is measurable, 2) that the questions in the instrument will have face and construct validity, 3) that the respondents will understand the questions and give truthful answers, 4) that the BI male will have adequate cognitive ability to respond to the FFFS (1988), and 5) having and caring for a BI male at home is a stressor which impacts on the level of family function. Levels of family functioning will be assessed among families who have had to care for a BI male in the home for at least three to six months post discharge from a rehabilitation facility.

# **Limitations**

The major limitations of this study are: 1) The small number of participants in the pilot study limits the forms of analysis and generalizability of the project's results. 2) A convenience sample will be utilized in this project which can result in biased results. Consequently, generalization should not be made beyond this group. 3) The study focuses only on a select segment of brain-injured adults (males between the ages of 20 to 40 years old). 4) There is no measurement of premorbid level of family function to compare to the post-injury level of family function.

5) Other intervening variables could affect both respondents perception of the level of family function such as respondent's denial of illness' impact on family unit, hope that the patient will continue to further recover, and negative self-image if she/he is head of household and family is floundering. These variables are not addressed in this study.

### IMPORTANCE AND SIGNIFICANCE OF THIS PROJECT

Brooks (1984) and Cole, Cope, and Cervelli (1985) state that caring for a brain-injured relative at home causes great psychological and physical stress on the BI patient and family unit. The family unit caring for a BI person who has suffered a high degree of mental handicap is prone to disruption of family cohesion (Bond, 1975; 1976). The application of empirical family assessment tools in the care of the BI patient and their families facilitate a better understanding of families based on quantifiable, measurable clinical research methods (Bishop & Miller, 1988). Information collected from this research project will provide background data for those working with BI patients and their families in the home setting as well as being an impetus for further research in this area.

Chapter One has provided an introduction and overview of this research project and discussed key concepts of family functioning relevant to families with a BI male at home. Chapter Two will delineate the theoretical framework which will provide the foundation for this project. Chapter Three will review the relevant literature on this topic. Chapter Four will provide a description and discussion of the methodology and design used for this study. Project results will be discussed and summarized in Chapter Five. Implications for advanced nursing practice and future research will be presented in Chapter Six.

# CHAPTER TWO

### Theoretical Framework

### <u>Overview</u>

In this chapter, the conceptual framework of the research study will be discussed. The conceptual framework of family systems theory will be related to King's conceptual model and theory of goal attainment for nursing practice.

Griffin (1980) states that although "any physical illness can assume a variety of forms, the usual context in which illness occurs and is resolved is the family" (p. 245). Since the family is a system of interrelated, interdependent parts, a change in one member of the family causes change to occur in other members (Miller & Janoski, 1980; Griffin, 1980). Consequently, illness not only alters the life of the patient but also alters the interdependent structures and functions of the family system, such as relationships, roles, and communication patterns (Griffin, 1980; Lezak, 1988). Behavioral alterations caused by traumatic brain injury compromises the quality of patients' lives and also affects the wellbeing of the family systems. Lezak (1988) states that family distress following head injury has been well documented..."emotional burdens and family disruptions are experienced by the immediate family" (p. 111). The changes in personality and functional mental and physical capacities of brain-damaged patients coupled with changes in families' financial and social situations "tend to create significant emotional and practical burdens on these patients' close family members" (Ibid., p. 111). Lezak states that the nature and severity of problems experienced by family members will differ from family to family depending on:

> ....premorbid cohesiveness, family attitudes about illness and responsibility, and financial and social supports. It will also differ among family members, with the person who assumes the role of primary caretaker frequently carrying the greater part of the burden; while the severity of stress on other family members most typically varies

according to their capacity for independence from the patient and primary caretaker (Lezak, 1988, p. 111).

Ultimately family functions and processes including decision making, determining policies and rules, acknowledging feelings, providing support and nurturance to family members, can be altered by the patient's illness (Sedgwick, 1974; in Griffin, 1980). As Griffin (1980) points out, the patient's illness represents a change in one part of the family system which necessitates compensatory change(s) in other parts. Family adaptability and cohesion are key factors which help to maintain the family system, especially, when illness and its associated stressors impact on the family system (Lezak, 1988; McCubbin & Patterson, 1983; McCubbin, H. & McCubbin, M., 1987; Olson & McCubbin, 1982; Olson, Sprenkle, & Russell, 1979).

This chapter will attempt to define the conceptual frameworks of family systems theory (see Table 1) and the concepts of King's theory of goal attainment. Connections between the illness of a family member (brain-injured male) and its perceived effect on the family unit's level of family function will be made by interrelating the major concepts of the proposed conceptual frameworks.

### Definition of Concepts

### of Family Systems Theory

Walsh (1982) notes that family systems theorists conceptualize the family as an "open system that functions in relation to its broader sociocultural context and that evolves over the life cycle" (p. 9). McCubbin and Figley (1983) emphasize that a family's available resources play a significant role in the family's ability to adapt to a stressor event and prevent it from becoming a crisis. A family unit needs to have an open system with permeable boundaries to maximize its access to social, economic, cultural, religious, educational, and medical resources in response to stressors on the family system (McCubbin & McCubbin, 1987; McCubbin & Patterson, 1983). King also views her conceptual framework as three interacting systems: personal systems (individuals); interpersonal systems (groups); and social systems (society) (George, 1985; Fitzpatrick & Whall, 1983; King, 1981). Miller

(1980) states that the family is classified as a social system since it is a structural complex of various elements among which are patterned relationships. Table 1

Circular Causality Nonsummativity Suprasystems/Subsystems Equifinality Dyads/Triads Communication Positive/Negative Feedback Rules, Values, Norms Entropy/Negentropy Family Roles/Tasks Homeostasis/Steady State/ Boundaries Dynamic Equilibrium Open/Closed Systems Morphogenesis/Morphostasis Disengagement Permeability of boundaries Enmeshment Multiple Goal-setting

Concepts in Family Systems Theory

Several concepts are inherent to family systems theory. The concept of <u>circular causality</u> denotes that there is a circular chain of influence within the family system. Since a family is comprised of a group of interrelated individuals, a change in one member causes a change in other family members and the group as a whole; i.e., for every action, there is a reaction in the family in a circular pattern (Walsh, 1982). For the purpose of this study, circular causality will be viewed in terms of the perceived change(s) that the brain-injured male's illness has created in the patient, other family members, and the family system as a whole.

Family systems are characterized by the concept of <u>nonsummativity</u>. The family is defined as a whole unit of interrelated parts and is greater than the sum of its parts. Walsh (1982) states that the family organizational and interactional patterns involve "an interlocking of the behavior of its members" (p. 9). Miller (1980) notes that it is the family's interdependence which is crucial to its survival since it allows self-interest and family interest to be mutually dependent. The expression of interactional patterns connects the various subsystems of the family system. Families of brain-injured patients undergo a change in their interactional patterns in response to the patient and each other (Lezak, 1988). The spouse of a brain-injured patient often perceives that patient

as being different from the person that he/she married, and thus, relates differently to the patient than he/she did premorbidly (Lezak, 1988; Mauss-Clum & Ryan, 1981; Rosenbaum & Najenson, 1976; Bond, 1975; 1976). Lezak (1988) stated that despite the quality of the interactional pattern between the marital dyad premorbidly, most healthy spouses report deterioration of sexual relations with the brain-damaged spouse. Frequently the brain-injured spouse will have decreased or absent libido or lacks the sensitivity to make sexual relations a mutually satisfying experience. The healthy spouse, usually the primary caretaker, often becomes the target of the patient's anger, frustrating behavior, paranoia, verbal and/or physical abuse (Lezak, 1988).

Lezak further notes that any enduring behavioral alteration of the patient makes it difficult for other family members to reintegrate the patient into the family system (1988). Family members need to relinquish old perceptions, affectional and reactional patterns connected with the patient and establish new perceptions and interactional patterns so that the

patient can be reintegrated into the family (Lezak, 1988).

The concept of <u>subsystems or components</u> denotes the interrelatedness of elements within the system (Kast & Rosenzweig, 1981). For this project, the brain-injured patient, the marital dyad, parent-child dyad/triad are all subsystems of the family system. The family is a subsystem of a suprasystem(s) which comprise(s) various social systems (work, church, school, health care) and the environment.

The concept of <u>equifinality</u> implies that the "same origin may lead to different outcomes, and the same outcome may result from different origins" (Walsh, 1982, p. 9). This concept is pertinent to family systems theory in that the "influence of initial conditions or events will be outweighed by the impact of the family organization - its ongoing interactional patterns and responses to stress" (Ibid., p. 10). The family genogram can be a very useful tool in operationalizing this concept. The genogram can be used in conjunction with family systems theory to denote interactional/relationship patterns within the family, roles, cross-generational life review, identify

potential stressors (e.g., illnesses), and to identify the potential for family dysfunction in response to stressors (McGoldrick & Gerson, 1985).

<u>Communication</u> is a key concept to all three conceptual frameworks. All behavior exhibited by members of the family systems creates communication. Communication serves two functions in the family system: to relate factual information and to define the nature of the relationship and roles through the formulation of family rules, policies, values, norms, or mutual agreement (Walsh, 1982). As Miller (1980) notes, family members convey feeling through affective communication and relay information via instrumental communication. "Disturbed families usually have difficulty with clarity and directness of communication in both the affective and instrumental areas" (Miller, 1980, p. 10). The brain-injured person (e.g., male) may suffer personality changes, impaired social perceptions and social awareness resulting in aberrant behavior, and impaired control resulting in expression of impulsive or acting-out behavior (Lezak, 1988). These psychosocial changes in the patient make communicating and interacting with family members and

others a very difficult situation. Relatives and friends often find the patient's personality and behavioral changes to be annoying, frightening, and unacceptable. Consequently, the patient and family members can become isolated from social systems, thereby, making their boundaries less permeable to receive input from interpersonal and social systems which may help them cope with the demands on the patient and family system better. Communication patterns with the family system can become disrupted in response to the patient's altered behavior (Mauss-Clum & Ryan, 1981; Lezak, 1988; Brooks, 1984).

The concept of <u>feedback</u> according to Miller (1980) is the process whereby the family gathers information about its level of functioning. Information regarding the outputs of the family system is fed back into it as an input which could perhaps lead to changes within the family system's transformation process and/or future outputs (Kast & Rosenzweig, 1981). The family system's outputs to its environment are in the form of information, behavior, or energy. Feedback helps the system to maintain a steady state or homeostasis. Feedback can either be negative or positive. <u>Negative</u>

<u>feedback</u> indicates that the system is deviating from its prescribed course and needs to readjust to a new steady state (Kast & Rosenzweig, 1981).

The concept of homeostasis (steady state, dynamic equilibrium) is the dynamic ability of an open system to cope with environmental stressors by allowing its boundaries to be penetrated by stressor(s) to achieve a steady state within the system. The stressors can create <u>entropy</u> which is a movement towards disorder, lack of resource transformation (available energy within the system) and can result in death of the system (Kast & Rosenzweig, 1981). In open systems, Kast and Rosenzweig state that entropy can be arrested and transformed into negative entropy (negentropy). <u>Negentropy</u> restores order (available energy for system) and organization out of chaos (entropy). The family system's strengths (coping mechanisms) allow it to respond to stressors and maintain the system's equilibrium or restore it to negentropy rather than becoming dysfunctional. Families of brain-damaged males experience multiple stresses including financial strain, social isolation, loss of emotional supports, restricted independence, physical and emotional illness

in response to caring for the affected family member (Lezak, 1988). If the family's strengths are inadequate to meet the demands of the stressors, family members may experience psychological and/or physical illness, interactional patterns breakdown, family disruption, and even divorce may occur between the marital dyad (Mauss-Clum & Ryan, 1981; Lezak, 1988; Bond, 1975).

Maintenance of a stable family system is facilitated by the concept of <u>family rules</u>. Implicit and explicit rules define and organize roles, relationships, and family interactions. Family rules function as norms within the system and are used to measure behavior (Walsh, 1982). The traumatic brain injury of a male who serves as the head of a household can place the family system in flux and necessitates redefinition of each family member's role, relationship in the system, and interactional patterns between BI male and family members (Griffin, 1980; Rogers & Kreutzer, 1984; Brooks, 1984; Stavros, 1987).

The concept of <u>boundaries</u> is a major component of systems theory. Chin (1969) defined boundaries as a "line forming a closed circle around selected

variables, where there is less interchange of energy (e.g., communication) across the line of the circle than within the delimiting circle" (Miller, 1980, p. 8). Boundaries resemble rules by determining who can participate within the system or subsystems and to what extent interactions can occur. Boundaries separate the systems from their environments.

An important characteristic of boundaries is their degree of permeability (penetrability) which determines the extent of openness or closedness of the system. Boundaries vary from being rigid, impenetrable (disengaged) to being diffuse, highly penetrable (enmeshed) (Miller, 1980; Kast & Rosenzweig, 1981; Olson, Sprenkle, & Russell, 1979). Family systems with diffuse boundaries have overinvolved family members and do not encourage autonomy or nurture individual growth. Systems with rigid (closed) boundaries have limited interchange between the subsystems and between its environment and social systems. During stressful events, the amount of entropy within a closed system may increase to the extent that it becomes highly disorganized, dysfunctional, disrupts, and dies. Miller (1980) states that the functions of boundaries

are to maintain the family system in a state of equilibrium, regulate the inflow of energy or information into the system according to its ability to cope with inputs from outside the family system, and permit the family system to adapt to changes, restructure itself, and grow. Boundaries can serve healthy and unhealthy functions within the system (Ibid., 1980). Subsystems may form within the system that permit limited communication with components of that subsystem (e.g., parent-child) thus blocking effective interactional patterns among all members of the family system. Families of brain-injured males are prone to having strong parent-child subsystems develop between healthy spouse and child (children). The altered personality and cognitive functions of the head-injured male may temporarily or permanently disrupt normal interactional patterns between the marital dyad and between the parent-child dyad/triad (Mauss-Clum & Ryan, 1981; Stavros, 1987; Livingston & Brooks, 1988).

The family system's ability to be flexible to adapt and reorganize (change) its structure in response to internal and external stimuli in its open system

reflects the concept of morphogenesis. The family system that is endowed with a greater repertoire of coping mechanisms will be better able to respond and adapt to these stressors (McCubbin & Figley, 1983; McCubbin & Patterson, 1983; McCubbin, H. & McCubbin, M., 1987; Olson & McCubbin, 1982). The brain-injured patient's family system will need to be receptive to a multitude of external stimuli to assist them in providing optimal care of their loved one as well as providing support in various ways to the entire family system. The sudden nature of the male's traumatic brain injury bombards the family system with multiple internal and external stimuli to which the system must respond, adapt, and restructure itself. Alternatively, the system can fail to adequately respond to these stimuli or maladapt to these circumstances and become dysfunctional and/or disruptive.

The concept of <u>multiple goal-setting</u> is relevant to biological and social systems since they appear to have multiple goals and purposes (Kast & Rosenzweig, 1981). Kast and Rosenzweig (1981) noted that social organizations seek multiple goals "if for no other reason than that they are composed of individuals and

subunits with different values and objectives" (p. 35). Goal seeking is conceptually related to both theoretical frameworks. As Miller (1980) points out, all families have implicit and explicit goals (e.g., producing and nurturing children). Family goals reflect family values and norms. Family (and individual) goals may vary according to the stage of the family life cycle (Miller, 1980). Family systems under stress seek to mobilize their resources and use coping mechanisms to successfully respond and adjust to stressors to achieve the goal of maintaining homeostasis within the family system. Adaptation of the family system to the stressor event(s) may necessitate a restructuring of the family unit. The restructuring process acts as the impetus to formulate new family goals including redefining family roles, responsibilities and tasks, communication patterns, and system boundaries. The family goals of client systems of brain-injured males should be directed towards strategies that promote an optimal level of patient and family function.

### Nursing Theoretical Framework

Imogene King (1981) developed a theory for nursing based on an open, interacting systems model. Her conceptual model and theory of goal attainment provides the theoretical framework for application of the nursing process to brain-injured males and their families. King's model and theoretical framework will be used in conjunction with family systems theory to analyze the perceived effect on the family unit's level of family function by having a traumatically braininjured male in the home. Assessment of families in this target population by applying concepts inherent to both theoretical frameworks will lead to observation of how and to what extent the brain-injured male's illness and care at home affects the family unit's level of family function. Application of the underlying concepts of King's theory of goal attainment can serve as a model for designing nursing care objectives and interventions specific to this client system.

Imogene King has been a major contributor to the development of nursing theory. Through her research

and writings, she has sought to provide a systematic conceptualization of nursing theory and establish a scientific basis for the discipline of nursing (Fitzpatrick & Whall, 1983). The philosophical assumptions of King's model (see Figure 1) include:

Individuals are social, sentient,
 reacting, perceiving, controlling, purposeful
 action oriented, time-oriented beings (King,
 1981, p. 143).

2) The perceptions, goals, needs, and values of the nurse and client influence the interactional process (King, 1981).

3) Individuals have a right to knowledge about themselves and to accept or reject health care (King, 1981).



# Figure 1. A Conceptual Framework for Nursing: Dynamic Interacting Systems.

Note. Toward a Theory for Nursing (p. 20) by I. M. King, 1971, New York: John Wiley & Sons. Copyright 1971 by John Wiley & Sons, Inc. Reprinted by permission.

4) Individuals have a right to participate
in decisions that influence their life,
health, and community services (King, 1981).
5) Health care professionals have a
responsibility to share information with
individuals that assists them in making
informed decisions regarding their health
care (King, 1981).

;

6) Incongruence may exist between the goals of health care professionals and the goals of the recipients of health care (King, 1981).

### Definition of Concepts

The focus of King's conceptual framework is the individual (personal system) interacting with other individuals/or groups (interpersonal systems) and with the environment (social systems) (King, 1981). The concept of person views man as an open system interacting with the environment. Both systems' boundaries are permeable and allow an exchange of matter, energy, and information to occur (King, 1981). The individual is a reacting being capable of

perceiving, thinking, feeling, making decisions, choosing alternative actions, setting goals, and determining the means to achieve goals through active participation in the nursing process (King, 1981).

According to King (1981), human beings react to persons, objects, and events in terms of their own perceptions (p. 20). Perception is defined as each person's unique representation of the base of one's selective input of stimuli from the environment (King, 1981). Perception is a process by which information is organized, interpreted, and transformed to influence one's behavior, provide a sense of reality and give meaning to one's experiences (King, 1981). Each person's perception of the environment is based on a spatial-temporal relationship with one's environment, level of individual development, and integrity of one's nervous system (King, 1981). An individual's perceptions are influenced by past events, values, needs, and one's role and status in the family and other social systems (King, 1981). Cognitive learning enhances perception and knowledge influences perception (Allport, 1955 and Bruner, 1973, in King, 1981). The effectiveness of actions is increased by the accuracy

of one's perceptions (Fitzpatrick & Whall, 1983).

