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The Effect of Family Participation on the Outcome of Patients with Traumatic Brain Injury in Rehabilitation

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THE EFFECT OF FAMILY PARTICIPATION ON THE OUTCOME OF PATIENTS WITH TRAUMATIC BRAIN INJURY IN REHABILITATION

By

Grant Middleton
Brett Ransom

THESIS

Submitted to the Department of Physical Therapy
at Grand Valley State University
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1995
THE EFFECT OF FAMILY PARTICIPATION IN THE REHABILITATION OF PATIENTS WITH TRAUMATIC BRAIN INJURY

ABSTRACT

The purpose of this study was to explore the relationship between physical therapists' perceptions and institutional policies relating to family participation in rehabilitation and rehabilitation outcome of patients with traumatic brain injury. Utilizing surveys, we collected information about institutional policy from institutions that were members of the Commission for Accreditation of Rehabilitation Facilities (CARF) in the Midwestern United States. Thirteen institutional surveys provided usable Functional Independence Measure (FIM) scores for patients rehabilitated in 1993, which were used as the outcome measure. The therapists' perceptions survey (n = 104) gathered data about the beliefs of physical therapists relating to family involvement in rehabilitation. No trends were found between physical therapists' beliefs and institutional policies about the role of family in rehabilitation and outcome of patients with traumatic brain injury. The small amount of outcome data limited this analysis. The majority of therapists in this study agreed that the level of family involvement in rehabilitation should be maximized.
ACKNOWLEDGMENTS

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CHAPTER ONE

INTRODUCTION

We feel that there is a pressing need in today's rehabilitation setting to develop therapeutic interventions that include family involvement in the recovery process. In order to establish a positive working relationship between the family and the health care team, a research based approach, which objectively defines a family's capacity for playing an active role in the rehabilitation process is needed (Watson, 1992).

In the many articles written on traumatic brain injury, an often mentioned aspect is the injury's devastating effect on the family. The stress that is incurred by the family may interfere with the family's ability to absorb information, maintain function, and utilize coping skills (Elliot & Smith, 1985). These stressors are often manifested by conflict with the rehabilitation team, poor adjustment to the patient's disability and a decreased satisfaction with rehabilitation outcome. A correlation exists between family and team conflict and lower physical and cognitive functioning, longer length of stay, younger patient age and lower program satisfaction (McLaughlin & Carey, 1993).

In order to reduce conflict between the family and the team, effective communication is essential (Foley, 1993). Family cannot give informed consent unless they are active participants in two way communication with the rehabilitation team (Foley, 1993). The likelihood of miscommunication is increased when the team and family: assume too much, lack openness, and deceive each other (Foley, 1993).

Elliott & Smith (1985) discuss the success of a multidisciplinary approach to family care. The quality of patient care is improved by a coordinated team. A coordinated team assures the patient receives maximum benefits of each discipline without overlap,
which improves the efficiency of services. Johnson & Higgins (1987) stated that rehabilitation outcomes are less predictable in the absence of an organized plan for family involvement. The team approach reduces stress by providing the family with consistent, correct information and by giving the family realistic expectations while permitting a feeling of hope.

Family expectations toward the rehabilitation process must be adequately explored by the team to discover areas where the family harbors unrealistic hopes (McLaughlin & Carey 1993). It is necessary to encourage the family to maintain hope while communicating an honest appraisal of the patient's possible outcomes. Families desire to learn more effective ways of dealing with negative feelings from the rehabilitation team (Gans, 1983).

Family feelings toward the rehabilitation team seem to go through a series of three stages. The initial stage is one of trust, followed by skepticism, and the final stage is a guarded alliance. At first the family doesn't know what to believe and accepts information at face value. Initial negative prognoses are common, and as the family sees the patient progress they come to disbelieve what they are told. Strains can be imposed on the family when their needs are not met by the health care team. When the family accepts that the rehabilitation team is striving to deliver the best possible care, they have entered the final stage of rehabilitation (Watson, 1992).

Different rehabilitation settings allow various levels of family involvement with the health care team. At one extreme, some facilities restrict families to visiting hours and staff conferences. At the other extreme, some facilities encourage the family to be present in all phases of rehabilitation. Bratt (1987) stated that staff conferences can be intimidating to the family when they are faced with a room full of health professionals. Conferences often emphasize the distance between the professional and the family, and can leave family members feeling isolated, guilty and angry. Families are required to make informed decisions. To do this, they need sufficient education in critical areas surrounding
the rehabilitation process. For example, the family needs to be educated about the preferred methods of dealing with the disabled patient after discharge (Meades, 1988).

Although there have been studies done regarding nursing's involvement with the patient and family, no studies were found regarding the family's role in the area of physical therapy intervention. With the exception of nursing staff, physical and occupational therapists spend more time with the patient and their family than any other staff member on the rehabilitation team (Watson, 1987). Literature searches have turned up few studies relating the degree of family involvement in rehabilitation to objective measures of patient outcome.

The purpose of this study was to identify policies of traumatic brain injury programs regarding the involvement of families in the rehabilitation process and compare these policies to patient outcome. In addition, our purpose was to identify perceptions/beliefs of physical therapists that work with patients with traumatic brain injury about involvement of the family in rehabilitation, and compare these perceptions to patient outcome.
CHAPTER TWO
LITERATURE REVIEW

We conducted a review of the literature but found few research studies pertaining to family participation in rehabilitation. However, a number of articles were found supporting family involvement in the rehabilitation process. This review addresses both theoretical papers covering the subject area of family in rehabilitation, and research studies conducted on the family's role in the health care setting.

We have found that the literature addressing the area of family function in the health care system addresses the following general areas: family needs and feelings, family participation, family/staff interaction and patient outcome. In order to effectively enlist the family's participation in the rehabilitation process, the health care team must understand the family's physical, psychosocial, and emotional needs (Molter, 1979).

Family needs and feelings

The family may initially experience a cascade of strong emotions when dealing with the disability of their loved one. These may include: shock, fright, disbelief, numbness, and guilt. They may also feel a sense of responsibility for the patient's condition. The family is disturbed by the foreign atmosphere that is associated with the health care facility. They are forced to trust the care of their family member to strangers, and they respond with anxiety, anger, depression and loneliness (Gardner and Stewart, 1978).

Glennon & Smith (1990) attempted to document issues of greatest concern to patients and their caregivers by recording questions asked at family conferences. Resident physicians at two sites recorded each question asked during the conference, noting who asked the question. The questions were arranged by topic. Patient populations consisted
of cerebrovascular accident, amputation, traumatic brain injury, hypoxic brain injury, and orthopedic injuries.

The most commonly addressed topic was that of general medical issues. This was followed in order by discharge planning, equipment issues, rehabilitation related medical issues, functional status and prognosis, the setting's rules and procedures, psychosocial issues, therapy issues, financial issues, and the family's role.

Glennon & Smith noted that patients, who have the greatest access to health care professionals, ask the greatest number of questions concerning medical issues at conferences, suggestive of the fact that these questions are not asked during acute hospitalization or preceding rehabilitation. They also noted that the families of traumatic brain injury patients asked fifty percent more questions than the other groups of patients, possibly reflecting the greater need for information.

Elliot & Smith (1985) stated that addressing the following areas of need may help the family better deal with the emotions they may be experiencing: to be reassured that there is hope, to feel that the patient is being well cared for, to be near the patient, to be informed about the patient's prognosis, and to be kept updated on changes in patient condition.

The most important area that the family needs to have addressed in rehabilitation is being given a feeling of hope (Molter, 1979). This can produce a basis for conflict between the family and staff. The family often harbors negative feelings toward the staff, when the family views the staff's prognosis for the patient's condition as too negative. The staff often responds to these attacks by pointing out the unreality or unfairness of the family (Gans, 1983). As a result, the relationship between the family and the staff is strained and progress is slowed because the family and staff are not working together in the rehabilitation process (Gardner, 1978).

In order to treat the whole family in rehabilitation it is important to understand what their needs are. In a study conducted on assessing the needs of families of critically
ill patients, Molter (1979) stated in her introduction that little time is committed to the
family in the critical care setting. In defending the need for her research study she quoted
Craven (1972) who stated, "if the nurse expands her concept of the patient from that of an
individual in a bed to that of a participating member of a family, then she will expand her
role to assist relatives to cope with the patient's illness while simultaneously maintaining
family function." The subjects in this study consisted of forty relatives of critically ill
patients that were surveyed over a two month period of time. The purpose of this study
was to define the needs of families of critically ill patients. To define these needs three
basic questions were formulated: what personal needs do relatives of critically ill patients
identify, what is the importance of these needs to the relatives, are these needs being met
and, if so, by whom. In her study she hoped to find that the family was aware of the staff's
commitment to helping the family cope, but this was not the case. To the contrary, the
family felt that patient centered care was the primary responsibility of the staff (Molter,
1979).

Although this study carried out its purpose effectively there are some weaknesses
in its design. The families surveyed in this study were asked to rank needs that were
predefined and may have shaped how the families responded to questions about important
needs. A problem with the study design is that it utilized a group of twenty-three nursing
graduate students in conjunction with a literature review to determine what needs were
most important to the families of critically ill patients. Input was not received from other
health professionals or families of critically ill patients. A follow up study conducted by
Leske (1986) in a different geographic area identified little response variance between
patients in her study and Molter's study in the area of needs that were defined as "primary
needs". These needs are: to receive information about the patient once a day, to be called
at home about changes in the patient's condition, to know why things were done for the
patient, to be assured that the best care possible is being given to the patient, to know
exactly what is being done for the patient, and to know how the patient is being medically treated (Leske, 1986).

