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The effect of unawareness of deficits on the marital adjustment of individuals with brain injury and their spouses

Tipton, Linda Campbell, Ph.D.
The Ohio State University, 1993
THE EFFECT OF UNAWARENESS OF DEFICITS
ON THE MARITAL ADJUSTMENT OF
INDIVIDUALS WITH BRAIN INJURY AND THEIR SPOUSES

A Dissertation
Presented in Partial Fulfillment of the Requirements for
the degree Doctor of Philosophy in the
Graduate School of The Ohio State University

By

Linda Campbell Tipton, B.A., M.A.

* * * * *

The Ohio State University
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Adviser
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To the Patients On the Head Injury Unit at Dodd Hall and Their Spouses.
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INTRODUCTION

Recent epidemiological studies have placed the incidence of brain injury in the United States at approximately 200 per 100,000 persons in the population per year, and medical advances have allowed more and more people to survive brain injuries (Sorenson and Kraus, 1991). Because of the higher survival rate, more individuals are living with significant cognitive and behavioral impairments. While the tremendous costs to society and the individual may be obvious, the negative effect of brain injury on the family may not be as readily apparent. Most individuals with brain injury return to their homes when discharged from the hospital or rehabilitation (83% according to Kraus et al., 1984) and their families assume the burden of their care. Willer, Abosh and Dahmer (1990) note that while the family pays a price, society pays more if the family cannot care for that person at home. A recent focus of the literature on brain injury has been on the many burdens of the family (cf. Brooks, 1984; Williams, 1991). The cognitive and behavioral problems of the individual place added strain and stress on families.

The risk of brain injury is highest between the ages of 16 and 25, with a drop off until another increase at the age of 60 (Sorenson and Kraus, 1991). The majority of persons with brain injury are male, and between the ages of 18 and 34 (Kraus et al., 1984). Most of the existing published research has
looked at young males whose main caretakers, should they require long-term assistance, tend to be their parents. As a result, most research to date has examined the adjustment and stressors of parents, but has not differentiated between parents, spouses or other caretakers. Few studies have specifically examined the effect of traumatic brain injury on the spouse. Those that did found significant negative effects. Panting and Merry (1972) found wives of men with a traumatic brain injury were more stressed than mothers over their caretaking role. Rosenbaum and Najenson (1976) found wives of men who received head injuries in battle were more depressed and socially isolated. In addition, spouses suffered greater financial losses than parents. Spouses were more likely to borrow money and lose possessions, and had a greater decrease in yearly family income ($13,800 vs. $2,100) than parents (McMordie & Barker, 1988). Spouses may also bear more psychosocial burden (Williams, 1991).

Many authors stress the importance of involving the family in the rehabilitation process. Livingston, Brooks and Bond (1985) advocated viewing relatives as “full-time, non-professional therapists.” (p. 874). One author, (Spivack, 1991) herself the mother of an individual with a brain injury, noted that earlier and more knowledgeable education and intervention can assist in the adjustment process. Certainly, both individuals and their families can benefit from greater preparation and education about the results of brain injury for the family. However, the effect of brain injury on the marital relationship seems different than on the parent/child or other familial relationship. Peters, Stambrock, Moore and Esses (1990) advocated more sensitivity and support for spouses, since they found spouses
experienced more depression and decreased marital satisfaction following their injured partners discharge from the hospital, just at the time they are most responsible for ongoing care and rehabilitation.

Many factors affect the amount of burden faced by families and spouses. The financial and psychosocial stability of the family or marital unit prior to the injury influences adjustment. The specific sequelae of the injury itself, including physical, cognitive, and behavioral impairments, and personality changes also contribute to family functioning. Oftentimes, individuals with brain injury lack awareness of their deficits, and thus make fewer attempts to correct behavior or improve cognitive functioning. This places an added burden on families or spouses, who must continually monitor or supervise their relative's behavior. Linn and Willer (1992) found that lack of awareness of social aggression was associated with higher levels of anxiety in spouses. Little published research has focused on the psychosocial and psychological effects of lack of awareness. Specifically, the effect on the marital relationship of individuals with brain injury has not been studied. This may be one problem for which patients and their spouses, not to mention rehabilitation professionals, are not well prepared. This study explored the effect of unawareness of deficits on the marital relationship of individuals with brain injury.
CHAPTER I

LITERATURE REVIEW

The literature surrounding brain injury which specifically applies to the issues in this study will be reviewed in the next section. First, brain injury and its common sequelae will be described, both as they affect the individual and the family. The next section will focus on those few studies which address the effect of brain injury on the marital relationship. Lastly, the literature describing awareness of deficits in the population of people with brain injury will be covered.

Brain Injury

Effects on the Individual

The term brain injury subsumes many different types of injury, including closed head injury, open head injury, and anoxia. Epidemiological studies in the United States have shown that mild brain injuries account for most of the injuries (50 to 86%), but those who are admitted to hospitals may have more moderate to severe damage (Sorenson and Kraus, 1991). However, all studies surveyed by Sorenson and Kraus (1984) showed that those who had suffered only mild brain injury still had significant cognitive, behavioral and physical problems. Damage to the brain can result from shearing, bruising or compression. Common problems caused by brain injury
can be classified as physical, cognitive, behavioral and social. Physical problems include hemiparesis, vision problems, dysarthria, and seizures.

Cognitive deficits following brain injury can include learning and memory impairments, executive function problems, perceptual changes and language deficits. Most persons with moderate to severe brain injury suffer to some degree from post-traumatic amnesia, or loss of memory for day-to-day events. Retrograde amnesia, or loss of memory for events pre-injury, also occurs. Brooks (1984a) noted recovery of memory and learning skills tends to take longer than recovery of physical abilities.

Intellectual abilities may be impaired following brain injury. As assessed by the Wechsler Adult Intelligence Scale-Revised, verbal skills typically show quicker and greater recovery, while non-verbal or performance skills may show long-term, severe deficits. Brooks (1984a) also noted the more complex a task, the slower the recovery of the ability. Length of PTA also negatively influenced non-verbal skills more than verbal. Language functions are often affected by brain injury. Expressive aphasia and other language problems are common. While they may be the first skill recovered, language abilities can be permanently impaired.

After brain injury, individuals may develop behavioral problems. Changes in behavior may be the most difficult consequence for families and caretakers to cope with, as they seriously impact the individual's social skills and lead to problems when re-entering the community or work environment. Lezak (1978) described common behavioral problems, including loss of social-perceptiveness, impulsivity, restlessness, dependency, poor planning skills, loss of initiative, inability to learn from experience, loss
of or increase in sexual desire, and emotional changes. Emotional difficulties included lability, apathy and irritability. Brooks (1984b) created a taxonomy of behavior disorders after brain injury, which categorized them as aggression, sexual behavior, attention seeking, motivation and arousal problems. Lezak (1978) noted behavior problems can be even more problematic for families to handle if the individual is unaware of them, or has no insight into their cause.

Socially, individuals with brain injury are at risk. Sale, West, Sherron and Wehman (1991) reviewed studies of return to work after brain injury, and found that anywhere from 3% to 19.2% of moderate to severe brain injury survivors were able to maintain paid, competitive employment. In addition, their income may be significantly less (McMordie & Barker, 1988). Leisure and social activities were found to be almost nonexistent in the population of those seen for rehabilitation (Oddy, 1984). This lack of social contact was not due to physical impairments, but instead was related to cognitive impairments and behavioral problems, such as aggression. Possibly one the most negatively affected social areas is the family. Oddy (1984) described several studies which found a decrease in communication, and an increase in family conflict following brain injury. Conflicts tend to be greater if the affected individual’s long-term deficits are more subjective, and less obvious (e.g. personality changes, memory or behavioral problems). The above mentioned cognitive, behavioral and social sequelae of brain injury can affect the family as severely as they do the patient. Livingston (1987) found factors in the patient (i.e. their subjective complaints) accounted for
more than 50% of the variance in the psychological and social adjustment of relatives, more than any of the relative’s personal abilities or characteristics.

**Effects on the Family**

As Williams (1991) stated, head injury happens to the whole family system, and the family recovers just as the individual does, in the process gaining a different identity. Kay and Cavallo (1991) described the similar stages gone through by the individual and the family. Individuals with traumatic brain injury may first lack awareness of their deficits, then as time goes on and they are faced with their limitations, they identify themselves as “head injured.” Finally, their focus may switch from their disabilities to their humanness, as their identity changes to a “person with a head injury.” Families go through similar stages. Immediately after the injury, they rally round their injured relative, unaware of the possible permanence of the impairments. Once the family has their relative home for awhile, they may be forced to identify themselves as a “head injured family” and focus on the person with the brain injury. Lastly, they may find not all family members are getting their needs met, and begin to function as a whole family, for all members.

Families tend to be unrealistically optimistic about full recovery during the early stages of rehabilitation. They do not expect behavior problems, or family conflict stemming from the individual’s deficits. (Lezak, 1986) Just as the individual may lack awareness of deficits, so too may families experience denial in the early stages of recovery. Families may have fantasies about full recovery, may refuse to believe clinicians prognosis or may respond inappropriately to their injured relative’s problems. (Brooks, 1984b) Several
studies have shown it takes time for relatives to believe changes are permanent. Brooks and McKinlay (1983) found families were more likely to acknowledge changes at 6 (73%) and 12 months (75%), than at 3 months (57%). Rosenbaum and Najenson (1976) found the crisis period was at one year. Lezak (1986) described a stage approximately 9 months to two years post-injury, during which families became discouraged and depressed as they realized their relative may not improve.

Adjustment of a family to brain injury may not be a linear progression through stages, but may instead be an ongoing experience or task. Muir and Haffey (1984) perceived of traumatic brain injury as a "partial death," in which some important part of a life is lost, (such as memory, physical abilities or personality) and in which recovery is uncertain. Families of persons with brain injury thus grieve in a specific way, called "mobile mourning" by Muir and Haffey (1984). In mobile mourning, families continue to search for complete recovery, and are stuck at times between hope and resignation to their loss. This continual alternation between hope and despair can lead to rage, to breakdowns in relationships among family members and to learned helplessness. Each family adapts in its own way, and according to Muir and Haffey (1984), should not be forced to "accept" the injury and give up hope. Instead, these authors encourage families to identify realistic goals for recovery and focus on the new relationship they must form with their family member.