Perceptions enable the individual to develop a concept of self and body image. <u>Self</u> is a person's collective awareness of the sum of one's total being including values, ideologies, beliefs, commitments; the central core of one's identity (Jersild, 1952, in King, 1981). Body image and self are related concepts. Body image is the mental picture one has of one's self (Schilder, 1951, in King, 1981). One's concept of body image is dynamic since it evolves over the growth and developmental cycle of the organism. "Body image is a person's perception of his own body, others' reaction to his appearance, and is a result of others' reaction to self" (King, 1981, p. 33). One's perception of self and body image may become altered by trauma, illness, and threats against one's being (King, 1981). Health care professionals may be asked to share their expertise with patient and family systems to help them respond effectively and cope with changes.

Nursing helps "individuals maintain their health so they can function in their roles" (King, 1981, p. 4). King defines nursing as a "process of action, reaction, and interaction, whereby nurse and client share information about their perceptions in the nursing situation" (p. 2). Specific goals, problems, and concerns are identified by the nurse and client through purposeful communication. Together they interact to assess the problem(s), explore purposeful strategies to resolve them by developing mutually satisfying goal-directed behaviors (King, 1981).

King's conceptual framework is composed of three interacting systems as previously noted. The stellar focus of her theory of goal attainment is the nurseclient interaction (interpersonal system). Major concepts of the theory include interaction, perception, communication, transaction, role, stress, growth and development, time, and space (King, 1981). The focus of this project will be the interactions between the interpersonal system of the marital dyad within the context of its family system as related to pertinent concepts of King's nursing theory and conceptual model.

Interaction is a dynamic process involving perceptions, values, nonverbal and verbal communication, and transaction between person and person or person and environment (King, 1981, in George, 1985). An individual brings one's own set of

beliefs, values, ideas, and perceptions to the interaction. Each individual comes to the interaction for a purpose and perceives each other, makes a judgment, reacts (intangible), and formulates a transaction (goal) (King, 1981). Interactions and transactions are observable processes; reaction is not. (See Figures 1, 2, and 3)

The interpersonal system is composed of two or more persons interacting within a particular situation. The two individuals react to each other and the situation to determine and achieve goals and communicate. The pertinent concepts of interpersonal systems are interaction, communication, transaction, role and stress (George, 1985). Communication is the "structure of significant signs and symbols that bring order and meaning to human interactions" (King, 1981, p. 62). Transactions are interactional processes that transfer something of value between two or more persons or between persons and environment. Communication between nurse-client in the transactional process results in goal-directed behaviors (King, 1981). Role is a "set of behaviors expected of one or more individuals interacting in specific situations for a



Figure 2. King's Representation of the Process of Human Interaction.

Note. <u>Toward a Theory for Nursing</u> (p. 92) by I.M. King, 1971, New York: John Wiley & Sons, Inc. Copyright 1971 by John Wiley & Sons, Inc. Reprinted by permission.



purpose" (King, 1981, p. 93). The role that an individual has within an organization is defined by rights, rules, obligations, and procedures specific to one's position within the organizational structure (King, 1981).

Stress is an interactional process between the human being and one's environment "to maintain balance for growth, development, and performance" (King, 1981, p. 147). Stress involves an expenditure of energy by the organism in response to a stimulus. "Stress is an energy factor in open systems that is increased and decreased by stressors in man-environment interactions" (King, 1981, p. 98) King further defines stress as:

> ...a dynamic state whereby a human being interacts with the environment to maintain balance...which involves an exchange of energy and information between the person and environment for regulation and control of stressors. Stress is negative and positive. It helps people reach the highest level of achievement and at the same time continuously wears them down (pp. 98-99).

Increased stress upon individuals decreases their perceptual field and rational decision making ability. The nurse-patient interaction and resultant transactions occur in an effort to control and regulate the stressors in the patient's interaction between himself/herself and his/her environment by developing goal-directed behaviors to achieve mutually desired outcomes (goals). The interaction between the nurse and the brain-injured patient/family system should be directed towards sharing information by communicating perceptions, problems, and concerns. (See Figure 2) Based on this exchange of energy and information, the nurse and patient should formulate transactions that would establish goals that would enhance the patient and family member's perceptions of each other, facilitate reintegration of the patient into the family system, and promote an optimal level of patient/family system functioning. Goal attainment is the end result of the interactional process between the nurse and client based on each person's perception, judgment, action, reaction, interaction, and transaction. Transaction is the observable transfer of something of value between two or more persons (Fitzpatrick & Whall,

1983). The active participation of both parties in the transactional process produces goal-directed behaviors which enable goal attainment. King's (1981) human interactional process model has a feedback loop that enables system outputs to be fed back into the system (see Figures 2 and 3).

Individuals interact with social systems to execute societal role expectations (e.g., going to school, work, church) and perform functions of daily living (Fitzpatrick & Whall, 1983). Organization, power, authority, status, and decision making are key concepts of social systems and are relevant to the nursing process (King, 1981).

# Relationship of King's Theory

## to Family Systems with Brain-Injured Males

King's conceptual model and theoretical framework will be integrated with the family systems conceptual framework. Several of the key concepts from King's nursing theory and conceptual model of mutual goal attainment will be operationalized in this study by use of the Feetham Family Functioning Survey (1988) to assess the perceived level of family function in these

family systems as perceived by the brain-injured male and his spouse when the patient is living in the home (at least three to six months post-discharge from a rehabilitation facility). The patient's altered perception of self/body image in response to head injury coupled with the family's altered perceptions of the patient and family system may make reintegration of the patient into the family unit difficult. The evaluation of the patient's family system by use of systems concepts and King's conceptual model of human interactions/interacting systems and theory of goal attainment, will provide information that may enable the health professionals to develop mutual goaldirected behaviors that restore the family system to a state of dynamic equilibrium. King's interactional model can be used to identify patient's and family system's perceptions and judgments about the illness, family resources, cohesiveness, and adaptability to cope with stressors.

King's theoretical concepts will be applied and related to this research project by examining the brain-injured male/patient's and spouse's perceptions of his traumatic brain injury (see Figure 4) with



Areas of Relationships" by C.S. Roberts and S. L. Peetham, 1982, Nursing Research, 31, p. 234. Note. The data in columns I, II, and III are from "Assessing Family Functioning Across Three Copyright 1982 by American Journal of Nursing Company. Reprinted by permission.

# SIMPLIFIED VERSION OF APPLICATION OF KING'S THEORY TO THE BRAIN-INJURED MALE, HIS SPOUSE, AND FAMILY FUNCTION AS PELATED TO THE CONCEPTUAL MODEL OF RESEARCH PROJECT Figure 4.

respect to: 1) the patient's and his spouse's perception of his degree of rehabilitation (functional recovery), and 2) patient's and spouse's perception of the effect on the family unit's level of function related to having a brain-injured male in the home. The scope of this project will be limited to focusing on the interrelationships of the marital dyad and its perception of level of function in their family system across three relationship areas. (See Figure 4)

Figure 3 depicts a more comprehensive schemata of the moderating variables (body image, illness, financial strains, and family resources) impacting on King's interpersonal system (family subsystem/marital dyad) of the brain-injured male and his spouse and their family system. The right side of Figure 3 depicts the intervening variables which affect each member of the marital dyad and his/her interactions with each other. All of the moderating variables depicted in Figure 3 impact on the marital dyad and family system. These variables may influence how the spouse perceives and is able to cope with the braininjured male's level of rehabilitation and reintegration into the family system/marital
relationship. If the spouse has significant personal health problems, then she will likely have decreased energy to meet the care demands of the brain-injured male. The primary focus of this research project will be limited to assessing each member of the marital dyad's perceived effect of specific components of each moderating variable upon each other's and their family system's level of family function based on the indicators of family function measured by Factors I, II, and III (see Figure 4).

The left side of Figure 4 illustrates the members of the family system (TBI male and spouse) who are the subjects chosen for this project and have been asked to give an assessment of their family system's perceived level of function at a given point in time since the husband's brain injury. The marital dyad's assessment of their family's perceived level of function is measured across three relationship areas which assess several indicators of family function as denoted under Factors I, II, and III in the middle of Figure 4. The right side of Figure 4 illustrates the dependent variable, family function. The family system's perceived level of function, as denoted by the marital

dyad, will be quantitatively assessed by their completion of the FFFS (1988). The FFFS (1988) will enable the researcher to quantitatively assess the BI male's and spouse's perceptions of family resources (i.e.: support systems and recreational activities), family strains (i.e.: problems with children, child(ren)'s absence from school, disagreements with spouse, and amount of assistance needed to perform family tasks), financial strains, body image, and amount of his/her illness(es). Actually, the respondents' assessment of their body images and their system's financial strains may be reflected indirectly by their measurement of patient's and spouse's abilities to do household chores, work outside the home, time spent in pursuit of leisure/recreational activities, and own illness(es), et cetera.

This project is focusing on (see Figure 3, left side) the level of family function as perceived by the BI male and spouse. The additional family roles, caregiving roles, tasks, and responsibilities that the spouse may have to assume will influence the amount of perceived disruption to family routines. The spouse's openness to interaction with interpersonal and social

systems will determine how effectively she will be able to mobilize and utilize available support systems (family resources). If friends and other relatives perceive the BI male's level of rehabilitation unfavorably, the spouse may isolate herself from these support systems. The spouse may attempt to minimize the BI male's limitations, increase his dependency on her, or have unrealistic expectations for his further improvement.

All of the moderating variables in conjunction with the feedback system impact on the individual perceptions of the BI male and spouse (see Figure 3). Less energy expenditure will be required for mutual goal attainment between the marital dyad if the individual perceptions within the dyad are congruent (Brooks, 1984; Livingston & Brooks, 1988; Brooks, Campsie, Symington, Beatties, & McKinlay, 1986; Lezak, 1986, 1988; McCubbin & Figley, 1983; McCubbin, H. & McCubbin, M., 1987). If the dyad's perceptions are congruent, then the feedback system will provide positive reinforcement and potentially strengthen their relationship. When the marital dyad's perceptions are incongruent and they are unable to identify mutual

goals, increased stress between the marital dyad and within the family system will likely occur. As the stress increases within the dyad/family system, entropy, disruption, and death of the family system may occur unless effective interventions are developed to mobilize family's resources (coping mechanisms), open lines of communication between the marital dyad and all family members, perceptions are altered to realistically deal with the couple's situation, mutually satisfying goals are identified, and strategies/goal-directed behaviors are enacted which promote mutual goal attainment. Chapter Six will delineate specific nursing interventions that can assist the marital dyad in growth producing transactions.

Chapter Two has presented family systems theory and King's theory of goal attainment to provide a conceptual framework for this research project. Chapter Three will review the relevant literature of traumatic brain injury, rehabilitation, chronic illness, and family function as related to this project.

## CHAPTER III

#### REVIEW OF THE LITERATURE

### Introduction

The purpose of this chapter is to present a scholarly review of the literature relevant to the concepts of traumatic brain injury, rehabilitation of brain injury patients, and family functioning in the context of chronic illness. The studies that will be identified will be related to: 1) initial assessment and classification of head-injured patients and predictive outcomes, 2) biopsychosocial sequelae of head injury and rehabilitation problems, and 3) the family system in response to chronic illness and disability in a brain-injured adult male spouse.

Although head injury and its sequelae has been a major health problem, until the 1970's only limited attention has been directed to research in this area of

the neurosciences. The bulk of the research related to head injury and its sequelae has been derived from the efforts of Dr. Bryan Jennett, a professor of neurosurgery at the University of Glasgow, and his research team of clinicians and scientists. He provided the impetus for the establishment of a multinational coma data bank involving centers in Great Britain, the Netherlands, and the United States (established in the late 1970's). Research regarding the family and traumatic brain injury is limited and there is definitely a need for more research in this Several family function assessment tools are area. available but have not been applied to assessing families dealing with traumatic brain injury. Bishop and Miller (1988) have evaluated several empirical family assessment techniques that may have merit in assessing families with a member who has a traumatic brain injury. The literature review will consist of two sections: 1) traumatic brain injury with a subsection on rehabilitation of brain-injured patients, and 2) the family system's functioning and response to chronic illness, specifically, in the context of traumatic brain injury with three subsections focusing

on the brain-injured spouse and the altered role performance of the brain-injured spouse and its impact on the family system's structure. A discussion of a family function assessment tool which may be applicable for use in this target population is also presented.

### TRAUMATIC BRAIN INJURY

Neuroscience literature regarding early management of acute, severe head injury is plentiful. In addition to the effective early treatment of head-injured patients, Dr. Jennett and his research team sought to identify and categorize the degree of head injury, predictive outcomes, types and severity of disabilities as sequelae to head injuries and their long-term consequences (Jennett, 1984 in Brooks, 1984).

Several empirical studies have shown that the type, severity and location of brain damage after injury determine the effects on the patient in both the acute and late stages (N=948, Jennett, Teasdale, & Braakman, in Bond, 1983; N=593, Jennett & Teasdale, 1981; Bond, N=56, 1975; N=56, 1976; N=56, 1978; N=42, McKinlay, Brooks, & Bond, 1983). Neurosurgeons have focused their attention on effective early treatment of

possible causes of brain damage in head injury because this <u>critical</u> period can have the greatest potential in making a difference in the patient's outcome (Teasdale & Mendelow, 1984; N=593, Jennett & Teasdale, 1981; N=581, Marshall, Toole, & Bowers, 1983).

Brain damage is either primary or secondary. Diffuse brain damage after head injury is receiving more emphasis now than syndromes produced by focal lesions (e.g., penetrating missile-type injuries) (Adams, Graham, Murray, & Scott, 1982, in Teasdale & Mendelow, 1984).

Diffuse axonal injury in the white matter is now thought to be the most important mechanism of primary traumatic brain damage (Teasdale & Mendelow, 1984). These injuries generally result from rotational acceleration forces (e.g., such as incurred during motor vehicle accidents) being exerted on the mobile, incompressible brain as it impacts against the rigid cranial vault.

The types of lesions that may occur subsequent to head injury include: 1) contusions which have a preponderance for the frontal and temporal lobes given the resultant forces exerted between the brain and the

bony separations of the anterior and middle cranial fossae, 2) extracranial/extracerebral hematomas (i.e., scalp and epidural, respectively), and 3) intracranial hematomas (i.e., subdural and intracerebral). Hydrocephalus (an increased accumulation of cerebrospinal fluid within the brain's ventricular system) can also be a sequelae to head injury if the cerebrospinal fluid absorption pathways become obstructed by blood. Secondary brain damage can occur due to these subsequent lesions or other intracranial factors resulting from a head injury: 1) brain edema, 2) infection, and 3) hydrocephalus, or from extracranial factors: 1) hypoxia (associated with chest injuries) and 2) hypertension (associated with other systemic injuries). The mechanisms responsible for secondary brain damage are either hypoxia/ischemia or a shift with distortion or compression of brain tissue regardless of the causative factor (Teasdale & Mendelow, 1984; N=593, Jennett & Teasdale, 1981). Consequently, vigilant attention and treatment must be directed to the early treatment of head-injured patients to prevent tissue ischemia and necrosis that could result in brain damage. The most common

indicator of status after head injury is the patient's level of consciousness. Teasdale's and Mendelow's (1984) theoretical study reported that deep, persistent coma indicates severe, diffuse axonal damage; transient loss of consciousness, as in mild concussion, reflects diffuse axonal injury without permanent structural damage to axonal fibers.

The research of Jennett, Teasdale, and associates in the 1970's produced scales (quantitative and qualitative types) that enabled: 1) the objective measurement of the depth and duration of coma as a prediction of prognosis after severe head injury (Glasgow Coma Scale) (Teasdale & Jennett, 1974 and 1976) (see Table 2); 2) prognostic determination of severity of head injury and sequelae based on length of post-traumatic amnesic period (based on PTA scale of Russell, 1932; refined in 1946 and 1961) (see Table 3); and 3) outcome scale of brain-damaged survivors reflecting overall social capability of patient based on the physical and neuropsychological deficits at six months and one year post-injury (Glasgow Outcome Scale) (Jennett & Bond, 1975) (see Table 4). Outcome after head injury is influenced by multiple factors based on

the complexity of the individual case. This gives merit to the use of formal predictive systems (such as developed by Jennett and colleagues) in determining prognosis after head injury (N=486, Teasdale & Jennett, 1981).

Table 2 Glasgow Coma Scale

Eye Opening		
Spontaneous	E	4
To Speech		3
To Pain		2
Nil		1
Best Motor Response		
Obeys	M	6
Localizes		5
Withdraws		4
Abnormal Flexion		3
Extensor Response		2
Nil		1
Verbal Response		•
Orientated	v	5
Confused Conversation		4
Inappropriate Words		3
Incomprehensible Sounds		2
Nil		1
Coma Score (E + M	+ V) = 3	to 15

<u>Note</u>. From "Management of Head Injuries" by Jennett and Teasdale, 1981, Philadelphia, F.A. Davis Company. Reprinted with permission.

Duration of Post Traumatic Amnesia Period	Severity of Head Injury		
Less than 5 minutes	Very Mild		
5 to 60 minutes	Milā		
1 to 24 hours	Moderate		
1 to 7 days	Severe		
1 to 4 weeks	Very Severe		
More than 4 weeks	Extremely Severe		

Table 3Post-Traumatic Amnesia Scale

<u>Note</u>. From "Management of Head Injuries" by Jennett and Teasdale, 1981, Philadelpha, F.A. Davis Company. Reprinted with permission. Table 4 Glasgow Outcome Scale for Head Injury Survivors

Classification	Definition
Persistent vegetative	Nonsentient state. No evidence of meaningful psychological response, may breathe spontaneously, have periods of spontaneous eye opening, respond to noxious stimuli with decerebrate or decorticate posturing.
Severe Disability	Conscious, needs assistance to perform ADLs (activities of daily living). Dependency is usually due to a combination of mental and physical deficits.
Moderate Disability	Independent but disabled. Can do self-care but some limitation in previous capacities (e.g., work/social).
Good Recovery	Independent. Able to resume normal work and social activities. Minor physical and/or mental deficits may be present.

<u>Note</u>. From "The Measurement of Outcome" by Bryan Jennett in "Closed Head Injury, Psychological, Social and Family Consequences", 1984, Oxford, Oxford University Press. Reprinted by permission.

