



Western Michigan University
ScholarWorks at WMU

Master's Theses

Graduate College

12-2004

A Closer Look at Development of Self-Awareness and Compensatory Strategy Use in Adults with Traumatic Brain Injury

Melissa A. Byrne

Follow this and additional works at: https://scholarworks.wmich.edu/masters_theses



Part of the Occupational Therapy Commons

Recommended Citation

Byrne, Melissa A., "A Closer Look at Development of Self-Awareness and Compensatory Strategy Use in Adults with Traumatic Brain Injury" (2004). *Master's Theses*. 4607.

https://scholarworks.wmich.edu/masters_theses/4607

This Masters Thesis-Open Access is brought to you for free and open access by the Graduate College at ScholarWorks at WMU. It has been accepted for inclusion in Master's Theses by an authorized administrator of ScholarWorks at WMU. For more information, please contact wmu-scholarworks@wmich.edu.



**A CLOSER LOOK AT DEVELOPMENT OF SELF-AWARENESS AND
COMPENSATORY STRATEGY USE IN ADULTS WITH
TRAUMATIC BRAIN INJURY**

by

Melissa A. Byrne

**A Thesis
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Master of Science
Department of Occupational Therapy**

**Western Michigan University
Kalamazoo, Michigan
December 2004**

Copyright by
Melissa A. Byrne
2004

ACKNOWLEDGEMENTS

I would like to begin by acknowledging the generosity and guidance of Dr. Diane Dirette who granted me the opportunity to be her research assistant, making this thesis possible. And, in addition, served as my graduate committee chairperson and provided insightful answers to my many questions. Secondly, I would like to thank the other members of my graduate committee, Dr. Richard Cooper and Dr. Debra Lindstrom-Hazel, for taking the time to review my thesis and provide valuable suggestions. Lastly, I would like to express my gratitude to my fiancé, family, and friends whose constant love and support sustained me throughout the thesis process.

Melissa A. Byrne

A CLOSER LOOK AT DEVELOPMENT OF SELF-AWARENESS AND COMPENSATORY STRATEGY USE IN ADULTS WITH TRAUMATIC BRAIN INJURY

Melissa A. Byrne, M.S.

Western Michigan University, 2004

My study investigates the development of self-awareness and use of compensatory strategies in eight adults with traumatic brain injuries using the Awareness Questionnaire (AQ) and three additional questions of descriptive nature. This study also examines whether or not the severity of brain injury (mild, moderate, severe) impacts the development of self-awareness. In addition, the spouses' perceptions of client awareness are compared to the relatives' to determine existence of potential variance.

Results indicate that while there is no significant difference in self-awareness between the mild and moderate groups, the severe group significantly varies from both the mild and moderate groups. Also, results indicate that there is no significant difference between significant other (SO) and relative perceptions of client self-awareness. Exploration of descriptive data reveals that development of self-awareness is a lengthier process for clients with severe TBI than clients with mild and/or moderate TBI. Three methods of self-awareness development are identified: self-identification, talking with loved ones, and contact with health care professionals. Further analysis of descriptive data indicates that writing things down is the most commonly identified compensatory strategy that was used. Implications for rehabilitation and future research are discussed.

TABLE OF CONTENTS

ACKNOWLEDGMENTS.....	ii
LIST OF TABLES.....	v
INTRODUCTION.....	1
Prevalence of Traumatic Brain Injury.....	1
Hallmark of Traumatic Brain Injury.....	1
Self-Awareness Deficits.....	1
Impact on Functional Performance.....	2
Compensatory Strategies.....	3
Interpersonal Relationship.....	4
LITERATURE REVIEW.....	6
Development of Self-Awareness.....	6
Informant's Perception.....	8
Severity of Injury.....	10
Impact of Self-Awareness Deficits on Interpersonal Relationship.....	11
The Variance in Perception Between SO and Relative.....	13
NEED FOR STUDY.....	15
PURPOSE/RESEARCH QUESTIONS.....	16
METHOD.....	17
Participants.....	17
Procedure.....	18

Table of Contents-Continued

Measures.....	19
ANALYSIS/RESULTS.....	22
Self-Awareness Variance Among the Groups of Severity.....	22
Self-Awareness Variance Within the Three Factors of the AQ.....	24
Variance Between SO and Relative Perception.....	25
Descriptive Data.....	26
Development of Self-Awareness.....	26
Compensatory Strategy Use.....	26
DISCUSSION.....	28
Impact of Severity of Injury on Development of Self-Awareness.....	28
Variance Between Relative and SO Perception.....	29
Descriptive Data.....	30
Limitations.....	31
CONCLUSION.....	33
APPENDICES	
A. Awareness Questionnaire Items.....	34
B. Approval Letter From the Human Subjects Institutional Review Board...	36
REFERENCES.....	40

LIST OF TABLES

1. Participant Demographic Characteristics (N=8).....	18
2. Interview Information.....	19
3. Self-Awareness Means and Discrepancy Scores.....	23
4. ANOVA Results of Variance Among the TBI Groups (Mild, Moderate, Severe).....	23
5. Post Hoc Exploration of Self-Awareness Variance Among the TBI Groups.....	24
6. Variance Among the Three Factors of the Awareness Questionnaire.....	25
7. Compensatory Strategies Used by Clients.....	27

INTRODUCTION

Prevalence of Traumatic Brain Injury

Traumatic brain injury (TBI) is not a rare occurrence in this country. On any given day, 4,000 individuals sustain a TBI (Centers for Disease Control, 2004). This equates to approximately 1.5 million annually (Thurman, Alverson, Dunnk, Guerrero, & Sniezek, 1999). While 25% of these individuals sustain severe traumatic brain injuries, an estimated 75%, or 1.1million, of these individuals suffer mild or moderate TBI's (Sosin, Sniezek, & Thurman, 1996). Each year, approximately 80,000 TBI survivors will endure life-long disabilities. Today there are between 2.5 and 6.5 million U.S. residents who have had a TBI, and many of these individuals experience difficulties with functional performance as a result of their injury (National Institute of Neurological Disorders and Stroke, 2003).

Hallmark of Traumatic Brain Injury

Self-Awareness Deficits

Lack of self-awareness of cognitive deficits is a frequent hallmark of TBI (Toglia, 1990). In a study conducted by Sherer, Boake, Levin, Silver, Ringholz & High (1998), results indicated that between 76% and 97% of TBI survivors displayed some degree of impaired self-awareness. The term awareness deficit has been defined by a plethora of authors. Crosson, Barco, Velozo, Bolesta, Cooper, Werts & Brobeck (1989) wrote that awareness deficit "refers to the patient's inability to recognize the problems caused by impaired brain function" (p. 47). Another definition of awareness deficit is the inability to attend, encode, and retrieve information concerning the self (Allen & Ruff, 1990). Prigatano and Schacter (1991) discussed the difficulties with devising a succinct definition for awareness in their book. Despite these self-admitted difficulties, the authors suggested that awareness involves

an interaction between thoughts (objectivity) and feelings (clientivity). For the purpose of this study, the term awareness deficit will be conceptualized by the inability to objectively identify deficits, and the inability to understand their impact on function (Port, Willmott, & Charlton, 2002).

A lack of awareness may be detrimental to clients' rehabilitation success. If individuals do not perceive their cognitive deficits, then they may not recognize the need to participate in rehabilitation, thus being unmotivated to seek treatment (Sherer, et al., 1998; Allen & Ruff, 1990). Furthermore, if they are participating in therapy, these same clients are likely to feel uncomfortable since their denial is being directly challenged (Allen & Ruff, 1990).