These studies support the need to address the family as a part of the total treatment of the patient in the critical care setting. These basic family needs may be applicable to the rehabilitation setting. Wright (1983) proposed a comanagement approach to rehabilitation, although no research study was found that supported the use of this approach. This comanagement principle called for the rehabilitation team and family to work as equal partners. In order for this relationship to be effective there must be effective communication between the family and the rehabilitation team (Foley, 1993).

**Family Participation and Communication in Rehabilitation**

Although rehabilitation today still focuses on client-centered treatment, there is an increasing emphasis being placed on enlisting family involvement in the rehabilitation process. This creates a need to accurately assess family function. This assessment determines if the family is healthy or dysfunctional, and identifies the nature of the dysfunction if one is present. Assessment is important in diagnosing the family's problems and forecasting the family's needs before setting goals and initiating interventions (Gillies, 1987). Members of the rehabilitation team must be able to assess the following areas: family needs, ability to resolve conflict, ability to communicate, problem solving and coping strategies for dealing with loss and change. Only when these areas are understood and addressed will the team be able to utilize the family as a contributing factor to the outcome of rehabilitation. (Hochberger, 1985)

A study conducted by Watson (1987) on family participation in the rehabilitation process, takes as its theoretical rationale, research carried out by Satir (1972), Safilios-Rothchild (1970) and Wright (1983), whose basic premise is that the family is a system. Therefore when a member of the family becomes disabled the whole family is affected. When rehabilitating a patient the whole family must be addressed to maximize adjustment to the disability.
Watson (1987) utilized the comanagement principle as a basis in designing a study for surveying beliefs of rehabilitation professionals about family participation and extent of family involvement in rehabilitation. The Family in Rehabilitation Inventory made use of sixty-three items divided into two categories. Section I consisted of forty items that measured beliefs about the family in rehabilitation. Section II consisted of twenty-three items on perception of family participation. The survey was administered to 198 health professionals at three hospitals, surveying all members of the rehabilitation team.

The respondents showed a high degree of agreement (90% or higher) on the following: family should ask questions and offer opinions, family participation results in better coping skills, family and team should agree on patient's abilities, family should participate from the beginning of the rehabilitation process. However, only a slight majority of respondents believed that the patient and family should be treated as a unit.

There was a discrepancy between what the rehabilitation team believed about family involvement and their practice in the clinical setting. Eighty percent of respondents believed that family was not always helpful in rehabilitation. Seventy-seven percent believed families could not always be depended on to carry out a plan of care. Seventy-four percent believed that families can be difficult to work with and get in the way in the rehabilitation unit.

Watson (1987) in the discussion of her research, suggested that rehabilitators believe in the theoretical framework of the family as important contributors to the rehabilitation process. In practical application, however, clinicians believe in a directive rehabilitation model with specified expectations for family participation. These expectations place the family under the direction of the rehabilitation team instead of allowing the family to work as an equal part of the total management team.

McKinlay & Hickox (1988) involved family members as cotherapists in addressing memory impairment and anger control in patients with brain injury. Stable baselines were established for each of the four participants in the study in regards to temper outbursts in
cases three and four, and memory lapses in cases one and two, for a period that was randomly assigned between four and eight weeks. Treatment consisted of two anger control strategies used for patients three and four and four memory techniques used for patients one and two. A family member was included in each treatment session. In cases one and two memory failures declined sharply and plateaued at a lower level. Cases three and four showed low frequency of temper outbursts even when establishing baseline. Temper outbursts continued in case three despite treatment. In case four there were no outbursts in the second half of treatment.

McKinlay & Hickox concluded that the results suggest that programs in which relatives play a key role may be effective in late rehabilitation of memory and temper-control deficits. The strength of this study was that the authors tried to involve family members as cotherapists in treatment sessions. The primary weakness was not treating any patients without the family present to serve as a control group. The second weakness was the limited sample size.

There are many ways for the family and team to communicate in the rehabilitation setting. The current trend is the use of team conferences that include the family. Conferences are held to coordinate staff efforts and update the family on the patient's progress. In order for the staff to completely understand the family's situation, they must be able to effectively communicate with the family/patient unit. In order for the family to give informed consent, and to act as a patient advocate, they must be participants in effective two way communication (Foley, 1993). Bratt (1987) discussed differing views held by families and health professionals on the effectiveness of conferences to establish communication: "Professionals feel they are doing a good job by involving relatives in care." In poorly run meetings, however, families can be left feeling isolated, guilty and angry and this experience may damage future attempts at joint efforts to rehabilitate the patient (Bratt, 1987).
In order to develop a system of healthy communication between the family and staff in rehabilitation, potential areas of conflict should be addressed, as defined by both groups (Dunn, Umlauf & Mermis, 1992). The Rehabilitation Situations Inventory (RSI) was a series of questions that were designed to identify problem areas that staff perceived as causing difficulty in their relationships with families in the rehabilitation process. One study looked at the effectiveness of the inventory in measuring staff perceptions of difficult behavioral situations in rehabilitation settings (Dunn, Umlauf & Mermis, 1992). The test was administered to staff at three rehabilitation clinics. Each item on the questionnaire was a different situation encountered in rehabilitation, which was rated on a scale of difficulty of one to five. Upon analysis of variance no significant difference was seen between staff gender or staff at different facilities and mean RSI score. Utilizing the Pearson correlation coefficient between mean RSI score and amount of years staff had spent in rehabilitation indicated that staff with higher levels of experience reported less difficulty with the family. The areas perceived to be the most difficult by staff were: negative interaction between professionals, unrealistic expectations of the family and noncompliant patients.

This study, while it covered a wide range of situations encountered in rehabilitation, has weaknesses, in that, the questions in the survey were based on input obtained from only one rehabilitation site, and it was administered to the staff of the facilities where the authors were employed. As a preliminary evaluation of a new tool, this study was shown to be internally reliable, but the authors admitted the necessity for the replication of their findings.

The amount of family/staff interaction is dependent on a number of factors including: workload of the facility, availability of staff and family members, staff attitudes regarding family visitation, and cultural biases on the part of staff. Problems in family/staff interactions can arise from hospital policy regarding visitation and from family confronting staff with repeated questions about patient status (Gardner & Stewart, 1978). Gans
(1983) stated that therapists often find themselves working with a family that feels that the rehabilitators are too negative, and the patient feels as though he doesn't have a problem. As a result, the family is constantly criticizing the therapist's actions and the patient is constantly denying the need for therapist's help at all.

McLaughlin & Carey (1993) stated that a synergism must develop between the families and staff involved in a therapeutic relationship. In their study they explored the relationship between patient discharge outcome and perceived family stress and satisfaction. The questionnaire completed by the family psychologist gathered information on the areas of: family satisfaction with rehabilitation services, family stress during rehabilitation, family/team conflict, number of family conferences, recommendations for psychological treatment and patient compliance with recommendations, and the extent to which family participated in educational/support programs. Correlations were shown between higher conflict levels and the following: lower patient cognitive levels at admission, lower cognitive levels at discharge, longer length of stay, lower satisfaction with program outcome, higher perceived family stress, increased conferences, more psychology sessions recommended by psychologists, and younger age of patient. Although this study attempted to answer a number of valid questions surrounding the relationship between the family and staff, its glaring weakness was that the family psychologist was the individual who was surveyed and not the family itself.

Evans, Bishop & Matlock (1987) addressed attempts to promote family adherence to stroke rehabilitation programs. In this study, the relationship between the level of family function and adherence to stroke treatment was investigated. A primary caregiver that was living with the patient was identified. The McMaster Family Assessment Device (FAD) was administered by a social worker to the primary caregiver of all stroke patients on a sixteen bed rehabilitation unit over the course of a year to assess the level of family function. The FAD was a sixty item paper and pencil device that evaluated seven dimensions of family functioning including: problem solving, communication, roles,
affective involvement - the interest family members invest in each other, affective responsiveness - the ability to respond with appropriate quantity and quality of feelings, behavior control - patterns adopted by the family to deal with dangerous situations, and general functioning - an overall assessment of family health. Physiatrists developed their own rating scale for the FAD based on observation of families during clinical follow up visits and notation of indicators of unsatisfactory outcome. The physiatrists compared the caregiver's report of poststroke care to expectations for positive outcome. Adherence to the physiatrists' scale was rated through an interview carried out by a social worker. How adherence was measured was not made clear. The social worker indicated the extent of agreement by the caregiver with a list of 60 items which evaluated the seven dimensions of family functioning. The rating scale used by the rater ranged from strongly agree (1) to strongly disagree (4). Good adherence to treatment showed a strong and significant relationship with affective involvement, problem solving, and communication. Adherence was also significantly related to general family functioning. The remaining family function measures did not correlate significantly to adherence.