Williams (1991) developed the idea of "episodic loss reaction", to explain how families appear to learn to adapt and deal with brain injury throughout the changing family life cycle. Like Muir and Haffey (1984),
Williams (1991) believes families do not adjust by gaining some sort of final acceptance of their loved one's injury, nor are they in a state of permanent sorrow. Instead, families tend to learn to cope with problems, and adapt to situations, but can have episodic grief and loss reactions to different events related to the brain injury, such as a developmental milestone the brain injured individual cannot reach or the anniversary of the injury. Family members can have different psychological and emotional responses to the same event, but tend to find different coping strategies to attain an adaptive balance and adjust to each event. Both of the above models help explain the different reactions possible from different family members.

Often, the problems suffered by the family are not easily seen by outsiders, since the individual with brain injury may appear to be functioning well. Behavioral and personality changes not evident during casual contact (i.e. emotional lability, irritability, apathy, lack of social judgment and dependency) are highly disruptive to the family (Lezak, 1986). Kreutzer, Marwitz and Kepler (1992) reviewed studies of family members adjustment to brain injury, and concluded that adjustment is influenced by behavioral and personality changes in the patient more than by changes in cognitive or physical abilities. McKinlay, Brooks, Bond, Martinage and Marshall (1981) found personality, behavioral and emotional changes of the injured person were more related to the perceived amount of family burden, than were speech problems or level of physical impairment. Interestingly, individuals with brain injury and their families may disagree when describing the results of the injury. McKinlay and Brooks (1984) found relatives and persons with brain injury agree strongly when describing
physical impairments, and agree moderately well when describing cognitive impairments. However, relative’s ratings of behavioral and emotional problems tend to be higher than the ratings of the person with brain injury. This lack of awareness on the part of the individual with brain injury may be one factor which increases subjective burden of the relatives. Brooks and McKinlay (1983) and Brooks, Campsie, Symington, Beattie and McKinlay (1986) found that subjective burden of relatives increased over time. In the 1986 study, only 24% of relatives reported high burden after one year, while 56% reported high burden after five years. This finding supports the stages of family adjustment described by Kay and Cavallo (1991) and by Lezak (1986). It seems it may take one year or more after injury for families to understand and experience the full effect on their lives.

Several studies have explored the significance of the type of family relationship (i.e. parent, spouse, sibling) to the amount of distress experienced. While all empirical studies found more psychological distress in relatives of persons with brain injury than in relatives of other rehabilitation populations (i.e. fractures, spinal cord injuries), they have differed in their findings on the differences among types of relatives. Panting and Merry (1972) found that wives of individuals with brain injury experienced greater stress than mothers. Thomsen (1974) found wives coped less well than parents. Mauss-Clum and Ryan (1981) found that wives were more emotionally affected than mothers because they were more irritable and depressed. In addition, wives in this study had less social interaction and less personal time. Livingston, Brooks and Bond (1985a, 1985b) found no statistically significant differences between wives and mothers levels of
depression, anxiety or perceived burden. However, when examined more closely, it appears mothers and wives may have differed in some important ways. Livingston, Brooks and Bond (1985a) did find wives were different from a control group of wives, while the mothers did not differ from their control group. Even though they had the same pattern of psychosocial problems, wives were more “socially handicapped” and had an overall poorer outcome in terms of social interaction. One problem with the above findings is that the interviews took place only three months post-injury, at a time when the individual with brain injury may not have attempted to return to work, or re-enter the community. Turnbull and Turnbull (1991) note that the conflicting results may reflect differences in the marital relationship prior to the brain injury. Differences in the adjustment of spouses from other family members deserves further study.

Brain Injury and the Marital Relationship

Several authors have speculated on reasons why the parent/child relationship may be more stable than the spousal relationship after brain injury, and why coping may be more difficult for the spouse. Brooks (1984b) noted parents may be able to share the burden, and that mothers may be more able to accept behavior changes. Spouses may be less likely to accept dependent behavior. The role changes demanded of a spouse are more drastic, from partner to caretaker, while a parent has been a caretaker of the individual before. Lezak (1978) described the spouse’s special difficulties as mainly social. She noted the spouse lives in “a social limbo,” without a partner for social occasions, but without freedom to find another. Society does not recognize the spouse’s grief, since the partner is still alive. Many
spouses feel they cannot divorce their injured partner because of social responsibility, guilt, or happy memories of the past. Importantly, a spouse’s “sexual and affectional needs” are no longer met. One wife of a man with brain injury described herself as “not single, divorced, widowed or a couple” (Beaver, 1991).

Despite these possible differences, the marital relationship has rarely been specifically addressed by researchers studying the effect of brain injury on the family. Turnbull and Turnbull (1991) stated the focus of most family research in the brain injury field is on the parent. In a review of the literature looking at brain injury and the marital relationship, Liss and Willer (in press) described the literature as “scant.” In fact, there was so little to work with, they formed many of their hypotheses by extrapolating from the spinal cord injury literature. They noted it would be prudent to “assume that individuals with traumatic brain injury...will experience higher rates of divorce and lower rates of post-injury marriage than the general population.” (p. 7) From the spinal cord injury literature, it would also be possible to assume divorce or separation would be most likely after the first year when rehabilitation and support services end. Marital roles are likely to change, so that the spouse might say “This is no longer the person I married,” and lead to stress on the relationship. The sexual relationship may also be negatively affected (Liss and Willer, in press).

One early exception to the above trend was a study by Panting and Merry (1972), who studied 30 consecutive admissions to a head injury rehabilitation unit for males at 1-5 years post-discharge. They found the husband-wife relationship was less stable than the parent-child relationship.
The age of patients living with spouses was older and these individuals may have had less complete recovery. The authors also found 61% of all wives and mothers surveyed required medication to cope with the strain of living with their injured relative. Thomsen (1974) also found wives coped less well than parents. In a follow up study, Thomsen (1984) found two-thirds of the persons with brain injury still had emotional and behavioral problems which were stressful for their families. She found families and spouses became isolated from the community and relationships continued to deteriorate. At fifteen year follow-up, Thomsen (1989) found only 2 of 9 subjects married at the time of injury had remained together.

Rosenbaum and Najenson (1976) studied the wives of men who had been injured in the Yom Kippur War in Israel one year after the war. They interviewed and compared ten wives of men with severe brain injury, six wives of men with paraplegia, and 14 women whose husbands had fought in the war but had not been injured. During face-to-face interviews the subjects were asked to respond to a questionnaire measuring changes in their life, roles and mood. The authors found wives of men with brain injury had experienced a great deal of change in their lives, and were more likely to show signs of depression. Their husbands were more childlike, self-centered and dependent than the other two control groups. They had more contact with in-laws, but found these relationships more stressful than the wives whose husbands had spinal cord injuries. They had fewer contacts with friends, and felt more strongly than the other groups that their husbands disability was a "social handicap." Their husbands played less of a role in childrearing than the spinal cord injured men. Wives of men with brain
injury had much reduced sexual relations, but unlike the wives of men with spinal cord injuries, it was not due to physical dysfunction. Rosenbaum and Najenson (1976) speculate it may be due to poorer interpersonal relationships. They had fewer positive experiences, and reported more symptoms of depression than the other two groups.

Many studies have shown depression has a negative effect on marital satisfaction and adjustment. Gotlib and Hooley (1988) reviewed studies on depression and marital distress and found that the marriages of depressed persons have more open and covert hostility, fewer positive interactions, more negative affect and poor communication. It is interesting to note that the wives in the Rosenbaum and Najenson (1976) study had such negative effects on their lives despite the fact they received substantial financial support as a result of their husband’s military injuries. While the Rosenbaum and Najenson (1976) findings are important, the results are limited due to the small sample size, and lack of further follow-up. Another limitation may be that the perceptions of the spouse with brain injury were not included.

Sexual relations were one problem area noted for the wives in the Rosenbaum and Najenson (1976) study. Kreutzer and Zasler (1989) surveyed 21 males with brain injury and found the majority had experienced negative changes in their sexual behavior (i.e. lowered libido, erectile dysfunction). Despite these sexual problems, they reported good overall marital relationships. Garden, Bontke and Hoffman (1990) surveyed 11 males and 4 females with traumatic brain injury. They found less sexual desire in their female subjects. Their male subjects seemed to have the same amount of
desire, but described their wives as uninterested. Intercourse frequency declined for 3 of the women, and 55% of the men. Only half of the spouses surveyed felt satisfied with their sexual adjustment. Zasler and Kreutzer (1991) described several reasons why problems with sexuality are common following brain injury. The unaffected partner may have a higher stress level, and thus have less sexual desire. Childish or aggressive behavior, personality changes and communication problems can also decrease sexual activity. Role changes can affect a spouse's willingness, since a partner who is more dependent and less responsible may be less attractive.

Several authors have noted the importance of role changes after brain injury (e.g. Lezak, 1986; Liss & Willer, in press). Spouses must be caretakers, sole providers and, at times, single parent, while individuals with brain injury often become more dependent, less social and lose their role as spouse, parent or provider. Willer, Allen, Durnam and Ferry (1991) used a structured group discussion format to explore common problems and coping strategies of persons with brain injury and their spouses. Their 31 couples (20 with injured husband, 11 with injured wife) were at least 18 months post-injury, married or living-together and younger than 60 years. Subjects were divided into four groups (injured husbands, injured wives, able-bodied husbands, able-bodied wives) and asked to come up with a list of their most common problems and their methods of coping with these problems.

Overall, the couples in the Willer, et al (1991) study found their problems were most likely to be “problems in living” or related to family relations, employment and personal satisfaction. Wives with brain injury were most disturbed by their loss of autonomy, loneliness, and diminished
interest in sex, while they most valued spousal and family support, support
groups and becoming assertive to cope with problems. Similar to their wives,
able-bodied husbands also found their wives loss of autonomy to be
disturbing along with her mood swings. To cope, they tended to suppress
their own feelings and tried not to blame all problems on the brain injury.
Husbands with brain injury found loss of independence, loss of husband,
father and provider roles and difficulty in recognizing their limitations to be
most disturbing. They found inclusion in family decisions, awareness of
other's concerns and involvement outside the home helped them cope.
Able-bodied wives noted that changes in their husband's personality and
cognitive abilities, along with his lack of insight and lack of acceptance of his
difficulties were problematic. To cope, they tried to be realistic, allowed their
husbands to be independent and became more assertive. This study produced
valuable information about coping skills, but is limited due to the
unstructured method used to generate data, and the homogeneity of the
sample. All subjects belonged to a head injury association and volunteered to
participate. They were also given a free weekend retreat for their
participation.