The results of empirical studies executed by the three multinational coma data banks have identified factors with varying degrees of predictive power in outcome after severe head injury (N=56, Bond, 1975, 1976, and 1979; N=30, Rosenbaum & Najenson, 1976; N=89, Brooks & Aughton, 1979; N=593, Teasdale & Jennett, 1981; N=581, Marshall, et al., 1983; N=33, Lezak, 1986; N=581, Bowers-Marshall, et al., 1988). The multinational study defined severe head injury as a: 1) Glasgow Coma Scale score of 8 or less following nonsurgical resuscitation or deterioration to a Glasgow Coma Scale score of less than 8 within 48 hours post head-injury and 2) "as one followed by at least six hours of coma, either immediately after impact, or after an interval of complete or relative lucidity" (Teasdale & Jennett, 1981, p. 319; Marshall, et al., 1983).

The multinational coma data bank has taken over 12 years to collect data on 1,500 severe head injury patients. Jennett and Teasdale's (1979) study reported the results (as shown in Table 5) of severely head injured patients six months post injury from the three countries participating in the coma data bank program.

Glasgow n=593 *	7	Netherlands n=239 %	Los Angeles n=68 %
Dead	48	50	50
Vegetative	2	2	5
Severe Disability	10	7	14
Moderate Disability	18	15	19
Good Recovery	23	26	12

Table 5	Severely Head-Injured	<u>Patients:</u>
	Outcome at Six Months	in Three Countries

<u>Note</u>. From "Management of Head Injuries" by Jennett, Teasdale, Braakman, et al., 1981. Reprinted with permission.

Bowers-Marshall's, et al., 1988 updated report of the results of the multinational coma data banks study further substantiates the results of Jennett and Teasdale (1987) that age has a strong predictive power with respect to mortality rate and degree of recovery in survivors of severe head injury (60% of U.S. Coma Data Bank patients were less than 30 years old; 50% of the multinational study patients were less than 30 years old). Jennett and Teasdale (N=593, 1981) report a continuous relationship between increasing age and bad outcome (death or vegetative state) in the Data Bank series.

Empirical studies have also shown that depth and duration of coma have a strong predictive power in prognosis of outcome in severe head injury (N=593, Jennett & Teasdale, 1979 and 1981; N=581 Marshall, et al., 1983; N=581, Bowers-Marshall, et al., 1988). Studies of outcomes associated with best level of responsiveness in the first 24 hours after coma revealed the following:

57 patients with Glasgow Coma Scale of greater than 11 = 12% dead or vegetative, 87% moderate disability or good recovery;

190 patients with Glasgow Coma Scale of 8/9/10 = 27% dead or vegetative, 68% moderate disability or good recovery;

525 patients with Glasgow Coma Scale of 5/6/7 = 53% dead or vegetative, 34% moderate disability or good recovery, and,

176 patients with Glasgow Coma Scale of 3/4 = 87% dead or vegetative, 7% moderate disability or good recovery.

In survivors, the post-traumatic amnesia period provided a permanent marker of duration of altered consciousness. Teasdale's (1981) study revealed that duration of post-traumatic amnesia period in 486 severely head-injured patients was closely correlated to outcome (see Table 6).

Post Traumatic Amnesia Period	n	Severely Disabled %	Moderately Disabled %	Good Recovery १
< 14 Days	101	0	17	83
15-28 Days	96	3	31	66
> 28 Days	289	30	43	27

Table 6 PTA and Outcome at Six Months

<u>Note</u>. From "Prognosis After Head Injury" in Management of Head Injuries by Jennett and Teasdale, 1981, Chapter 14. Reprinted with permission.

Jennett and Teasdale's (1981) report on results obtained from patients in the multinational data bank program indicated that factors less strongly related to outcome were autonomic abnormalities (e.g., respiratory, cardiovascular and thermoregulatory dysfunction), intracranial hematoma, skull fracture, side of cerebral hemisphere damage (right or left cerebrum), and cause of injury (e.g., alcohol, fall, motor vehicle accident, work or assault).

A major limitation of the research studies executed by Jennett and his Glasgow colleagues as well as all participating centers in the multinational program has been the method of reporting admissions to emergency centers. Patients admitted to emergency departments with significant injuries may have succumbed from these injuries before they were able to be assessed for any degree of associated head trauma (Jennett and Teasdale, 1981).

The purpose of the multinational data bank program is to collect data longitudinally on a large number of head-injured patients to help provide information regarding: 1) quality of survival of various types of head injury, 2) the impact of rapid and aggressive preadmission and emergency room care, 3) identification of early predictors of clinical course and outcome, 4) usefulness of monitoring intracranial pressure (ICP),

5) clinical course of patients treated for intracranial hypertension, 6) sequelae associated with degree of head injury, and 7) rate of functional recovery from sequelae of head injury (N=593, Jennett & Teasdale, 1981; N=581, Marshall, et al., 1983; N=42, Brooks, 1984; N=33, Lezak, 1986.)

Rehabilitation of Patients with Traumatic Brain Injury

Rehabilitation is defined as "the restoration of patients to their fullest physical, mental and social capability" (Editorial in Scottish Medical Journal, 1972). Rehabilitation services for the traumatically brain-injured patient are often inadequate since major emphasis tends to be directed to one's physical disability rather than one's emotional, social and intellectual disabilities (N=56, Bond, 1975, 1976, 1979; N=35, Bond, Brooks, & McKinlay, 1979; N=42, McKinlay, Brooks, & Bond, 1983; N=57, Livingston, Brooks, & Bond, 1985a, 1985b; N=41, Sbordone, et al., 1984; N=98, Livingston, 1987; N=89, Brooks & Aughton, 1979; N=54, Oddy, Humphrey, & Uttley, 1978; N=30, Rosenbaum & Najenson, 1976; N=33, Lezak, 1986, 1988). Rehabilitation literature pertinent to traumatic brain

-injured patients and their families identifies significant sequelae that brain-injured patients experience in response to the head injury and the concomitant problems that are experienced by their family systems.

Bond (1975, 1976, & 1979) studied the psychosocial outcome of 56 severely brain-injured patients (male=47, female=9). Ages ranged from 15 to 64 years, posttraumatic amnesia ranged from 0 to greater than 13 weeks. He examined the patient through use of the Wechsler Adult Intelligence Scale (WAIS) for psychometric testing and a neurological examination (including past psychiatric history and current mental status) was also performed. Patients tested were at least three to 24 months post-injury. Study results were displayed in three assessment scales: neurophysical, mental and social. Memory impairment, changes in personality from pre-morbid state, and presence of mental symptoms (e.g., aggression, increased irritability) were evaluated on the mental scale; the social scale reflected changes in work status, leisure activities, family cohesion, sexual behavior, and development of alcohol abuse or

criminality subsequent to head injury. The absence or presence of neurological deficits were evaluated on the neurophysical scale. His study revealed that duration of post traumatic amnesia period (post traumatic amnesia period > four weeks) correlated highly with the degree of social. mental and physical impairment incurred by the patient. Age and amount of brain tissue damage are also associated with increased severity of intellectual impairment, especially memory (Bond, 1975, 1976, & 1979; Brooks & Aughton, 1979; Lezak, 1986, 1988; Jennett & Teasdale, 1981; Livingston, et al., 1985a, 1985b; Brooks, 1984). Comparison of handicaps showed a significant correlation between degree of social and mental (r=.54, p=<.0001) and social and physical handicaps (r=.48, p=<.0001) but not between mental and physical handicap (r=.24, p=NS). Physical handicap was associated with impairment of work capacity, but not with degree of family cohesion, pursuit of leisure activities, or level of sexual activity. Intellectual recovery after severe brain injury revealed that an IQ level of not greater than 80 points was achieved by patients with a post traumatic amnesia period of greater than 12 weeks;

scores did not change significantly at six months and at 13 months post injury. Verbal IQ scores showed rapid return in patients with a post traumatic amnesia period of greater than seven weeks; slower return in patients with post traumatic amnesia of eight to 11 weeks; little return of intellectual capacity in patient with PTA of equal to or greater than 12 weeks. Performance scores revealed the same pattern as verbal scores with an extended rate of recovery for these complex skills. A major limitation of this study was that premorbid psychometric test results were unknown for these patients. Major conclusions from Bond's research were: 1) degree of social disability in 56 severely brain-injured patients was significantly related to neurological and physical handicap, and degree of mental impairment, 2) length of PTA associated with degree of social, mental and neurophysical disability, 3) social disability was primarily due to memory impairment, personality and physical handicaps, 4) rapid return of all intellectual skills (to varying degrees depending on duration of PTA) occurred within the first six months post injury, 5) personality changes and symptoms of mental illness

were not significantly related to intellectual capacity, and 6) family cohesion appeared resistant to physical disability but less resistant to mental impairment and personality changes (Bond, 1975, 1976, & 1979).

Jennett and Teasdale's (1981) report on 593 severely brain-injured patients indicated that based on their Glasgow Outcome Scale (GOS, 1975); 53% had survived at six months post injury, 41% of these patients were categorized as having made a good recovery or were moderately disabled.

Recovery of function is a dynamic process. Review of a large series of head-injured patients categorized as moderately disabled or good recovery on the Glascow Outcome Scale at one year post-injury, revealed that two-thirds had achieved that category at three months post-injury and >90% within six months post-injury (Jennett, 1984). Continued functional recovery can occur six to 12 months post-injury but it generally is indicative of improved social adjustment to disabilities rather than marked decrease in deficits (Jennett, 1984).

Jennett's (1984) retrospective case review of severely head-injured patients (n=150) revealed that 75% had neurophysical deficits (including epilepsy), two-thirds suffered personality changes, and 60% had measurable cognitive deficits.

Hemiparesis was the most common (60%) neurophysical deficit but not considered a major handicap by these patients. Cranial nerve palsies associated with visual loss or disturbance (diplopia), sensorineural hearing loss, and anosmia occurred in one-third of these patients.

Jennett (N=150, 1984) reported that the occurrence of post-traumatic epilepsy varies according to the type of injury and is a serious sequela to head injury due to its social implications. It is less likely to occur subsequent to an extracranial or epidural hematoma since neither the dura is invaded, nor is there direct contact made with the brain tissue. Epilepsy occurs in about one-third of survivors with intracranial hematoma secondary to scarring (Jennett, 1984). Jennett (1984) noted that development of a seizure one week postinjury generally suggests increased liability for further seizure activity. 50% of head-injured patients

who develop onset of late epilepsy do so within one year of injury, but onset can occur as late as four years or more post-injury (Jennett, 1984). These patients have to be maintained on anticonvulsant therapy for seizure control. Legal restrictions as designated in the motor vehicle code of a given state/country may inhibit the patient's driving capability until it can be documented that the patient has had no seizure activity for a defined period of time.

Mental sequelae (including personality change) to head injury pose a more significant handicap than do neurological deficits (N=150, Jennett, 1984; N=593, Jennett & Teasdale, 1981; N=56, Bond, 1975, 1976, & 1979; N=33, Lezak, 1986, 1988; N=98, Livingston, 1987; N=57, Livingston, et al., 1985a, 1985b; N=42, Brooks, et al., 1986; N=54, Oddy, et al., 1978; N=30, Rosenbaum & Najenson, 1976). Jennett and Teasdale's (1981) study found that 70% (n=593) of the conscious patients rated their mental impairment as more significant than their physical impairment.

Bond (1979) reviewed a decade of research regarding physical and psychosocial sequelae in brain-

injured adults and late recovery. He classified the process of recovery from head injury into three stages: 1) Stage I, lasting days to weeks after injury during which the patient is unconscious and efforts are directed to physical care; 2) Stage II, subdivided into IIA (< three months), end of PTA and IIB (< six months) involves the period of maximum recovery of basic physical and mental functions. During Stage II, Oddy, et al., (N=54, 1978) noted that the patient was more concerned about physical impairments but relatives revealed that mental changes in the patient created the greatest burden on the family (N=56, Bond, 1975, 1976, & 1979; N=35/89, Brooks & Aughton, 1979; N=54; Livingston, et al., 1985b; N=42, Brooks, et al., 1986; N=30, Mauss-Clum & Ryan, 1981; N=33, Lezak, 1986). Stage III (> three to six months): Final levels of disabilities are evidenced with only further change occurring slowly. During this phase, the patient and family have to adapt to residual deficits and develop coping behaviors (Bond, 1979).

Bond (1979) noted that in Jennett's (1978) study of 150 severely brain-injured patients and their families in the Glasgow area who were in the third

stage of recovery that mental deficits overshadowed physical deficits in more than 50% of these patients irrespective of their final outcome based on the Glasgow Outcome Scale. One-third of these patients (N=150) had physical handicaps that were the predominant deficit as sequelae to their head injury (Jennett, 1978). The results of Jennett's (1978) study concluded that 97% of these 150 patients had some form of mental or physical handicap, two-thirds of these patients had experienced changes in personality and cognitive ability (Bond, 1979). Reportedly, "marked changes in personality were noted in patients who had little or no physical handicap" (Bond, 1979, p. 157).

Bond's (1979) review of the 54 severely braininjured patients studied by Oddy, et al., (1978) revealed that those researchers also concluded that their families reported mental changes as being the predominant symptom in these patients at three months post-injury and imposed the greatest burden on their families. Oddy, et al., (1978) used the Wechsler Adult Intelligence Scale (WAIS) to test the cognitive abilities of these patients at six months post-injury. The 54 patients were categorized according to outcome

on the Glasgow Outcome Scale (see Table 4). Based on their performance on the WAIS, Oddy, et al., (1978) noted that non-verbal and verbal memory was the most commonly reported mental handicap in these patients. The next most commonly disturbed cognitive function in their patient study was complex visuo-spacial tasks (Oddy, et al., 1978).

Lezak (1986 and 1988) further substantiated this psychological sequelae to traumatic brain injury experienced by patients and families. The patient's behavioral changes can be significant enough to cause serious adjustment problems and disruption or disintegration of the family system (Lezak, 1986, 1988). Lezak (1986) studied 33 traumatically braininjured male subjects and their families to determine psychological sequelae incurred by patients and families, family's perception of patient and family's expectation of patient's recovery. She conceptualized the process of the family's reaction to the patient evolving over six stages (from 0-1 month to > 24 months since hospitalization). Lezak (1986) identified family counseling interventions appropriate to each stage that would enable counselors to help families of brain-

injured patients adapt to the emotional and social problems caused by the head injury. She reported that in a study of 33 traumatically brain-injured males (Lezak, et al., 1980) that 46% of their family members had reported a deterioration of patient's significant relationships within 6 months post-injury; 76% reported this finding at 7-12 months; and 81% noted this finding by 24 months post injury (Lezak, 1986). Rosenbaum and Najenson's empirical study (N=30, 1976) of the wives of soldiers who fought in the Yom Kippur War revealed that the wives of the brain-injured soldiers went through a crisis period at one year after the husband's injury (Lezak, 1986). The wives of the Israeli soldiers noted at that point in time that they had given up hope for their husbands' full recovery and realized that they had to face "living with a person whose needs are great while he can give little in return" (Rosenbaum & Najenson, 1976, p. 881). She noted (1986 and 1988) that profoundly impaired brain-injured patients have decreased capacity for self-awareness and selfappreciation due to the severity/extent of brain tissue damage. Consequently, mild to severely brain-injured patients often have an altered perception of their

ability, appearance and behavior. The patient's altered perception of self can cause significant hardship to other family members. Loss of emotional support from relatives and friends, financial strain, restricted independence, marital conflict and divorce, and isolation are social problems typically experienced by families of brain-injured patients.

The study conducted by Brooks, et al., (1986) in a review of the families of 42 brain-injured patients at one and five years after injury noted the interval change of the ten patient problems most frequently reported by relatives (see Table 7). Several trends in problem areas were noted at five year follow-up: 1) continuing personality change increased from 60% to 74%, 2) overall level of continuing memory problems increased from a mean of 1.6 to 2.9, 3) dependency (mostly requiring someone to be at home only to supervise patient) increased from a mean of 1.3 to 2.3, and 4) increased report of disturbed behavior (including bizarre, violent, criminal or inappropriate social behavior) from a mean of 2.0 to 3.7.

Problem	Percent Relatives Reporting		
	1 Year	5 Years	
Personality	60	74	
Slowness	65	67	
Poor Memory	67	67	
Irritability	67	64	
Bad Temper	64	64	
Tiredness	69	62	
Depression	51	57	
Rapid Mood Change	57	57	
Tension and Anxiety	57	57	
Threats of Violence	15	54	

<u>Table 7</u> <u>Common Problems of Head-Injured Patients at One</u> <u>Year and Five Years After Head Injury</u>

<u>Note</u>, From "The Five Year Outcome of Severe Blunt Head Injury: A Relative's View" by Brooks, Campsie, Symington, Beattie and McKinlay, 1986, <u>Journal of</u> <u>Neurosurgery, 765.</u>

Mauss-Clum and Ryan's (1981) study of 30 families of brain-injured men identified similar patient problems and family reactions as noted by the Scottish investigators. Mauss-Clum and Ryan had asked these families to respond to a questionnaire that dealt with issues experienced at the time of the patient's injury (including type of help received and needed) and longterm experiences (including changes in the patient, family reactions, and coping aids) post-injury. Nineteen wives and 11 mothers responded to the questionnaire. Feelings of frustration, anger, irritability, annoyance and depression were expressed by over 50% of the mothers and wives in their sample (n=30). Divorce was considered or filed for by onethird of the wives. Violent and/or abusive behavior expressed by the patient was experienced by 54% of the mothers and 47% of the wives in this sample.

In summary, the literature supports that the physical and, perhaps more importantly, psychological sequelae of traumatic brain injury creates significant problems for the patient and his family system. These sequelae can act as significant stressors which may hinder the patient's attainment of optimal rehabilitation as well as impact on the family system's level of functioning.

# FAMILY SYSTEM RESPONSE TO CHRONIC ILLNESS AND DISABILITY IN A BRAIN-INJURED SPOUSE

The focus of this section is to discuss how the chronic illness/disabilities of a brain-injured family member impacts the family system and the family's system response to these stimuli. A review of the

literature relevant to chronic illness in this context and family functioning will be discussed. A discussion of a family function assessment instrument which may applicable for use with this patient population will also be presented.

Chronic illness is a treatable, but not curable disease process (Zarski, et al., 1988). It is an impaired state of health evidenced by the following characteristics: 1) it is permanent, 2) it leaves residual disability(ies), 3) is caused by irreversible pathologic alterations, 4) it requires special training of the person and family for rehabilitation, and 5) may require an extended period of care, observation, and supervision (Stuifbergen, 1987).