Weaknesses of the study include: the same individual reporting adherence levels and family functioning levels which could increase the chance of finding a positive relationship, basing construct validity on a consensus of professional opinion and a tendency by the authors to extrapolate conclusions past the extent of the data collected. An example of an unwarranted conclusion was stating, "Our findings suggest that families that support adherence to treatment have members who share positive affective involvement with each other, are generally invested and interested in each other, and are not over, under, or narcissistically involved with each other" (Evans, Bishop & Matlock, 1987). The experimental design and presentation was unclear about how critical data was collected and evaluated. The strength of the study is in the tool used. The FAD has been shown to have sound psychometric properties, good test/retest reliability, internal consistency, and concurrent discriminate validity. The authors of this study concluded
that their findings support the positive benefits of including family in the rehabilitation process.

In summary the articles reviewed in this section place an emphasis on assessing the needs of the family and the patient as a unit and enlisting the family as an equal participant in the holistic treatment of the patient. This can only be accomplished by assessing patient and family needs, by establishing effective two way communication and avoiding unproductive staff/family conflict.

Gardner and Stewart (1978) in their article about staff involvement with families of patients in the CCU, stated that familiar family members may bring about faster recovery than a strange staff member. We feel that this may be true in the rehabilitation of patients with traumatic brain injury. If this is the case, then the more involved the family is in the rehabilitation process the better the outcome.

**Patient outcome**

Seale (1989) states that the psychosocial aspect of hospice is to treat the patient and family as a unit, and allow them to express their needs and preferences regarding how care will be provided. The relationship of the following study on hospice care to research on the family role in the rehabilitation of patients with traumatic brain injury, is the common element of family involvement in both studies. The hospice setting in this study had a lower staff to patient ratio, and the staff sought to spend more time with the patient and family to help them cope with the patient's impending death, allowing for more staff/family interaction. In this study, a comparison was made between outcomes in inpatient and home hospice programs and conventional hospital treatment for patients with terminal disease. The sample for this study was 133 hospice patients and 110 control patients at a veteran's facility. Criteria for enrollment into the study was a prognosis of 2 weeks to 6 months of remaining life. Patients and their families were interviewed over the course of time spanning from patients' enrollment into the study to the time of patients' death. As the patients neared death, time intervals between interviews was increased in
order to lessen the burden on the respondents. The authors of the hospice research study found that there was no significant difference between hospice care and conventional treatment in the areas of: pain, symptoms, activities of daily living, or affect. There was, however, a significantly higher satisfaction and lower anxiety level in the hospice group when compared to the control group (Kane & Wales et. al., 1984).

The primary weakness of this study was the lack of discrimination made between the control and hospice groups. In Kane and Wales, et. al. (1984) study, the authors state that they could not separate home and inpatient hospice settings from one another because many patients were present in both settings at different times during their participation in the research study. The problem with this is that 108 of the 133 patients in the hospice population were considered inpatient. This population had a higher percentage of invasive surgeries and chemotherapy intervention than the group that was labeled a control in the study. Because the hospice group had a greater percentage of invasive treatment intervention than the control group, which was expected to receive more invasive treatment, there is no real basis for comparison between the two groups used in the study. Therefore, the conclusions that Kane and Wales et. al. (1984) make regarding the lack of statistical difference between the hospice and conventional treatment programs have questionable validity. Had the study by Kane and Wales et. al. (1984), set up a sample differently this may have set some trends for outcome (measured by patient/family satisfaction) that could have been correlated with increased utilization of the family in the health care setting.

In order to effectively assess treatment of patients with traumatic brain injury, it is necessary to have an instrument that is statistically reliable and valid and measures change in patient functional status (Hall, Hamilton, Gordon & Zasler, 1993). The Functional Independence Measure (FIM) is a widely used scale in rehabilitation to measure functional change. The FIM consists of a total of eighteen items divided into the following six general categories: self-care, sphincter control, mobility, locomotion, communication and
social cognition. The score in each category is ranked between one and seven points, with seven points being the maximum score in each item measured. The validity of the FIM has been demonstrated in the areas of content validity and construct validity. Content validity has been demonstrated by clinicians. Construct validity has been assessed by home visits by clinicians. In addition, admission FIM motor items were found to be the best predictors of length of stay. Reliability of the FIM has been shown through interrater agreement, the correlation coefficient being 0.97. Precision, defined by the authors as the ability of the instrument to detect meaningful change in level of function during rehabilitation, has been observed to be high in the FIM. This was determined by taking FIM values for patients with traumatic brain injury discharged from model systems hospitals between March 1989 and March 1992. Differences between admission and discharge scores were shown to be statistically significant but the authors did not show the FIM to be valid specifically for patients with traumatic brain injury. The FIM, originally developed as a global functional assessment measure to assist in documenting disability severity and outcome, is not diagnosis specific, which may be a possible limitation in regard to evaluating patients with traumatic brain injury (Hall, Hamilton, Gordon & Zasler, 1993).

Bunch and Dvonch (1994) investigated the tendency of clinicians to use total FIM scores as values rather than an indicator of patients status on admission. This tendency leads to two problems. The first problem is that the section scores may not be additive, and second that although FIM numbers may be ordinal, intervals between numbers may not be equal.

In determining the relative desirability of the four components of the FIM score tested in this study (self care, continence, mobility and communication), the authors surveyed nurses and therapists. The results were that scaling for continence and mobility was uniform and therefore the numbers for these sections was both ordinal and interval
equivalent. Scores for self care and communication, however, were not found to be linear but fit a more curvilinear relationship (Bunch & Dvonch, 1994).

To test the importance of the scaling differences the authors utilized data on 142 patients with fractures of the proximal femur. Using the initial eighteen FIM scores, the sex, age, type of fracture, co-morbidities and other information available at admission, the authors developed a regression equation to predict FIM score. Then the authors recoded the initial scores to account for interval changes in self care and communication and recalculated the regression equation (Bunch & Dvonch, 1994).

The regression equation obtained from the unadjusted FIM score and the regression equation calculated from the adjusted FIM scores were both tested on fifty additional patients that were not defined by the authors as a specific population. The results showed that they both had the exact same outcome. The authors concluded that, in the strictest sense, the FIM scores were neither additive nor of equal interval scaling, but they also concluded that for practical purposes, the FIM scores when compared to other functional scores, seemed to possess the desirable characteristics of being additive and of having equal interval scaling (Bunch & Dvonch, 1994).

The primary weakness of this study is that it was ambiguous. It stated that the FIM was not additive or of equal interval scaling, but then stated that for all practical purposes that the FIM was additive and of equal interval scaling when compared to other functional measures because of the minor deviations that were found in the study. It would appear that if it was additive and of equal interval scaling where it is being utilized then that should be the conclusion of the authors of this study.

The primary strength of this study was that it produced results that showed that the original FIM was as reliable for predicting outcome in the sample of patients used in this study as the adjusted FIM that the authors created. This reinforces the use of FIM as an additive total measure of an individual's functional status, but the authors of this FIM
study failed to show that their results could be extrapolated to other populations that the FIM is currently being used to assess.

Another study conducted by Cook, Smith & Truman (1994) stated that functional change is the best measure of the effectiveness of patient outcome in a rehabilitation program. In this study the authors stated that the FIM was one way to measure patient outcome in rehabilitation. They did, however, state that there were problems with the psychometric properties of FIM. This problem arises when the results of the FIM are presented as a cumulative score combining motor and cognitive scales. The purpose of this study was to examine changes in median admission and discharge FIM scores in a group of brain injury patients that were divided into three groups based on length of stay to determine if the FIM was an effective way to measure functional change.

FIM scores were obtained from a database of 53 patients with traumatic brain injury who were admitted to rehabilitation between January 1992 and October 1992. The severity of the brain injury ranged from moderate to extremely severe. The severity of brain injury was not assessed in half of the patients because Cook, Smith & Truman stated they were aphasic and discharged with post-traumatic amnesia. Their ages ranged from 16 years 11 months to 76 years 3 months and their length of stay varied from 1 day to 38 weeks. Patients were divided into three groups of equal numbers according to length of stay. The short stay group was in the unit for three weeks or less; the medium stay group was in the unit for three to nine weeks, and the long stay group was in the unit for greater than nine weeks (Cook, Smith & Truman, 1994).

The results for the short stay group showed no improvement between median FIM admission and discharge scores except for bathing, social interaction, problem solving, and memory because these areas were at their highest at admission. The medium stay group had lower median scores, upon admission than the short stay group, but the discharge median scores with the exception of comprehension, were equal to the short stay group. The long stay group had lower median admission scores than the other groups and were
the minimum for all activities except comprehension. With the exception of stairs, all median scores were higher at discharge than at admission, but no median scores achieved the maximum level on the FIM. The authors concluded that the short stay and medium stay groups were both discharged from rehabilitation with a high level of functional independence, and the long stay group was discharged with an increased level but not a high level of functional independence (Cook, Smith & Truman, 1994).

The primary strength of this study is that it uses the FIM in conjunction with average length of stay data, to consider not only functional improvement, but also the amount of time that it took to reach that level of functional improvement. The limitations that are apparent in this study are, that half of the individuals in the study were not assessed and therefore statistical tests were based on less than 27 patients, and the study did not control for age difference among the three groups (Cook, Smith & Truman, 1994).

In conclusion, this study addressed an important issue in determining patient outcome in rehabilitation, which is considering the amount of time that it takes for the patient to make functional gains. By utilizing the FIM in conjunction with average length of stay data it is possible to get a clearer picture of the functional gains made in rehabilitation.