Interestingly, Willer et al (1991) found gender differences in problems
faced by men and women with brain injury, and in the methods they used to
cope, following typical sex-roles in our society. Possibly due to the 2-1 or 3-1
ratio of men to women with brain injury, few studies have included women
and this issue has not been explored. It is also important to note this study
valued the perspective of individuals with brain injury equally with their
spouse. All too often in published research, they are ignored as a source of
information. DePompeii and Zarski (1991) suggest always including the individual with brain injury in assessment, unless he or she is unable to communicate in any way. They note "regardless of the accuracy of the perception, assessment results give a picture of where the family member with a head injury believes himself or herself to be within the family system." (p. 113).

All of the studies mentioned above were more descriptive than predictive. Peters, Stambrook, Moore and Esses (1990) tried to predict the effect of severity of brain injury on marital adjustment. They surveyed the spouses of 55 males with brain injury, and divided them into three groups based on the severity of the injury, mild (n=10), moderate (n=25) and severe (n=20). They hypothesized several patient-related factors (severity of injury, physical limitations, time since injury, psychological adjustment), spousal factors (personality, coping skills) and family factors (recent changes, financial strain) would predict marital adjustment and intimacy. All ratings were provided by the spouse. Results of this study empirically documented that wives of individuals with severe brain injury perceived themselves as having poor overall marital adjustment, affectional expression and poor dyadic consensus when compared with wives of men with mild or moderate brain injury. Along with financial strain, several patient based factors (severity of injury, psychosocial maladjustment of the patient and dependency of the patient) were the best predictors of marital problems. The wives' personalities and methods of coping were not related to marital maladjustment. The authors noted the more permanent factors which affect daily life led to stress and problems, regardless of how well spouses handle
stress. Once again, the perception of the person with brain injury was not measured.

Taken as a whole, the literature on brain injury and marriage has just begun to explore the effects of trauma on marital functioning. Role changes and sexual functioning have only been superficially addressed. The changes in marital adjustment over the course of time after rehabilitation has not been studied in depth or detail. Only one study (Willer et al, 1991) asked for the perceptions of the person with brain injury. Most viewed them as possibly inaccurate or unable to give consistent information, due to difficulties with insight or self-awareness. Individuals with brain injury may tend to underestimate their behavioral and cognitive impairments, sometimes leading to a higher level of family conflict. Although several authors noted the importance of the injured person's level of awareness of his/her deficits, no studies have measured its effect on marital adjustment or satisfaction. With this lack of attention to the injured person and spouse as a unit, it is impossible to tell if level of self-awareness actually affects the marital relationship. However, the literature on awareness of deficits, apart from the marital relationship, is available and will be reviewed.

Awareness of Deficits

Prigatano and Schachter (1991), in their book titled *Awareness of Deficit After Brain Injury: Clinical and Theoretical Issues*, defined self-awareness as the ability to perceive the self objectively while understanding it is somewhat subjective. After injury to the brain, a lack of self-awareness is termed anosognosia, or the "apparent unawareness, misinterpretation, or explicit denial of an illness...usually refers to the patients behavior in relation to the
consequence of a brain lesion” (p. 263). This is not psychological denial, but is “rooted in damage to the frontal lobes, which impairs executive functions: the ability to anticipate, plan and organize, develop a strategy, self-monitor and self-correct, and judge the appropriateness of one’s own behavior.” (Kay & Cavallo, 1991, p. 139) This unawareness of deficits can lead to unrealistic goals, can hinder re-entry into the community and can disrupt social relationships. (Kay & Cavallo, 1991)

Anosognosia in a pure form, in which severe physical disability (such as paralysis) is denied, is usually associated with right hemisphere lesions or frontal lobe injuries (Heilman, 1991). However, Prigatano (1991) noted diffuse injuries to the brain can also produce poor self-awareness. Stuss (1991) theorized self-awareness is one of the highest and most integrated of brain functions. It can be present with normal sensory abilities, even with normal intelligence and memory.

Prigatano (1991) stated higher cognitive functions, such as self-awareness, are usually not given enough attention during rehabilitation and community re-entry. Problems in social relationships and the workplace can stem directly from an individuals inability to self-monitor. However, standard neuropsychological tests do not predict awareness of deficits. Instead, activities of daily living may best reveal this problem. Thus, those who have daily contact with the injured person, such as spouses, can be the best source of information. In a brief review of the literature, Prigatano (1991) found patients tended to underestimate their behavioral and memory difficulties when compared to the ratings of staff and family. This author also described a clinical example of the effect of awareness. In evaluating a
rehabilitation program, he found the patients with productive lives, good interpersonal relationships and active participation in rehabilitation activities were those whose ratings of their level of awareness were the same as the staff. These individuals realized they were not totally aware of the impact of brain injury on their lives. In contrast, those rated as failures on the above criteria were those who felt they were totally aware, when their ratings were actually the opposite of the staff ratings of their awareness.

Prigatano (1991) reported another study of awareness of deficits, which found 64 patients with brain injury as a group tended to underestimate their social and emotional problems. Patients and staff agreed on their self-care needs, but patients overestimated their ability to deal with arguments, control their temper and understand when they have upset others. While this issue deserves further study, no consistent method of measuring awareness of deficits has been developed.

Prigatano and Altman (1990) proposed comparing persons with brain injury and relatives ratings of deficits as a measure of awareness. They conducted a retrospective study which divided 64 patients with brain injury (17 women, 47 men) into three groups based on the differences of their ratings on the Patient Competency Rating Scale (PCRS), a measure of behavioral problems. Patients (25%) with higher PCRS scores than their relatives overestimated their competencies, thus showing a lack of awareness of deficits. Another group (53%) had ratings similar to their relatives ratings, showing good awareness of deficits. A third, and smaller group (17%), underestimated their behavioral competencies, and overestimated their deficits. Study results showed the first group was more likely to have bilateral
brain lesions, more abnormal neuroradiographic findings and slower left hand finger tapping. They also found the third group had functional or psychiatric reasons for overemphasizing their limitations. This study showed that comparisons of patient and relative ratings to determine awareness of deficits is a useful measure.

Ranseen, Bohaska and Schmitt (1990) studied 32 patients with brain injury (28 males, 4 females) during rehabilitation. Subjects were divided into three groups based on the type of injury: left hemisphere (n=13), right hemisphere (n=8) and diffuse/bilateral (n=11). The groups did not differ in age, education, severity of injury or on the results of a brief neuropsychological battery. However, a main effect of group on patient rating of behavioral competency vs. staff rating of behavioral competency was found. The right hemisphere injured group had, on average, twice as large a difference between self and staff rating than the other groups. The study also found a weak but significant relationship between depression and awareness. As awareness increased, so did depression.

Linn and Willer (1992) conducted a study of awareness of cognitive disability and social behavior, and its relationship to emotional distress. They hypothesized awareness is not "all-or-nothing," but is multi-modal, and awareness of different types of deficits can lead to different emotional impacts. Subjects were 48 couples, one of whom suffered a severe brain injury (68% with brain injury were male). Each person filled out a portion of the Symptom Checklist-90-Revised (SCL-90-R), a measure of emotional distress, the Cognitive Disability Scale (CDS) and Social Aggression Scale (SAS), measures of problem areas in cognition and behavior after brain injury. The
individual with brain injury rated himself or herself, while the spouse rated
the individual with brain injury. As in previous studies, "awareness" was
operationalized as the discrepancy between the injured person's and spouse's
ratings on the CDS and SAS. The authors found individuals with brain
injury who had good awareness of cognitive deficits endorsed more items
showing subjective emotional distress. There was a low positive correlation
between awareness of cognitive disability and awareness of social aggression,
which supports the notion that awareness is multi-modal. Spouses reported
higher anxiety if the injured partner had poor awareness of social aggression,
thus spouses may be more upset by social/behavioral changes than by
cognitive changes. This study did not examine the impact of awareness of
different types of deficits on the marital adjustment of these couples.

Problem Statement

No published studies have explored the direct effect of unawareness of
deficits on the marital relationship. This study attempted to examine the
effects of lack of awareness of deficits in an individual with brain injury on
the marital relationship. It also noted the effect of other variables, such as
depression, degree of community reintegration, severity of injury, and
financial strain on the marital relationship.

The primary hypothesis of this investigation was that unawareness of
deficits in the person with brain injury leads to poor overall marital
satisfaction and less sexual satisfaction for both the person with brain injury
and spouse. It was believed that lack of awareness of deficits was multimodal
and more likely to be noted for behavioral difficulties than for cognitive or
physical problems. The literature also suggests the spouse may experience
more emotional distress than the person with brain injury. Depression in both partners was believed to be related to lower levels of marital satisfaction. Good community re-integration, signifying positive psychosocial adjustment, was predicted to be associated with better marital satisfaction and less emotional distress for both partners. More severe injuries and more financial strain also appeared to be possible negative influences on marital satisfaction. 

**Hypotheses**

Specific hypotheses are stated as null hypotheses due to the limited amount of research on this topic. As there is not a strong and consistent empirical framework to guide these hypotheses, they are not specifically predictive of the direction of relationships. The hypotheses are listed in the order in which they will be presented in the results section.

**H₀ 1:** Unawareness of deficits is global, indicating that awareness is not significantly different for cognitive, behavioral or physical awareness.

**H₀ 2:** Relationship satisfaction and sexual satisfaction of the person with brain injury are not significantly different from his or her spouse.

**H₀ 3:** Unawareness of deficits in an individual with brain injury is not associated with overall relationship satisfaction.

**H₀ 4:** Unawareness of deficits in an individual with brain injury is not associated with sexual satisfaction in the relationship.

**H₀ 5:** Emotional distress of the person with brain injury or the spouse is not related to awareness of deficits, relationship satisfaction or sexual satisfaction.
H0 6: Burden of care for and community integration of an individual with brain injury are not related to the relationship satisfaction, sexual satisfaction or emotional distress of that individual or the spouse.