Impact of Brain-Injured Spouse on the Family System

The severity of residual disabilities of the brain-injured patient may change over time, necessitating change in the prognosis, treatment, and functional capabilities of the patient (N=593, Jennett & Teasdale, 1981; N=56, Bond, 1975, 1976, & 1979; N=42 Brooks, 1984; N=42, Brooks, et al., 1986; N=45, Zarski,

et al., 1988; N=57, Livingston, Brooks, & Bond, 1985a, 1985b; N=33, Lezak, 1986, 1988). Initially, the catastrophic impact of chronic illness/disability can create disequilibrium in the lives of the patient and his/her family system which may result in a family crisis (London & Smith, 1982; McCubbin & McCubbin, 1987). The patient's chronic illness/disability can place the family unit into a crisis situation depending on the family's perception of the stressor(s) and whether or not existing family resources are adequate to meet the demands placed on the family system (Hill, 1958; McCubbin & McCubbin, 1987). Consequently, the long-term management created by the changes of chronic illness/disability generates stress within the patient and family system which can lead to disorganization, disruption, morphogenesis, or death of the family system (Stuifbergen, 1987; Zarski, Hall, & DePompei, 1987; Zarski, et al., 1988; McCubbin & Thompson, 1982; Olson, Sprenkle, & Russell, 1979; Olson & McCubbin, 1982; Bond, 1983; Reiss, Gonzalez, & Kramer, 1984; Penn, 1983; Koch-Hattem, 1987; Roberts & Feetham, 1982; Bubolz & Whiren, 1984). The family's cognitive appraisal of the level of threat that the patient's

illness/disability imposes on its well being will depend on the adequacy of the system's resources to meet and cope with the added demands (stresses) placed on it due to the spouse's impaired health. Demands on family systems vary as do the available resources to meet these demands. Consequently, the level of stress response to a patient's chronic illness will vary also (Lazarus & Folkman, 1984).

The crisis period associated with the diagnosis of brain injury in a family member has two general phases: acute and chronic. The acute phase occurs immediately at the time of injury and lasts a few days (or possibly weeks); the subsequent chronic phase is characterized by further functional recovery of the patient and more adaptive coping by the patient and family (N=56, Bond, 1975, 1976, & 1979; N=150, Jennett, 1984 ; N=42, Brooks, 1984; N=30, Mauss-Clum & Ryan, 1981).

Familial responses during the acute phase after head injury have not been well documented in the literature. Initially, family members express gratitude that their loved one is alive. Families also react with anger, shock, resentment, denial, and sadness to the traumatic event (Rogers & Kreutzer,

1984; Mauss-Clum & Ryan, 1981; Jennett, 1984; Brooks, Theoretical works conducted at medical centers 1984). caring for brain-injured patients and their families have reported that the nature and severity of the traumatic brain injury creates stress in the family system which may interfere with the family's ability to process information, maintain family functions, mobilize resources, and utilize coping skills (Elliott & Smith, 1985; Rogers & Kreutzer, 1984; Zarski, et al., 1988). Elliott and Smith (1985) noted that multidisciplinary team conferences held weekly and family support groups (called family huddles) facilitated communication and exchange of information between family members and caregivers in the acute setting which resulted in decreased stress on the family system.

The theoretical study by Zarski, et al., (1988) proposed the use of a conceptual model in the counseling of brain-injured patients and their families to develop family-focused interventions which would facilitate their ability to adjust to the patient's illness and cope with additional stresses on the family system. Their work focuses on several key areas related
to family functioning: 1) an examination of the family's organization around the symptoms and the chronically ill patient, 2) the structure of alliances, coalitions, and triangles within the family system, and 3) the family's view of reality in relation to patient and expectations of the patient 1988). The researchers reviewed two cases of head-injured patients and their families utilizing their suggested counseling strategies and were able to create new, effective subsystems within these families to enhance their collective system's functioning (Zarski, et al., 1988). Zarski, et al., (1988) concluded that the adjustment process for a family coping with a chronically ill member is a major event and by using their model, "mental health clinicians can better assess families and develop interventions to effectively alter and improve family capabilities and adjustment" (p. 156). A limitation of their research in determining the effectiveness of their proposed conceptual model, however, is the small number of cases reported in their study.

There is a dearth of literature focusing on the impact of chronic illness/disability on the patient;

however, the impact of chronic illness/disability on the family rather than the individual per se, has not received as much attention in the literature. Research regarding the impact of chronic disability associated with traumatic brain injury on the family system is even more sparse and has been recognized as a crucial area in need of further research efforts (Livingston & Brooks, 1988; Bishop & Miller, 1988; Zarski, DePompei & Zook, 1988; Zarski, Hall, West, & DePompei, 1987; Grinspun, 1987; Stavros, 1987; Brooks, 1984; Bond, 1983; Jennett, 1984). Despite the major concerns created by the psychosocial and physical sequelae to brain injury and its concomitant stresses upon the family system, Brooks (1984) noted that only limited research has been done in this area until a decade ago.

Koch-Hattem's (1987) review of theoretical research in families and chronic illness noted that for the family system to effectively deal with the impact of a traumatically brain-injured member, it has to define what the illness means to the family in view of the family's paradigm, health and illness beliefs, and previous experiences with illness. Stuifbergen's (1987) theoretical research noted that there is a

paucity of empirical studies about the disruptive effect of chronic illness on the family despite ample speculation about this subject.

Theoretical research studies (Olson & McCubbin, 1982; Lezak, 1988; McCubbin & McCubbin, 1987; Koch-Hattem, 1987; Stuifbergen, 1987; Kazak, 1989) have indicated that the family response to chronic illness/disability necessitates a restructuring of family functions in the system including: assignment of new roles and responsibilities; altered communication patterns; changes in family rules, values, and norms; change in allocation of family resources; and altered marital and parent-child subsystem relations. The families of brain-injured persons report that the patient's psychosocial sequelae (specifically personality change and memory impairment) of head injury placed a greater burden on families than residual physical deficits (N=150, Jennett, 1984; N=56, Bond, 1975, 1976, & 1979; N=42, Brooks, 1984; N=92, Brooks & Livingston, 1988; N=30, Rosenbaum & Najenson, 1976; N=33, Lezak, 1986; N=45, Zarksi, et al., 1987). Lezak (1986) studied 33 traumatically braininjured males in her research dealing with developing

effective interventions to help their families cope with and adjust to their reaction to the BI family member. She reported that profoundly impaired patients typically have very limited perception or insight into their dysfunctions. These patients have a decreased sense of self-awareness, self-appreciation, and selfcontrol resulting in their altered perception of personal hygiene and dress, socially acceptable behavior patterns, functional abilities for role and task performance, and ability to function safely and independently without any type of supervision. Consequently, the traumatically brain-injured male spouse's altered perception of reality makes the reorganizing of the family system more difficult (Lezak, 1988). Lezak (1986) developed a paradigm that divided the family's reaction to the BI member into six stages. She discussed appropriate interventions to deal with the problems encountered at each stage to enable both the successful reintegration of the patient into the family system and the family's adjustment to the patient. She concluded that psychological counseling will not protect these families from dealing with the pain and problems associated with each of these stages,

but it can help the BI patients and their families work through each stage more expediently and with less distress (Lezak, 1986). She also stipulated that these families periodically may need psychological counseling even after they have progressed through the sixth stage. Her research did not provide any longitudinal data to indicate how well these BI patients and their families were functioning after progressing through the sixth stage.

Zarski, et al., (1987), conducted an empirical study of 45 spouses or parents of head-injured patients to provide further evidence of the social and psychological impact that this trauma has on the family system. Subjects included seven males (1 spouse; 6 fathers) and 38 females (5 spouses; 33 mothers). The head-injured patients consisted of 33 males and 12 females ranging in age from 14 to 53 years old. Their primary objective was to explore the differences between the various family types on the dimensions of family functioning based on Olson's Circumplex Model (1979). The two main themes in marital and family dynamics that the Circumplex Model focuses on are cohesion and adaptability. They used the Family

Adaptability and Cohesion Scales III (FACES III), the Family Assessment Device (FAD), and the Family Invulnerability Test (FIT) as their measurement tools. Results of the FACES III, FAD, and FIT were analyzed using a one-way MANOVA to determine if there were significant differences between the family types according to the Circumplex Model. They stated that the resulting analysis was not significant, with Wilk's = .39, approximate F=1.56, P=.08. Further analysis to determine if a significant difference existed on the FAD (possible score range of 1 to 4) general functioning variable depending on family function (FACES III), family capabilities (FIT), length of head injury, age, gender, and education was done with oneway MANOVA. It showed that those with FAD score of 3 or 4 (i.e., less functional) had a significantly higher family satisfaction score (X=24.7) than those with a FAD score of 1 or 2 (X=6.6) (Zarski, et al., 1987). They concluded that the results of their study supports the importance of understanding family functioning when examining the family's adaptation to a major stressor, i.e., a head injury (Zarski, et al., 1987). Family satisfaction was the only variable significantly

contributing to general family functioning (Zarski, et al., 1987). Zarski and his colleagues (1987) deduced that "families of head-injured members who successfully adjust to this trauma, reorganize by changing their power structure, role relationships, and relationship rules in response to situational stress" (pp. 38-39).

The studies conducted by the Scottish researchers previously discussed (Bond, 1975, 1976, & 1979; Jennett, 1984; Jennett & Teasdale, 1981; Brooks, 1984; Brooks, et al., 1986; Livingston, 1987) reported that the incidence of head injury is highest among males between the ages of 15 and 35 who are at the developmental stage of establishing and raising families. Most head-injured males have a premorbid history of antisocial behavior (e.g., alcohol abuse and criminal behavior) and were physically active and emotionally immature men prior to injury (Bond, 1983).

# Burden on Spouse

The patient's altered perception of self and the biopsychosocial sequelae of head injury (which may accentuate or ameliorate previous antisocial behavior)

make his reintegration into the family system and resumption of marital and parental roles difficult (Lezak, 1988; Bond, 1983; Brooks, 1984; Brooks, et al., 1986; Mauss-Clum & Ryan, 1981). Bond (1983) noted that in Panting and Merry's (1972) study of 30 severely head-injured patients, there was a 40% divorce rate and 61% of the relatives reported being under stress.

Rosenbaum's and Najenson's (1976) classic study investigated the impact of a brain-injured spouse's disability on the wife at one year after injury. The subjects were 30 Israeli women (10 wives of braininjured men; 6 wives of paraplegics; and 14 wives of uninjured men). All were wives of Israeli soldiers who had fought in the Yom Kippur War and all injured husband's had suffered their disability for one year. A four-part questionnaire regarding family life preand post-injury, husband-wife interpersonal behavior, Marital Roles Inventory, and mood disturbance was admininstered to all wives. One-way factorial analyis of variance was used and showed that wives of braininjured patients reported a greater decrease in various family activities and were significantly more disturbed by these changes than were wives in the other two

One-way analysis of variance applied to view aroups. of current family life revealed a significant main effect for groups (p <.01) except all groups reported no change in contact with their own parents. Wives of brain-injured men reported more dependency behavior exhibited by husband, husband's disability(ies) were a social handicap precipitating loss of social support system, tense relationships with in-laws, sense of isolation and loneliness, decreased sharing of childrearing responsibilities by husband, lack of "father figure" for children, having to assume husband's family responsiblities, and decreased frequency and pleasure in sexual activity (Rosenbaum & Najenson, 1976). Lezak's (1988) theoretical report also cited that the brain-injured patient may experience either an increase or decrease in libido, but the well spouse's perception of and response to the patient may prevent the couple from exercising their marital role expectation of mutually satisfying sexual relations.

The burden on the spouse and relatives of the brain-injured patient was investigated longitudinally at various time intervals of three, six, 12 months, and five-year follow-up by Livingston and Brooks (N=57, Subjects were 57 BI patients and their spouse 1985b). or parent. Relatives of the patients were administered three tests: a general health questionnaire, the Leeds anxiety scale, and the Leeds depression scale. Results revealed that the relatives were found to have significant psychiatric difficulties throughout the year following the patient's injury. Over 30% of the relatives had anxiety levels of clinical significance and had symptoms of persistent malfunctioning. Marital functioning reportedly had deteriorated within three months after the patient was back in the family home. Relatives reported that they did not notice any improvement in the patient and perceived this as a high level of burden throughout the year (Livingston, et al., 1985b).

Altered Role Performance of Brain-Injured Spouse and its Impact on the Structure of the Family System

There is a marked paucity of empirical research dealing with the impact on the structure of the family system in the presence of having a TBI spouse in the home. Consequently, this section is limited to a discussion of primarily theoretical research studies.

As Lezak's (1988) theoretical treatise has noted that the brain-injured patient may be unable to fulfill all the previous responsibilities of his/her parental role, thus shifting a greater parenting burden onto the well parent. This also results in alterations in the parent-child interactional patterns and loss of father figure to the child (Lezak, 1988; Penn, 1983, Zarski, et al., 1988; N=30, Rosenbaum & Najenson, 1976). The child(ren) typically experience(s) a sharp reduction in parental attention from the brain-injured parent, are given additional family roles/responsiblities to perform, experience feelings of shame, anger, and fear towards the impaired parent, and have limitations placed on their participation in extracurricular school activities due to their added family role responsibilities, shame of having friends interact with the impaired parent, and restraints on available family financial resources (Lezak, 1988; Penn, 1983; Zarski, et al., 1988).

Jennett's (1984) review of 150 BI patients revealed that physically and/or cognitively impaired

patients may have experienced alter work performance abilities. Thus, the brain-injured male spouse may be unable to fulfill his traditional role as breadwinner even if he is able to return to gainful employment. He may function at a reduced working capacity due to cognitive, physical, and psychosocial deficits which may necessitate employment on a lower-skilled, lowerpaying job (Jennett, 1984; Koch-Hattem, 1987; Lezak, 1988; Foxall & Ekberg, 1989). The depletion of the family's financial resources by the cost of the patient's medical care may be further negatively affected by his inability to execute his fiscal responsibilities in the family (Koch-Hattem, 1987).

The cost of chronic illness can exact a heavy toll on the family's financial resources, causing them to accumulate debts, possibly lower their standard of living (e.g., move to less expensive housing), decrease social interactions due to expense involved, and alter plans for children's education and couple's retirement (Koch-Hattem, 1987; Lezak, 1988).

Lezak's (1988) observations regarding the braininjured patient's altered perception of his/her deficits and functional capabilities, impaired control

and impulsivity, and structure-dependency needs limit the patient's ability to execute former decision-making powers of his parental and spousal roles (e.g., planning and managing expenditure of financial resources, grocery shopping, taking children to appointments and social functions). The chronically disabled spouse's previous role expectations may be delegated to other capable adults (adult relatives, friends, social support services) in the family system's social network. The longitudinal effects of chronic illness on the family system's social network may result in depletion of social resources to meet the family's ongoing needs (Koch-Hattem, 1987; Lezak, 1988; N=42, Brooks, 1984; N=30, Mauss-Clum & Ryan, 1981). Koch-Hattem (1987) noted that families with chronically ill or disabled members usually adapt more effectively to this stressor if they have an adequate social network to utilize. The family may experience decreased access to social resources due to the braininjured patient's limited social capabilities (Lezak, 1988; Koch-Hattem, 1987; Stuifbergen, 1987).

The communication, interactional and family relationship patterns of the family system are often

altered as a result of chronic illness (Griffin, 1980; Lezak, 1988; Zarski, et al., 1988; Koch-Hattem, 1987; Penn, 1983). New coalitions and binding interactions are formed within the family system between parentchild, child-child and cross-generationally between grandparents, aunt, uncle-child in response to chronic illness (Penn, 1983; Lezak, 1988). These newly formed coalitions (i.e., parent-child) may appear to be a positive adaptation to chronic illness but may actually be representative of a past pathological coalition (spouse-spouse's parent) (Penn, 1983).

The communication patterns within the family system may undergo change in an attempt to deal with the brain-injured spouse's psychosocial sequelae (e.g., increased irritability, frustration, outbursts of anger, decreased cognitive ability) (N=56, Bond, 1975, 1976, & 1979; N=42, Brooks, 1984; N=42, Livingston, Brooks, & Bond, 1985; Lezak, 1988). The impaired communicability of the brain-injured spouse may contribute further to his spouse's feelings of social isolation, marital dissatisfaction, and increased burden of her family roles/responsibilities (Lezak,

1988; Zarski, et al., 1988; N=42, Brooks, 1984; N= 150, Jennett, 1984).

Successful adaptation to chronic illness is fostered by the family's flexibility in communication patterns that enable members to express their feelings and concerns (Zarski, et al., 1988; Koch-Hattem, 1987; McCubbin & McCubbin, 1987). Koch-Hattem's (1985, cited in 1987 text) research on families experiencing childhood cancer noted that families which shared the responsibility of providing emotional support to its members rather than assigning that responsibility to one member adapted better to the illness.

The family's flexibility is viewed as a mental health resource enabling the system to maintain a balance between member and family needs (Koch-Hattem, 1987). It facilitates the restructuring of family rules, norms, and values that allows the system to promote autonomy and meet the developmental needs of all family members (Koch-Hattem, 1987; Zarski, et al., 1988; Stuifbergen, 1987).

Family rules provide the structural framework under which the family functions are executed. Koch-Hattem (1987) noted that family rules may be conceptualized "as the structure through which family members negotiate adaptive changes in the presence of chronic stressors" (p. 39) (McCubbin & Patterson, 1983). Rules provide the guidelines for the family members to express their feelings regarding the impact of the chronic illness on the family unit and to mourn the loss of patient and family as they were and might have been (Koch-Hattem, 1987; Zarski, et al., 1987 & 1988; Reiss, et al., 1984; Stuifbergen, 1987).

# Traumatic Brain Injury and Family Function: Empirical Assessment Methods

The focus of this section will be to present an empirical assessment device which may be useful in evaluating the concept of family function in relation to traumatic brain injury. The exigencies that the health care delivery system exerts on the patient and the family system presently require families to assume an important role in the rehabilitation of their traumatically brain-injured relative. The pivotal role of family issues in the treatment of traumatic brain injury is currently receiving more attention from researchers and clinicians (Bishop & Miller, 1988). Increased emphasis is being placed on the need for objective methods of quantifying family function in traumatic brain injury to assist in judicious resource allocation, determine cost effectiveness of treatment, and justify nonbillable services (e.g., certain social work services) (Bishop & Miller, 1988; Roberts & Feetham, 1982; Zarski, et al., 1988). Bishop and Miller (1988) have noted that increased interest in traumatic brain injury and empirical methods of family assessment have evolved in a parallel manner.

The instrument chosen for use in this project is an adapted version of the Feetham Family Functioning Survey (FFFS). Several researchers have defined family function in a variety of ways yet it remains poorly defined. The operational definition that Feetham has given family functioning in the FFFS is that it "consists of those activities and relationships among and between persons and the environment which in combination enable the family to maintain itself as an open system" (Roberts & Feetham, 1982, p. 231). The holistic conceptualization of family functioning is based on a family ecological systems framework. The FFFS measures family functioning across three relationship areas (family and broader social units, family and subsystems, and family and each individual) using 21 indicators (see Table 8). Previous family functioning instruments (e.g., Family Functioning Index) had examined the relationship area of family and each individual (Roberts & Feetham, 1982).