A research study conducted by Hamilton & Granger (1994) investigated the FIM scores for functional outcomes of interest to physical therapists. They found that physical therapists most frequently assessed bed/chair transfers, locomotion, stair climbing, toilet transfer and tub transfer. They also found that physical therapists were not significantly involved in assessing any of the other FIM items. The authors found that use of a uniform functional assessment instrument allows facilities to compare their findings with those of other programs. Relevant to our study was the use of gain in FIM score divided by the length of stay to calculate a more efficient method of measuring patient outcome.

Hamilton and Granger utilized FIM data from accredited inpatient rehabilitation facilities in 44 states during the calendar year 1992. They limited their study to a total of
27,034 patients who sustained cerebral vascular accidents. They investigated the difference between average FIM score at admission and average FIM score at discharge, and found that the average gain was 23.9 points. The average length of stay was 28 days. By dividing the average FIM score gain by the average length of stay, the authors found that the average FIM gain per day was 0.85 FIM units. Function in the five areas assessed by physical therapists increased from an average of 2.5 at admission to an average of 4.2 at discharge (Hamilton & Granger, 1994).

The authors adopt the position that summed FIM scores can be treated with parametric analysis. In addition, the authors stated that the FIM appears to work well for program evaluation, classifying patient level of disability and predicting certain outcomes such as, discharge level of function and length of stay.

The primary strength of this study was its large sample and widespread geographic distribution of facilities from which data was collected. This study carried out its purpose effectively and did not have any major weaknesses.

The literature that we have reviewed shows that the FIM is a uniform method of measuring patient outcome. In order to investigate the effects that family participation has on patient outcome in the rehabilitation of traumatic brain injury patients, it is necessary to have a reliable instrument to measure outcome. In reviewing the literature, we found that FIM, when used in conjunction with length of stay, may be an effective tool for measuring patient outcome. Our review showed that the FIM was valid for the stroke and muscular sclerosis populations, but we could find no literature with regard to validity in the traumatic brain injury population. Due to our need to use a standardized outcome measure in our research study we decided that the FIM was the only option available to us at this time.

Our review of the literature revealed that there is a need to address the family's needs as a part of the total treatment of the patient. In order to accomplish this the literature stated that the family should be assessed to determine what their needs are.
Some of the needs that were listed in the literature were, the need to be kept informed as to the patient's condition and current treatment, and to be reassured that the best possible treatment is being given. The most important need that families expressed was the importance of feeling that there is hope.

When the family's needs are understood then the family can begin to take an active role in the patient's treatment. The literature that we reviewed found that there was a discrepancy between what the rehabilitation team believed about family involvement, and their practice in the clinical setting. Although rehabilitators believed in the enlistment of the family in the rehabilitation process in theory, in practice it was found that the therapists felt that the family was not always helpful or dependable. The literature that we reviewed showed that the family has been shown to be of benefit in facilitating treatment with critical care patients, and with patients with brain injury undergoing memory and anger control rehabilitation. Unfortunately, we found no studies that looked directly at the effect of the family on outcome in patients with traumatic brain injury in physical rehabilitation.

We could find no studies in our review of the literature that relate family participation in rehabilitation of patients with traumatic brain injury to patient outcome. We therefore set forth the following as our research questions: "What are the beliefs of physical therapists regarding family participation in the rehabilitation of patients with traumatic brain injury? Do sites with physical therapists that believe in increased family participation in the rehabilitation of patients with traumatic brain injury have improved patient outcomes? And, does institutional policy that encourages family participation in rehabilitation of patients with traumatic brain injury improve patient outcomes?"
CHAPTER THREE

METHODOLOGY

We developed two surveys to gather the data needed for our research. Our sample consisted of all rehabilitation sites that were accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) from the midwestern United States including: Michigan, Ohio, Indiana, Illinois, Wisconsin and Minnesota. The total sample size consisted of ninety four sites. The site used for our pilot study was not included in the sample. Additionally, three sites were found to be affiliates of other sites in the sample, data from these sites were included with the primary respondent. This reduced our sample size to ninety sites. The purpose of our first survey (Appendix A) was to collect outcome data on length of stay and change in FIM scores, determine institutional policy regarding family participation in the rehabilitation of patients with traumatic brain injury, and to find out how many physical therapists worked with patients with traumatic brain injury at that site. Following the return of the first survey, a second survey (Appendix B) was sent to the director of rehabilitation for distribution to the physical therapists that worked with patients with traumatic brain injury at that site. This survey examined the perceptions of physical therapists regarding the role of the family in the rehabilitation of patients with traumatic brain injury.

In the institutional survey, we used the Functional Independence Measure (FIM) and average length of stay to measure patient outcome. We requested both total admission FIM scores and total discharge FIM scores, as well as, admission and discharge FIM scores in the subsections of mobility and transfers. In addition, information was collected regarding the institution's policies for family participation in the rehabilitation of patients with traumatic brain injury.
The therapist perceptions survey utilized a Likert-like rating scale ranging from strongly agree to strongly disagree with the central selection representing a position of neither agree nor disagree. Construct validity was tested with a series of questions that were designed to examine respondents understanding of the questions being asked. This was accomplished by examining whether or not respondents answered similar questions with consistent opinions.

Before we initiated our research study, we conducted a pilot study of the institutional survey and physical therapist perceptions survey at a local hospital. The institutional survey was completed by the director of rehabilitation. The physical therapist perceptions survey was completed by three physical therapists working with patients with brain injury at that hospital. The institutional survey was completely redesigned to utilize FIM to measure patient outcome instead of our original questions. The physical therapist perceptions survey was significantly shortened, and some questions were reworded to make their meaning clearer to the reader.

Following approval by Grand Valley State University's Human Subjects Review Committee, we sent out the first survey to all the institutions we had selected for our study, but due to the low return rate we resubmitted the first survey to all of the sites that had not responded by our first deadline. We then set another return deadline for those institutions included in the second mailing. When the new deadline was reached, we submitted the second survey to the directors of rehabilitation of all those institutions who chose to participate in our study. We included individual return envelopes for each physical therapist participating at each site. Prior to the deadline for the second survey, reminder letters were sent to the directors of rehabilitation. Because of the sensitive nature of the data being collected, therapist and rehabilitation site names were kept strictly confidential. This was accomplished by number coding the surveys sent to each institution so that the surveys could be matched when they were returned.
In examining the institutional survey using the Statistical Package for the Social Sciences (SPSS) software program, we looked at the following areas, characteristics of the patient population, and comparison of institutional policies with regard to the family participation in rehabilitation and patient outcomes. We examined the characteristics of the patient populations of each institution, by computing frequencies on questions seven and eight on the institutional survey (see Appendix A). These questions were used to determine the percentage of each site's patient population that consisted of patients with traumatic brain injury, and the percentage of these patients within the traumatic brain injury population that were discharged to the home setting following rehabilitation.

Institutional surveys were analyzed by comparing patient outcomes to institutional policies regarding the role of family in the rehabilitation of patients with traumatic brain injury. This analysis was completed on those sites that completed the FIM portion of the survey. Policies were addressed by question number two on the institutional survey (Appendix A). The sites were asked to select any or all of the four areas that matched their policies regarding the role of the family in the rehabilitation of patients with traumatic brain injury. A scatterplot graph was then completed by placing patient outcome data on the X-axis, and placing policy concerning family involvement in rehabilitation on the Y-axis. Sites that selected either the first or first and second responses to question two, and did not select either of the last two responses were considered to be in agreement with increased family involvement. Sites that agreed with increased family participation in question two were represented by the "A" column on our scatterplot, and those sites that were not in agreement with increased family involvement were represented by the "B" column on our scatterplot. Patient outcomes were computed by subtracting total FIM discharge scores from total FIM admission scores and dividing by the average length of stay for each site, to obtain FIM gain per day. We then looked for any trends between institutional policies regarding family participation and FIM gain per day.
Questions three and four were analyzed by calculating the percentage of sites that responded "yes" and the percentage of sites that answered "no" for each question. Question three asked sites if families were routinely included in family conferences. Question four asked sites if they offered support groups to patients and family.

Using the SPSS software program to enter and analyze data from the second survey, we determined the following: agreement of physical therapists with increased family involvement, agreement of physical therapists with individual questions within the survey, the mean score for each question in the survey, and comparison of physical therapists' perceptions regarding family participation in rehabilitation with patient outcome data from the site in which the physical therapists work. Validity of the therapist survey was tested by using a series of six paired questions to determine if therapists answered similar questions with answers that were in agreement with each other. This was determined by calculating the percentage of respondents that answered each of the pairs of questions with responses that were in agreement with each other.

Agreement of physical therapists with increased family involvement in rehabilitation was determined by ranking the responses to our questions on a scale of one to five, with five indicating the greatest amount of agreement with increased involvement of family, and one indicating the least amount of agreement with family involvement. The numerical ranks assigned to each item were summed for each respondent and the percentage of agreement was determined by dividing each respondent's sum by the highest score possible, which indicated the highest level of agreement with increased involvement of the family. The agreement of therapists for each individual question was determined by counting the number of times therapists chose either "agree" or "strongly agree" for each question, and calculating this as a percentage of the total number of responses. The mean score for each question was also calculated.