H0 7: More severe brain injuries are not related to the relationship satisfaction, sexual satisfaction or emotional distress of that individual or the spouse.

H0 8: More financial strain is not associated with the relationship satisfaction, sexual satisfaction or emotional distress of the person with brain injury or the spouse.
CHAPTER II

METHODS

Subjects

All married patients treated by the Head Injury Service at Dodd Hall, The Ohio State University Hospitals during the period 1990-1992, and their spouses were approached to participate in this study. A search of the computer database at Dodd Hall identified all patients meeting the following criteria who were discharged during 1990-1992: diagnosis of acquired brain injury; married at time of discharge. Acquired brain injury included closed head injury, open head injury, anoxia, or aneurysm. A search of the database identified 108 possible subjects who fit the requirements of this study. Surveys were mailed to all 108, with 17 surveys undeliverable. Four subjects were now divorced or separated and no longer appropriate for the study. Out of the 87 couples appropriate for the study, a total of 26 complete and usable surveys were returned for a 29.9% return rate.

Instruments

Participants completed questionnaires designed to assess awareness of deficits, marital adjustment, and residual deficits related to brain injury. Awareness of deficits was measured using the Cognitive Disability Scale (CDS), the Social Aggression Scale (SAS), and the somatization subscale of the
Trauma Complaints List (TCL). Relationship satisfaction and overall adjustment were assessed by the Relationship Assessment Scale (RAS), the Affectional Expression Subscale of the Dyadic Adjustment Scale (AE-DAS) and the Beck Depression Inventory (BDI). Cognitive and self care abilities at discharge were measured by the Functional Independence Measure (FIM) gathered from hospital records. The Community Integration Questionnaire (CIQ) was included in the survey to assess current handicap. They also responded to several questions asking for basic demographic information. Information on the severity of the individual's injury was obtained from hospital records.

**Awareness of Deficits**

An individual’s awareness of deficits was assessed by comparing the differences between the rating of deficits by the affected individual and spouse on the CDS, SAS and TCL. If the brain-injured individual views him/herself as having fewer deficits than the spouse views him/her as having, that individual lacks awareness of deficits. If the affected spouse reports the same number of deficits as the unaffected spouse, he/she was aware of deficits.

**Cognitive Disability Scale** The Cognitive Disability Scale (CDS), (Linn & Willer, 1992) is an eight-item true/false scale designed to measure problem areas surrounding cognitive dysfunction in individuals who have suffered traumatic brain injury. All items ask about specific behaviors possibly affected by residual cognitive deficits from traumatic brain injury, such as trouble following directions, getting lost, decision making difficulties and memory problems. Each true response is scored a one, thus the scale range is 0-8. Both the individual with a brain injury and his/her spouse completed
this scale to describe the individual with brain injury, and a discrepancy score between their ratings was obtained by subtracting the spouse with the head injury’s score from the rating provided by the unaffected spouse. This discrepancy score was used to assess awareness of cognitive disability. No information on the reliability and validity of the CDS was available, although all items have face validity. The absence of information on the psychometric properties of this scale may not be crucial, as it was not used as a criterion measure of the individuals actual cognitive disability. (See Appendix A.)

Social Aggression Scale The Social Aggression Scale (SAS), (Linn & Willer, 1992) measures aggressive behavior, and was designed specifically for the population of individuals with brain injury. Similar to the CDS, it contains eight true/false items, but focuses on behavior problems such as frustration, verbal and physical outbursts, and obscene or threatening gestures. The same procedure was followed as the CDS to obtain a discrepancy score in order to assess the brain-injured individual’s awareness of social aggression. No information on the reliability or validity of the SAS was available, but the items have face validity. As with the CDS, the SAS was not used as a measure of the amount of social aggression, but was used to determine awareness. Thus, the absence of psychometric properties did not rule out its utility. (See Appendix B.)

Trauma Complaints List The somatization subscale of the Trauma Complaints List, or TCL, (van Zomeren and van den Berg, 1985) contains 8 items which assess the subjective somatic complaints of the individual with brain injury. A variety of complaints are measured on a Likert scale of 0-2, including intolerance of noise and light, headache, depressed mood, trouble
following conversations, and general slowness. The TCL used in this study is an English translation from the original Dutch used in Hinkleday (1987) and reported in Hinkleday and Corrigan (1990). Factor analysis revealed three main factors within the TCL: general complaints, somatization and severity. This structure seemed to conform to the variety of complaints voiced by individuals with traumatic brain injury. No other information was available on reliability or validity of the TCL, although it does have face validity. The TCL was not used as a criterion measure, as the ratings of patient and spouse were compared. (See Appendix C.)

Marital Adjustment

Relationship Assessment Scale. Both the person with brain injury and the spouse completed the Relationship Assessment Scale, or RAS (Hendrick, 1988) to measure their current overall satisfaction with the marriage. RAS scores can be reported for individuals or couples. This brief, 7-item Likert scaled inventory measures general relationship satisfaction. Items are rated on a scale of 1 to 5, with 5 indicating more satisfaction and items number 4 and 7 being reversed scored. The RAS has been shown to have a unifactorial scale structure and internal consistency, with a coefficient alpha of .86. (Hendrick, 1988) The RAS was shown to have construct validity, since it was correlated with measures of commitment, love and self-esteem. (Hendrick, 1988) In comparison to a longer and well-respected measure of relationship satisfaction, the Dyadic Adjustment Scale, the RAS was shown to have concurrent validity. It was found to be a slightly better predictor than the DAS of which couples would break up, and was just as effective in predicting which couples would stay together (Hendrick, 1988). (See Appendix D.)
Affectional Expression Subscale of Dyadic Adjustment Scale

The Dyadic Adjustment Scale or DAS (Spanier, 1976) is one of the most widely used measures of marital adjustment. However, it contains 32 items, with seven different formats, and can be complicated and time consuming. Factor analysis of the DAS revealed four subscales which can be used separately without losing reliability or validity (Spanier, 1976). The Affectional Expression Subscale of the DAS (AE-DAS) consists of two Likert-scaled items and two yes/no items, and measures satisfaction with sexual relations and expression of affection within a relationship. The AE-DAS had a Cronbach's alpha of .73, and was judged to be reliable. Criterion validity for the AE-DAS was demonstrated by a study in which all subscales of the DAS (including the AE-DAS) significantly distinguished a married and divorced sample (Spanier, 1976). The DAS was highly correlated (.86) with another measure of marital adjustment and measures of communication and commitment to a relationship (Spanier, 1976). (See Appendix E.)

Beck Depression Inventory. Each member of the couple completed the Beck Depression Inventory, or BDI (Beck, Rush, Shaw & Emery, 1979). Depression has been found to be a moderator of marital adjustment (Gotlib & Hooley, 1988), and was measured to assess its impact on the couple. One of the most popular and widely used measures of depression, the BDI has 21, four-alternative multiple choice format items. Scores can range from 0-63, with a score of less than 10 indicating no or minimal depression, from 10-18 indicating mild to moderate depression, from 19-29 indicating moderate to severe depression and from 30-63 indicating severe depression (Beck, Steer and Garbin, 1988). According to the DSM-III R (American Psychiatric
Association, 1987), mild depression results in minor social or occupational impairments, while severe depression leads to almost total impairment in these areas, with moderate depression falling in between. Beck, Steer and Garbin (1988) reviewed the psychometric properties of the BDI in 25 years worth of studies. Internal consistency in both psychiatric and non-psychiatric samples ranges from .80-90. Test-retest reliability in non-psychiatric samples ranges from .60 to .70. Concurrent validity with other measures of depression is good (Berndt, 1990). Construct validity has been found with variables from sleep difficulties to suicidal behaviors. It has been found useful as a screening measure of depression (Berndt, 1990). (See Appendix F for sample questions.)

**Assessment of Residual Deficits**

**Functional Independence Measure.** At discharge, all patients with brain injury are rated on the Functional Independence Measure (FIM) (Research Foundation, SUNY-Buffalo, 1990). The FIM includes measures of cognitive (social interaction, problem solving, memory), and functional (self care, eating, locomotion) deficits, and is designed to reflect the burden of care of an individual on others. Therefore, the FIM communicates the cost of a disability in both economic and social spheres. Ratings on each item in the FIM range from 1 (complete dependence) to 7 (complete independence). Interrater reliability at admission was found to be .86, and at discharge was .88. Granger, Hamilton, Keith, Zielezny and Sherwin (1986) found the FIM was more precise than other measures of functioning. They reported a group of expert clinicians found it to have content validity. Predictive validity was evident in the FIM’s significant negative correlation with “help in minutes”
required by a sample of individuals with multiple sclerosis (Granger, Cotter, Hamilton, Fiedler & Hens, 1990). (See Appendix G.)

Community Integration Questionnaire. Current handicap was detected by the Community Integration Questionnaire (CIQ; Willer, Linn & Allen, in press) which measures an individual's integration into home and community, and was developed specifically for persons with traumatic brain injury. It contains 15 questions which ask about specific behaviors at home, at work and in social environments. Overall scores range from 0 to 29, with higher scores indicating more integration. The coefficient alpha of the overall CIQ was .76 for the pilot study (Willer, Linn & Allen, in press). A principal components analysis of the pilot study data yielded three factors. The Home Integration factor consists of items which assess domestic activities. The Social Integration factor contains items which measure shopping, visiting friends and participating in leisure activities. Productivity, the third factor, consists of items involved with work, school and volunteer activities. Coefficient alphas for the Home and Social subscales were .84 and .73 respectively. The coefficient alpha for the Productivity subscale was low (.35) possibly due to the small number of items (only 2) in the factor (Willer, Linn & Allen, in press). The unaffected spouse completed the CIQ as applied to the person with brain injury. (See Appendix H.)

Assessment of Severity of Injury

Information was gathered from hospital records regarding the date and severity of the brain injury. Severity of injury was assessed by determining the length of time from injury to rehabilitation admission. Jennett (1976) noted that, in general, the longer the hospital stay between injury and
admission to a rehabilitation hospital or other treatment facility, the greater the severity of the head injury. Length of the acute-care hospital stay is indicative of the length of coma and of any possible medical complications which may inhibit recovery. Clinical experience also indicates the longer the period of time between injury and rehabilitation, the poorer the outcome.