The revised FFFS (1988) consists of 25 items utilizing the Porter format and two additional openended questions. Feetham studied 102 parents of 70 myelodysplastic infants longitudinally over five time periods from birth to 18 months. Results of her study indicated an increasing family functioning discrepancy score for both parents longitudinally as well as increasing differences between mothers' and fathers' scores at each time period (Roberts & Feetham, 1982). Reliability of the instrument was 0.81 (Cronbach's alpha). The validity of the FFFS was tested using varimax rotation factor analysis. Results of factor analysis supported the validity of the FFFS as a measurement of family functioning across the three relationship areas. Recent correspondence from Dr. Feetham (1990) stated that the FFFS has been used in a

variety of research studies since her 1982 publication. The FFFS has been administered to families with healthy children, families with adult children, families of children with a variety of health problems, and even to single-parent families. This additional research has further validated the validity and reliability of the FFFS as a measure of the construct of family functioning. This project will assess the applicability of the FFFS as a measurement of family function across three relationship areas (as measured by 21 indicators of family function) in families of traumatically brain-injured patients by means of a pilot study. The FFFS has not been previously used to study this target population.

## Summary

In summary, perceived level of family functioning can be qualitatively and quantitatively measured by various empirical assessment tools developed by family therapists and nurse researchers. Greater emphasis is being placed on quantitative measurement devices that can assess the impact of traumatic brain injury on

family systems and the patient. The assessment tool chosen for use in this project has been substantiated as measuring the construct of family function but it has not been applied to TBI patients and their families.

The latest version of the Feetham Family Functioning Survey (1988) was chosen for use in this research project because it: 1) measures family function across three relationship areas rather than one relationship area as measured by the FFI, 2) has been validated as being a reliable and valid instrument for quantitatively measuring the construct of family function, 3) the human ecological systems framework of the FFFS instrument is congruent with the underlying concepts of this project's conceptual framework (i.e., family systems theory, family developmental theory, and King's open systems theory of nursing), 4) has not previously been used to study this target population, and 5) several of the earlier developed family function tools provide qualitative data rather than quantitatively measurable data.

While significant research has been conducted regarding the impact of chronic illness/disability on

the patient and spouse, scarce research has been focused on its impact on the <u>family system</u>. Traumatic brain injury and its sequelae have also escaped the researcher's interest until recently. The logical relationship between the level of family function and impact of traumatic brain injury on family systems has not been investigated to any significant extent. Further research efforts in traumatic brain injury/chronic illness and impact on the family can provide the clinician and family with better guidelines to treat the patient and the family, enhance the optimal rehabilitation of the patient, maximize the level of family function, and more cost effectively utilize resources to treat these client systems. Limited health care resources have given further impetus to researchers to utilize empirical assessment tools which will yield quantifiable outcome measures. This empirical data will enable health care providers to more judiciously and accountably allocate funds in treating the health problems of the traumatically brain-injured patient and his/her family system. This research project will assess the patient's and spouse's perceptions of the level of family function within the

family system according to the study's admission criteria as noted in Chapter Four.

This chapter has been a review of the literature relevant to the concepts of traumatic brain injury and rehabilitation, chronic illness, and family function. Chapter Four will further describe the Feetham Family Functioning Survey instrument as it has been adapted for use with this target population, the sample population, protection of human rights, and proposed methodology for this project. Chapter Five will present and summarize the results of the pilot study. Chapter Six will present areas for further research, implications for advanced nursing practice, and the relevance to the conceptual framework.

## CHAPTER FOUR

# METHODOLOGY AND PROCEDURES

# <u>Overview</u>

The purpose of this project is to assess the level of family function in a family unit containing a traumatically brain-injured (BI) male at home as perceived by the brain-injured male and his spouse. The Feetham Family Functioning Survey (FFFS, 1988 version) was the instrument chosen for this project because it was conceptually consistent with a family systems framework (Bubolz & Whiren, 1984) and measured 21 family functioning indicators across three major relationship areas as noted by Factors One, Two, and Three (see Table 8) (Roberts & Feetham, 1982)

#### Table 8

#### FAMILY FUNCTIONING INDICATORS MEASURED ACROSS THREE

#### RELATIONSHIP AREAS BY FEETHAM'S INSTRUMENT (FFFS)

Factor 1	Factor 2	Factor 3
Relationship between family and individual	Relationship between family and subsystems	Relationship between family and broader social units
Satisfaction with marriage	Emotional support from friends and relatives	Time you are ill
Discussion of concerns and problems with spouse	Talk with friends and relatives	Time spouse misses work (includes housework)
Emotional support from spouse	Help from relatives	Problems with children
Time spent with spouse	Help from friends	Time other children miss school
Satisfaction with sexual relations	Time with neighbors	Time with health professionals
Disagreements with spouse	Time with housework	
Time with children		
Help from spouse		

<u>Note</u>. Above items are ranked according to their factor loading based on varimax rotation factor analysis of the FFFS. The item of time spent in leisure/recreational activities did not have a high loading on any of the above factors.

<u>Note</u>. From "Assessing Family Functioning Across Three Areas of Relationships" by C.S. Roberts and S.L. Feetham, 1982, <u>Nursing Research</u>, <u>1</u>, p. 234. Copyright 1982 by American Journal of Nursing Company. Reprinted by permission. The three relationship areas in which family functioning is measured by the FFFS are:

- The relationships between family and broader social units including the family and community and family and economy (e.g.: schools, employment outside the home, McIntyre, 1966).
- The relationships between family and subsystems--including division of labor, such as housework.
- 3. The relationships between the family and each individual--focusing on reciprocal relationships between husband and wife and parents and children (McIntyre, 1966; Sprey, 1983, in Roberts and Feetham, 1982, pp. 231-232).

The clinical application of the FFFS (1988) was also compatible with the nursing conceptual model and framework used in this project--Imogene King's open, interacting systems model. The methods and procedures used in this pilot project will be examined in this chapter.

# Research Question

The instrument used in this project had been selected to provide information concerning the following research question:

What is the level of family function in a family unit containing a traumatically brain-injured male at home as perceived by the brain-injured male and his spouse?

# Sample

Admission criteria for those subjects included in the sample were: 1) male, 2) had incurred a traumatic brain injury, 2) age 20 to 40 years old, 3) married, 4) at least one child at home, 5) alert and oriented to person, place, and time, 6) able to verbalize, 7) able to read and write in English, 8) living in the home for at least three to six months post discharge from a rehabilitation facility, and 9) the spouse of the BI male who met the above eligibility criteria.

The sample for this project consisted of 9 couples randomly selected from a list of 585 (males=411; females=174) brain-injured patients who were being actively followed in an outpatient program at a western Michigan rehabilitation facility and its satellite clinics. A list of patients being actively followed in the brain injury program was reviewed by the program manager and clinic nurse to identify potential candidates for the sample population. The program manager and clinic nurse randomly selected a total of 40 patients from their active patient list.

Using a table of random numbers, the list of 40 patients were randomized into a list with each patient receiving a number from one to forty. A table of random numbers was then used to select 20 names from the list of 40 subjects. These twenty brain-injured males were contacted by mail by means of a written letter mailed to them by the clinic nurse of the outpatient BI program and by phone to have the study explained to him and his spouse. It was hoped that 10 BI males and their spouses would agree to participate in this pilot study, but only nine couples agreed to do so.

# **Operational Definitions**

For the purposes of this study, subjects were brain-injured males who had sustained a head injury which was the direct result of distinct mechanical factors that had impacted on the brain and caused damage. The wives of the BI male subjects were also included as subjects in this study. BI male subjects were further screened for participation in this project by being required to pass a mini-mental status screening examination as evidenced by their ability to verbalize and appropriately answer simple questions asked by the clinic nurse relating to their orientation to person, place, and time. The BI male's communication skills were also screened by the clinic nurse through her review of the patient's clinical records to determine that he had previously shown that he possessed minimal verbal and written communication skills (as outlined in the admission criteria). Braininjured male subjects and their families were included in the study if they were able to verify by direct questioning that: 1) the patient had been living at home for at least three to six months after discharge

from a rehabilitation facility, and 2) at least one child lived at home (this project was not controlling for the age of the child).

Family function was operationally defined in this study in terms of Feetham's definition as being "those activities and relationships among and between persons and the environment which in combination enable the family to maintain itself as an open system" (Roberts & Feetham, 1982, p. 231). Family function is operationalized and measured in Feetham's instrument (FFFS, 1988) in the context of function as: 1) process (i.e.: communication, socialization, protection, education); b) content (i.e.: communicating family's and society's rules, values, norms; providing nurturance to all family members); and, c) as outcome measures (effective energy transformation of inputs into family system/subsystems and energy outputs from family system/subsystems to broader social system, (i.e.: rearing of children to become responsible, productive members of society) (Roberts & Feetham, 1982). "Families which function effectively are seen as successful in narrowing the discrepancies between what might be achieved and what is achieved" (Duvall,

1971, in Roberts & Feetham, 1982, p. 231). Perceived family function was assessed in this population by having the BI male and his spouse evaluate their family unit on 21 family function indicators as measured across three relationship areas (Factors One, Two, and Three; see Table 8) by using the FFFS instrument (Feetham, 1988) (see Appendix A).

# Procedure

Participants for the pilot study consisted of nine couples randomly selected from the active patient list of a western Michigan rehabilitation facility's brain injury program. The program manager and clinic nurse of the outpatient brain-injury program reviewed the list of BI patients that were being actively followed at their facility. After eliminating the patients who did not meet the research criteria, the program manager and clinic nurse applied a table of random numbers to the active patient list to obtain a total of 40 potential candidates for this study. The list of 40 patients was then randomized into a list with each patient receiving a number from one to 40. A table of random numbers was then used to select 20 names from the list of 40 subjects.

The clinic nurse then mailed a letter to each of the twenty potential couples which explained: 1) the purpose of the study (see Appendix B), 2) the support of the program director/physiatrist and human subjects and research committees at the rehabilitation facility, 3) how to contact the researcher to have the opportunity to ask any questions and express their concerns about the study, 4) assurances of anonymity and confidentiality (letter and attached postage-paid return postcard, expressing couple's desire to either be a participant in the study or not, was be sent out by the rehabilitation facility itself), 4) that the participants had the freedom to withdraw from the study at any time without any risk of penalty or restrictions in the care of the BI patient, his spouse, or his family, and 5) what were the potential risks and benefits of participating in the study. Potential subjects were informed that there were no apparent physical, legal, or economic risks likely to be experienced by any of the participants in this project. However, the brain-injured male and his spouse may

have perceived that he or she could have potentially experienced some degree of psychosocial discomfort related to having to express their feelings regarding past traumatic events and how these events had altered: a) their individual lives, b) their marital relationship and sexual relations, c) their life as a family in terms of what it was prior to BI male's injury, what it is now, and what it may have been if he had not been injured. Since the nature of the research project and content of the FFFS instrument was explained to the BI male and his spouse prior to their agreement to participate in the study, their consent, once given, indicated a willingness on their part to confront these issues. If the BI male and his spouse needed any assistance in dealing with feelings that were conjured up as a result of confronting these issues, appropriate support services were available through the health care staff affiliated with the outpatient brain injury program. It was emphasized that a participant could withdraw from the study at any time without penalty, but if one member of the couple ceased participation in the study, then the other member would also be disqualified from further

participation given the admission criteria of the project. The BI male and his spouse may have perceived potential benefits to be gained from participation in the study as: a) a greater awareness of how illness in the male affects which social support systems are accessed by patient, spouse, and family and to what degree, b) the significance of these support systems as perceived by both respondents, and c) identifying discrepancies between BI male's and spouse's perceived desired amount of an activity and actual achieved amount of an activity and its perceived importance to each respondent. Consequently, participants may have perceived that useful strategies and interventions may have been identified which could help them to more effectively deal with problem areas which might be expressed by their discrepancy scores on the particular items measured by the FFFS under Factors One, Two, and Three (see Table 8). The subjects were informed that they would not receive any remuneration if they agreed to participate in the study. Subjects were informed that they could gain access to the project's results by submitting a written request for this information to the investigator. Subjects were informed that

couples who chose not to participate gave the following reasons: a) too busy, b) waiting to be sent overseas to the Persian Gulf, c) did not want to bring up the past, d) two patients were noncommittal, and d) one patient was completely lost to follow up. Those couples who had expressed their willingness to participate in the study were again informed of the purpose of the study, were given the opportunity to ask questions and express concerns about the study, were given assurances of anonymity and confidentiality, were assured of freedom to withdraw their participation in the study without incurring any penalty, and of the potential risks and benefits that they might experience by participating in the study. Each particpant was then be asked to sign a written form of consent (see Appendix C).

After the consent form was signed, the investigator administered the FFFS (1988) separately to each member of the participating couples at their own homes to assess respondents' perception of family functioning after the BI male had resided in the home for at least three to six months. Each participant was asked to answer all three subsets of each of the 25

questions. The respondent was asked to provide a written or verbal response (which was recorded by the researcher or respondent) to the two open-ended questions. Confidentiality was assured and a code number and either a letter M (for male respondent) or F (for female respondent) was assigned to the questionnaire form filled out by each subject. Approval to conduct the research study was obtained from the Research in Human Subjects Committee at Michigan State University and the Research and Human Subjects Committees at Mary Free Bed Rehabilitation Hospital.

## Instrument Development

The Feetham Family Functioning Survey (FFFS) was used to operationalize and measure perceived family function in this study. The FFFS was developed because of the limitation of existing family functioning instruments to measure only one relationship area, i.e., between the family and each individual (Olson, Bell, & Porter, 1978; Pless & Satterwhite, 1973, in Roberts & Feetham, 1982). The FFFS measures family

function across the three major relationship areas designated under Factors One, Two, and Three (see Table The FFFS measured additional family functions 8). known to be altered in families with children with health problems which preexisting tools did not do (Roberts & Feetham, 1982). The family function indicators were derived from the instrument designer's clinical observations of families with myelodysplastic infants and a review of the family functioning literature (Roberts & Feetham, 1982). For the design of the FFFS, Roberts and Feetham (1982) state that "family functioning consists of those activities and relationships among and between persons and the environment which in combination enable the family to maintain itself as an open system" (p. 231).

The instrument was initially comprised of 21 items and could be self-administered in approximately 10 minutes. Further refinements concerning work disruption and emotional support systems led to a revised instrument consisting of 27 items and two openended questions. The latest revision (1988) of the FFFS consists of 25 items and two open-ended questions which may realistically require approximately 15 to 20
minutes to complete, but not more than 30 minutes to complete. Administration of the FFFS can be done by self-administration or by interview with no significant differences in the distribution of the responses being attributable to either method (Feetham, 1980, in Roberts & Feetham, 1982).

The instrument was constructed using the Porter format which consists of a stem that acts as a referent for three questions. The respondent rates each question on a 7-point scale ranging from little to much (1 to 7). Porter did note that persons with less than a high school education may have difficulty with this format. Studies of mothers with myelodysplastic infants and children conducted by Roberts (1979) and Feetham (1981) supported Porter's contention (Roberts & Feetham, 1982).

Porter's instrument was designed to measure worker's perception of their work environment/situation. The Porter format allows for measurement of the existing degree of need fulfillment, the discrepancy between expected and achieved levels, and the importance of each item to the respondent. The discrepancy score (a-b) is computed for each family

function item. The discrepancy score is the amount of agreement between the activity (a) and the desired amount of the activity (b). Each score is then converted to an absolute score because the difference between "a" and "b" scores is of relevance to the degree of satisfaction with family functioning. Consequently, "scores closest to 0 indicate the greatest degree of satisfaction with family functioning and those farthest from 0 indicate that family functioning is not what it should be as perceived by the respondents" (Roberts & Feetham, 1982).

The importance question (c) can be used as a score to: 1) examine values, 2) examine the relationship of importance of family functions to perceived attainment of the function (Roberts & Feetham, 1982). The clinical application of the importance question can be used to identify priorities for nursing interventions in cases in which the respondent has a high discrepancy score (a-b) and a high importance score (c) (Roberts & Feetham, 1982).

The FFFS permits measurement of change in family functioning over time. Feetham (1980) conducted a study of 103 parents of 70 myelodysplastic infants from

birth through 18 months at five time periods. Results of Feetham's study revealed a "pattern of an increasing family functioning discrepancy score for both parents and an increasing difference between the mother's and father's scores at each time period" (Roberts & Feetham, 1982, p. 233). This project examines the couple's perception of family functioning at post injury after the patient has been in the home for at least three to six months post discharge from a rehabilitation facility. It was projected that this study's results would reveal a difference beween the discrepancy scores of the BI male and his spouse. Given the natural history of head injury and its biopsychosocial sequelae and reported research findings (Brooks, 1988; Mauss-Clum & Ryan, 1981; Bond, 1975, 1976; Lezak, 1986), it was further projected that there would be a probable trend towards increasing differences in the family function discrepancy scores of both respondents and between each respondent if this population was studied longitudinally. It was beyond the scope of this project to study the target population longitudinally but it could serve as the basis for further research.

The FFFS' utilization of the Porter format of a multiple response set has several advantages: 1) it reduces the tendency for a simple response set since it is more difficult for the respondent to manipulate an actual situation to conform to a socially desirable response, 2) it controls for cultural and ethnic diversity since the valuing of each item is done by the respondent (Evans, 1962, in Roberts & Feetham, 1982), 3) it provides an indirect measure of satisfaction (the discrepancy score) with the activity inherent in each item (Porter, 1962, in Roberts & Feetham, 1982).

The two open-ended questions at the end of the FFFS allowed each respondent to further verbalize his/her perceptions of conditions which were beneficial and problematic to them at this time period since the BI male's injury. The data from these questions were analyzed for any patterns of responses among the respondents. The health care professional could use such data to identify interventions and strategies that could provide anticipatory guidance and assistance to future traumatically brain-injured patients and their families.