The final analysis that we conducted on our second survey was the comparison of therapists' perceptions regarding the role of the family in the rehabilitation of patients with
traumatic brain injury, and the outcomes of patients with traumatic brain injury within the sites in which the physical therapists worked. The percentage of agreement with increased family involvement was averaged for all of the physical therapists that worked at each site. Using a scatterplot for comparison, percentage of agreement with increased family involvement was plotted on the X-axis, and FIM gain per day was plotted on the Y-axis. We then looked for correlations between therapists perceptions and FIM gain per day.
A total of 50 institutional surveys were returned, a return rate of 56%, of which 15 included data on overall FIM admission and discharge scores, and 9 of which included additional data regarding transfer and mobility FIM subsection scores. Of the 15 institutional surveys that included general FIM scores, two were excluded from analysis due to invalid scores. The lowest score possible on the FIM is 7, and the scores reported in the two excluded surveys were less than this minimum score. These two surveys were included in analysis of the total group of fifty institutions. Of the 35 institutions that did not include FIM data, 22 facilities did not use the FIM as their functional assessment measure, 4 facilities did not have FIM data readily available, 5 had just begun using the FIM and could not provide the data requested, and one facility used the Functional Assessment Measure (FAM) as an assessment tool. Three facilities that used the FIM did not provide a reason for not including the requested data, this may have been due to concerns about confidentiality.

Due to the large discrepancy between the total institutional surveys that we received and the number of surveys that provided FIM data, we decided to analyze the characteristics of the population as a whole, and as a subgroup of those institutions providing FIM data. When facilities provided a range for length of stay the midpoint in the range was used as the length of stay for that institution. The average length of stay of the 48 institutions that provided this data was 130 days with the minimum being 7.6 days and the maximum being 930 days. The total institutional group had a median length of stay of 90.0 days. The FIM subgroup had an average length of stay of 42.4 days with a minimum of 18.0 days and a maximum of 133.5 days. The median length of stay for the FIM subgroup was 31.0 days. The percentage of the patient population with traumatic
brain injury (TBI) in the total institutional group and FIM subgroup is displayed in Table 1. The percentage of the traumatic brain injury population that was discharged to home within the total institutional group and FIM subgroup is summarized in Table 2.

A comparison between the total facility group and the FIM subgroup showed the following results for percentage of the patient population with traumatic brain injury and percentage of this population discharged to the home. The total facility group had 14 of the 50 sites with less than 15%, and 12 of the 50 sites with greater than 90% of their total population consisting of patients with traumatic brain injury. Within the FIM subgroup, 9 of the 13 total sites had less than 15%, and only one of the sites had greater than 90% of their total patient population consisting of patients with traumatic brain injury. In the total facility group, 30 of the 50 sites had 75% or greater of patients with traumatic brain injury discharged to the home setting. The FIM subgroup had 9 of the 13 sites with 75% or greater of patients discharged to the home setting.

Question two on our institutional survey was intended to give us an indication of each facility's policy regarding the involvement of the family in the rehabilitation of patients with traumatic brain injury. Sites were asked to select as many of the four possible responses for question two as applied to their facility. We concluded that sites selecting either 2A or 2A and 2B, advocated increased involvement of the family in the rehabilitation process. The percentages reported in Table 3 indicate the frequency that sites selected each response for question two. These percentages are reported for both the total facility group and the FIM subgroup. The distribution of responses for question two for the total facility group are reported in Table 4.

We found that greater than 78% of the respondents answered 2A or 2A and 2B exclusively, for question two in both the FIM subgroup and the total institutional group. These percentages show that the majority of the sites that we surveyed were interested in family presence and family participation in treatment sessions throughout rehabilitation.
Patient outcome scores were determined by subtracting total discharge FIM scores from total admission FIM scores, and dividing this difference by the average length of stay of the institution to determine the total FIM gain per day. This data is displayed in Table 5. Institutional policies that favored increased family participation were determined by calculating the number of sites that selected 2A or 2A and B, and did not select either 2C or 2D (see Table 3 for definition of these questions). To determine if there was a correlation between FIM gain per day and institutional policies within the FIM subgroup, we utilized a scatterplot (Figure 1). Visual analysis of this comparison revealed no trends between institutional policies regarding family participation in rehabilitation, and the outcome of patients with traumatic brain injury.

Question three in the institutional survey asked if facilities routinely included the family in team conferences, and question four asked if facilities had support groups for family and patients. We found that 80% of respondents routinely included the family in team conferences, and 77.6% of the facilities offered support groups to family and patients.

Within the physical therapists' perceptions questionnaire, 105 surveys were returned. One of the surveys was dropped from the study because the respondent failed to complete one page of questions, so 104 surveys were used for data analysis. These surveys were returned by physical therapists working at those sites that returned the institutional survey. The institutional and therapists' surveys were numbered in order to allow matching of the surveys from each site without breaching confidentiality. We looked at two general trends within these surveys: how physical therapists within both the FIM subgroup and the total group viewed the role of the family, and if physical therapists' beliefs about the family correlated with the outcome of patients with traumatic brain injury within the FIM subgroup.

Construct validity was checked within the survey by determining how consistently physical therapists answered pairs of questions that were worded opposites of each other.
For example, if a physical therapist answered one of the paired questions with a "strongly agree or agree", we would expect that the other question would be answered with a "strongly disagree or disagree". There were six pairs of questions placed in the therapist survey. Table 6 presents the frequency and percentage of consistent and inconsistent responses.

We looked at beliefs of therapists regarding increased family participation, by examining the average percentage of agreement of each respondent with all of the questions together, the average percentage of agreement of all of the respondents with each individual question and the mean score of each question. We examined therapists' beliefs about increased family participation for all of the questions in both the total group of physical therapists (Figure 2) and the FIM subgroup of physical therapists (Figure 3). The percentage of agreement and mean score for each individual question is displayed in Table 7.

Those questions that ranked highest by percentage in Table 7 were 1, 19, 22, and 7. According to these questions, physical therapists strongly believed that the family should not be limited to family conferences, or limited to observation of treatment sessions in the rehabilitation process. The respondents also believed that the more the family participated in rehabilitation the better prepared they were to care for the patient at home.

In exploring therapists' opinions with regard to the effects of family participation on patient outcome, we found that in question 10, 83.7% believed that family participation had a direct effect on patient outcome. Questions 11 and 21 indicated that greater than 79.8% of therapists believed that increased participation by the family leads to better outcome by the patient with traumatic brain injury.

In examining the area of conflict between family members and staff, greater than seventy-six percent of therapists felt that when families participated in goal setting, conflict was not increased between family and staff. Greater than 79% percent of respondents believed that lack of education regarding prognosis increases conflict between the family
and staff. In addition, we found that 66.4% of the respondents felt that increased participation of the family in the rehabilitation of patients with traumatic brain injury did not increase stress between family and staff, and 62.5% believed that decreased participation of the family in the rehabilitation of patients with traumatic brain injury increases stress between family and staff.

Questions 9, 18, 12 and 16 were the four lowest values for both percentage and mean in Table 7. Responses to question 9 and 18 indicated that therapists did not strongly believe in either treating the family and patient as a unit, or considering the family an equal partner in the rehabilitation process. Question 12 asked whether institutions with unwritten policies regarding family participation in rehabilitation have poorer patient outcomes than those institutions that had written policies. Analysis of question 12, showed that 67% of the respondents answered "neither agree nor disagree". Question 16 asked whether the patient should give consent to the rehabilitation team before the patient's family is allowed to participate in the rehabilitation process. Analysis of the responses showed 36% answered "neither agree nor disagree", 35% answered with a response of "agree or strongly agree" and 27% answered with a response of "disagree or strongly disagree". The large percentage of neutral responses in question 12 indicates that respondents had no opinion about the effect of institutional written policies regarding family participation in rehabilitation. Greater than eighty one percent of therapists in question 8, however, believed there should be written guidelines for the family in rehabilitation. The split of responses for question 16 indicates that therapists beliefs are divided about whether the patient should give consent to the rehabilitation team before allowing family participation.

The final portion of our analysis involved comparing the therapists' percentage of agreement with family participation, and the FIM outcome scores of the corresponding site. For those sites with more than one therapist returning a survey the percentage of agreement was presented as an average score of all the therapists at that site. A
scatterplot graph was then composed to determine if there was a correlation between therapists' perceptions and FIM outcome scores at that site. The results are displayed in Figure 4. Visual inspection of the scatterplot, showed no apparent trends between patient outcome and physical therapists' agreement with family participation.
Table 1

**Percentage of Facility Patient Population with TBI within Total Institutional Group and FIM Subgroup**

<table>
<thead>
<tr>
<th>Response Values</th>
<th>Total institutional group</th>
<th>FIM subgroup</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (n=49)</td>
<td>% of sites</td>
</tr>
<tr>
<td>0-15%</td>
<td>14</td>
<td>28.6</td>
</tr>
<tr>
<td>15-30%</td>
<td>9</td>
<td>18.4</td>
</tr>
<tr>
<td>30-45%</td>
<td>2</td>
<td>4.1</td>
</tr>
<tr>
<td>45-60%</td>
<td>5</td>
<td>10.2</td>
</tr>
<tr>
<td>60-75%</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>75-90%</td>
<td>6</td>
<td>12.2</td>
</tr>
<tr>
<td>&gt;90%</td>
<td>12</td>
<td>24.5</td>
</tr>
</tbody>
</table>

Table 2

**Percentage of Facility TBI Population Discharged to Home in Total Institutional Group and FIM Subgroup**

<table>
<thead>
<tr>
<th>Response Values</th>
<th>Total institutional group</th>
<th>FIM subgroup</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (n=47)</td>
<td>% of sites</td>
</tr>
<tr>
<td>0-15%</td>
<td>3</td>
<td>6.4</td>
</tr>
<tr>
<td>15-30%</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>30-45%</td>
<td>3</td>
<td>6.4</td>
</tr>
<tr>
<td>45-60%</td>
<td>4</td>
<td>8.5</td>
</tr>
<tr>
<td>60-75%</td>
<td>6</td>
<td>12.8</td>
</tr>
<tr>
<td>75-90%</td>
<td>18</td>
<td>38.3</td>
</tr>
<tr>
<td>&gt;90%</td>
<td>12</td>
<td>25.5</td>
</tr>
</tbody>
</table>
Table 3

**Distribution of Responses for Question Two of the Institutional Survey**

Q2. Check all of the following ways that most accurately reflect ways in which your facility utilizes the family in the rehabilitation of patients with traumatic brain injury.