Demographic Information

The unaffected spouse was asked to answer basic demographic questions concerning information to be used in data analysis. This information included their ages, past and present marital history (e.g. prior marriages, separations), number and ages of children, and years married to the current spouse. They were also asked to estimate their yearly family income prior to the injury, and currently. (See Appendix I.)

Both partners also were questioned about their current alcohol use. They completed a written version of the CAGE questionnaire, developed by Ewing and Rouse, and reported in Ewing (1984). The CAGE questions are efficient and easy to administer clinical interview questions which assess alcohol use. The questions ask about Cutting down, Annoyance by criticism, Guilt, and Eye openers, all important areas to assess in screening for an alcohol problem, and thus the acronym CAGE (Ewing, 1984). Suspicion of alcoholism exists with positive responses to two or more of the four questions. The CAGE questions differentiated between those who were in an alcoholism treatment program, and those who were hospitalized and were non-drinkers. It also identified those in the treatment program who denied alcoholism or just described themselves as heavy drinkers (Ewing, 1984). (See Appendix J.)
Procedures

All patients who met the requirements, (i.e. had a primary diagnosis of brain injury, and were married at the time of discharge) were contacted to participate in this study. They and their spouses were sent a packet including a letter of introduction (See Appendix K.), color coded surveys clearly marked for each person, and a stamped return envelope. Two couples who attended regular follow-up visits to the Head Injury Diagnostic Clinic at Dodd Hall were approached to participate in this study during their visit to Dodd during regular clinic hours. These individuals were given the introduction letter and surveys to take home and return. Completion of the surveys was taken as consent to participate. To ensure collection of data from as many couples as possible, surveys were identified by number and a follow-up postcard (See Appendix L.) and another set of questionnaires was mailed to those who did not return surveys initially. Although responses were not anonymous, they were strictly confidential. Follow up phone calls were made after sending the second survey to approximately 50 couples to encourage survey return. (See Appendix M.)

The couple was asked to complete the surveys separately to avoid any influence or bias. The individual with brain injury completed the SAS, CDS, and TCL as applied to him/herself, while the spouse reported on his/her perceptions of the injured spouse in these three measures. The unaffected spouse also completed the CIQ as applied to the person with brain injury, and the demographic questionnaire. In some cases, the injured person had difficulty completing the survey due to cognitive or physical deficits. At these times, another party besides the spouse was asked to assist him or her. The
importance of completing the surveys separately was stressed. (See cover letter in Appendix K.)
CHAPTER III

RESULTS

Survey results and the information from hospital records were coded and data was analyzed using SYSTAT-5 (Wilkinson, 1989) for the Macintosh. Independent samples t-tests were used to examine the differences between those who returned surveys and those who did not on hospital data. Paired sample t-tests and Pearson product moment correlations were used to test all hypotheses. Multiple regression analyses were conducted to examine whether awareness of deficits and other independent variables predicted relationship satisfaction. Due to the low number of couples included in this study, all stated results should be interpreted with caution, and may best be viewed as exploratory in nature.

In this section, the demographics of the sample will be reported, followed by a comparison of this sample to the population from which it was drawn. Next, the results of hypothesis testing on the awareness and relationship satisfaction variables will be presented. Following this, the emotional distress, residual deficits, severity and financial strain variables will be explored and hypotheses related to them will be reported.

Demographics

Twenty-six couples returned completed, usable surveys. The age of
respondents ranged from 22 to 66 years old, while the average age of the person with brain injury was 41.8, and the mean age of the spouse was 40.9 years. In six of the couples, the person with brain injury was female, while in 20 couples the person with brain injury was male. The couples had been married an average of 16 years, with a range of 1 to 42 years. On average, they had 1.7 children. Yearly family income averaged $47,900 before the injury, and $29,600 after the injury, reflecting a mean decline of $18,300 in yearly family income. Four individuals with brain injury and two spouses (from different couples) answered yes to all four CAGE questions, but all noted on the survey that they no longer drank and this applied only to past drinking behavior.

The amount of time since injury varied from 6 months to 34 months, with an average of 23.4 months. Length of stay in the rehabilitation hospital for the person with brain injury varied from 5 to 90 days, with a mean of 44.6 days. Length of time from injury to admission to rehabilitation ranged from 6 to 212 days in this sample, with an average onset to admission of 45.8 days (see Table 1).

**Comparison of Sample to Hospital Population**

Information was obtained from hospital records of those who did not return surveys. These data included age at time of injury and gender of person with brain injury, length of stay in rehabilitation, onset to admission, admission and discharge FIMs and length of time since injury. To assess the representativeness of this sample, this information was compared on the same variables to those who returned surveys. Independent samples t-tests with pooled variances were performed with returned/not returned as the
Table 1

Means, Standard Deviations and Results of T-Tests for Hospital Data by Returned Survey or Did Not Return Survey Groups

<table>
<thead>
<tr>
<th></th>
<th>Returned (n=26)</th>
<th>Not Returned (n=57)</th>
<th>t*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
<td>Mean</td>
</tr>
<tr>
<td>Age</td>
<td>39.92</td>
<td>12.48</td>
<td>44.33</td>
</tr>
<tr>
<td>Gender **</td>
<td>0.23</td>
<td>0.43</td>
<td>0.19</td>
</tr>
<tr>
<td>Length of Stay</td>
<td>44.19</td>
<td>24.13</td>
<td>40.26</td>
</tr>
<tr>
<td>Onset to Admission</td>
<td>44.57</td>
<td>46.97</td>
<td>59.37</td>
</tr>
<tr>
<td>Admission FIM</td>
<td>59.04</td>
<td>21.35</td>
<td>60.58</td>
</tr>
<tr>
<td>Discharge FIM</td>
<td>104.42</td>
<td>19.58</td>
<td>94.54</td>
</tr>
<tr>
<td>Time Since Injury</td>
<td>22.85</td>
<td>9.10</td>
<td>22.79</td>
</tr>
</tbody>
</table>

*none significant at .05 level
**(male=0, female=1)
grouping variable. While group means on some variables differed, none of the differences between the two groups were statistically significant, (see Table 1). Thus, based on these criterion, this sample appears to be representative of married individuals with brain injury seen at Dodd Hall from 1990-1992.

Awareness of Deficits and Relationship Satisfaction

Awareness of Deficits

Ratings by the spouse and the individual with brain injury were compared and a difference score was calculated on each awareness measure, resulting in a rating of awareness on the Cognitive Disability Scale (CDS), Social Aggression Scale (SAS) and Trauma Complaints List (TCL) for each person with brain injury. Scores on the CDS and SAS could range from -8.00 to +8.00, and scores on the TCL could range from -16.00 to +16.00. A higher negative score indicates the person with injury feels they have more problems in an area than their spouse believes they have, while a higher positive score indicates the person with brain injury is unaware of their difficulties. A score closer to 0 indicates good awareness of problems in an area.

On the CDS, which measured awareness of cognitive dysfunction, scores ranged from -4.00 to 8.00, with a mean of 1.38. The SAS, which measured behavioral problems, had less variation and a lower mean (range of -3.00 to 4.00, mean of 0.46). Scores on the somatization subscale of the TCL showed greater range and a higher mean because they were scored on a 0-2 Likert Scale. They varied from -8.00 to 9.00, with a mean of 2.00. See Table 2 for a listing of means and standard deviations of awareness measures.
Table 2

Means and Standard Deviations of Awareness of Deficits Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean</th>
<th>S.D.</th>
</tr>
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<tbody>
<tr>
<td>Cognitive Disability Scale (CDS)</td>
<td>1.38</td>
<td>2.64</td>
</tr>
<tr>
<td>Social Aggression Scale (SAS)</td>
<td>0.46</td>
<td>1.82</td>
</tr>
<tr>
<td>Trauma Complaints List (TCL)</td>
<td>2.00</td>
<td>4.28</td>
</tr>
</tbody>
</table>
Gender differences were found on the Trauma Complaints List, but not on the Cognitive Disability Scale or Social Aggression Scale. Independent samples t-tests with gender as a group variable showed men had higher scores on the TCL, with group means of 2.90 for men and -1.00 for women (t=2.08, p=.048, n=26). This would suggest that men and women were equally aware of cognitive dysfunction and aggressive behavior, while men were less aware of somatic complaints.

Paired sample t-tests were conducted to test hypothesis H0 1, that unawareness of deficits is global or not significantly different for cognitive, behavioral or physical awareness. T-tests showed statistically significant differences for the CDS and SAS (t= 2.098, p=.046, n=26), and the SAS and TCL (t=2.198, p=.037, n=26) for this sample. However, the CDS and TCL are not significantly different (t=.846, p=.406, n=26). This finding suggests that group means for awareness of cognitive dysfunction and social aggression, and social aggression and somatic complaints are significantly different. However, awareness of cognitive dysfunction and somatic complaints are not significantly different. Thus, hypothesis H0 1 is partially rejected.

Pearson correlations were calculated for all three measures to assess their relationship. All were significantly positively correlated, p<.01, (see Table 3). Thus, when an individual lacked awareness in one area, he/she tended to lack awareness in the other areas. Again, these findings may partially support the rejection of hypothesis H0 1 and indicate awareness of deficits is somewhat multimodal, but that different types of awareness are moderately related.
Table 3

Results of Pearson Correlations of Awareness of Deficits Measures

<table>
<thead>
<tr>
<th></th>
<th>CDS</th>
<th>SAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>SAS</td>
<td>0.562 * *</td>
<td></td>
</tr>
<tr>
<td>TCL</td>
<td>0.510 * *</td>
<td>0.570 * *</td>
</tr>
</tbody>
</table>

n=26, **p<.01
Relationship Satisfaction

Both spouses completed the Relationship Assessment Scale (RAS) and the Affectional Expression Subscale of the DAS (AE-DAS). The RAS score for an individual can range from 0 to 35, with higher scores associated with higher relationship satisfaction. AE-DAS scores can range from 0 to 12, with higher scores indicating more satisfaction with the sexual and affectional relationship.