Impact on Functional Performance

The relationship between self-awareness deficits and TBI is of particular interest to occupational therapists because of the potential impact a client's lack of self-awareness has on his/her functional performance. The concept of functional performance is paramount to the profession of occupational therapy. Self-awareness deficits impact a client's ability to reach his/her functional performance potential. Katz and Hartman-Maeir (1997) emphasized the importance of this relationship. "Occupational performance is the core concept and focus of our profession, but awareness of strengths and deficits and executive functions are prerequisites for successful functioning in any occupation, task, or activity" (p. 61). An individual with self-awareness deficits will demonstrate inability in planning appropriately, detecting, and correcting difficulties. The limitations in executive functioning that individuals with lack of self-awareness may experience impact their utilization of compensatory strategies.

Compensatory Strategies

Crosson et al. (1989) defined compensation as the “deliberate application of a procedure that enables a patient to obtain a goal the realization of which would otherwise be prevented by impaired functioning” (p. 46). According to White, Seckinger, and Doyle (1997), compensatory strategies enable people to reach a greater consistency of success and a greater level of independence in performing a functional task. Awareness plays an integral role in the development of compensatory strategies. A client’s awareness of deficits and comprehension of how these deficits impact daily life is vital in determining how independently a person can use or generalize a strategy. Decreased awareness results in an inability to effectively utilize compensatory strategies (Toglia, 1990). Without awareness of his/her deficits, the client does not appreciate the need for and may not be receptive to learning compensatory strategies (Katz & Hartman-Maeir, 1997).

The severity of the brain injury is one variable that may impact self-awareness development and use of compensatory strategies. For the purpose of this study the Glasgow Coma Scale (GCS) will be used to determine the severity of the brain injury. The GCS is a respected, standardized method for evaluating the consciousness level in patients with acute neurological disorders. It is comprised of three response scores: eye opening, motor score, and verbal score. These three scores are typically combined for one total score that is between 3 and 15. A score of 13 or higher correlates with a mild brain injury, 9 to 12 is a moderate injury, and 8 or below is a severe brain injury (Sherer, Bergloff, Boake, High, & Levin, 1998).

Interpersonal Relationships

Impaired self-awareness may negatively impact the client's interpersonal relationships, which may be detrimental to the rehabilitation process (Webster, Daisley, & King, 1999). A plethora of research conducted on TBI has suggested that family plays a vital role in the rehabilitation process of the brain-injured individual (Kreutzer, Gervasio, & Camplair, 1994). Several studies have depicted the havoc the neurobehavioral sequelae commonly associated with TBI (cognitive, emotional, and behavioral deficits) may have on a TBI survivor's family life (Webster, et al., 1999, Wood & Yurdakul, 1997, Kreutzer, et al., 1994). Moreover, behavioral changes, such as uncontrollable emotions and impulsivity that may cause embarrassment and stress, may be more damaging to families than physical or even cognitive problems (Santos, Castro-Caldas, & DeSousa, 1998).

Often times, families must deal with the sometimes significant changes in their loved one's personality as well as the burden of finding or providing care for their brain-injured loved one (Kreutzer et al., 1994). This newly, turbulent home environment may hinder the family's abilities to function effectively and facilitate their loved one's rehabilitation. This stressful situation may explain the increased rate of divorce and separation following a TBI. In a study conducted by Wood and Yurdakul (1997), 49% of the sample population reported that they had divorced or separated from their partners during a five- to eight-year period following brain injuries. The authors also determined that the likelihood of separation increased with time post-injury and was not decreased if the couple had children.

The stress of the situation might impact relatives and/or significant others (SO's) differently depending on the nature of their relationship with the clients (Santos, et al., 1998, Kreutzer, et al., 1994, Webster, et. al, 1999). Research has revealed that spouses who are caregivers often have more difficulty coping with a loved one's TBI than parental caregivers. This phenomenon may be attributed in part to the complexity of the marital relationship.

While parents may revert back to a familiar role of caregiver, spouses are stepping into foreign, and perhaps uncomfortable, territory (Webster, et al., 1999, Kreutzer, et al., 1994). This study will compare the perception of SO's with the perceptions of relatives by examining the degree of variance between their scores and the scores of the clients on the Awareness Questionnaire (AQ).

LITERATURE REVIEW

There have been numerous studies during the last few years that investigated the phenomenon of self-awareness deficits following traumatic brain injuries. Often these studies examined how impaired self-awareness impacts the rehabilitation process as well as interpersonal relationships. Research has yielded varying results, as to be expected with the complexity of the human brain and the various types of injuries. Typically, the extent of the self-awareness impairment is determined by comparing the patient's self-reports with those of a relative or significant other, and possibly a treating clinician. Although there are a multitude of studies on the relationship between brain injury and self-awareness, there is limited research on the actual development of self-awareness in individuals with brain injury (Dirette, 2002, Fleming & Strong, 1997).

Development of Self-Awareness

The limited quantity of research that has been conducted regarding this matter has suggested that functional activities play a vital role in the development of awareness following brain injuries (Dirette, 2002, Fleming & Strong, 1997). Dirette (2002) investigated the development of intellectual awareness and use of compensatory strategies by adults with moderate-to-severe acquired brain injury using a qualitative, three-client study format. The three clients were considered to have a "good recovery" by the neuropsychologist and had successfully completed a cognitive rehabilitation day treatment program. Interviews with clients and questionnaires with staff were used to gather information.

While client 3 described the process of developing awareness as immediate, clients 1 and 2 described the process of developing awareness as a slow process manifested by "aha" moments. These clients described how they became aware of their deficits after engaging in

functional activity in a familiar environment. This was in direct opposition to the staff who believed that the clients' awareness started to develop in the clinic during activities.

Regarding the use of compensatory strategies, all three clients reported writing down information as the main compensatory strategy they have continued to use outside the clinic. The clients reported using strategies because they were practical, made task completion easier, or they felt greater confidence in their functional ability when using the strategies. According to the author, client and staff responses regarding the strategies being used by the clients were in agreement. Although this study provided insight into the development of awareness, generalization of these results is limited considering the small sample size. Another limitation stated by the author was the fact that the study relied on the limited cognition of the clients. The memory deficits that the clients reported may have impacted their ability to remember the process of developing awareness of deficits and use of compensatory strategies. Thus, the clients may have begun to develop awareness in the clinic, but simply do not remember that phase in their recovery (Dirette, 2002).

Fleming and Strong (1997) conducted a longitudinal study on the development of insight of fifty-five adults with severe traumatic brain injury. A primary purpose of the study was to examine the change in self-awareness over time by investigating self-awareness at two stages post-injury. Data was collected 3 and 12 months post using the Patient Competency Rating Scale (PCRS). Self-awareness was measured by comparing patient self-ratings with the ratings of an informant (nominated relative, friend, therapist). The results were consistent with those from previous studies. While self-awareness was found to be most impaired for behaviors of a cognitive, interpersonal, emotional nature or for behaviors that represent important areas of independence and self-esteem (i.e. driving), self-awareness appeared *less* impaired for concrete behaviors, such as basic activities of daily living, memory activities, and overt emotional responses. The authors suggested that since these later activities are

often addressed in the earlier stages of rehabilitation, possibly clients had recent experience with attempting these tasks prior to completing the questionnaire, while more cognitively complex activities (i.e. driving) are not addressed until the later stages of rehabilitation. This suggests that personal experiences might be linked to the development of self-awareness, thus placing emphasis on the importance engaging clients in functional activity during rehabilitation.