<table>
<thead>
<tr>
<th>Response Description</th>
<th>Total facility group</th>
<th>FIM subgroup</th>
</tr>
</thead>
<tbody>
<tr>
<td>2A. Family participation in treatment sessions throughout rehabilitation.</td>
<td>84.0%</td>
<td>92.3%</td>
</tr>
<tr>
<td>2B. Observation of treatment sessions.</td>
<td>88.0%</td>
<td>84.6%</td>
</tr>
<tr>
<td>2C. Family limited to visiting hours when patient is not being treated.</td>
<td>8.0%</td>
<td>15.4%</td>
</tr>
<tr>
<td>2D. Family participation in treatment sessions only during education sessions with the therapist.</td>
<td>20.0%</td>
<td>15.4%</td>
</tr>
</tbody>
</table>

Table 4

**Distribution of Answers to Question 2**

<table>
<thead>
<tr>
<th>Response number</th>
<th># of sites that selected response</th>
</tr>
</thead>
<tbody>
<tr>
<td>2A only.</td>
<td>5</td>
</tr>
<tr>
<td>2D only.</td>
<td>1</td>
</tr>
<tr>
<td>2A &amp; 2B</td>
<td>34</td>
</tr>
<tr>
<td>2A &amp; 2C</td>
<td>6</td>
</tr>
<tr>
<td>2A &amp; 2B &amp; 2D</td>
<td>1</td>
</tr>
<tr>
<td>2A &amp; 2C &amp; 2D</td>
<td>1</td>
</tr>
<tr>
<td>2B &amp; 2C &amp; 2D</td>
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</tr>
<tr>
<td>2A &amp; 2B &amp; 2C &amp; 2D</td>
<td>1</td>
</tr>
<tr>
<td>Site #</td>
<td>FIM admission score</td>
</tr>
<tr>
<td>-------</td>
<td>---------------------</td>
</tr>
<tr>
<td>1</td>
<td>60.5</td>
</tr>
<tr>
<td>2</td>
<td>38.9</td>
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<td>3</td>
<td>56.4</td>
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</tr>
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<td>5</td>
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<tr>
<td>6</td>
<td>71.0</td>
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<tr>
<td>7</td>
<td>66.4</td>
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<tr>
<td>8</td>
<td>56.2</td>
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<tr>
<td>12</td>
<td>55.8</td>
</tr>
<tr>
<td>13</td>
<td>67.1</td>
</tr>
</tbody>
</table>
Figure 1. FIM gain/day vs. institutional policy regarding family participation
(A represents all those respondents who selected either 2A or 2A and 2B. B represents all those respondents who selected other than 2A or 2A and 2B.)
Table 6  
Check for Construct Validity of Second Survey

<table>
<thead>
<tr>
<th>Paired question</th>
<th>Type of data</th>
<th>Frequency n=104</th>
<th>Percent of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>11 &amp; 21</td>
<td>consistent*</td>
<td>81</td>
<td>94.2</td>
</tr>
<tr>
<td></td>
<td>inconsistent**</td>
<td>23</td>
<td>5.8</td>
</tr>
<tr>
<td>9 &amp; 25</td>
<td>consistent</td>
<td>73</td>
<td>88.5</td>
</tr>
<tr>
<td></td>
<td>inconsistent</td>
<td>31</td>
<td>11.5</td>
</tr>
<tr>
<td>13 &amp; 22</td>
<td>consistent</td>
<td>96</td>
<td>95.2</td>
</tr>
<tr>
<td></td>
<td>inconsistent</td>
<td>8</td>
<td>4.8</td>
</tr>
<tr>
<td>17 &amp; 27</td>
<td>consistent</td>
<td>88</td>
<td>90.4</td>
</tr>
<tr>
<td></td>
<td>inconsistent</td>
<td>16</td>
<td>9.6</td>
</tr>
<tr>
<td>14 &amp; 23</td>
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<td>65</td>
<td>85.8</td>
</tr>
<tr>
<td></td>
<td>inconsistent</td>
<td>39</td>
<td>14.2</td>
</tr>
<tr>
<td>1 &amp; 19</td>
<td>consistent</td>
<td>102</td>
<td>99.1</td>
</tr>
<tr>
<td></td>
<td>inconsistent</td>
<td>2</td>
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</table>

* consistent is defined by the percentage of respondents that answered the paired questions with answers that were either equal in value or separated by one response on the Likert scale.

** inconsistent is defined as a difference between response values greater than one response on the Likert scale.
Figure 2  Frequency of occurrence of the percentage of the total possible survey score within the institutional group on the physical therapist survey.

Figure 3  Frequency of occurrence of the percentage of the total possible survey score within the FIM subgroup on the physical therapist survey.
Table 7

Distribution of Questions for Total Physical Therapist Group

<table>
<thead>
<tr>
<th>Question number</th>
<th>Mean score for each question</th>
<th>Respondents in agreement with increased family participation (%)</th>
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<tr>
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<tr>
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<td>4.1</td>
<td>81.7</td>
</tr>
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Figure 4. FIM outcome scores of institutions vs. average percentage of total score on the physical therapist perceptions' survey at each site.
CHAPTER FIVE
DISCUSSION

The main purpose of our study was to explore the relationship between the involvement of the family, and the outcomes of patients with traumatic brain injury in the rehabilitation process. Our hypothesis was that the greater the family participation in rehabilitation, the better the outcome of the patient with traumatic brain injury. Unfortunately, we were unable to explore this correlation because we received such a small amount of FIM data from our institutional survey. We were however, able to explore the beliefs of physical therapists with regard to the role of family in rehabilitation.

Institutional Survey: Policy and Population Characteristics

The institutional survey provided us with information about each site's general policies regarding the enlistment of the family in the rehabilitation, the percentages of the institution's patient population with traumatic brain injury, and the percentage of the patient population with traumatic brain injury that were discharged home. In comparing the population characteristics of the total group of institutional group and the FIM subgroup, we found that the percentage of patients with traumatic brain injury at each site was much higher in the total group than in the FIM subgroup. The total institutional group and the FIM subgroup had similar home discharge rates for their populations of patients with traumatic brain injury. Our hope in collecting this data was to give us an idea of the general characteristics of the patient populations in the sites that we were surveying.

We found that within the total institutional group and the FIM subgroup 84%-88% of the sample had policies that included the involvement of the family in treatment sessions throughout rehabilitation, or allowed the family to observe treatment sessions. Based on
this data, we think that the majority of institutions want to involve the family in the rehabilitation process as much as possible. Question two may have provided us with more accurate information if the sites had been limited to only one of the four possible responses that best reflected the institution's policy toward family involvement in rehabilitation. This would have provided us with more accurate information in comparing institutional policy and patient outcome. By allowing respondents to choose more than one response, we found that some sites chose responses that we intended to be mutually exclusive. This may indicate that the sites either allowed different levels of participation or that they interpreted the meaning of some responses other than how we intended.

Due to the low availability of FIM data in our institutional survey, we were unable to explore any correlations between patient outcomes and institutional policies, and patient outcomes and physical therapists' perceptions with regard to family involvement in rehabilitation. We utilized scatterplots to explore any possible relationships between the areas of institutional policies regarding the family and patient outcome, and physical therapists' perceptions regarding the family and patient outcome, but found no apparent trends between institutional policy or physical therapists' perceptions and outcome of patients with traumatic brain injury. Because of the small data set used to make this comparison, we can make no conclusions regarding any possible correlations that may exist between the areas of institutional policy or physical therapists' perceptions and outcome of patients with traumatic brain injury.

**Physical Therapists' Beliefs about the Family**

The six paired questions designed to check construct validity demonstrated a high percentage of consistency between questions. Because of this high percentage of consistency we concluded that physical therapists understood the meaning of the questions being asked.

In examining the beliefs of physical therapists with regard to the role of the family in rehabilitation, we found agreement with increased family participation within the total
therapist group ranged from 58% to 96% with the average being 80%, and the agreement within the FIM subgroup ranged from 69% to 96% with the average being 80%. Based on this data, a high percentage of physical therapists believe that the family should be involved in the rehabilitation of patients with traumatic brain injury.