Table 4 presents means and standard deviations for scores of individuals with brain injury and their spouses on the RAS and AE-DAS. On the RAS, the mean scores of both spouse and person with injury are lower than the mean score of persons in committed relationships sampled by Hendrick (1988) when developing the measure. In that study, the average relationship satisfaction score was 29.14 with a standard deviation of 6.41. Spanier (1976) reported the mean of a sample of happily married individuals on the AE-DAS was 9.0 with a standard deviation of 2.3, while those who were divorced had an average score on the AE-DAS of 5.1 with a standard deviation of 2.8. Table 4 shows that the average sexual satisfaction score of the person with injury is closer to the score of those happily married, while the average score of the spouse is similar to the group of divorced persons. Thus, on both measures, it appears relationship and sexual satisfaction for spouses was lower than the person with injury, and lower than a non-affected population, and that the sexual satisfaction of spouses is similar to persons who have left a relationship. As Table 4 indicates, means of spouses are lower on both measures.
Table 4

Means, Standard Deviations, and Results of T-Tests for Relationship Satisfaction Measures for both Person with Injury and Spouse

<table>
<thead>
<tr>
<th></th>
<th>Person with Injury (n=26)</th>
<th>Spouse (n=26)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>RAS</td>
<td>27.23</td>
<td>6.95</td>
</tr>
<tr>
<td>AE-DAS</td>
<td>8.35</td>
<td>3.48</td>
</tr>
</tbody>
</table>

**p<.01
Paired sample t-tests were performed to test hypothesis H0 2, that relationship and sexual satisfaction of the person with brain injury are not significantly different from the spouse. Both t-tests were statistically significant, and are listed in Table 4. Thus, hypothesis H0 2 was rejected, as spouses' were less satisfied with their overall relationships and sexual relationships than the individuals with brain injury.

Pearson correlations were calculated to assess the intercorrelation among the different relationship measures (see Table 5). All measures were highly positively correlated with each other. Thus, satisfaction with the relationship overall is associated with satisfaction with the sexual/affectional relationship, and satisfaction of the person with the injury and the spouse tend to vary together.

Relationship Between Awareness of Deficits and Relationship Satisfaction

Pearson correlations and probabilities were calculated to test hypotheses H0 3 and H0 4: that unawareness of deficits in an individual with brain injury is not associated with overall relationship satisfaction, or with sexual satisfaction. These correlations assessed the relationship between the awareness measures (CDS, SAS and TCL) and relationship satisfaction measures (RAS and AE-DAS). Table 6 shows the correlation matrix and probabilities. None of the correlations are statistically significant, and the absolute values of the correlation coefficients are low (ranging from .017 to .291). Thus, hypotheses H0 3 and H0 4 cannot be rejected. These findings suggest that unawareness of deficits has little effect on relationship satisfaction.
Table 5

Results of Pearson Correlations of Relationship Satisfaction Measures for Person with Injury (pwi) and Spouse (s)

<table>
<thead>
<tr>
<th></th>
<th>RAS-s</th>
<th>RAS-pwi</th>
<th>AE-DAS-s</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAS-pwi</td>
<td>0.614 ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AE-DAS-s</td>
<td>0.691 ***</td>
<td>0.504 **</td>
<td></td>
</tr>
<tr>
<td>AE-DAS-pwi</td>
<td>0.582 ***</td>
<td>0.772 ***</td>
<td>0.647 ***</td>
</tr>
</tbody>
</table>

n=26, **p<.01, ***p<.001
Table 6

Results of Pearson Correlations of Relationship Measures and Awareness Measures

<table>
<thead>
<tr>
<th></th>
<th>CDS</th>
<th>SAS</th>
<th>TCL</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAS-s</td>
<td>-0.107</td>
<td>-0.110</td>
<td>-0.204</td>
</tr>
<tr>
<td>RAS-pwi</td>
<td>0.165</td>
<td>0.077</td>
<td>0.291</td>
</tr>
<tr>
<td>AE-DAS-s</td>
<td>-0.157</td>
<td>-0.100</td>
<td>0.107</td>
</tr>
<tr>
<td>AE-DAS-pwi</td>
<td>0.048</td>
<td>-0.005</td>
<td>0.196</td>
</tr>
</tbody>
</table>

n=26, none significant <.05
As a multivariate test of the relationships between relationship satisfaction and the independent variables in this study, two multiple regressions were conducted, one each to predict overall relationship satisfaction and sexual relationship satisfaction. For these analyses, the RAS and AE-DAS scores of the person with injury and the spouse were summed to make the dependent variables. Because of the small sample size, only those variables directly theorized to have an effect on relationship satisfaction were included in the equations (awareness of deficits measures, depression measures and the number of years married).

Table 7 illustrates the results of these two analyses. In equation 1, with the total RAS score for each couple as the dependent variable, the Adjusted \( R^2 \) was not statistically significant, nor were the regression coefficients of any of the awareness of deficits variables (i.e. the CDS, SAS, and TCL) significant. In this equation, the Beck Depression Inventory (BDI) score for the person with brain injury had a significant negative coefficient. These results indicate that the independent variables in this equation did not account for a significant amount of the variance in overall relationship satisfaction. Of the variance explained, a significant amount was accounted for by the amount of depression in the person with brain injury; the more depressed that individual, the lower the overall marital satisfaction.

The total AE-DAS score for each couple was the dependent variable in equation 2. As shown in Table 7, the Adjusted \( R^2 \) of this equation was statistically significant at the .01 level. However, only one of the awareness variables, the TCL, accounted for a significant amount of this variance. Much of the variance was explained by the Beck Depression Inventory (BDI) score of
Table 7

Results of Multiple Regression Equations Predicting Relationship Satisfaction from Awareness of Deficits, Depression of Person with Injury (pwi) and Spouse (s), and Years Married

**Equation 1** - RAS total = dependent variable
(Adjusted $R^2 = 0.142$, $F=1.635$, df=17, $p=0.198$)

<table>
<thead>
<tr>
<th></th>
<th>Coeff.</th>
<th>St. Error</th>
<th>St. Coeff.</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>62.431</td>
<td>5.892</td>
<td>0.000</td>
<td>10.596</td>
</tr>
<tr>
<td>CDS</td>
<td>1.874</td>
<td>1.185</td>
<td>0.383</td>
<td>1.581</td>
</tr>
<tr>
<td>SAS</td>
<td>-3.237</td>
<td>2.078</td>
<td>-0.464</td>
<td>-1.558</td>
</tr>
<tr>
<td>TCL</td>
<td>1.148</td>
<td>0.773</td>
<td>0.364</td>
<td>1.485</td>
</tr>
<tr>
<td>BDI-s</td>
<td>-0.288</td>
<td>0.458</td>
<td>-0.167</td>
<td>-0.629</td>
</tr>
<tr>
<td>BDI-pwi</td>
<td>-0.868</td>
<td>0.378</td>
<td>-0.562</td>
<td>-2.294*</td>
</tr>
<tr>
<td>Yrs. Married</td>
<td>-0.064</td>
<td>0.215</td>
<td>-0.061</td>
<td>-0.299</td>
</tr>
</tbody>
</table>

**Equation 2** - AE-DAS total = dependent variable
(Adjusted $R^2 = 0.464$, $F=4.314$, df=17, $p=0.008$)

<table>
<thead>
<tr>
<th></th>
<th>Coeff.</th>
<th>St. Error</th>
<th>St. Coeff.</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>24.300</td>
<td>2.534</td>
<td>0.000</td>
<td>9.589</td>
</tr>
<tr>
<td>CDS</td>
<td>0.999</td>
<td>0.510</td>
<td>0.376</td>
<td>1.959</td>
</tr>
<tr>
<td>SAS</td>
<td>-1.360</td>
<td>0.894</td>
<td>-0.358</td>
<td>-1.522</td>
</tr>
<tr>
<td>TCL</td>
<td>0.730</td>
<td>0.332</td>
<td>0.425</td>
<td>2.197*</td>
</tr>
<tr>
<td>BDI-s</td>
<td>-0.360</td>
<td>0.197</td>
<td>-0.383</td>
<td>-1.825</td>
</tr>
<tr>
<td>BDI-pwi</td>
<td>-0.427</td>
<td>0.163</td>
<td>-0.508</td>
<td>-2.622*</td>
</tr>
<tr>
<td>Yrs. Married</td>
<td>-0.215</td>
<td>0.093</td>
<td>-0.373</td>
<td>-2.324*</td>
</tr>
</tbody>
</table>

n=24, *p(2 tail)<.05
the person with brain injury and the number of years the couple had been married. These results indicate that sexual satisfaction of the couple can be predicted by the level of depression of the person with brain injury, the number of years they have been married and the level of awareness of somatic complaints. It appears that the more depressed the individual with brain injury and longer the marriage the lower the level of sexual satisfaction, while the higher the unawareness of somatic complaints the higher the sexual satisfaction.

Taken together, the multiple regression equations indicate that awareness of deficits does not have a significant effect on relationship satisfaction, and that variables such as emotional distress and length of the marriage may be better predictors. Although awareness of somatic complaints did significantly predict sexual satisfaction, it was not in the direction that would have been predicted by the literature (i.e. unawareness of deficits did not lower sexual satisfaction.) Thus, these results lend further support to the conclusion that hypotheses H0 3 and H0 4 cannot be rejected.

Emotional Distress

Both members of the couple completed the Beck Depression Inventory, a measure of depression which gives a possible score of 0 to 63, with higher scores indicating more depression. The BDI from two subjects with brain injury were unusable (they skipped pages), and these were treated as missing data in analyses. While the DSM-III R (1987) notes there is always some social or occupational impairment with symptoms of depression, mild or moderate depression would result in significant but minor impairments in work or social activities and relationships. Beck and Beamesderfer (1974)
noted that setting cut-off scores for measuring depression depends on the individual situation. However, they stated that among medical or non-psychiatric patients a cutoff score of 10 indicates some depression which should be given further attention.