## **Reliability**

Polit and Hungler (1983) define reliability as the "degree of consistency or dependability with which an instrument measures the attribute it is designed to measure" (p. 621). The use of the FFFS in this study was for the purpose of measuring family function in a family system with a brain-injured male at home as perceived by the BI male and his spouse. Stability, internal consistency, and equivalence are three components of reliability which require further consideration. Stability of a measurement tool means "the extent to which the same results are obtained on repeated administrations of the instrument" (Polit & Hungler, p. 387). Feetham tested the FFFS in both cross-sectional and longitudinal studies of families with normal infants and families with myelodysplastic infants and children. She calculated reliability estimates on 103 mothers of myelodysplastic children using Cronbach's alpha coefficient (Roberts, 1979, in Roberts & Feetham, 1982). Polit & Hungler (1983) define the Cronbach alpha coefficient as a "reliability index that estimates the internal consistency or

homogeneity of a measure composed of several items or subparts" (p. 610). The coefficient alpha is interpreted in the same manner as the correlation coefficient used to measure instrument stability--both reliability coefficients produce a range of -1.00 to +1.00. Higher correlation and alpha coefficients indicate that an instrument is more stable and internally consistent. Internal consistency "refers to the degree to which the subparts of an instrument are all measuring the same attribute or dimension" (Polit & Hungler, 1983, p. 615). Feetham's Cronbach alpha reliability coefficient for the discrepancy score (sum of a-b) was .81, for "a" score was .66; "b" score was .75; "c" was .84--attesting to the instrument's acceptable degree of internal consistency in measuring the indicators of family functioning. Reliability of the stability of the FFFS was further substantiated by a test-retest procedure. Two weeks later 22 of the 103 mothers were retested and the alpha reliability coefficient was .85 indicating a high degree of instrument stability over time (Roberts, 1979, in Roberts & Feetham, 1982).

<u>Validity</u>

An instrument is evaluated by another major criterion--its validity. Validity refers to "the degree to which an instrument measures what it is supposed to be measuring" (Polit & Hungler, 1983, p. The quality of an instrument is assured by its 394). reliability and validity but an instrument's validity is difficult to establish. Content validity reflects the sampling adequacy of the content area being measured by the proposed instrument. Feetham obtained content on family functioning from five sources: a) review of family functioning literature, b) research of families of children with chronic health problems, c) clinical observations of families of children with myelodysplasia, d) test items reviewed by experts in care of children with chronic health problems or e) experts in family theory (Roberts & Feetham, 1982). She pretested the instrument on parents of myelodysplastic children. Then Feetham discussed the instrument with these parents which led to further refinement of the terminology and sequencing of items in the instrument. The FFFS was developed to assess

the level of family functioning of family systems with children with health problems. This study used the FFFS to assess the level of perceived family function in family systems that contained a brain-injured male whose health problems created different ramifications within the family system than those imposed on the families with children with health problems as studied by Feetham (1981).

Construct validity is concerned with what the instrument is attempting to measure--the attribute or concept. Construct validity is difficult to establish, particularly if the concept under investigation is quite abstract. To help substantiate the FFFS' acceptability as an instrument for measuring the construct of family function across three relationship areas versus only one relationship area as measured by other family function instruments, Feetham factor analyzed data collected from 103 mothers of myelodysplastic children. Feetham states that the results of factor analysis of the FFFS using varimax rotation "supports the conceptualization of the instrument (i.e., the FFFS) as a measure of family functioning in the three relationships identified by

McIntyre (1966)" (p. 234), (Factor I: relationship between family and individual; Factor II: relationship between family and subsystem; and, Factor III: relationship between family and broader social units) (Roberts & Feetham, 1982). Roberts and Feetham (1982) stated that only three items had low factor loadings but these were retained in the instrument for further testing. The higher factor loadings of all other test items indicate that they were measuring the same construct of family functioning. This finding supports the FFFS instrument's construct validity as a measurement of family functioning across the three factors.

## Proposed Scoring and Statistical Analysis

The data obtained from the administration of the FFFS was analyzed in an effort to describe and quantify the level of family function in a family unit containing a traumatically brain-injured male at home as perceived by the brain-injured male and his spouse. As noted by Duvall (1971), "families which function effectively are seen as successful in narrowing the discrepancies between what might be achieved and what is achieved" (Roberts & Feetham, 1982, p. 231). The concept of family function was quantified in this study by determining the discrepancy scores (a-b) of each respondent to the items in the FFFS and converting this to an absolute number. Computation of the (a-b) score for each item yielded a possible score range of 0 to 6. The sum of the discrepancy scores across the 25 items had a possible range of 0 to 150. The higher the score, the greater the discrepancy between the actual amount of the activity and the desired amount of the activity, and this implied that the respondent was likely to be dissatisfied with the perceived level of family function (Roberts & Feetham, 1982). The higher the discrepancy score, the more suggestive it is of "greater dissonance among or within the three major areas of family functioning" (Roberts & Feetham, 1982, p. 232).

The data obtained from the responses of the respondents to the two direct measures, "a" and "b", were analyzed in terms of the discrepancy score yielded by the indirect measure (a-b score) for each of the 25 items and a sum of the discrepancy score for the total

FFFS to quantifiably measure each respondent's perceived level of family function.

The sum score of the discrepancy scores of the FFFS for each BI male and his spouse were presented in a table format (see Table 10). The sum score of the discrepancy scores of all the BI males and the sum score of the discrepancy scores of all their spouses were then analyzed collectively. These scores were expressed to reflect their means and percentage of difference between husband's and wife's sum discrepancy scores in a table format (see Table 10). A comparative analysis of the sum of the discrepancy scores between all BI males and all their spouses was then analyzed by using the Wilcoxon ranked-sum score test (see Table 11) and the sign test (see Table 12) which examines the median distribution of signs (based on respondents' sum discrepancy scores) between two groups.

Each couple's collective sum total discrepancy scores on the FFFS was expressed in a table (see Table 13). The collective sum total discrepancy score for all couples was further analyzed by using the Wilcoxon signed-rank test. The absolute difference in the total discrepancy score for each couple was computed and was given a "=" or "-" sign based on the difference between the husband's and wife's scores and then the absolute differences were rank ordered to compare the differences between group means. Given the limitations of this project as a pilot study, these results cannot be generalized to the larger population. General trends in this client population were expressed in a table format and noted in terms of percentages (see Table 14).

The importance score (subset c of each item) provided information that combined with the respondent's discrepancy score yielded both the direction and degree of dissatisfaction with the perceived existing family function as measured (Roberts & Feetham, 1982). Data obtained from the importance question (c) could be analyzed with the respondent's discrepancy score (a-b score) to determine the direction and degree of satisfaction or dissatisfaction with family function in the family unit of the BI male and his spouse as measured by their responses to the items on the FFFS which measured 21 indicators of family function. Results of the importance and discrepancy scores on each of the 25 items for each BI

male and his spouse could be utilized to identify specific problem areas in family function. Consequently, when a high importance score and a high discrepancy score on a given item was reported by the BI male respondent and/or his wife this provided information which could enable the health care professional to identify: 1) the specific family function problem area(s), and 2) priorities for developing strategies and interventions in dealing with this client population. Feetham (1982) states that the relationship of the "professional's perception of the family to the family functioning discrepancy score in the FFFS must be further tested for content validity" She noted that in some instances (p. 234). professionals at the Myelodysplasia Care Center where she conducted her research had reported high family dysfunction based on their clinical judgment (Roberts & Feetham, 1982). A review of the family function discrepancy scores of the parents in question "revealed a score above the mean score for the total sample of parents in the longitudinal study" (Feetham & Roberts, 1982, p. 234). Feetham & Roberts (1982) further state that "when the parent indicated a high discrepancy

score (a-b) on individual family functions, the parent also tended to score the importance question (c) as high on those same functions" (p. 234). Given these research findings, the potential clinical applicability of this instrument warrants further clinical investigation (Roberts & Feetham, 1982). General trends and tendencies towards specific problem areas in this population have been presented in a table format (see Table 14).

The two open-ended questions were analyzed qualitatively based on the BI male's and his spouse's reported assessment of their evaluation of what was helpful (agreeable) and what was difficult (disagreeable) about their present situation. General group trends and differences have been reported in Table 15.

#### Summary

This chapter has discussed the methods and procedures used in addressing the research question: What is the level of family function in a family unit containing a traumatically brain-injured male at home as perceived by the brain-injured male and his spouse? The sample and methods for administering the research questionnaire have been described. Modes of proposed statistical analysis were presented. Chapter Five will discuss the significance of data obtained in the pilot study. Chapter Six will discuss the implications of this project on both advanced nursing practice and areas for further research.

## CHAPTER FIVE

#### <u>Overview</u>

In Chapter V, the pretest sample will be discussed with respect to its sociodemographic characteristics. A summary of the sample's pilot study test results in response to the 25 Porter format type questions and two open ended questions on the Feetham Family Functioning Survey (FFFS, 1988) will also be presented. The participants in this convenience sample were randomly selected patients from an outpatient brain injury clinic at a western Michigan rehabilitation facility and consisted of nine traumatically brain-injured males and their wives.

## Pretest Participants: Sociodemographic Data

Nine traumatically brain-injured males and their wives each completed the FFFS (1988). Male subjects

had to be between 20 to 40 years of age to be included in the study, but the age of the wives was not an eligibility criterion for the study. Male subjects ranged in age from 23 to 40 years with an average age of 32.6 years.

Eight of the nine couples had been married for three or more years prior to the husband's brain The ninth couple had been cohabitating prior injurv. to his injury and have been married since his brain injury (approximately one year ago). Three of the couples had had a previous marriage. Of these three couples, two of the wives had had previous marriages with one offspring resulting from that union and had one offspring from their present marriage. Both husband and wife of the third couple had been previously married and each had one offspring from their previous unions and two offspring from their present union. Offspring of the nine couples ranged in age from one month to 19 years of age. The number of children in each family system ranged from one to five.

Five of the men had returned to full time employment (40 hours or > per week). Three of the five men had returned to their previous jobs, a fourth had

obtained employment in a sheltered workshop, and a fifth had returned to his previous job but was planning to obtain vocational rehabilitation to try to remedy difficulties encountered with his previous job responsibilities dealing with information systems. Two men were employed parttime in relative-owned businesses and worked flexible hours. Two men had been unemployed ever since their head injuries (three and seven years, respectively). Five wives were employed full time outside of the home. Two wives were employed at parttime jobs. One of the latter group was currently on maternity leave, but planned to return to her parttime professional job. The remaining two wives had several small children to care for (four and five, respectively) and were not employed outside of the home.

Eight of the men had completed at least a high school education. Three men had had some additional college education or skilled labor training. One man was dyslexic and had completed his formal education at the tenth grade level. Sociodemographic data is summarized in Table 9.

Table 9Sample Characteristics

<u>N=18</u>	Percent
9	50
9	50
8	89
1	11
3	33
5	56
2	22
2	22
5	56
2	22
2	22
1/0	11/0
8/9	89/100
3/2	33/22
	N=18 9 9 8 1 3 5 2 2 2 5 2 2 2 2 1/0 8/9 3/2

The length of time that the TBI males had been residing at home since discharge from the

rehabilitation facility ranged from 4 months to seven years with a mean of 3.5 years.

## Feetham Family Functioning Survey (1988): Pilot Study Test Results

The Feetham Family Functioning Survey (1988) (see Appendix A) presented in Chapter IV is designed to measure the construct of family function across three relationship areas (see Table 8). The results of the participants' responses to the FFFS (1988) will be presented as descriptive data. Nonparametric statistical tests, i.e., the sign, Wilcoxon ranked-sum, and Wilcoxon sign-ranked tests, were chosen because the instrument's scale was based on ordinal numbers rather than on a continuous interval scale.

The construct of family function as measured by 21 family function indicators on the FFFS (1988) was assessed by each TBI male and his spouse by their responses to 25 Porter format type questions. The collective sum of each respondent's discrepancy score on the FFFS and the percentage of difference between each TBI male and his spouse's score are noted in Table 10. Roberts and Feetham (1982) reported that no significant differences have been found in the distribution of respondents' scores when this

instrument is self-administered or completed by means of an interview situation. However, every TBI male had to ask the investigator about the meaning of several test questions in order to assess how he would evaluate the actual amount of an activity ("a" score), desired amount of an activity ("b" score), and the importance of that activity to him ("c" score).

Table 10

Collective Sums of Respondents' Discrepancy Scores

<u>#</u>	<u>TBI Male</u>	<u>Female</u>	<pre>% Difference M/F</pre>
1	22	52	42
2	37	57	65
3	25	35	71
4	42	61	69
5	19	39	49
6	21	44	48
7	33	68	49
8	23	21	110
9	23	18	128
	Total Scores:	Males = 2	245 <u>Females = 395</u>
	Mean_Scores:	Males = 2	27.2 Females =43.9

Approximately half of the wives also had to ask about the meaning of some questions, (e.g., the meaning of "disagreements with spouse," the distinction between neighbors and friends) but were able to score the instrument without further assistance. The TBI patient's degree of cognitive impairment as a result of his head injury may limit the administration of the FFFS (1988) to this target population by means of an interview situation only. It was beyond the scope of this research project, but it would be of interest and practical value in further research to categorize patients according to their actual Glasgow Coma Scale scores, Post-Traumatic Amnesia scores, and Glasgow Outcome Scale scores and administer the FFFS (1988) to these various groups in both an interview and selfadministered format. Then the test results could be evaluated for any difference between the two methods of administering the FFFS (1988) to TBI patients and compare those results to a control group of non-injured persons.

The sum discrepancy scores of the TBI male and their spouses were comparatively analyzed by means of the Wilcoxon ranked-sum scores (see Table 11) and the

sign test (see Table 12) to determine if there was a significant difference between the scores of the TBI males and their spouses on the FFFS (1988). Table 11

> <u>Wilcoxon Ranked-Sum Scores of Males and Females</u> on the FFFS (1988)

 <u>TBI Males</u>	<u>Females</u>
64.5	106.5

The Wilcoxon ranked-sum scores reflect the fact that the TBI males collectively had lower scores on the FFFS (1988) than did their wives. This would give support to the hypothesis that there would be a difference between the TBI male's perceived level of family function and his spouse's perceived level of family function as reflected by their scores on the FFFS (1988). The lower discrepancy score of the TBI males reflects their greater degree of satisfaction with their family system's perceived level of family function than their wives degree of satisfaction with family function as reflected by the latter group's

higher score (see Table 11).

## Table 12

#### Distribution of Male and Female Scores

<u>Couple #</u>	<u>Male</u>	<u>Female</u>	<u>Sign</u>	
1	22	52	-	
2	37	57	-	
3	25	35	-	
4	42	61	-	
5	19	39	-	
6	21	44	-	
7	33	68	-	
8	23	21	+	
9	23	18	+	

<u>Using the Sign Test</u>

The sign test is used to examine the median distribution of signs between two groups. The null hypothesis (Ho) states that there is no difference between the TBI male's perceived level of family

function and his spouse's perceived level of family function. For the null hypothesis to be supported by the data, there should be an equal distribution of signs between the two groups which would reflect that Ho:u=0 and there would be no difference in the distribution of signs (sum of TBI male and female discrepancy scores on the FFFS (1988)) between the two This hypothetical situation would indicate groups. that there was no difference between the TBI male's perceived level of family function and his spouse's perceived level of family function in their family system. The alternate hypothesis (Ha) states that there will be a difference between the brain-injured male's perceived level of family function and his spouse's perceived level of family function in their family system. For the alternate hypothesis to be supported, the distribution of signs (+ and -) would not reflect a median distribution between the two groups being tested.

As reflected by Table 12, there was an unequal distribution of signs (i.e., difference between TBI male's and spouse's sum discrepancy scores on the FFFS (1988)) between the two groups tested in this pilot

study. The results of the pilot study revealed that seven of the TBI males had lower sum discrepancy scores on the FFFS (1988) than did their wives; two of the TBI males had slightly higher sum discrepancy scores than Therefore, if "X" equals the number of their wives. minus (-) signs, using the appropriate statistical tables, under Ho (null hypothesis) the probability that "X" is greater than or equal to 7 is .0899 and the probability of "X" being greater than or equal to 8 is .0196. If the significance level is .05, then having seven out of nine males score lower than females is not significant and we should accept Ho. If the significance level is .10, then having seven out of nine males score lower than females would be significant and we should reject Ho and accept Ha. Hence, there is some statistical evidence that Ha is acceptable but the results as reflected by the sign test are borderline. Consequently, the investigator utilized the Wilcoxon signed-rank test to further comparatively analyze the two groups of respondents to the FFFS (1988).

#### Table 13

## Wilcoxon Signed-Rank Distribution of Absolute

Differences	of	Couple's	Sum D	iscrepancy

<u>Couple</u>	<u>Male (X)</u>	<u>Female (Y)</u>	<u>X-Y Score/Sign</u>	<u>Rank</u>
1	22	52	30 (-)	8
2	37	57	20 (-)	5.5
3	25	35	10 (-)	3
4	42	61	19 (-)	4
5	19	39	20 (-)	5.5
6	21	44	23 (-)	7
7	33	68	35 (-)	9
8	23	21	2 (+)	1
9	23	18	5 (+)	2

Score on the FFFS

The value of the "+" signed-ranks equals three and the value of the "-" signed-ranks equals 42 for a sum total of 45 for all the signed-ranks in Table 13. Using the appropriate statistical table for the critical values and probabilities for the null distribution of the Wilcoxon signed-rank statistic, under Ho the probability that "S" (sum of the "-" signs) would be greater than or equal to 37 is .049 and the probability that "S" would be greater than or equal to 42 is .010. Hence, at the significance level of .05 we can reject Ho and at the significance level of .01 we can also reject Ho and accept Ha. Therefore, on the basis of the comparative statistical analysis of the TBI males' sum discrepancy scores and their spouses' sum discrepancy scores on the FFFS (1988) there is supportive evidence for the acceptance of the hypothesis proposed in this pilot study.

### **Discussion**

Based on the work of Bond (1975, 1976, and 1979), Jennett (1984), and Lezak (1986 and 1988) as well as the investigator's clinical experience, it was anticipated that not only would there be a difference in the TBI male's and his spouse's sum discrepancy scores but also, the results of the sum discrepancy scores on the FFFS (1988) would reflect lower scores for the TBI males than their spouses. This distinction

was evidenced based on the couples' sum discrepancy scores (see Table 10). This finding is of clinical significance for health professionals to bear in mind when working with TBI patients and their families. As Lezak (1986 and 1988) noted, the TBI patient may not be able to accurately perceive his/her cognitive impairments as a result of the brain damage subsequent to his/her head injury. Consequently, the TBI male's perception of his environment and how he interacts with those who are a part of it may be quite different than how others within that same environment perceive it and his interaction within it. Therefore, while the TBI male's sum discrepancy score would reflect that he perceives greater harmonious relationships within his family system's level of function than did the wife's score in seven out of the nine couples studied, given his cognitive impairments he may not accurately perceive how he and his family system are truly functioning. The clinical value of the FFFS (1988) is that it permits the health care professional to obtain a baseline assessment of the couple's perceived level of function across several family function indicators and the couples sum scores provide a collective

assessment of the amount of dissonance or harmony between the spouses, but the discrepancy scores of the spouses can be compared on individual items to identify specific family function problem areas for that couple (Roberts & Feetham). When the FFFS (1988) is used in this fashion as a clinical tool, it enables the health care professional to develop strategies and interventions to assist the couple in taking effective actions to decrease their dissonance in a specific family function area. The effectiveness of prescribed interventions, strategies, and actions can be assessed by using the FFFS (1988) on a longitudinal basis to evaluate for any change in the direction and magnitude of the couples' discrepancy scores on that particular item(s) over time and to further refine or develop new interventions in working with the couple.