Further supporting this hypothesis is the fact that self-awareness did improve in most functional areas during the first year post-injury, which indicates that self-awareness does not usually begin to develop until the client experiences difficulty performing activities as compared to pre-injury abilities. However, as the authors pointed out, many of the clients continued to receive therapy throughout the first year, making it unclear whether or not increase in self-awareness was a result of experience with functional activity in the rehabilitation setting or experience with functional activity in the client's natural environment (Fleming & Strong, 1997).

Informant's Perception

Since individuals with TBI frequently have impaired self-awareness of their cognitive deficits, the use of a designated informant's (relative, significant other, treating clinician) perception is commonly accepted as reliable external criterion in studies that examine self-awareness deficits and/or development (Coetzer & duToit, 2002, Fleming & Strong, 1997, Port, et al., 2002, Prigatano, Bruna, Mataro, Munoz, Fernandez, & Junque, 1998, Sherer, Hart, Nick, Whyte, Thompson, & Yablon, 2003).

The previously discussed study conducted by Fleming & Strong (1997) utilized clinicians for the three-month interview and SO's or relatives for the 12-month interview. Before the informant substitutions were made, the authors had to establish that there were no significant differences between clinician and SO/relative ratings of the same individual on the

PCRS scale. Mean total PCRS scores were calculated then paired-sample t-tests indicated no significant variance existed ($p=.60$) between clinician and SO/relative ratings for the same client. While the authors in this study concluded that there was no significant difference between clinician and SO/relative perceptions, other studies have suggested that the clinician perception represents a more accurate portrayal of the client's self-awareness level.

In a study conducted by Sherer et al., (2003) predictors of early-impaired self-awareness were evaluated and inter-relationships of the perceptions of 129 patients with TBI and their families, SO, and clinicians were examined in an inception cohort study using the AQ and employability. The results were consistent with previous studies. Overall, the patients' self-ratings did not correlate with the families', SOs', or clinicians' ratings of the patients. Patients consistently rated themselves as less impaired than did the family, SO, or clinician. However, while family ratings of patient functional status were correlated more closely with clinician ratings than with patient self-ratings, family generally rated the patient's functioning as *less* impaired than the clinician.

The importance of including a clinician's perception was further emphasized in a cross-sectional analysis conducted by Port, et al., (2002). The level of insight across several domains of function of 30 patients with a history of moderate to severe TBI and their SO's were examined using written questionnaires. All patients were less than two years post-brain injury. Results indicated substantial agreement between patients and their SO in every domain except for executive functioning. In the latter domain, patients were less likely to acknowledge their executive problems than their SO. Both groups reported low to moderate levels of difficulty.

These findings suggest that SO awareness may also be limited in the earlier stages of recovery, thus emphasizing the importance of including a clinician's perception to strengthen the validity of research examining self-awareness deficits. The authors believed that one

possible reason for this is at the relatively beginning stage of recovery, perhaps specific impairments have not emerged in a functional context yet. Thus, family and friends have not observed the changes in daily activities. Also interesting was that the ratings of the significant others and patients did not reflect a correlation between severity of injury and impact on outcome (Port et al., 2002).

Severity of Injury

Research exploring the relationship between level of awareness and severity of injury has yielded varied findings. Prigatano, et al., (1998) conducted a prospective, between-client study that examined awareness impairment cross-culturally in 30 patients with TBI. Findings suggested that measures of severity of injury (Glasgow Coma Scale and retrospective posttraumatic amnesia) in moderately to severely brain-injured participants were significantly correlated with deficits in self-awareness. However, a wide disparity of participants in the three severity groups (mild = 3.3%, moderate = 6.6%, and severe = 66.7%) may have impacted the findings.

In direct dispute of the previous study, Coetzer and duToit (2002) investigated impaired awareness and its affiliation to placement and employment outcome following brain injuries and determined that there was not a relationship between severity of injury and awareness. The study included 3 participants with mild TBI, 4 with moderate TBI, and 33 with severe TBI for a total of 40 participants. Glasgow Coma Scores (GCS) or period of loss of consciousness (LOC) determined severity of injury. Participants' levels of awareness were determined by subtracting their score on the European Brain Injury Questionnaire (EBIQ) from the caregivers' scores. Of the 27 participants who had available GCS, there was not a significant correlation coefficient between severity of TBI and awareness.

Of interest, the findings reflected an inverse relationship between LOC and awareness. The authors suggested that this phenomenon was caused by the possible tendency

for patients (relative to caregivers) to overestimate difficulties after less severe brain injuries. As the authors mention, the study had several limitations. First, the unequal number of participants in the three severity groups, with a small number of participants in the mild and moderate groups, may have skewed the results. The use of a single measure of awareness (EBIQ) is another limitation. Also, since this was a retrospective study, the dynamic aspects of awareness may not have been taken into account (Coetzer & duToit, 2002).

Impact of Self-Awareness Deficits on Interpersonal Relationships

There has been an abundance of studies that examine the impact the personality changes commonly associated with TBI's have on interpersonal relationships (Kosciulek, 1997, Kreutzer, et al. 1994, Santos, et al., 1998 Wallace & Bogner, 2000, Webster, et al. 1999, Wood & Yurdakul, 1997). Wood and Yurdakul (1997) conducted one such study, which examined the change in relationships following TBI's. The cohort group for the study was comprised of 131 (34 females and 97 males) clients with traumatic brain injury who were referred to the Brain Injury Rehabilitation Trust. Of these 131 clients, varying from mild to severe TBI's, only 42% of couples were able to maintain their relationship longer than 5 years post-injury.

After analysis, the authors concluded that it was not the severity of brain injury rather it was the nature of the neurobehavioral sequelae that was a vital factor in the collapse of relationships. When the neurobehavioral deficits of the injury were significant enough to warrant a period of rehabilitation, a substantial increase of clients, 89%, had separated from their partner. The authors concluded that a closer examination needed to be conducted on how the factors that contribute to the collapse of relationships inflict stress and create the perception of emotional burden.

Another study conducted by Kreutzer, et al. (1994) investigated the prevalence of distress and unhealthy family functioning among caregivers of 62 adult, outpatient TBI

survivors during a one-year period. Thirty-four of the caregivers were spouses and 28 were parents, with an overall 85.5% being female. Participants completed self-report measures, including the Brief Symptom Inventory (BSI) and the Family Assessment Device (FAD). Consistent with previous studies, approximately 50% of the caregivers reported elevated distress as indicated by the BSI General Stress index. One-third of the participants had elevated Anxiety scale scores and 25% demonstrated elevations on the Depression subscale. The author's further analysis of the BSI yielded findings not previously reported. For instance, 37% of caregivers demonstrated elevations in both the Obsessive Compulsive and Psychoticism scales. The authors noted that these findings may be contributed to the fact that the BSI was designed to be used primarily with the psychiatric population, thus the value of the conventional labels as clinical descriptors is yet to be established.

In response to questions on family functioning, based on the FAD, caregivers displayed greater levels of unhealthy family functioning when compared to published norms for non-patient and medical patient samples, but showed better functioning than psychiatric samples. Of course, as the authors point out, this may be due in part to the fact that research has suggested that pre-injury problems are common among individuals with TBI. Thus, unhealthy family functioning may have existed pre-injury. As the authors predicted, spouses reported higher levels of depression than parental caregivers. However, the variance between spouse and parent self-reports on unhealthy family functioning was insignificant.