In examining the percentage of agreement with individual questions in the therapists' perception survey, we found that the questions could be broken into the following general areas: conflict (questions 14, 15, 23, 24 and 26), institutional policy (questions 8 and 12), and participation (all remaining questions). Each of these areas is important in determining how therapists think the family should be involved in rehabilitation, and what factors effect how much the family can contribute to the rehabilitation process.

Molter (1979) stated that family needs must be addressed in the rehabilitation process, especially meeting the primary need of feeling that there is hope. Molter believed that when a family's need to be informed about the patient's condition is not addressed stress between family and staff can result from the family's unrealistic expectations for patient progress. In our survey, physical therapists believed that lack of education regarding prognosis could cause increased conflict between family and staff members. Physical therapists did not believe that families who were aware of the prognosis of the patient had increased conflict with the staff. They also did not believe that conflict was increased when the family was allowed to participate in goal setting. We could not conclude whether physical therapists felt that greater education regarding prognosis and family involvement in goal setting decreased conflict between family and staff, but we concluded that therapists did not feel that education concerning prognosis or family involvement in goal setting increased the conflict between family and staff. We believe, based on this information, that continual education of the family concerning prognosis and family involvement in goal setting may help the family contribute to the
rehabilitation process by increasing the family's awareness of patient progress and anticipated patient outcome.

Watson (1987) stated that health care professionals participating in her research study viewed the family as not always helpful in the rehabilitation process. She found that 80% of respondents believed that family was not always helpful in rehabilitation, 77% believed families could not always be depended on to carry out a plan of care, and 74% found that families can be difficult to work with and get in the way in the rehabilitation unit. In our study, we found that physical therapists believed that decreased participation of the family in rehabilitation increased stress between family and staff. When families do not participate in the rehabilitation process there may be increased stress between family and staff due to unrealistic expectations of the family. Watson found that health care professionals did not view the family as always helpful in the rehabilitation process. Our results indicate that the majority of physical therapists desire to work with the family in rehabilitation.

Watson (1987) stated that in the clinic health care professionals believed in a directive rehabilitation model with specified expectations for family participation. This places the family under the direction of the rehabilitation team. Wright (1983) and McKinlay & Hickox (1988) believe in a comanagement approach to rehabilitation. In our research study, therapists agreed that family should be involved in goal setting, but therapists were more reluctant in agreeing that the family should be an equal partner on the rehabilitation team. We believe that Watson's conclusions about health care professionals' belief in a directive rehabilitation model, could be a possible explanation for the discrepancy between agreement of therapists in allowing the family to set goals, and agreement of therapists in admitting the family as an equal part of the rehabilitation team.

Watson (1987) took as her theoretical rationale for her study, research carried out by Satir (1972), Safilos-Rothchild (1970) and Wright (1983) whose basic premise was that the family and the patient should be treated as a unit. We found in our study, that
58.7% of physical therapists believed that the patient and family should be considered as a unit. Although this percentage represents the majority, 19.2% of therapists in our study have not accepted the family and patient as a unit within clinical practice.

In summarizing physical therapists' beliefs about family participation in the rehabilitation process, we found that therapists believed that the family should not be limited to conferences, education sessions or observation of treatment sessions. Therapists also believed that increased participation of the family leads to better patient outcome and better prepares the family to care for the patient at home. Therapists were undecided if institutions with unwritten policies about the role of the family in rehabilitation had poorer patient outcomes than institutions with written policies about the role of the family in rehabilitation. We concluded that therapists believed in enlisting the family in the rehabilitation process wherever possible, but therapists believed less strongly in considering the family as an equal partner on the rehabilitation team and considering the family and patient as a unit in rehabilitation.

Foley (1993) stated that the current method of family/staff interaction in rehabilitation is the use of conferences that involve the family. In our study, we found that 80% of the sites routinely included the family in team conferences. There are a variety of ways in which the staff/family unit can communicate and interact in the rehabilitation process. The overwhelming majority of therapists in our study believed that the family should not be limited to conferences. Therapists also believed that the family should not be limited to visiting hours and education sessions.

In exploring therapists' opinions with regard to the effects of family participation on outcome of patients with traumatic brain injury, we found that greater than 84% believed that family participation has a direct effect on patient outcome. Within the total therapist population, 81% believed that increased participation by the family leads to better outcome by the patient with traumatic brain injury. Greater than 94% believe that
the more the family participates in the rehabilitation process, the more prepared they are to care for the patient with traumatic brain injury in the home setting.

The most surprising statistic we found in the therapist perceptions survey was that only 36% of respondents believed that the patient should give consent to the rehabilitation team before allowing the family to be involved in the patient's rehabilitation. In addition, we found that 27% of respondents believed that patient consent was not necessary for the rehabilitation team to include the family in the rehabilitation process. The final 36% of respondents had no feelings either way about patient consent before enlisting the family into rehabilitation. Cognitive factors in traumatic brain injury rehabilitation may have been a contributing factor to this response. This question would have been more accurate if we had explained that consent would only be given when the patient with traumatic brain injury was capable of making an informed decision.

Limitations

The limitations of this study were primarily related to design flaws. Within the sample of institutions there was a small number that provided us with FIM data. This small number was mostly due to institutions not using the FIM as a measure of outcome. A small number of institutions who utilized the FIM and did not provide us with data, did not give a reason for not completing the FIM portion of the institutional survey. This small number made it impossible to conduct a statistical investigation of patient outcome. Our structuring of question number two in our institutional survey did not allow us to rank institutions by the level of family participation that they allowed, and again this made it difficult to investigate correlations between patient outcome and institutional policies regarding family participation in the rehabilitation process. The length of stay data that we received was provided as a range in many cases and this did not allow us to determine the average length of stay for each institution. Another limitation to our study was that we did not compare patient outcomes within one type of institution. For example, we did not
conduct our study exclusively in inpatient, subacute, outpatient or long term care rehabilitation settings within the sites that we surveyed.

**Application to education and practice**

Our literature review revealed a desire by health care professionals to incorporate the family in rehabilitation, but limited evidence to show that the family improves patient outcome in the rehabilitation process. Although, we did not prove with our research study that patient outcome is improved when the family is more actively enlisted in the rehabilitation process, the majority of therapists in this study agreed that the level of family participation in the rehabilitation process should be increased. Based on this majority agreement we concluded that therapists believe that the involvement of family is a crucial part of the rehabilitation of patients with traumatic brain injury. We believe that it is important as physical therapists to continue to be advocates for family participation in the rehabilitation process. This can begin in the physical therapy education programs by stressing not only the treatment of the whole person in rehabilitation but the whole family as well.

**Suggestions for further research**

In summary, we feel there is a need to conduct further research on the effect of family involvement in the rehabilitation of patients with traumatic brain injury. This research should focus on further study of the correlation between family involvement and patient outcome in the rehabilitation of patients with traumatic brain injury. This research should be conducted by measuring actual family involvement and determine if there is a correlation with patient outcome. In addition, studies should be conducted on therapists' beliefs and patient outcomes relating to family participation within other types of patient populations in the rehabilitation setting. Finally, future research may show the importance that the family plays in the rehabilitation process, and may encourage rehabilitation sites and therapists to actively enlist the family as a comanager in the rehabilitation process.
REFERENCE LIST


APPENDIX A
Dear physical therapy director,

We are conducting a research study to complete the requirement for our Master's of Science Degree in Physical Therapy at Grand Valley State University. Our thesis focuses on the effect that family participation has on the rehabilitation of patients with traumatic brain injury. This study involves the use of two surveys that will be sent to you, the first of which is included with this letter. The first survey has been submitted to you, the director of rehabilitation, and the second survey will be submitted to the physical therapists that are in the traumatic brain injury unit, or in absence of a traumatic brain injury unit, the physical therapists that work most often with traumatic brain injury patients. All institutions and therapists participating in this research study will be kept strictly confidential.

We believe that the role of the family is important, and hope that you and your facility will commit to helping us conduct a study that investigates one of the crucial issues facing therapists in the rehabilitation setting today. We would greatly appreciate if you would take some time and answer the following questions on the attached survey.

Thank you in advance for the contribution of your valuable time. Please return this survey no later than January 5, 1995. We have enclosed a self-addressed, stamped envelope for your convenience. Return of this form will indicate your informed consent to participate in this research study.

If you have any questions during this study we will be glad to answer them. You can contact us at: Grant Middleton, Brett Ransom, or Karen Ozga; Dept of Physical Therapy; Grand Valley State University; Allendale, MI 49401. Phone number: (616) 895-3356.

Sincerely,

Karen Ozga MMSc, PT

Grant Middleton SPT

Brett Ransom SPT
January 6, 1995

Dear physical therapy director,

This letter is in regard to the survey you were sent examining the effect family has in the rehabilitation of patients with traumatic brain injury.

We have not received any response from your facility at this time, and have sent you another survey and return envelope in case you have not received our survey. Please return this survey no later than January 17, 1995.

If you have sent back a survey to us already then please disregard this letter. We appreciate your participation in our study and look forward to hearing from your facility.

If you have any questions please feel free to contact us at: Karen Ozga, Grant Middleton and Brett Ransom, Dept. of Physical Therapy, Grand Valley State University, Allendale, MI 49401, (616) 895-3356.

Sincerely yours,

Grant Middleton, SPT

Brett Ransom, SPT
FAMILY PARTICIPATION IN TRAUMATIC BRAIN INJURY REHABILITATION: SURVEY ONE

DIRECTIONS: Please answer the following questions by filling in the appropriate answer or circling the appropriate response utilizing data from the 1993 calendar year.