Of the nine TBI males and spouses interviewed, all the men identified having problems with their memory and being forgetful. One TBI male considered chronic fatigue to be a major problem for him and precluded him from returning to gainful employment since his head injury. Eight of the nine TBI males identified communication as being a problem with respect to being

assimilated into the workplace, executing job responsiblities, and interacting with peers, relatives, and their own nuclear family systems. The wife of the ninth TBI male also identified communication as a problem for him, though he did not. In the latter case, the wife thought that his problems with communication increased her role responsibilities within their family system because he would not take an active role in the decision making process regarding family issues and concerns. Eight of the wives verbalized that the most disturbing changes they noted in their husbands in response to their head injuries were (in order of importance): 1) personality change, 2) behavioral problems, 3) memory changes, 4) altered communication and interactional patterns between her and spouse and between spouse and children, 5) lack of emotional support, and 6) dissatisfaction with present marital situation.

Based on their responses to the FFFS, there were greater differences between the couples discrepancy scores dealing with items regarding emotional support, work disruption, satisfaction with marital situation, and satisfaction with sexual relations with spouse.

The wives tended to have a higher discrepancy score on items related to emotional support and placed a higher importance value on these than did their spouses. Six of the nine couples individually had a significant discrepancy score on the amount of time that their own routine was disrupted. Six couples had significant differences in their discrepancy scores on the items pertaining to satisfaction with marriage and sexual relations with spouse. Their responses reflected a tendency for these wives to have a high discrepancy and importance score with respect to their marital satisfaction; an inverse relationship of scores was noted in the husband's response to this item. The same relationship was noted on the sexual relations item (see Table 14).

Behavioral problems in the TBI male were a significant obstacle for seven of the families. The wives verbally reported to the investigator that their husbands no longer were sensitive to others' feelings, had difficulty in relating to their children and children's friends, difficult for wives to deal with at times (ranging from being unreasonable, argumentative, to actual impulsive outbursts of anger with little

provocation and without warning). One wife reported that her husband's anger outbursts had become so embarrassing that her children no longer brought their friends home to visit and she and her children rarely took part in any public social activities with her husband. One wife had noticed that her husband had obtained better control over his anger outbursts since he was placed on Tegretol for this purpose rather than as an anticonvulsant. One wife reported that her husband's personality and behavior actually improved after his head injury, i.e., less guick-tempered and easier to get along with. Two of the wives recently had gone through childbirth and both had reported difficulty with not having their husbands' being able to carry out their supportive roles, especially during their last trimesters of pregnancy. Both wives reported that they "wanted to have him take care of me at that point instead of me taking care of him." It is interesting to note that based on the TBI male's initial CAT Scan findings at time of injury, six had either unilateral or bilateral frontotemporal injuries and three had right temporoparietal brain injuries, yet the wives and families of all TBI males reported

personality and behavioral changes in the patient subsequent to his head injury. Three of the men had residual right-sided paresis involving the right upper limb; a fourth TBI male, had a persistent ataxic gait and writing apraxia. In all these cases, the families were more disturbed by the patient's psychosocial sequelae rather than his biological sequelae to the head injury. The types and importance of the biopsychosocial sequelae to head injury reported by the families studied in this project reflect similar findings noted in the works of Jennett (1981, 1984), Brooks, et al., (1983), Bond (1975, 1976, & 1979), and Lezak (1986, 1988).

Table 14

# <u>General Trends in Differences Between Couple's</u> <u>Discrepancy Scores to Item Responses on the FFFS (1988)</u>

<u>Item</u> i	# and $%$ of Couples (n=9) with			
	<u>Significant a-b</u>	Scores		
Emotional Support	5	56%		
Disruption of work routine	6	67%		
Satisfaction with marriage	6	67%		
Satisfaction with sexual re	elations 6	67%		

#### Additional Findings

General patterns of responses to the two openended questions on the FFFS (1988) by each TBI male and his spouse are summarized in Table 15. It is interesting to note that in response to the question: "What is most difficult for you now?," most of the TBI males focused their attention on their psychosocial deficits rather than their physical deficits. Five of the eight males who answered that question (one couple chose not to do the open-ended questions) cited communication-type difficulties, verbal and written. Four of the five noted residual cognitive deficits as also being a significant obstacle to their interactions with others. Four of the five addressed aspects of their communication problems which made it difficult for them to perform their work responsibilities.

In contrast, the eight wives who responded to the same question all cited aspects of their marital relationship as being most difficult for them (wives) now. Seven of the wives stated that their husbands' no longer seemed to understand their needs, did not

## Table 15 General Patterns of Male and Female Responses

to Open-Ended Questions on the FFFS (1988)

Question	<u>N=8</u>	<u>∦ of N</u>			
What is most difficult for you now?					
Male					
Communicating with others	5	63			
Short term memory	3	38			
Frustration at the workplace	4	50			
Comprehension & Organizational S	kills 4	50			
Physical Impairment	3	38			
Female					
Husband does not understand her n	needs 7	88			
Communicating with husband	7	88			
Marital relationship	7	88			
What is most helpful for you now	?				
Male					
Supportive wife	4	50			
Emotional support of friends	3	38			
Emotional support from relatives	3	38			
<u>Female</u>					
Emotional support of relatives	4	50			
Emotional support of friends	4	50			
Marital/Family Counselling	4	50			
communicate effectively with wife and/or children. One wife commented that her husband seemed insensitive to her physical and emotional needs which resulted in her decreased satisfaction with their marital and sexual relationship. Another wife asked if couples in her same situation ever divorced.

In contrast to the wives' perception of the supportive role of their mate, the responses of four of the husbands to the question, "What is most helpful to you now?," was the emotional support of their wives. Three of the eight TBI males also noted that emotional support from relatives (other than spouse) and friends was also most helpful to them now. Whereas, 50% of the wives responded that emotional support from relatives and friends was most helpful. Two additional wives and two from the former group were also receiving marital and family counseling which they thought was quite helpful in dealing with their feelings about the husband's illness, her added family role responsibilities, communication problems between husband-children and between husband-wife subsystems, et cetera. Eight of the wives who participated in this

study all expressed the need and desire for contact with a support group comprised of families of braininjured patients so they could share their common problems, concerns, and experiences. Some of the couples had participated in a support group for a limited time after the TBI male had returned home but thought their needs were not adequately met by that specific group or they were not able to continue in the group due to financial and geographic distance constraints. Four of the TBI males expressed an interest in participating in a such a support group because they had reported a decrease in their own circle of close friends since their head injury.

### Summary

In Chapter Five, the pilot study test results utilizing the FFFS (1988) instrument were presented and analyzed. The results of this pilot study indicate that having a TBI male in the home does effect the family system's level of function according to the perceptions of the TBI male and his spouse as noted on the FFFS (1988). There is also descriptive and

statistical evidence to support the study's hypothesis that there would be a difference between the TBI male's and spouse's family function sum discrepancy score. As projected, the majority of the TBI males had lower sum discrepancy scores than did their spouses indicating that the former had a greater satisfaction with their family system's perceived level of family function than the latter.

Consideration must also be given to the appropriateness of using the FFFS (1988) in evaluating the brain-injured patient. Given the patient's degree of cognitive impairment, the test may not be amenable to being administered in other than an interview format versus self-administration. The method of administering the FFFS (1988) test in this target population needs to be more comprehensively evaluated.

Chapter Six will discuss areas of future research, implications for advanced nursing practice, and relevance of conceptual framework as presented in chapter two.

#### CHAPTER SIX

## <u>Overview</u>

Chapter Six will present areas for further research in working with TBI patients and their families and discuss the relationship of the conceptual model (see Figure 4) to this project. Implications for advanced nursing practice and education in working with this population will also be addressed.

The purpose of this project was to assess the level of function in the family unit in the presence of having a TBI male at home as perceived by the TBI male and his spouse. A pilot study was conducted using the FFFS (1988) instrument to determine if this measurement tool of 21 family functions across three relationship areas would be amenable to use in testing cognitively impaired individuals' perception of family function.

The FFFS (1988) has a distinct advantage over other available empirical family function assessment instruments because it measures specific family functions in three relationship areas (Factors I, II, and III; see Table 8). Roberts and Feetham (1982), have reported that other family function instruments only measure one relationship area, i.e., between individuals. Given the facts that all the TBI males and approximately 50% of their wives had some difficulty understanding the meaning of several of the referent stems (Porter format questions) on the FFFS (1988) and all TBI males took longer to complete the questionnaire than authors estimated (as much as three times longer), it seems reasonable to investigate other assessment tools which may be easier for the respondent to answer and yet quantifiably measure a family system's level of function in the presence of having a TBI male (or other member) at home. As the results of this pilot study have shown, the TBI males (78%) had a more harmonious perception of their families' level of functioning than did their wives. Communication skills were viewed to be a problem for 63% of the TBI males (88% of the wives concurred with this finding) and

their physical sequelae to head injury were regarded as less problematic than the former. Dissatisfaction with the marital relationship was expressed by 88% of the wives who responded to the FFFS (1988). (See Tables 12, 13, and 15.) It may be of practical value to utilize one or several instruments concurrently in working with TBI patients. This may enable the researchers to obtain greater insight into the family system's actual and perceived level of activity in specific family function areas.

Further research could be conducted with the FFFS (1988) to examine if the method of test administration would reflect a difference in the scores of TBI patients. One could investigate this by categorizing TBI patients into three groups (i.e.: mild, moderate, or severe TBI) determined by the severity of their head injury based on their Glasgow Coma Scores (at six hours post injury), Post-Traumatic Amnesia Scale Score, Glasgow Outcome Scale Score, and recent (within three to six months) neuropsychological examination results. The FFFS (2988) could be administered to these three groups and a control group of non-injured patients first by self-administration and then in an interview

format. The differences between the test scores of all four groups could be statistically analyzed. It would also be helpful to identify the test-retest reliability of these groups. Therefore, a retest of the FFFS (1988) could be conducted a few weeks after the first administration of the test using both methods of administration.

As Baker (1990) has stated, "head injury has reached epidemic proportions" and both the patient and his/her family are affected by the TBI of a family member (Bishop & Miller, 1988). The exigencies that the health care delivery system exerts on the patient and family system presently require families to assume an important role in the rehabilitation of their TBI relative. The pivotal role of family issues in the treatment of TBI is currently receiving more attention from researchers and clinicians (Bishop and Miller, 1988). Increased emphasis is being placed on the need for objective methods of quantifying family function in TBI to assist in judicious resource allocation, determine cost effectiveness of treatment, and justify nonbillable services (e.g., certain social work services) (Bishop & Miller, 1988; Roberts & Feetham,

1982; Zarski, et al., 1988). Bishop and Miller (1988) have noted that increased interest in TBI and empirical methods of family assessment have evolved in a parallel manner. Additional family assessment tools which may be applicable to this target population deserve consideration, e.g.: the Family Functioning Index (Pless & Satterwhite, 1973); Smilkstein's (1978) Family APGAR; FACES/FACES III (Olson & McCubbin, 1982); and the Family Assessment Device based on Epstein's, et al., McMaster Model of Family Functioning (1983).

Pless and Satterwhite (1973) attempted to measure family functioning as a holistic concept by developing the Family Functioning Index (FFI). The emphasis of the FFI is on the dynamic interactions betweeen family and each individual rather than the structural characteristics of the family as in Feetham's instrument. They studied the psychological adjustment of children in 399 families (209 families had children with chronic disorders; 190 families had well children) in an attempt to identify those children at risk for psychological problems. The self-administered test consisted of 15 questions about role function, marital relations, and communication patterns. The

instrument's reliability correlation of 0.72 between wife's and husband's scores support its reliability. The test-retest reliability of the FFI was substantiated by following 30 families over a five year period. The correlation between the FFI scores on a test-retest basis yielded a score of 0.83 indicating a high degree of instrument stability over time. Several methods were used to determine the instrument's validity. High correlation between the scores of husbands, wives, and caseworkers was determined to support the instrument's validity in measuring the construct of family function.

Satterwhite, et al., (1976) purport that the FFI's clinical utility is that it may be an acceptable tool that can provide the health care professional with a quick assessment of the patient's quality of family life. The FFI can, therefore, be used as a screening device to enable the health care worker to determine when a family needs assistance, develop appropriate interventions, and facilitate the patient/family's successful use of coping strategies.

Smilkstein (1978) developed the family APGAR as a holistic tool to measure family function. The APGAR

was designed to measure a family member's satisfaction with five basic components of family function (Smilkstein, 1978). The five areas identified by the researcher as basic components of family function are: adaptation, partnership, growth, affection, and resolve. The instrument provides only a qualitative measurement of member's satisfaction with family function.

The family APGAR was initially tested for construct validity by comparing its scores to those of the FFI (Pless & Satterwhite, 1973) and scores rendered by clinical psychotherapists (Smilkstein, et al., 1982). Construct validity of the instrument was validated by high correlation scores of .80 and .64 obtained from each of the two comparison groups, respectively (Smilkstein, et al., 1982). Further validation studies of the APGAR have been implemented in colleges, family medical centers, psychiatric outpatient clinics, and cross-culturally, at a foreign university. These results further substantiated the validity and reliability of the APGAR (Smilkstein, et al., 1982).

The clinical use of the APGAR helps the health care practitioner develop a data base on the patient's view of the level of family function in his/her system. It assists the clinician in assessing a family's resources, to identify family's strengths and weaknesses, and develop interventions to enhance the family's level of function.

Bishop and Miller (1988) suggest that FACES/FACES III (family adaptation and cohesion evaluation scales) and the FAD (family assessment device) may be tools that can be used to quantify and formalize the assessment of families of TBI patients. The FACES/FACES III instrument is based on the research model of Olson, et al., which delineated two dimensions of marital and family behavior--adaptability and cohesion (Olson & McCubbin, 1982). FACES/FACES III versions are 20-item questionnaires which assess each family member's perception of his/her family system's cohesion and adaptability. FACES I assessed nine concepts related to cohesion (boundaries, independence, coalitions, time, space, friends, emotional bonding, decision making, interests, and recreation) and concepts related to adaptability (assertiveness,

control, negotiation, rules, roles, and discipline ) (McCubbin, J. & McCubbin, M., 1987). FACES III is the latest version of FACES. These tests are administered in two versions: one assesses perceived current family functioning and the other assesses the respondent's "ideal" perception of family functioning (Bishop & Miller, 1988).

Data was collected from 201 families and a total sample size of 603 was obtained. Factor analysis was used to determine internal consistency reliability for adaptability (.75) and cohesion (.83) for the original FACES tool indicating good psychometric properties. Validity data is not yet available on the FACES III version, but later versions of the original scale do not distinguish family dysfunction in distressed and nondistressed families in a curvilinear fashion as predicted by the instrument's designers (Bishop & Miller, 1988).

The Family Assessment Device (FAD) is a 60-item questionnaire designed to assess family function based on the six parameters represented in the McMaster Model of Family Functioning (Epstein, Bishop, & Levin, 1978; Epstein, Baldwin, & Bishop, 1983; Bishop & Miller,

1988). It is comprised of seven scales which measure problem solving, communication, roles, affective responsiveness, affective involvement, behavior control, and general functioning (Epstein, et al., 1983).

Multiple studies of the FAD were conducted on clinical and nonclinical samples to establish its validity, concurrent validity, and test-retest reliability. It was concluded that the FAD had overall good psychometric properties (Epstein, Baldwin, & Bishop, 1983; Smilkstein, 1984; Bishop & Miller, 1988). FAD has also been used to assess the relationship of family functioning in stroke (cerebrovascular accident) to health and functional capacity, rehabilitation outcome, and adherence to treatment. The FAD may be a particularly quantitative psychometric device in assessing family function parameters in other types of brain-injured patients (e.g., TBI patients) (Bishop & Miller, 1988).

#### Recommendations for Further Research

This pilot study has provided food to serve as an impetus for guiding additional research in TBI patients

and their family systems. Suggestions for further research in working with TBI patients and their families to evaluate the concept of family function include:

1. Administer the FFFS (1988) to a larger group of TBI patients and their families. The TBI patients should be selected on the basis of the severity of their head injury. A larger sample size could permit generalizability of the findings which, given the small sample size of this project, was not possible.

2. Use the FFFS (1988) in conjunction with another assessment tool, i.e., POMS (Profile of Mood States) to gain further insight into how the respondent is actually feeling about his/her life situation and compare the respondent scores on each of the tests. Using this combination of tests, may give the spouse/parent of the TBI patient a better understanding of the patient's perception of his/her environment and how he views him/herself.

3. Perform longitudinal cohort studies on the TBI groups using the FFFS (1988) to try to substantiate the hypothesis that the TBI male/female would have a different sum discrepancy score than the noninjured

spouse.

4. Evaluate the findings in the above groups to determine if the differences between the sum discrepancy scores of the brain-injured spouses and the sum discrepancy score of the uninjured spouses increases at each interval that the FFFS (1988) is given.

5. Obtain two groups of TBI males that have problems with anger outbursts. Treat one group with tegretol and the other group would be the control (anger outbursts without tegretol) group. Study these two groups over time (e.g., at three-month intervals for two years) to attempt to determine the efficacy of this use of tegretol in treating behavioral problems versus its standard use as anticonvulsant or for relief of dysesthetic pain.

6. Longitudinally administer the FFFS (1988) to the TBI males on tegretol for treatment of anger outbursts and those in the control group plus the wives of all the TBI males to determine if there is a difference between the couples' sum discrepancy scores between the two groups of TBI males and their wives.

7. Administer the FFFS (1988) to a group of TBI males and comparably TBI females and their spouses and compare the results.

8. Longitudinally administer the FFFS (1988) to parents of a TBI school-age child (not a teenager) in the home to determine the parents perceived level of family function in the presence of having a TBI school age child in the home as perceived by the parents.

9. Longitudinally administer the FFFS (1988) to parents of a TBI adult child in the home to determine the parents perceived level of family function in the presence of having a TBI adult child in the home.

In summary, even though interest in empirical family assessment tools and in TBI patients and their families has historically developed in a parallel fashion, there is a paucity of applied research in this area. The FCNS with his/her advanced education in family health and advanced clinical expertise, is in a unique position to be a valuable contributor to conducting research in the assessment TBI patients and their families.