The authors offer possible explanations for this apparently contradictory finding. One such hypothesis is that perhaps the family unit has the same needs regardless of whether the spouse or parent is the primary caregiver, and when these needs are not met, the family becomes strained. A limitation of the study is the subjective nature of the research. Data was gathered solely through caregivers' self-reports, which may impact both validity and reliability. The authors noted that future research needs to be conducted that includes

objective clinical interviews or problem solving tasks to confirm perceptions of family functioning. Another possible limitation is the homogeneous nature of the study's sample (primarily a young, urban-based group of people) and comparability with other studies, this study used different measures than previous research, yet comparisons were regularly made between the present study and prior research.

The Variance in Perception Between SO and Relative

While variance may exist between the perceptions of the therapist and relative, family members may have different perceptions according to their relationship with the clients. Research has revealed that spouses who hold the caregiver role frequently display greater distress than parental caregivers (Kreutzer, et al., 1994, Santos, et al., 1998, Wallace, et al., 2000, Webster, et al., 1999, Wood & Yurdakul, 1997). Santos, et al. (1998) examined the spontaneous complaints of long-term brain injured adult clients as compared to the impression of their relatives or SO's, usually a mother or wife respectively. Forty-eight clients and their relatives were interviewed more than six years post-injury. Participants were asked to verbalize their present complaints.

Overall, relatives referred more complaints about the clients than the clients made about themselves. For example, relatives referred more to aggressiveness and irritability and lack of control than did the clients. Mothers' opinions showed more resemblance to their TBI sons' in all aspects where the wives' perceptions highlighted differences between the clients' and relatives' points of view. The wives did not match the opinions of their brain-injured husbands in the somatic complaints category (headaches), even though the husbands noted more complaints in this area.

From their results, the authors proposed that wives might have a more realistic approach than parents. However, wives seem more distant than the parents in some aspects. The authors wrote that the negative impact on the marriage and the stress experienced by

wives, who are now married to a seemingly different person, are probably responsible for that finding. Thus, it was concluded that “mothers would be a better source on information on the concerns of the brain injured person and the issues that affect his/her quality of life” (p. 766).

There were several limitations to this study. The first author conducted all interviews which raises the question of potential bias. Also, it was acknowledged in the study that the client’s perception might be skewed due to the nature of his/her injury. Therefore, concluding that mothers would be better sources of information because they have greater agreement with their child may not be a legitimate deduction.

NEED FOR STUDY

The substantial number of occupational therapy clients who have sustained a TBI and the contradictory results generated by prior research studies warrant further investigation into the factors possibly correlated with the development of self-awareness and use of compensatory strategies once self-awareness emerges. By examining the development of awareness, usage of compensatory strategies, and potential impact TBI has on interpersonal relationships or the family structure, clinicians can apply this newfound information to designing rehabilitation programs for adults with TBI that facilitate greater functional outcomes, which would benefit survivors of TBI and their families, as well as their employers.

PURPOSE/RESEARCH QUESTIONS

The phenomenon of awareness deficits after TBI has been studied extensively.

However, as the literature review revealed there is limited examination of how severity of injury impacts the development of self-awareness and use of compensatory strategies. The purpose of the present study is to examine whether or not the severity of injury impacts how self-awareness and use of compensatory strategies develop in adults with traumatic brain injury, as well as investigate the possible variance between SO and relative perception of clients' self-awareness. The following specific questions were investigated:

1. Does the severity of injury (mild, moderate, severe) impact the development of awareness?
2. Does a spouse's perception of the client's level of awareness vary from that of a relative?

METHOD

Participants

Fourteen clients with a diagnosis of traumatic brain injury were selected by convenience as they entered a mid-size, Midwestern hospital over a one-year period. Of these fourteen, three participants did not qualify due to lack of a relative/S.O., and three participants did not demonstrate measurable cognitive impairment resulting from their head injury as determined by comparing their scores with that of a S.O./relative data. Data from eight clients and their relative/S.O. was used (mild = 4, moderate = 2, severe = 2). All eight participants had been injured in motor vehicle accidents. Five of the participants were male and three were female. They ranged in age from 21 to 64 years (mean = 32.25). The breakdown of the S.O./relative participants is as follows: three of the eight were significant others (wife = 2, husband = 1) and five were relatives (mother = 2, father = 1, and daughter = 1). Participant demographic information is presented in detail in Table 1.

The participants were identified by hospital personnel according to the inclusion criteria for this study. The inclusion criteria was comprised of 1) a diagnosis of TBI, 2) 16 to 65 years of age, 3) adequate communication and language skills to participate in the interview process by one month post-injury. A member of the nursing staff read a recruitment script and gave the client an information sheet regarding the study. The primary interviewer then met with the client and obtained the informed consent if the client was interested in participating in the study.

Table 1. Participant Demographic Characteristics (N=8)

Characteristics	N	%
Marital status		
Currently married	7	87.5%
Single (never married)	1	12.5%
Severity of injury		
Mild	4	50%
Moderate	2	25%
Severe	2	25%
Relation to member with TBI		
Mother	2	25%
Wife	2	25%
Father	1	12.5%
Husband	1	12.5%
Daughter	2	25%

Procedure

Structured interviews were conducted with clients and relatives or S.O.'s at one week (if possible), one month, and four months post-injury. Due to timing logistics and attrition, the number of interviews varied among the clients. During the period of time the study was conducted, clients 1 and 4 were interviewed three times, however client 4's SO was interviewed on only two occasions: 1 month and 4 months. Clients 11, 13, and 14 were interviewed only twice because of time constraints. Due to attrition, clients 7 and 8 were interviewed on only one occasion, and client 5 was interviewed twice. Interview frequency is presented in detail in Table 2. Since the number of interviews varied, the mean of the total scores were utilized when tabulating variance.

Reviewing the clients' medical records provided demographic data that included gender, age, and history of injury, a permanent address, and the address of a contact person. The Glasgow Coma Scale results were used to determine the severity of injury (mild 13 to 15, moderate 9 to 12, severe 8 and below). The results of CAT scans and/or MRIs were examined to determine the area(s) of the brain that was damaged. The findings of cognitive

screenings and/or cognitive evaluations were reviewed to determine the cognitive deficits experienced by the client.

In effort to control bias, which would possibly impact reliability and validity, inclusion criteria were followed, hospital personnel abided by a designed recruitment script, and the interviewer followed the structured instruments. Furthermore, the use of one primary interviewer promoted greater reliability. To ensure that self-awareness is accurately assessed, the client's perception was compared to the significant other's perception of the client, thus establishing greater validity. The treating clinician's perception of client awareness was available on only one of the eight participants. This clinician data was collected from the one-month interview.

Table 2. Interview Information

CLIENT	TOTAL # OF INTERVIEWS	1 WEEK	1 MONTH	4 MONTHS
1	3	X	X	X
4	3	X*	X	X
5	2	X	X	
7	1	X		
8	1	X		
11	2	X	X	
13	2		X**	X
14	2	X	X	

* Client 4 was interviewed, no SO interview was conducted.

** Clinician, relative, and client were interviewed.

Measures

The instruments were used during the interviews: Awareness Questionnaire (AQ), Patient Assessment of Own Functioning Inventory, and the Personal Evaluation of

Community Integration. Due to the nature of this specific study, only the data collected via the Awareness Questionnaire was utilized.

Awareness Questionnaire. The AQ measures client awareness of functional performance in the following domains: cognitive, behavioral, physical, and functioning in the community. There are three forms of the questionnaire. For the client form, the individual who sustained the TBI answers the questions regarding his/her self-awareness. A relative or significant other who is familiar with the client pre and post-injury rates the clients functional performance on the same items. The third form, completed by a clinician who has been working with client since post-injury, rates the client's performance in the same items. This form has one additional question, which asks the clinician to rate the client's self-awareness of deficits (Sherer, et al., 1998).