For the group of individuals with brain injury, BDI scores ranged from 2 to 28, with a mean of 12.3, indicating that as a group they were mildly to moderately depressed, with associated minor impairments in social or occupational functioning. For the spouses, BDI scores ranged from 0 to 24, with a mean of 9.65. As measured by the BDI, the spouses did not report significant levels of depression. Cutoff scores would indicate spouses as a group were minimally depressed, and had little or no impairment in social or occupational functioning. A paired sample t-test was run to test for a difference between the two groups, and was not statistically significant (t=-1.591, p=.125, n=24). Thus, spouses were not more or less depressed than persons with brain injury. Although this sample included individuals who were not depressed to those who were moderately to severely depressed, on average this sample was minimally to moderately depressed.

To test hypothesis H0 5, that emotional distress of the person with brain injury or the spouse is not related to awareness of deficits, relationship satisfaction or sexual satisfaction, Pearson correlation coefficients were calculated between the BDI scores of the spouse and person with injury, and the three measures of awareness (see Table 8). Statistically significant positive correlations were obtained for the BDI of the spouse with the CDS, SAS and TCL. None of these correlations was significant for the BDI of the person with injury. This finding suggests that the more unawareness in the person
Table 8

Results of Pearson Correlations of Beck Depression Inventory Scores for Person with Injury (pwi) and Spouse (s) with Awareness Measures and Relationship Satisfaction Measures

<table>
<thead>
<tr>
<th></th>
<th>BDI-s</th>
<th>BDI-pwi</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDS</td>
<td>0.442 *</td>
<td>0.169</td>
</tr>
<tr>
<td>SAS</td>
<td>0.461 *</td>
<td>-0.272</td>
</tr>
<tr>
<td>TCL</td>
<td>0.493 *</td>
<td>0.128</td>
</tr>
<tr>
<td>RAS-s</td>
<td>-0.412 *</td>
<td>-0.540 **</td>
</tr>
<tr>
<td>RAS-pwi</td>
<td>-0.047</td>
<td>-0.245</td>
</tr>
<tr>
<td>AE-DAS-s</td>
<td>-0.417 *</td>
<td>-0.474 *</td>
</tr>
<tr>
<td>AE-DAS-pwi</td>
<td>-0.266</td>
<td>-0.346</td>
</tr>
</tbody>
</table>

n=26 for BDI-s
# n=24 for BDI-pwi
*p<.05, **p<.01
with injury, the higher the level of depression in the spouse. However, the level of unawareness was not related to depression in the person with brain injury. This suggests hypothesis H0 5 can be partially rejected, since emotional distress of the spouse does appear to be related to level of unawareness in the person with injury.

Hypothesis H0 5 was further tested by examining the Pearson correlations between BDI scores and the relationship measures. Table 8 shows the correlation coefficients of the BDI for spouse and person with injury, and the RAS and AE-DAS results for both. BDI scores for both spouse and person with injury are significantly negatively correlated with the RAS and AE-DAS scores of the spouse only. These results lend further support to the rejection of hypothesis H0 5, since level of depression in both the spouse and the person with injury tends to covary with the relationship and sexual satisfaction for the spouse. The more depressed both members, the less satisfied the spouse.

Residual Deficits

The burden of care of an individual after rehabilitation was measured by the Functional Independence Measure (FIM) score at time of discharge. The discharge FIM can range from 7 to 126, with higher scores indicating less burden of care. Discharge FIM scores for this sample ranged from 59 to 122, with an average of 104.4. Granger and Hamilton (1993), in the Annual Report of the Uniform Data System for 1991, stated the mean FIM total for all patients with traumatic brain dysfunction was 96.6, thus this sample may have had a lower burden of care than most brain injured persons. No
significant gender differences were found on the discharge FIM, based on an independent samples t-test ($t=.719, p=.479, n=26$).

The spouse completed the Community Integration Questionnaire, which measures integration into home and community for persons with brain injury. Overall scores can range from 0 to 29, with higher scores indicating better integration. In this sample, CIQ scores ranged from 0 to 23, with an average of 11.8. An independent sample t-test revealed a significant gender difference on the CIQ, with women having a mean score of 16.00 compared to the men’s average of 10.55 ($t=2.262, p=.03, n=26$).

Pearson correlation coefficients were calculated to test hypothesis H0 6, that burden of care for and community integration of an individual with brain injury is not related to relationship satisfaction or emotional distress of that individual or the spouse. Results of these analyses can be seen in Table 9. The discharge FIM was not significantly correlated with relationship satisfaction or emotional distress measures for either the spouse or the person with brain injury. However, discharge FIM was significantly negatively correlated with the AE-DAS score of the person with brain injury, indicating the more care required by the person with injury, the lower the sexual satisfaction of that individual. The CIQ was not significantly correlated with any measures of relationship or sexual satisfaction, however, nor was it significantly correlated with the BDI of the spouse. The CIQ was significantly negatively correlated with the BDI of the individual with brain injury suggesting that poorer community integration was related to depression in the person with brain injury.
Table 9

Results of Pearson Correlations of Residual Deficits Measures with Relationship Satisfaction and Emotional Distress Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>CIQ</th>
<th>DC FIM</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAS-s</td>
<td>0.202</td>
<td>-0.192</td>
</tr>
<tr>
<td>RAS-pwi</td>
<td>-0.223</td>
<td>-0.370</td>
</tr>
<tr>
<td>AE-DAS-s</td>
<td>-0.391</td>
<td>-0.195</td>
</tr>
<tr>
<td>AE-DAS-pwi</td>
<td>-0.071</td>
<td>-0.465 *</td>
</tr>
<tr>
<td>BDI-s</td>
<td>-0.297</td>
<td>0.071</td>
</tr>
<tr>
<td>BDI-pwi#</td>
<td>-0.592 **</td>
<td>-0.245</td>
</tr>
</tbody>
</table>

---

n=26

# n=24 for BDI-pwi

*p<.05, **p<.01

CIQ=Community Integration Questionnaire
DC FIM=Discharge Functional Independence Measure
These findings suggest that burden of care is not related to the emotional distress of either partner, nor to the relationship satisfaction of the spouse. However, sexual/affectional relationship satisfaction of the individual with brain injury tends to vary with burden of care. As burden of care increases, sexual satisfaction decreases. Community integration of the person with brain injury does not appear to be associated with the relationship satisfaction of both parties, nor the emotional distress of the spouse. The CIQ does appear to be associated with emotional distress in the person with brain injury, however. The poorer the community integration, the greater the emotional distress. Taken together, these results suggest that H0 6 can be partially rejected.

Severity

Severity of the brain injury was determined by length of time from injury to rehabilitation admission. Onset to admission (OTA) varied from 6 to 212 days for this sample, with an average of 44.5 days. No gender differences were found in OTA using an independent samples t-test (t=.463, p=.65, n=26).

Hypothesis H0 7, that severity of brain injury was not related to relationship satisfaction or emotional distress, was tested using Pearson correlation between OTA and relationship satisfaction and emotional distress measures (see Table 10). While it is interesting to note that the correlations with relationship satisfaction (RAS and AE-DAS) are in a negative direction for the spouse, and a positive direction for the person with injury, none of these correlations was significant, nor are the correlations with emotional distress. Thus, severity of injury was not found to be related to relationship
Table 10

Results of Pearson Correlations of Onset to Admission (OTA) with Relationship Satisfaction and Emotional Distress Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Correlation Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAS-s</td>
<td>-0.047</td>
</tr>
<tr>
<td>RAS-pwi</td>
<td>0.225</td>
</tr>
<tr>
<td>AE-DAS-s</td>
<td>-0.039</td>
</tr>
<tr>
<td>AE-DAS-pwi</td>
<td>0.224</td>
</tr>
<tr>
<td>BDI-s</td>
<td>0.364</td>
</tr>
<tr>
<td>BDI-pwi #</td>
<td>0.116</td>
</tr>
</tbody>
</table>

n=26
# n=24 for BDI-pwi
none significant at .05 level
satisfaction or emotional distress of the individual with brain injury or the spouse, and $H_0$ 7 cannot be rejected.

**Financial Strain**

Financial strain was believed to have an effect on relationship satisfaction ($H_0$ 8) and was measured here by subtracting estimated yearly family income before the injury from estimated yearly family income after the injury. This new figure, income change, ranged from -$150,000 to +$5,000, with an average of -$18,300. (Although -$150,000 can be viewed as an outlier, when it is deleted the mean income change is -$10,730.) Income data was omitted by six couples. Hypothesis $H_0$ 8, that financial strain is not associated with relationship satisfaction, sexual satisfaction or emotional distress of the person with brain injury or spouse, was tested using Pearson correlations. Table 11 shows that income change is not significantly correlated with any of the relationship measures or BDI for spouse or person with injury. While it should be noted that the coefficients of income change and relationship satisfaction may not be significant because of the low n, they are of moderate size and in a negative direction. However, hypothesis $H_0$ 8 cannot be rejected based on this data.
Table 11

Results of Pearson Correlations of Income Change with Relationship Satisfaction and Emotional Distress Measures

<table>
<thead>
<tr>
<th>Income Change</th>
<th>RAS-s</th>
<th>RAS-pwi</th>
<th>AE-DAS-s</th>
<th>AE-DAS-pwi</th>
<th>BDI-s</th>
<th>BDI-pwi</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAS-s</td>
<td>-0.411</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RAS-pwi</td>
<td></td>
<td>-0.372</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AE-DAS-s</td>
<td></td>
<td></td>
<td>-0.309</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AE-DAS-pwi</td>
<td></td>
<td></td>
<td></td>
<td>-0.283</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI-s</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.157</td>
<td></td>
</tr>
<tr>
<td>BDI-pwi</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.377</td>
</tr>
</tbody>
</table>

n=19, none significant at .05 level
CHAPTER IV

DISCUSSION

Summary

Due to the difficulty obtaining an ideal sample size, any interpretation of the results of this study would best be done with caution and in an exploratory manner. Because there are few studies on the topic and one purpose of the research was to identify issues for further study, the risk of Type II errors (i.e. mistakenly concluding a significant finding is insignificant) due to low power and low n was troubling. Accordingly, the critical value for the analyses was not controlled to maintain an investigation-wide .05 probability of Type I error (i.e. spuriously concluding insignificant findings are significant). Nevertheless, it is important to note that many findings in this study were statistically significant with a limited number of subjects, and that many published studies in this area have smaller than desirable n (i.e 15-31 subjects, see Panting and Merry, 1972; Rosenbaum and Najenson, 1976; Kreutzer and Zasler, 1989; Garden, Bontke and Hoffman, 1990; and Willer et al, 1991). The results of this study also appear to make an argument for further research on the effect of brain injury on the marital relationship.