1. How many physical therapists are involved with the rehabilitation of patients with traumatic brain injury at your site? _________

2. Check all of the following ways that most accurately reflect ways in which your facility utilizes the family in the rehabilitation of patients with traumatic brain injury.

_____ Family participation in treatment sessions throughout rehabilitation.
_____ Observation of treatment sessions.
_____ Family limited to visiting hours when patient is not being treated.
_____ Family participation in treatment sessions only during education sessions with the therapist.

3. Does your facility routinely include the family in team conferences?

   YES   NO

4. Does your facility have support groups for patients and family?

   YES   NO

5. What was the average length of stay of patients with traumatic brain injury at your facility?

   ________

7. What percentage of your patient population are patients with traumatic brain injury?

   A. 0-15%
   B. 15-30%
   C. 30-45%
   D. 45-60%
   E. 60-75%
   F. 75-90%
   G. >90%
8. What percentage of your patients with traumatic brain injury are discharged to the home?
   A. 0-15%
   B. 15-30%
   C. 30-45%
   D. 45-60%
   E. 60-75%
   F. 75-90%
   G. >90%

9. During the calendar year of 1993 did your facility utilize the Functional Independence Measure (FIM) to measure function of patients with traumatic brain injury at admission and discharge?

   YES  NO

IF THE ANSWER TO NUMBER 9 IS NO, THEN PLEASE DISREGARD QUESTIONS 10-16. IF THE ANSWER TO NUMBER 9 IS YES THEN PLEASE CONTINUE WITH THE SURVEY.

10. What was the average Functional Independence Measure (FIM) score of patients with traumatic brain injury at your facility upon admission.

11. What was the average Functional Independence Measure score of patients with traumatic brain injury at your facility upon discharge.

12. Is admission and discharge FIM score data in the locomotion and mobility sections available for patients with traumatic brain injury going through rehabilitation at your facility during the calendar year of 1993?

   YES  NO

IF THE ANSWER TO NUMBER 12 IS NO, PLEASE DISREGARD QUESTIONS 13-16. IF THE ANSWER TO NUMBER 12 IS YES PLEASE ANSWER QUESTIONS 13-16.

13. What was the average score on the locomotion section of the FIM of patients with traumatic brain injury at your facility upon admission.

   ________
14. What was the average score on the locomotion section of the FIM of patients with traumatic brain injury at your facility upon discharge.

15. What was the average score on the transfer section of the FIM of patients with traumatic brain injury at your facility upon admission.

16. What was the average score on the transfer section of the FIM of patients with traumatic brain injury at your facility upon discharge.
APPENDIX B
Dear physical therapy director,

Thank you for your commitment to our research project. Here are the surveys to be submitted to the physical therapists working with patients with traumatic brain injury at your site. Please be sure that the physical therapists at your site receive them. Individual self-addressed, stamped envelopes have been provided for each physical therapist participating in this research study. Physical therapists' names are not requested in order to assure anonymity. Please keep in mind that the surveys should be returned by (date to be added later).

Thank you again for your interest in our research study,
Sincerely yours,

Karen Ozga M.M.Sc., PT

Grant Middleton SPT

Brett Ransom SPT
Dear physical therapist,

We are conducting a research study to complete the requirements for our Master's of Science Degree in Physical Therapy at Grand Valley State University. Our thesis focuses on the effect that family participation has on the rehabilitation of patients with traumatic brain injury. Physical therapists from CARF approved sites in the midwestern United States were selected as participants.

By filling out the enclosed survey, you will be helping us determine the factors related to family participation that are of concern to therapists in their daily practice. Once these factors have been determined, rationales for family participation may be constructed.

Participation in this study is entirely voluntary. Your completion and return of this questionnaire will be taken as evidence of your willingness to participate and your consent to have the information used for the purposes of this study. We request that you do not place your name on the included survey so that we can maintain your anonymity. Please return in the self-addressed, stamped envelope no later than (date to be added later).

If you have any questions during this study we will be glad to answer them. You can contact us at: Grant Middleton, Brett Ransom, or Karen Ozga; Dept of Physical Therapy; Grand Valley State University; Allendale, MI 49401. Phone number: (616) 895-3356.

We will gladly share the final results of the study upon request.

Sincerely,

Karen Ozga M.M.Sc., PT

Grant Middleton SPT

Brett Ransom SPT
REMINDER LETTER FOR FAMILY PARTICIPATION
IN TRAUMATIC BRAIN INJURY REHABILITATION: SURVEY TWO

January 6, 1995

Dear physical therapy director,

This letter is in regard to the survey(s) you were sent to distribute to the physical therapist(s) at your site that work with patients with traumatic brain injury. We would just like to express our appreciation of your participation in our study, and remind you that these surveys should be returned by January 30, 1995.

If you have any questions please feel free to contact us at: Karen Ozga, Grant Middleton and Brett Ransom, Dept. of Physical Therapy, Grand Valley State University, Allendale, MI 49401, (616) 895-3356.

Sincerely yours,

Grant Middleton, SPT

Brett Ransom, SPT
FAMILY PARTICIPATION
IN TRAUMATIC BRAIN INJURY REHABILITATION: SURVEY TWO

INSTRUCTIONS: Using the definitions in the box below, circle the letter that best describes your position in regards to the following statements:

(SA) strongly agree (A) agree (N) neither agree nor disagree

(D) disagree (SD) strongly disagree

1. Family participation in rehabilitation of patients with traumatic brain injury should be limited to family conferences.

(SA) (A) (N) (D) (SD)

2. Family participation in rehabilitation of patients with traumatic brain injury should include setting patient goals.

(SA) (A) (N) (D) (SD)

3. Family participation in rehabilitation of patients with traumatic brain injury should include presence at treatment sessions.

(SA) (A) (N) (D) (SD)

4. Family participation in rehabilitation of patients with traumatic brain injury should be limited to visiting hours.

(SA) (A) (N) (D) (SD)

5. In regards to treatment sessions, families of patients with traumatic brain injury should be limited to education sessions with the therapist.

(SA) (A) (N) (D) (SD)

6. Families of patients with traumatic brain injury should be limited to education sessions and family conferences.

(SA) (A) (N) (D) (SD)
7. The family's role in treatment sessions should be limited to observation.

(SA) (A) (N) (D) (SD)

8. There should be guidelines set by the institution concerning family participation in the rehabilitation process.

(SA) (A) (N) (D) (SD)

9. Families should act as equal partners with staff in the rehabilitation of patients with traumatic brain injury.

(SA) (A) (N) (D) (SD)

10. The degree to which families participate in rehabilitation has a direct effect on the outcome of patients with traumatic brain injury.

(SA) (A) (N) (D) (SD)

11. Increased participation of the family leads to better outcomes in the rehabilitation of the patient with traumatic brain injury.

(SA) (A) (N) (D) (SD)

12. Institutions with unwritten policies on family participation have poorer outcomes than those who have written policies regarding family participation.

(SA) (A) (N) (D) (SD)

13. The more the family participates in the rehabilitation process the more prepared they are to care for the patient with traumatic brain injury in the home setting.

(SA) (A) (N) (D) (SD)

14. Decreased family participation in the rehabilitation of the traumatic brain injury patient increases stress between family and staff.

(SA) (A) (N) (D) (SD)
15. Lack of family education concerning prognosis of the patient with traumatic brain injury causes increased conflict between family and staff.

(SA) (A) (N) (D) (SD)

16. The patient being rehabilitated for traumatic brain injury should give the rehabilitation team consent regarding family participation in the rehabilitation process.

(SA) (A) (N) (D) (SD)

17. Family need only participate in education sessions when the patient with a traumatic brain injury is nearing discharge.

(SA) (A) (N) (D) (SD)

18. The patient and the family should be considered a unit.

(SA) (A) (N) (D) (SD)

19. The family of patients with traumatic brain injury should be given more access to the rehabilitation process than just conferences.

(SA) (A) (N) (D) (SD)

20. Family of patients with traumatic brain injury should be granted more access to therapists than just education sessions and family conferences.

(SA) (A) (N) (D) (SD)

21. The amount of involvement the family has with the patient with traumatic brain injury in rehabilitation does not directly affect the patient's outcome.

(SA) (A) (N) (D) (SD)

22. The amount of family participation in rehabilitation has no effect on the ability of the family to care for the patient with traumatic brain injury in the home.

(SA) (A) (N) (D) (SD)

23. Increased family participation in rehabilitation causes increased stress on the family/staff relationship.

(SA) (A) (N) (D) (SD)
24. Families of patients with traumatic brain injury have increased conflict with the staff when they are more aware of the prognosis of the patient.

(SA) (A) (N) (D) (SD)

25. Staff should not consider the family as an equal partner on the rehabilitation team.

(SA) (A) (N) (D) (SD)

26. There is an increase in conflict between the staff and the family of the patient with traumatic brain injury when the family is allowed to participate in goal setting.

(SA) (A) (N) (D) (SD)

27. It is important for the family of the patient with traumatic brain injury to participate in continuing education sessions from the time that treatment is first initiated in rehabilitation.

(SA) (A) (N) (D) (SD)

Thank you for your participation in our research study. Please place this survey in the self-addressed stamped envelope provided for your convenience.