A study conducted by Sherer et al. (1998) that examined the factor structure and internal consistency of the AQ yielded encouraging results. To test reliability, internal consistency scores of 126 TBI survivors and 75 relatives/SO's were calculated for each of the three factors: behavioral/affective (six items), motor/sensory (four items), and cognitive (seven items). Coefficient scores were generally strong ranging from .80 (cognition factor) to .57 (motor/sensory), suggesting acceptable reliability.

The AQ was given to the client, significant other, and the treating clinician at one week, one month, and four months post-injury. Each form consisted of 17 or 18 questions that could be divided into the following factors: cognitive, behavioral/affective, and motor/sensory. These questions compared current functional performance to prior injury performance. Questions were scored according to a five- point rating scale: 1 = much worse (than prior to injury), 2= a little worse, 3= about the same, 4= a little better, 5= much better. Awareness of deficits was determined by subtracting relative/SO or clinician ratings from client's self-ratings (Sherer et al., 1998).

For this study, three open-ended questions were added to the AQ to gather additional information regarding compensatory strategy use:

- 1) When did you first realize you had a problem with (list aforementioned problems)?
- 2) Describe how you become aware of having these problems., and
- 3) For any of these problems you have, do you do anything to make it easier for yourself? (If yes, what do you do? Describe how you started doing that/those?)

ANALYSIS/ RESULTS

Self-Awareness Variance Among the Groups of Severity

Since the number of interviews differed among the eight clients and their SO/relatives, to evaluate the variance of self-awareness between the mild, moderate, and severe groups, means were calculated from the total AQ scores for both the client and SO/relative. The SO/relative score was then subtracted from the self-awareness score, thus determining the client's level of awareness. Based on previous research including Fleming and Strong (1997), Sherer, et al. (2003), and Port, et al. (2002), it was assumed that SO/relatives have more accurate perception of the client's awareness than the client him/herself (Sherer, et al., 2003). The clinician's perception was not utilized, since the majority of the clients did not receive additional rehabilitation following their acute hospitalizations so they had little contact, if any, with a clinician.

ANOVA was selected to compare the level of awareness among the three groups of clients (mild = 1, moderate = 2 and severe = 3) using the calculated discrepancy scores. A significance level of .032 ($p < .05$) was achieved, thus demonstrating a significant variance among the three groups. The self-awareness and discrepancy scores that were used when running ANOVA are presented in detail in Table 3. The detailed results generated from ANOVA are presented in Table 4.

Post Hoc analysis was then used to further determine where the variance existed between the groups. Both the Tukey HSD and Scheffe revealed a significant difference between the severe group and the mild group (Tukey, $p = .043$ and Scheffe, $p = .050$) and the severe group and moderate group (Tukey, $p = .041$ and Scheffe, $p = .048$). The variance between the mild and the moderate groups was determined to be insignificant by the Tukey ($p = .842$) and the Scheffe ($p = .855$). Thus while there is no significant variance in self-awareness between the mild and moderate TBI groups, a significant variance does exist

between the severe TBI group and both the mild and moderate groups. Specific Post Hoc analysis results are presented in Table 5.

Table 3. Self-Awareness Means and Discrepancy Scores

Client Code	Severity Of Injury	Self-Awareness Average	Relative Average	Family Discrepancy Score	SO Average	SO Discrepancy Score
1	Mild	37	37.33	+0.33		
4	Mild	35.33			41	5.67
5	Mild	45			45	0
8	Mild	28	41	+13		
7	Moderate	43	44	+1		
11	Moderate	48			44.5	3.5
13	Severe	47	30	-17		
14	Severe	48.5	26	-22.5		

Table 4. ANOVA Results of Variance Among the TBI Groups (Mild, Moderate, Severe)

Unique Method					
	Sum of Squares	df	Mean Square	F	Sig.
VARIANCE Main Effects LOWHIGH	384.375	2	192.188	7.434	.032
Model	384.375	2	192.187	7.434	.032
Residual	129.258	5	25.852		
Total	513.633	7	73.376		

a VARIANCE by LOWHIGH(mild to severe TBI)

b All effects entered simultaneously

c. LOWHIGH (1=mild, 2= moderate, 3=severe)

Table 5. Post Hoc Exploration of Self-Awareness Variance Among the TBI Groups

			Mean Difference (I- J)	Std. Error	Sig.	95% Confidence Interval	
	(I) LOWHIGH	(J) LOWHIGH				Lower Bound	Upper Bound
Tukey HSD	1	2	2.5000	4.40326	.842	-11.8278	16.8278
		3	*-15.0000	4.40326	.043	-29.3278	-.6722
	2	1	-2.5000	4.40326	.842	-16.8278	11.8278
		3	*-17.5000	5.08444	.041	-34.0443	-.9557
	3	1	*15.0000	4.40326	.043	.6722	29.3278
		2	*17.5000	5.08444	.041	.9557	34.0443
Scheffe	1	2	2.5000	4.40326	.855	-12.4790	17.4790
		3	*-15.0000	4.40326	.050	-29.9790	-.0210
	2	1	-2.5000	4.40326	.855	-17.4790	12.4790
		3	*-17.5000	5.08444	.048	-34.7963	-.2037
	3	1	*15.0000	4.40326	.050	.0210	29.9790
		2	*17.5000	5.08444	.048	.2037	34.7963

* The mean difference is significant at the .05 level.

Self-Awareness Variance Within the Three Factors of the AQ

Next, the variant AQ scores (SO/relative subtracted from self-awareness) were then subdivided into the three established factors (cognitive, behavioral/affective, and motor/sensory) in order to explore the possible variance among the TBI levels within the three factors. ANOVA revealed a significant variance in only the behavioral/affective category ($p=.003$). The detailed categorization of the AQ questions according to the three factors is presented in the Appendix. Within that category, Post Hoc analysis determined that the clients with severe TBI significantly varied from the clients with mild TBI (Tukey, $p=.003$ and Scheffe, $p=.004$) and moderate TBI (Tukey, $p=.012$ and Scheffe, $p=.015$). Both Post Hoc tests revealed no significant difference between the mild and moderate groups (Tukey, $p=.591$ and Scheffe, $p=.618$). Table 6 displays a detailed description of the Post Hoc analysis.

Table 6. Variance Among the Three Factors of the Awareness Questionnaire

		Sum of Squares	df	Mean Square	F	Significance
Cognition	Between Groups	44.478	2	22.239	5.005	.064
	Within Groups	22.216	5	4.443		
	Total	66.694	7			
Behavioral/Affective	Between Groups	59.054	2	*29.527	21.550	.003
	Within Groups	6.851	5	1.370		
	Total	65.905	7			
Sensory/ Motor	Between Groups	1.363	2	.681	.642	.565
	Within Groups	5.305	5	1.061		
	Total	6.668	7			

* The mean difference is significant at the .05 level.

Variance Between SO and Relative Perception

To answer the second hypotheses regarding the variance between the SO's and the relative's perception of awareness, the discrepancy scores were calculated between self-awareness and family awareness and, also, self-awareness and SO awareness. Since the relatives and SO's participated in an unequal number of interviews, total AQ scores were first averaged. The mean relative and SO discrepancy scores equaled 10.77 and 3.06 respectively. While the standard deviations (SD) were determined at 9.82 for the relatives and 2.86 for the SO's. Utilizing the means, an individualized t-test revealed that Levene's Test for Equality of Variances was significant ($p=.044$). Therefore, equal variances were not assumed. A 2-tailed test determined that $p=.161$, which is not significant ($p>.05$). Despite the fact that the mean of discrepancy for the relatives is larger than the one for the SO's, there is no statistically significant difference in the perceptions of client self-awareness between these two groups.