#### Relationship to Conceptual Framework

King's theory of nursing and goal attainment is based on an interacting, open systems model. She uses a general systems theoretical framework to explain the interrelationships between man, environment, health, and nursing. She views man as an open interacting system with other individual systems, interpersonal systems (groups), and broader social groups (society), to fulfill his needs. King conceptualized human beings as open systems with permeable boundaries that permit the flow of energy into and out from the system.

Feetham (1982) also derived her concept of family functioning from a human ecosytems model. She defines family functioning as consisting of "those activities and relationships among and between persons and the environment which in combination enable the family to maintain itself as an open system" (p. 231). The purpose of this project was to identify the <u>perceived</u> level of family function in the family systems that have a TBI male at home. The hypothesis of the study was that there would be a difference between the TBI male's (husband) perceived level of family function and

the spouse's perceived level of family function. The TBI male's and his spouse's responses to the FFFS (1988) were based upon their perceptions of their family system's interactions across three relationship areas (see Figure 4). The ultimate outcome of the FFFS (1988) was a sum discrepancy score for each member of the marital dyad which reflected that member's perceived level of satisfaction with their family system's level of family function. Each member of the marital dyad responded to the questions based on his/her own perception (representation of reality) about an activity that required an interaction across one of the relationship areas (see Figure 4). The cognitive impairments of the TBI male may alter his perception of reality and not permit him to perceive and judge himself as others do. It does not mean that one way is more right or wrong than the other, but what the FFFS (1988) attempts to do is to identify areas where there is a dissonance between the husband's and wife's perception of reality and use this as a tool to develop appropriate interventions. The unique body of advanced education that the FCNS has obtained should enable him/her to use the FFFS (1988) with this

population to identify specific problem areas in family function and interact with the TBI male and wife to develop appropriate interventions to enhance the level of family function in a given problem area. The TBI male, spouse, and nurse determine those interventions based on the perceptions, judgments, and values that each brings to their interaction to form mutual goals.

The purpose of this project was not to measure interventions of the FCNS, but rather to determine the perceived level of family function in a family unit in the presence of having a TBI male in the home as perceived by the TBI male and his wife. The sum discrepancy scores of the couples in this study did demonstrate that most of the husbands had a lower sum discrepancy score of family function than did their wives indicating that they were more satisfied with the level of family function than their wives. Given the biopsychosocial sequelae to head injury, the investigator would have anticipated such an outcome. The FFFS (1988) is a useful empirical family assessment tool because helps to identify interactions between the various systems of man's environment, the frequency of those interactions (i.e.: little to much), his

perceived value of those interactions, and any discrepancy between the actual amount and the desired amount of an activity. The FCNS can use the FFFS (1988) to identify those discrepancies and develop interventions and strategies focused on decreasing the amount of discrepancy.

#### Implications for Nursing Practice

Despite the fact that this project was not designed to measure interventions of the FCNS, there are many implications for advanced nursing practice in working with this patient population. Given the FCNS' background in family theory and health care, the problems that a TBI male's potential biopsychosocial deficits may impose on his family system are numerous. The FCNS can use his/her knowledge of family theory, chronic illness, and the sequelae of brain injury to facilitate communication between the patient, his spouse, and their children regarding their feelings and concerns about the TBI male's injury; the resultant change in family subsystems interactional patterns; family roles, rules, and responsibilities, etc. The FCNS can utilize advanced listening and counselling skills to facilitate open communication of family members feelings regarding their level of family function and how it may have been altered by the husband's brain injury. The FCNS can use his/her expertise to develop strategies which may empower family members to relinquish clinging to old interactional patterns with the TBI male and develop interventions that may promote better interactions between TBI male/spouse, TBI-male/child, and spousechild.

The FCNS can also try to facilitate the TBI male and his family's access to health care. While conducting the research for this project and traversing to rural areas in Michigan, the problem of access to health care in rural areas became very blatantly apparent to the investigator. These TBI patients have to deal with the sequelae of the brain injury for a long time after their discharge from the rehabilitation setting--health care resources are very scarce in some of these rural areas. Careful planning and costeffective use of health care resources is continually becoming more problematic. The FCNS should utilize

his/her knowledge of the health care system and clinical expertise to assume a leadership and patient advocacy role to help devise strategies that would promote the wise use of our limited health care resources in a cost-effective manner while simultaneously striving to provide quality health care to as much of the public as possible.

The FCNS can develop his/her role as an educator in working with TBI patients and their families to enhance their understanding of patients' deficits and develop reasonable expectations of patients abilities, provide anticipatory guidance to patients and their families regarding hope of patient's further improvement. The FCNS also has a professional obligation to the public to use his/her education about the causes, costs, and effects of head injury to educate others and advocate the promotion of health behaviors that prevent or minimize the severity of head injury. Consequently, the FCNS has an obligation to take a leadership role and be politically aware of legislation that would help to prevent or decrease the incidence of head injury (i.e.: strict enforcement of drunk driving laws, avoid using drugs and driving,

wearing helmets when engaging in sports activities, passing seatbelt restraint laws, and lowering highway speeds). The nurse in advanced practice should be aware of the legislative process, monitor bills, encourage public support for passage or defeat of bills that can have a beneficial or deleterious effect on the quality of health care, and be politically astute to get legislation proposed that would promote the delivery of quality health care to society.

### **Conclusion**

This project resulted in the pretesting of an empirical family function assessment instrument (FFFS 1988) among nine TBI males and their wives to determine the level of family function in their family systems in the presence of having a TBI male in the home based upon the TBI male's and his wife's perceptions. Although greater interest has been sparked in being able to quantitatively assess the effect of illness on the family system, there is limited research available regarding the application of empirical family assessment tools in working with TBI patients and their

family systems. The need to be more judicious in allocation and use of limited health care resources serves as an impetus for using quantitative measures to assess how effectively these resources are used.

Chapter VI has presented areas for further research, relevance of conceptual framework to research project, and implications for advanced nursing practice and education.

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APPENDIX A

#### FEETHAM FAMILY FUNCTIONING SURVEY

Family Code

In this survey you are asked to rate activities (functions) that occur in the family and with family members. For <u>each</u> family function you are asked to answer three questions:

How much is there now? How much should there be? How important is this to you?

Please answer all three questions for each family function by circling the number which represents how you feel now about the family function.

The term spouse refers to your husband or wife or the person who assumes the functions of a spouse. If you do not have a person in the spouse role answer the questions based on how much you want the functions met.

PLEASE TRY TO ANSWER ALL ITEMS.

. •

1. The amount of discussion with your <u>friends</u> regarding your concerns and problems.

a. Lit	How tle	much	is the	ere n	ow? M	uch
1	2	3	4	5	6	7
b. Lit	How tle	much	shoul	d the	re be M	? uch
1	2	3	4	5	6	7
c. Lit	How tle	impo	rtant	is th	is to M	you? luch
1	2	3	4	5	6	7

2. The amount of discussion with your <u>relatives</u> regarding your concerns and problems (do not include your spouse).

a. How much is there now? Little Much 1 2 3 4 5 6 7

b. How much should there be? Little Much

<u>1 2 3 4 5 6 7</u>

c. How important is this to you?

· ·

3. The amount of time you spend with your spouse.

a. Liti	How tle	much	is the	ere n	.ow? M	uch
1	2	3	4	5	6	7
b. Litt	How tle	much	should	d the	re be M	? uch
1	2	3	4	5	6	7
c. Liti	How tle	impor	tant :	is th	is to M	you? uch
1	2	3	4	5	6	7

4. The amount of discussion of your concerns and problems with your <u>spouse</u>.

a. How much is there now? Little Much 1 2 3 4 5 6 7b. How much should there be? Little Much 1 2 3 4 5 6 7c. How important is this to you? Little Much 1 2 3 4 5 6 75. The amount of time you spend with <u>neighbors</u>. a. How much is there now?

> Little Much 1 2 3\_\_\_\_ 5 6 7 4 b. How much should there be? Little Much 1 2 3 4 5 6 7 c. How important is this to you? Little Much

1 2 3 4 5 6 7

6. The amount of time you spend in leisure/recreational activities.

a. Lit	How tle	much	is th	ere n	ow? M	uch
1	2	3	4	5	6	7
b. Lit	How tle	much	shoul	d the	re be M	? uch
1	2	3	- 4	5	6	7
c. Lit	How tle	impoi	tant	is th	is to M	you? auch
1	2	3	4	5	6	7

7. The amount of help from your <u>spouse</u> with family tasks such as care of children, house repairs, household chores, etc.

a. Lit	How tle	much	is th	ere n	ow? _ M	uch
1	2	3	4	5	6	7
b. Lit	How tle	much	shoul	d the	re be M	? uch
1	2	3	4	5	6	7
c. Lit	How tle	impor	tant	is th	is to M	you? uch
1	2	3	4	5	6	7

8. The amount of help from <u>relatives</u> with family tasks such as care of children, house repairs, household chores, etc. (do not include spouse).

a. Lit	How tle	much	is the	re r	now? M	uch
1	2	3	4	5	6	7
b. Lit	How tle	much	should	the	ere be M	? uch
1	2	3	4	5	6	7
c. Lit	How tle	impo	ctant i	s tì	nis to M	you? uch

3

. . . . .

9. The amount of time with health professionals (doctors, nurses, social workers, etc.).

a. Litt	How tle	much	is the	ere n	ow? M	uch
1	2	3	4	5	6	7
b. Litt	How tle	much	shoul	d the	re be M	? uch
1	2	3	4	5	6	7
c. Litt	How tle	impor	tant :	is th	is to M	you? uch
1	2	3	4	5	6	7

10. The amount of help from your <u>friends</u> with family tasks such as care of children, house repairs, household chores, etc.

a. How much is there now? Little Much 1 2 3 4 5 6 7b. How much should there be? Little Much 1 2 3 4 5 6 7c. How important is this to you? Little Much

<u>1 2 3 4 5 6 7</u>

If you don't have a <u>child(ren)</u>, check here \_\_\_\_\_ and omit questions 11, 12, and 13.

11. The number of problems with your child (ren).

a. Lit	How tle	much	is th	ere n	.ow? M	luch
1	2	3	4	5	6	7
b. Lit	How tle	much	shoul	d the	re be M	? luch
1	2	3	4	5	6	7
c. Lit	How tle	impo	rtant	is th	is to M	you? Iuch

1 2 2 4 5 6 7

. .

12. The amount of time you spend with your child(ren).

a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much 1 2 3 4 5 6 7 c. How important is this to you? Little Much <u>1 2 3 4 5 6 7</u> If you do not have a child in school, check here and omit question 13. 13. The amount of time your child(ren) miss school. a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much 1 2 3 4 5 6 7 c. How important is this to you? Little Much 1 2 3 4 5 6 7 The number of disagreements with your spouse. 14. a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much

1 2 3 4 5 6 7

c. How important is this to you? Little Much

<u>1 2 3 4 5 6 7</u>

15. The amount of time you are ill. a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much 1 2 3 4 5 6 7 c. How important is this to you? Little Much 1 2 3 4 5 6 7 The amount of time you spend doing housework 16. (cooking, cleaning, washing, yardwork, etc.) a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much 1 2 3 4 5 6 7 c. How important is this to you? Little Much 1 2 3 4 5 6 7 17. The amount of time you miss work (including housework). a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much

<u>1 2 3 4 5 6 7</u>

c. How important is this to you? Little Much

<u>1 2 3 4 5 6 7</u>

20.

18. The amount of time your spouse misses work (including housework).

a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much <u>1 2 3 4 5 6 7</u> c. How important is this to you? Little Much <u>1 2 3 4 5 6 7</u> The amount of emotional support from friends. 19. a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much 1 2 3 4 5 6 7 c. How important is this to you? Little Much 1 2 3 4 5 6 7 The amount of emotional support from relatives. a. How much is there now? Little Much 1 2 3 4 5 6 7 b. How much should there be? Little Much 1 2 3 4 5 6 7 c. How important is this to you? Little Much 1 2 3 4 5 6 7

. .

23.

21. The amount of emotional support from your spouse.

a. How much is there now? Little Much 1 2 3 4 5 6 7b. How much should there be? Little Much 1 2 3 4 5 6 7C. How important is this to you? Little Much

1 2 3 4 5 6 7

22. The amount of time your work routine is disrupted (including housework).

	a. Litt	How le	much	is the	ere n	low? M	luch		
	1	2	3	4	5	6	7		
	b. Litt	How le	much	should	l the	re be M	? luch		
	1	2	3	4	5	6	7		
	c. Litt	How le	impor	tant i	ls th	is to M	you: luch	?	
	1	2	3	4	5	6	7		
The a disru	amour aptec	nt of 1 (ir	time time	your .ng hou	spou isewo	se's ork).	work	routine	is
	a. Litt	How le	much	is the	ere n	low? M	luch		
	1	2	3	4	5	6	7		
	b. Litt	How le	much	should	l the	re be M	? luch		
	1	2	3	4	5	6	7		

c. How important is this to you? Little Much

1 2 3 4 5 6 7

24. The amount of satisfaction with your marriage.

a. Liti	How tle	much	is the	ere n	ow? M	uch	
1	2	3	4	5	6	7	
b. Liti	How tle	much	should	d the	re be M	? uch	
1	2	3	4	5	6	7	
c. Liti	How tle	impor	tant :	is th	is to M	you: uch	?
1	2	3	4	5	6	. 7	

25. The amount of satisfaction with the sexual relations with your <u>spouse</u>.

a. Lit	How tle	much	is th	ere n	low? M	luch
1	2	3	4	5	6	7
b. Lit	How tle	much	shoul	d the	re be M	e? Much
1	2	3	4	5	6	7
c. Lit	How tle	impor	ctant	is th	is to M	you Nuch
•	h	2	4	-	c	_

26. What is most <u>difficult</u> for you now?

. . .

27. What is most <u>helpful</u> for you now?

Feetham Family Functioning Survey Suzanne L. Feetham, Ph.D., R.N., F.A.A.N. Children's Hospital National Medical Center Washington, D.C.

Developed under agent #N0063 H.H.S., U.S.P.H.S. Division of Nursing 1977-1980. Wayne State University, Detroit. Center for Health Research Rev. 3/1/83, 5/88

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APPENDIX B
Dear\_\_\_\_

I am Lorraine Pearl, R.N., a nurse researcher in the Master's of Science in Nursing program at Michigan State University. I am working on a project that is designed to help health care workers learn more about brain-injured patients and their families. As a result of this research study, health care workers will learn how to more effectively care and serve these patients and their families. I would like to talk with you and your wife regarding your perceptions about your family and its level of functioning since your traumatic brain injury. All responses given by you and your wife will be kept confidential. If the study's results are published, names will not be used in any of the tabulations. The results of the study will be made available to any participant who submits a written request for this information. Dr. Kreitsch and the research committees at Mary Free Bed Rehabilitation Hospital have given me approval to conduct this study.

If you and your wife would agree to participate in this study, either of you may withdraw from further participation at any time without incurring any restrictions in the care provided to you and your family by Dr. Kreitsch or by Mary Free Bed Rehabilitation Hospital staff. Both of you would be removed from the study if one of you decides not to continue to participate in the project, but there would be no other penalties incurred by you or your wife. Participants will not experience any potential risks from this study. Participation also does not guarantee that you or your wife will receive any beneficial results from your actions.

If you would both like to participate in this study, please indicate so on the enclosed postage-paid postcard and return it to me. I will contact you once I have received your postcard and will arrange an appointment to meet with you both. Our discussion will take about one hour of your time. During our visit, I would like each of you to fill out a questionnaire which will take about ten minutes to complete. I would like to meet with you in your home or if more convenient, at your next clinic visit at Mary Free Bed Hospital.

If you and your wife have any questions or concerns about this study, please feel free to call me at my office at 1-800-832-1815 or 616-454-3465 or at my home at 616-942-6094. Thank you for your help.

Sincerely,

Lorraine J. Pearl, R.N., CNRN, M.S.N. Candidate .

APPENDIX C

## CONSENT FORM

The program in which we are asking for your participation is designed to assist health care professionals working with spouses and families of brain-injured clients learn to identify how family functions are affected and develop interventions which will preserve, maintain, and enhance the functioning of these family systems. If you agree to participate in this program, you will be asked to complete a questionnaire focusing on your family unit's perceived level of functioning since your brain injury. The questionnaire will require about ten to fifteen minutes to complete.

If you agree to participate in this study, please sign the following statement:

 I have freely consented to take part in a study of families with a traumatically brain-injured male at home being conducted by Lorraine J. Pearl, R.N., CNRN, M.S.N. candidate. R

- The study has been discussed and explained to me. I have had the opportunity to ask any questions regarding the study and I understand what my participation will involve.
- 3) I understand that I can withdraw from participation in this study at any time. I understand that my withdrawal from the study will not result in any limitation or restriction to care provided to me or my family through Mary Free Bed Rehabilitation Hospital's Brain Injury Program or by Dr. Kreitsch.
- 4) I understand that the results of this study will be kept in strict confidence, and if published, both my name and my spouse's name will remain anonymous. I also understand that if I submit a written request, these results can be made available to me.
- 5) I understand that my participation in this study will not involve any potentially harmful risks to me.
- 6) I understand that my participation in this study does not guarantee any beneficial results will be derived from this action.

I,\_\_\_\_\_, state that I understand

(print name)

what is required of me as a participant and agree to enroll in this program.

Si	<b>g</b> T	ıeđ

Date

## CONSENT FORM

1

The program in which we are asking for your participation is designed to assist health care professionals working with spouses and families of brain-injured clients learn to identify how family functions are affected and develop interventions which will preserve, maintain, and enhance the functioning of these family systems. If you agree to participate in this program, you will be asked to complete a questionnaire focusing on your family unit's perceived level of functioning since the husband's brain injury. The questionnaire will require about ten to fifteen minutes to complete.

If you agree to participate in this study, please sign the following statement:

 I have freely consented to take part in a study of families with a traumatically brain-injured male at home being conducted by Lorraine J. Pearl, R.N., CNRN, M.S.N. candidate. .

- 2) The study has been discussed and explained to me. I have had the opportunity to ask any questions regarding the study and I understand what my participation will involve.
- 3) I understand that I can withdraw from participation in this study at any time. I understand that my withdrawal from the study will not result in any limitation or restriction to care provided to my spouse, myself, or my family through Mary Free Bed Rehabilitation Hospital's Brain Injury Program or by Dr. Kreitsch.
- 4) I understand that the results of this study will be kept in strict confidence, and if published, both my name and my spouse's name will remain anonymous. I also understand that if I submit a written request, these results can be made available to me.
- I understand that my participation in this study will not involve any potentially harmful risks to me.
- 6) I understand that my participation in this study does not guarantee any beneficial results will be derived from this action.

I, \_\_\_\_\_, state that I understand (print name)

what is required of me as a participant and agree to enroll in this program.

Signed

\* . \*• •

Date

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