Descriptive Data

Development of Self- Awareness

The three additional questions on the AQ yielded descriptive data. Several themes emerged from this data. One such example is that development of awareness varied among the clients. The clients with severe TBI (client 13 and client 14) reported awareness development being a lengthier process than compared to the clients with mild or moderate TBI. The clients with severe TBI reported that self-awareness occurred three to five weeks post-injury. Furthermore, both these clients were participating in rehabilitation programs during this time range. Clients with moderate TBI (client 7 and client 11) reported awareness of deficits two to three days post-injury. While clients with mild TBI (clients 1,4,5, and 8) reported initial awareness of deficits ranging from immediately after waking up post-injury to two days post-injury. Two of the four clients with mild TBI reported emerging awareness of deficits that continued up to three weeks post-injury.

Three general methods of self-awareness of deficits were reported by the clients and their relatives, S.O.'s, and, if applicable, their therapist. All eight clients reported noticing their deficits, at least to some extent, by themselves. For example, client 1 noticed word finding difficulty when she was conversing. Secondly, two of the clients with mild TBI's reported greater awareness of deficits by talking with loved ones. For example, client 4 reported that her husband informed her of some of her cognitive deficits. Thirdly, 3 of the clients reported that health care professionals aided in the development of self-awareness either from cognitive testing or participating in the AQ interview.

Compensatory Strategy Use

According to the responses, compensatory strategies for cognitive deficits were implemented gradually. At the one-week post-injury interview, two of the seven participants interviewed utilized compensatory strategies (client 13 was unable to participate in the one-

week interview). Client 7, a client with moderate TBI, had his daughter write down things to help him remember. Client 11, another client with moderate TBI, stated that he “worked more closely” with his wife. By the second interview, approximately one-month post-injury, three out of six participants reported compensatory strategy use (two clients were no longer participating at the one-month mark). Two clients, one with mild TBI and one with severe TBI reported writing things down to compensate for memory deficits or “make things easier.” Client 1, who had a mild TBI, stated that she listened to music to improve her mood.

At the four-month mark, two clients reported compensatory strategy use, while client 1 reported she no longer had a need to use them. Clients 4 and 13 continued to write things down. In addition, Client 13, who had sustained a severe TBI, reported that he “used a memory book for foggy days.” The compensatory strategies used by the clients are summarized in Table 7.

Table 7. Compensatory Strategies Used by Clients

Compensatory Strategies Used by Clients
1. Writing things down (clients 4, 13)
2. Have relative write things down (client 7)
3. Work more closely with spouse (client 11)
4. Memory book (client 13)
5. Listening to music (client 1)

DISCUSSION

Impact of Severity of Injury on Development of Self-Awareness

The first goal of this study was to investigate whether the severity of injury (mild, moderate, severe) impacts the development of awareness and use of compensatory strategies. This was conducted by calculating the difference of self-awareness scores (difference = SO/family score - self-awareness score) among the three TBI groups (mild, moderate, and severe). The results indicate that while there is not a significant difference in self-awareness between the mild and moderate groups, the severe group significantly varies from both the mild and moderate groups. Since the severe group has the largest discrepancy score, one can derive that the clients with severe TBI have greater self-awareness impairments than clients in the mild and moderate groups. More specifically, these significant variances exist in only the behavioral/affective factor and not in the cognitive or motor/sensory factors. These findings contradict previous research that has suggested that self-awareness deficits in the area of cognition are a frequent hallmark of TBI (Fleming & Strong, 1997, Toglia, 1990, Prigatano & Schacter, 1991).

Another possible explanation for the lack of significant difference in self-awareness of cognitive deficits among the clients is that the family may have also been unaware of these cognitive deficits. In the study conducted by Port et al. (2002) while patients were less likely to acknowledge their cognitive deficits than their relative/SO, both groups reported low to moderate levels of difficulty. This phenomenon often occurs because the relatives/SO's have yet to see their loved one function in an everyday setting where deficits in cognition may be more apparent.

This study's findings that self-awareness deficits were only significantly correlated with severe TBI support previous research conducted by Prigatano, et al. (1998) and

contradict the findings of Coetzer & duToit (2002). Prigatano, et al. (1998) suggested that deficits in self-awareness were significantly correlated with measures of severity in moderately to severely brain-injured survivors. On the other hand, Coetzer and duToit (2002) determined there was no significance between severity of TBI and awareness in their study of 27 participants ranging from mild to severe TBI's. These conflicting results may be partially attributed to the fact that participants in the present study were between 1-week to 4 months post-injury, while the participants in the Coetzer and duToit study were an average of 56.03 months post-injury. This vast difference in time post-injury may have generated varying perceptions of self-awareness.

Variance Between Relative and SO Perception

The second aim of this study was to examine if the relative's perception of the client's self-awareness varied from the perception of the SO. The results indicate that relative perception of client self-awareness does not significantly differ from SO perception. Possible reasons for the absence of variance may be attributed to several factors. Of most importance to mention is the fact that there was unequal representation of relatives (n=5) and SO's (n=3) in the study, as well as among the three severity groups. For instance, both clients with severe TBI had relatives participate, thus no comparison could be drawn between a SO's and relative's perception. This is noteworthy since previous research has determined that self-awareness is most impaired in individuals with severe TBI. Thus, one could presume the variance between the clients and their relatives or significant others would be greatest within the severe TBI group. While in the instances of mild or moderate TBI, less variance often exists. Furthermore, the small sample size makes this study vulnerable to skewed results.

The findings of insignificant variance between SO's and relatives contradict previous research conducted by Santos et al. (1998), which highlighted differences between mothers' and wives' opinions and more specifically, determined a higher correlation between mothers'

and clients' perceptions than between wives' and clients'. Again this study had a larger sample- 48 clients and their relatives or SO's. Also worth mentioning was that these participants were interviewed more than 6 years post-injury, while the participants in the present study were interviewed over a period between 1-week to 4-months post-injury. Thus, both the clients and the relatives or SO's in the present study may have not yet realized the full extent of the TBI.

Regarding clinician perception, since clinician input was included with only one client, there were insufficient cases ($n=1$) to run ANOVA. Therefore, variance among relatives, SO's, and therapists was unable to be determined. However, on an interesting note, both the therapist and relative reported more impairments than the client, with the therapist AQ score varying 16 points from the client, and the relative's score varying 17 points. The one point discrepancy between the clinician and relative score is an insignificant variance.

Descriptive Data

Exploration of descriptive data provided further insight into self-awareness development and compensatory strategy use. It was revealed that development of self-awareness was a lengthier process for the clients with severe TBI than the clients with mild and/or moderate TBI. Also, three general methods of self-awareness of deficits were identified: self-identification, talking with loved ones, and contact with health care professionals.

Furthermore, the majority of clients who used compensatory strategies implemented them following the one-week interview. (Exceptions were both clients with moderate TBI who reported compensatory strategy use within one-week post-injury). This is to be expected since six of the seven clients who were interviewed during the first week post-injury were still in acute care. Thus, the circumstances where compensatory strategies would be helpful may have not yet occurred. These findings partially support prior research conducted by

Dirette (2002) and Fleming & Strong (1997) in which functional activity in familiar environments appeared to facilitate self-awareness of cognitive deficits in participants with TBI. However, research by Dirette (2002) and Fleming & Strong (1997) determined that contact with clinicians also aided self-awareness development, while this was not demonstrated in the present study.

The most identified compensatory strategy was writing things down, whether it is by the client him/herself or a relative on behalf of the client. This result supports previous research conducted by Dirette (2002) that identified writing down information as the main compensatory strategy used by clients with TBI.

Limitations

There were several limitations in this study. First, the small sample size ($n=8$) limits generalization of results. It also increases the possibility of a Type II error (accepting a false null hypothesis), since the low number of participants may make it difficult to find a significant difference, even though one may actually exist. With the small sample size, using ANOVA to examine the data may further contribute to the possibility of falsely determining non-significance due to the low power of the numbers. Secondly, level of self-awareness is based on the assumption that SO/relatives' perceptions of self-awareness are more accurate than the clients'. Previous research has suggested that this may not always be the case. In a study conducted by Port, et al. (2002), the authors suggested that SO awareness may also be impaired in the earlier stages of recovery as evidenced by substantial agreement between patients and their SO across every domain of function, except for one. Furthermore, in the present study the validity of the SO/relatives' perceptions could not be tested, since therapist input was included for only one client.

Thirdly, the unequal number of interviews, diverse periods of time the interviews transpired, and the variant participation of SO/relatives all hindered a longitudinal study of

awareness development. Fourthly, only one measure, AQ, was used to determine level of self-awareness, which further impedes validity of results. Also, the fact that the AQ relies on the discrepancy score between the client and his/her SO or relative to determine level of self-awareness may be somewhat limiting. The significance of such a discrepancy score is actually limited by the score used as the external criteria (SO or another relative score), which is typically selected for its presumed relation to the “true” level of functional ability. By assuming that the ratings of the SO or relative represent the client’s true functional ability, then as the level increases (greater self-awareness), the discrepancy score decreases. Thus, comparing the discrepancy scores of less impaired versus more impaired clients could thus paint the picture that the latter have more impaired self-awareness (greater difference scores), even though some of this effect could be attributed to their merely having greater latitude to disagree on the AQ rating scale (Sherer, et al., 2003).

Another limitation is the possible bias of the primary interviewer who is also the author of this study. Even though the primary interviewer followed the structured instruments, the participants may have been unintentionally influenced in order to achieve desired results. Finally, the comparison of relative and SO perceptions may have been tainted by the unequal dispersion among the severity groups, making it difficult to formulate cross-comparisons.

CONCLUSION

This pilot study provided insight into the development of self-awareness. Results were generated that may contribute to the improvement of TBI rehabilitation programs. In summary, individuals with severe TBI varied significantly from individuals with mild and moderate TBI, while self-awareness variance was insignificant between members of the mild and moderate groups. Also, results suggested that relative perception of client self-awareness did not vary significantly from SO perception. Development of self-awareness proved to be a lengthier process for individuals with severe TBI than with those with mild and/or moderate TBI. Concerning compensatory strategies, the majority of individuals who used compensatory strategies implemented them following the one-week interview, and writing things down was the compensatory strategy individuals identified using the most.

As for future research, larger studies need to be conducted on how severity of brain injury impacts the development of awareness over periods of time to generate additional research that may benefit rehabilitation programs. Furthermore, since family often plays a pivotal role in the rehabilitation process, additional examination of how TBI impacts family dynamics needs to be performed.

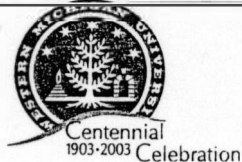
Appendix A
AWARENESS QUESTIONNAIRE ITEMS

Item
<p>Factor 1 (cognition)</p> <p>How good is your memory for recent events now as compared to before your injury?</p> <p>How good are you at keeping up with the time and date and where you are now as compared to before your injury?</p> <p>How well can you concentrate now was compared to before your injury?</p> <p>How well can you express your thoughts to others now as compared to before your injury?</p> <p>How well can you do on tests that measure thinking and memory skills now as compared to before your injury?</p> <p>How well organized are you now as compared to before your injury?</p> <p>How good is your ability to live independently now as compared to before your injury?</p> <p>Factor 2 (behavioral/affective)</p> <p>How well adjusted emotionally are you now as compared to before your injury?</p> <p>How good are you at planning things now as compared to before your injury?</p> <p>How well can you keep your feelings in control now as compared to before your injury?</p> <p>How well do you get along with people now was compared to before your injury?</p> <p>How good is your ability to manage money now was compared to before your injury?</p> <p>How well can you do the things you want to do in life now as compared to before your injury?</p> <p>Factor 3 (motor/sensory)</p> <p>How well can you move your arms and legs now as compared to before your injury?</p> <p>How well are you able to see now as compared to before your injury?</p> <p>How good is your coordination now was compared to before your injury?</p> <p>How well can you hear now was compared to before your injury?</p>

Appendix B

**APPROVAL LETTER FROM THE HUMAN SUBJECTS
INSTITUTIONAL REVIEW BOARD**

WESTERN MICHIGAN UNIVERSITY



Human Subjects Institutional Review Board

Date: June 17, 2003

To: Diane Durette, Principal Investigator
Melissa Byrns, Student Investigator for thesis

From: Mary Lagerwey, Chair

A handwritten signature in cursive script, appearing to read "Mary Lagerwey".

Re: HSIRB Project Number: 02-08-28

This letter will serve as confirmation that the changes to your research project "An Examination of the Development of Awareness and Compensatory Strategies for Cognitive Deficits in Adults with Traumatic Brain Injuries" requested in your memo dated June 12, 2003 have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: September 18, 2003

Walwood Hall, Kalamazoo, MI 49008-5456
PHONE: (269) 387-8293 FAX: (269) 387-8276

WESTERN MICHIGAN UNIVERSITY
Human Subjects Institutional Review Board
WMU Mail Stop: 5456 Phone: (269) 387-8293

RECEIVED

AUG 29 2003

APPLICATION FOR CONTINUING REVIEW OR FINAL REPORT FORM H.S.I.R.B.

In compliance with Western Michigan University's policy that "the HSIRB's review of research will be conducted at appropriate intervals but not less than once per year," the HSIRB requests the following information:

I. PROJECT INFORMATION

PROJECT TITLE: "An Examination of the Development of Awareness and Compensatory Strategies Use by Adults with Traumatic Brain Injuries."

HSIRB Project Number: 7003060 02-08-28

Previous level of review: ☒ Full Board Review ☐ Expedited Review ☐ Administrative (Exempt) Review

Date of Review Request: 09/17/03

Date of Last Approval: 09/18/02

II. INVESTIGATOR INFORMATION

PRINCIPAL INVESTIGATOR OR ADVISOR

Name: Diane Durette, Ph.D. OT.

Department: O.T. Mail Stop:

Electronic Mail Address: diane.durette@wmich.edu

(1) CO-PRINCIPAL OR STUDENT INVESTIGATOR

Name: Melissa A. Byrne

Department: O.T. Mail Stop:

Electronic Mail Address: turtlelover_25@yahoo.com

(2) CO-PRINCIPAL OR STUDENT INVESTIGATOR

Name:

Department: Mail Stop:

Electronic Mail Address:

III. CURRENT STATUS OF RESEARCH PROJECT

Please answer questions 1-4 to determine if this project requires continuing review by the HSIRB.

1. The project is closed to recruitment of new subjects.
☐ Yes (Date of last enrollment:) ☒ No (Project must be reviewed for renewal.)
2. All subjects have completed research related interventions.
☐ Yes ☐ Not Applicable ☒ No (Project must be reviewed for renewal.)
3. Long-term follow-up of subjects has been completed.
☐ Yes ☐ Not Applicable ☒ No (Project must be reviewed for renewal.)
4. Analysis of data is complete.
☐ Yes ☒ No (Project must be reviewed for renewal.)
- If you have answered "No" to ANY of the questions above, you must apply for **Continuing Review**. Please complete numbers 5-12 on page 2. If you need to make changes in your protocol, please submit a separate memo detailing the changes that you are requesting.
- If you have answered "Yes" or "Not Applicable" to ALL of the above questions, the project may be closed.
- If your protocol has been open for three years and you still want to collect or analyze data, you must close this protocol by filing a final report using this form and apply for approval of a new protocol using an **Application for Initial Review**. Please make a **Final Report** on your project by completing numbers 5-9 on page 2.

IV. ☒ Application for Continuing Review

V. ☐ Final Report


HSIRB Project Number: 7003060

5. Have there been changes in Principal or Co-Principal Investigators? ☐ Yes ☒ No
(If **yes**, provide details on an "Additional Investigators" form (available at the HSIRB web site, http://www.wmich.edu/research/compliance/hsirb/hsirb_2.html).)
6. Has the approved protocol been modified or added to with respect to:
(If **yes** to any item below, provide the details on an attached sheet.)
- | | | |
|--------------------|------------------------------|--|
| a. Procedures | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |
| b. Subjects | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |
| c. Design | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |
| d. Data collection | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |
7. Has any instrumentation been modified or added to the protocol? ☐ Yes ☒ No
(If **yes**, attach new instrumentation or indicate the modifications made.)
8. Have there been any adverse events that need to be reported to the HSIRB? ☐ Yes ☒ No
(If **yes**, provide details on an attached sheet.)
9. Total number of subjects approved in original protocol: **20**
10. Total number of subjects enrolled so far: **6**
If applicable: Number of subjects in experimental group: **0** Number in control group: **0**
- If this is a **FINAL REPORT** you may stop here and return the form electronically.
 - If this is an **APPLICATION FOR CONTINUING REVIEW** continue with numbers 10-12 below.
11. Estimated number of subjects yet to be enrolled: **14**
12. **Verification of Consent Procedure:** Provide copies of the consent documents signed by the last two subjects enrolled in the project. Cover the signature in such a way that the name is not clear but there is evidence of signature. If subjects are not required to sign the consent document, provide a copy of the most current consent document being used.
13. If you are continuing to recruit subjects for this project, please remember to include a clean original of the consent documents to receive a renewed approval stamp.


Principal Investigator/Faculty Advisor Signature 8/29/03
Date


Co-Principal or Student Investigator Signature 8/29/03
Date

Approved by the HSIRB:


HSIRB Chair Signature 9-18-03
Date

Western Michigan University
Human Subject Institutional Review Board – Mail Stop 5456

Revised 7/03 WMU HSIRB
All other versions obsolete

REFERENCES

1. Allen, C.C., Ruff, R.M. (1990). Self-rating versus neuropsychological performance of moderate versus severe head-injured patients. *Brain Injury*, 4(1): 7-17.
2. Centers for Disease Control. Traumatic brain injury in the United States: a report to congress. www: Centers for Disease Control, (May 18th, 2004)
<http://www.cdc.gov/ncipc/pub-res/tbicongress.htm>.
3. Coetzer, B.R. & duToit, P.L. (2002). Impaired awareness following brain injury and its relationship to placement and employment outcome. *The Journal of Cognitive Rehabilitation*: 20-24.
4. Crosson, B., Barco, P.P., Velozo, C.A., Bolesta, M.M., Cooper, P.V., Werts, D., & Brobeck, T.C. (1989). Awareness and compensation in postacute head injury rehabilitation. *Journal of Head Trauma Rehabilitation*, 4(3): 46-54.
5. Dirette, D.K. (2002). The development of awareness and the use of compensatory strategies for cognitive deficits. *Brain Injury*, 16(10): 861-871.
6. Fleming, J.M. & Strong, J. (1997). The development of insight following severe traumatic brain injury: three case studies. *British Journal of Occupational Therapy*, 60(7): 295-300.
7. Katz, N. & Hartman-Maeir, A. (1997). Occupational performance and metacognition. *Canadian Journal of Occupational Therapy*, 64(2): 53-62.
8. Kosciulek, J.F. (1997). Relationship of family schema to family adaptation to brain injury. *Brain Injury*, 11(11): 821-830.
9. Kreutzer, J.S., Gervasio, A.H., Camplair, P.J. (1994). Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Injury*, 8(3): 197-210.
10. Kreutzer, J.S., Gervasio, A.H., Camplair, P.J. (1994). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury*, 8(3): 211-230.
11. National Institute of Neurological Disorders and Stroke.
www.ninds.nih.gov/health_and_medical/pubs/TBI.htm (July 7th, 2004).
12. Port, A., Willmott & C. Charlton, J. (2002). Self-awareness following traumatic brain injury and implications for rehabilitation. *Brain Injury*, 16(4): 277-289.

13. Prigatono, G.P., & Schacter, D.L. (Eds.). (1991). *Awareness of deficit after brain injury: Clinical and theoretical issues*. New York: Oxford University Press.
14. Prigatono, G.P., Bruna, O., Mataro, M., Munoz, J.M., Fernandez, S., & Junque, C. (1998). Initial Disturbances of Consciousness and Resultant Impaired Awareness in Spanish Patients with Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*, 13(5): 29-37.
15. Santos, M.E., Castro-Caldas, A., & DeSousa, L. (1998). Spontaneous complaints of long-term traumatic brain injured subjects and their close relatives. *Brain Injury*, 12(9): 759-767.
16. Sherer, M. Bergloff, P., Boake, C., High, W., Jr., & Levin, E. (1998). The awareness questionnaire: factor structure and internal consistency. *Brain Injury*, 12(1): 63-68.
17. Sherer, M., Boake, C., Levin, E., Silver, B.V., Ringholz, G., & High, W.M., Jr. (1998). Characteristics of impaired awareness after traumatic brain injury. *Journal of the International Neuropsychological Society*, 4: 380-387.
18. Sherer, M., Hart, T., Nick, T., Whyte, J., Thompson, R.N., & Yablon, S.A. (2003). Early impaired self-awareness after traumatic brain injury. *Archives of Physical Medicine Rehabilitation*, 83: 168-176.
19. Sosin, D.M., Sniezek, J.M., & Thurman, D.J. (1996). Incidence of mild and moderate brain injury in the United States, 1991. *Brain Injury*, 10: 47-54.
20. Thurman, D., Alverson, C., Dunn, K., Guerrero, J., & Sniezek, J. (1999) Traumatic brain injury in the United States: a public health perspective. *Journal of Head Trauma Rehabilitation*, 14(6): 602-15.
21. Tolia, J.P. (1990). Generalization of treatment: a multicontext approach to cognitive perceptual impairment in adults with brain injury. *The American Journal of Occupational Therapy*, 45(6): 505-515.
22. Wallace, C.A. & Bogner, J. (2002). Awareness of deficits: emotional implications for person with brain injury and their significant others. *Brain Injury*, 14(6): 549-562.
23. Webster, G., Daisley, A., & King, N. (1999). Relationship and family breakdown following acquired brain injury: the role of the rehabilitation team. *Brain Injury*, 13(8): 593-603.
24. White, S.M., Seckinger, S., Doyle, M., & Strauss, D.L. (1997). Compensatory strategies for people with traumatic brain injury. *NeuroRehabilitation*, 9: 205-212.

25. Wood, R. L. & Yurdakul, L.K. (1997). Change in relationship status following traumatic brain injury. *Brain Injury*, 11(8): 491-502.