In this study, the sample of individuals who returned surveys
appeared to be similar to the populations from which it was drawn in terms of age, gender, length of stay, severity of injury, burden of care in the hospital and at discharge, and length of time since the injury. Thus, they are assumed to be representative of the population of married individuals treated at Dodd Hall on the Head Injury Unit between 1990 and 1992. These results can be applied reasonably to the other individuals in this group who did not participate in the study. Information from this study, and further hypotheses drawn from it, may be applied tentatively to married individuals with moderate to severe brain injury suffered 1-3 years ago who were treated at facilities similar to Dodd Hall, an acute comprehensive rehabilitation facility.

The results of this study suggest a tentative rejection of 4 of the 8 null hypotheses. Hypothesis H₀ 1 was partially rejected, as unawareness of deficits appeared multi-modal, or different for cognitive, behavioral and physical problems, but moderately related. Data indicated spouses were significantly less satisfied than their partners with brain injury in terms of overall relationship satisfaction and sexual satisfaction, thus hypothesis H₀ 2 was rejected. The two main hypotheses (H₀ 3 and H₀ 4), that unawareness of deficits is not associated with overall relationship satisfaction or with sexual satisfaction, could not be rejected. Hypothesis H₀ 5 was partially rejected, since emotional distress of spouses was related to level of unawareness in the person with injury, and level of depression in both spouse and person with injury were related to relationship and sexual satisfaction in the spouse. Analysis of data also showed burden of care was related to sexual satisfaction of the person with brain injury, and his or her level of community integration was correlated with emotional distress, therefore H₀ 6 was
partially rejected. Hypotheses H₀ 7 and H₀ 8, that severity and financial strain, respectively, are not related to relationship satisfaction, sexual satisfaction or emotional distress, could not be rejected according to these data.

One important construct in this study was unawareness of deficits. Linn and Willer (1992) suggested that awareness of deficits was multi-modal, and the results of this study lend support to their notion. Cognitive and behavioral (as in Linn and Willer, 1992), and behavioral and somatic awarenesses were significantly different, but awareness of cognitive and somatic problems was not. In addition, the three types of awareness were moderately positively correlated. While the concept of awareness of deficits may be made up of different variables or types, data from this study suggest they are significantly related, and likely to vary together. Although it seems possible for the individual with brain injury to be unaware of deficits in one area (such as behavioral or cognitive), it may be more likely that he or she is to some degree unaware of deficits in other areas as well.

The second important area of interest in this study was the relationship and sexual satisfaction of the person with brain injury and his or her spouse. Hypothesis H₀ 2, that the relationship and sexual satisfaction of the person with brain injury and his or her spouse are not significantly different, was rejected. Spouses in this study perceived themselves to be significantly less satisfied with their overall relationships and sexual/affectional relationships. However, the relationship and sexual satisfaction for each member of the couple tended to vary together. Spouses reported less satisfaction as a group, but when a spouse was dissatisfied, the person with brain injury also tended
to be dissatisfied. Causal linkages cannot be determined based on these data, and it is unclear whether one member of the couple becomes dissatisfied first and influences the other, or if both are unhappy due to the brain injury. It may also be possible that other variables or experiences influence their perceptions of their relationship.

This study was conducted mainly to investigate the effect of unawareness of deficits in a person with brain injury on the relationship and sexual satisfaction of the individual and his or her spouse. Hypotheses H0 3 and H0 4, that unawareness of deficits is not associated with overall relationship satisfaction or with sexual satisfaction, respectively, could not be rejected. Data suggested that unawareness of deficits is not directly associated with and cannot be used to predict relationship or sexual satisfaction. The lack of a significant association could mean unawareness has no effect on the marital relationship, or unawareness could possibly influence other variables, which then effect the marital relationship (e.g. depression or community integration).

Theoretically, it was believed that unawareness of deficits would be associated with lower relationship and sexual satisfaction. The results showed little association between the two constructs, with one exception—unawareness of somatic complaints positively predicted sexual satisfaction (the more unawareness of the person with brain injury of somatic concerns, the more sexual satisfaction for the couple). While this was a statistically significant finding, it was opposite the expected direction and possibly due to chance. In addition, other variables in the study were better predictors of relationship and sexual satisfaction. One of these variables, emotional
distress, may have also been measured by the awareness of somatic complaints scale (i.e. questions on the Trauma Complaints List asked about depressed mood and general slowness), and this may account for its significance as a predictor.

Analyses related to hypotheses H0 3 and H0 4 showed that other variables, (i.e. level of depression of the person with brain injury and the number of years a couple had been married), were more predictive of relationship and sexual satisfaction than unawareness of deficits. The more depressed the person with injury, and the longer the marriage, the lower the sexual satisfaction. In addition, the more depressed the person with injury, the lower the relationship satisfaction. Level of depression of the spouse and unawareness of deficits did not contribute any explanatory power when trying to predict relationship or sexual satisfaction. This suggests that much of the couple’s perception of sexual satisfaction may stem from the emotional status of the person with brain injury, similar to the findings of Kreutzer and Zasler (1989) who found that the majority of their subjects (males with brain injury) perceived negative changes in sexual behavior, but still perceived themselves as having good overall marital relationships.

Emotional distress appears to be an important explanatory variable in this study. Hypothesis H0 5 was partially rejected, as it appeared that emotional distress of the spouse was related to unawareness of deficits in the person with brain injury, (the more unawareness, the higher the reported depression in the spouse). However, the same did not hold true for the person with injury, since their depression was not related to unawareness. While this would seem obvious, (i.e. how can an individual be depressed by
something he or she is not aware of?), it does not fit with the findings of Ranseen, Bohaska and Schmitt (1990), and Linn and Willer (1992) who found that the more awareness a person had of deficits, the more depression he or she reported, and vice versa.

Analyses related to hypothesis H0 5 also found that the level of depression in both spouse and person with brain injury varies with the relationship and sexual satisfaction of the spouse only, and not with the relationship and sexual satisfaction of the person with injury. Causality cannot be determined, thus, the more depressed both members of the couple the less satisfied the spouse, or alternatively, the less satisfied the spouse, the more depressed both members. However, in the multivariate analysis, only the level of depression of the person with brain injury was predictive of the couples' sexual satisfaction. These results suggest that the spouse's satisfaction influences or is influenced by the level of depression for both the spouse and the person with injury, but the person with injury's satisfaction is not related to either. In other words, it appears most of the variables in this study can help explain or predict the spouse's marital satisfaction, but not the person with brain injury's marital satisfaction.

While awareness of deficits and relationship satisfaction were not directly related, a third variable, emotional distress, appears to be related to them both (e.g. level of unawareness of person with brain injury was related to level of depression of the spouse, which was related to relationship satisfaction of the spouse). The importance of the perceived level of emotional distress of both members of the couple should be recognized here, since they are related to spousal satisfaction. While causality is unclear, there
do appear to be significant relationships between emotional distress, relationship/sexual satisfaction and unawareness of deficits.

It also seems likely that other factors play a role in determining the perception of marital satisfaction. Several other variables studied in this investigation may fit the part. Hypothesis H₀ 6 was partially rejected, since results indicated the level of sexual satisfaction of the person with brain injury was related to burden of care at discharge. It appears that the higher burden of care at discharge, the lower sexual satisfaction for the person with injury. Explanations for this finding could include that the injury had a negative effect on the individual's ability to function, or that changes in roles between the couple (i.e. spouse becomes more of a caretaker than partner) led to less desire from either party. In addition, spouses in this study were less satisfied with their sexual relationships, and their perceptions of emotional distress or relationship satisfaction were not related to burden of care. Taken together, these results indicate that it may be the person with injury's perception of being more dependent which is less attractive, as hypothesized by Zasler and Kreutzer (1991), and not the actual amount of care required.

Another factor which appeared to influence emotional distress was the level of community integration of the person with brain injury. The emotional distress of the person with brain injury was related to his or her community integration; these results also supported the rejection of hypothesis H₀ 6. The poorer community integration, the higher the level of depression of the individual with brain injury. Results suggest that if an individual is not as active, social or productive, he or she is more depressed. Women with brain injury in this study had better levels of integration into
the community than men, and thus appear to have been more active domestically, socially or vocationally. Interestingly, women with injury also had better awareness of somatic concerns than men. Sale, West, Sherron and Wehmen (1991), and Prigatano (1991) all noted that better awareness of problems led to better functioning in the workplace. It may be that women’s better awareness (though only on one measure) of problems enhanced their ability to function in the home, socially or at work.

Two other variables which could have affected marital satisfaction or emotional distress based on the literature were severity and financial strain. Neither hypothesis H0 7 or hypothesis H0 8 could be rejected based on these results. Severity of injury and financial strain, respectively, were not related to relationship and sexual satisfaction, or emotional distress. The lack of significant findings on hypothesis H0 7 or hypothesis H0 8 is curious, since Peters, Stambrook, Moore and Esses (1990) found that severity of injury and financial strain were related to marital problems. The lack of a relationship in this study could be due to the small number of subjects, especially in terms of financial strain. Although many couples did not report their incomes, the correlations were still of moderate size and negative direction, but not statistically significant. The amount of income lost by many couples was practically, if not statistically, significant ($150,000 and $57,000 for example). The method of measuring these variables may also have been problematic, particularly for the severity variable. While onset to admission is one way to measure severity of injury, it may not be as valid or reliable as those used in the Peters, Stambrook, Moore and Esses (1990) study (e.g. CT scans, neurological findings, Glasgow Coma Scale scores).
It is possible to develop a hypothetical model of the causal interactions among the variables in this study (see Figure 1). Based on these results, it appears that unawareness of deficits in the person with brain injury may cause more emotional distress in that individual's spouse. A higher level of emotional distress tends to be related to lower levels of relationship and sexual satisfaction (Gotlib and Hooley, 1988). In this model, a higher level of emotional distress would cause lower relationship and sexual satisfaction in the spouse. Lower marital and sexual satisfaction for the spouse may then lead to more emotional distress in the person with brain injury, and also further distress for the spouse. Gotlib and Hooley (1988) noted that marriages of depressed persons tended to contain more hostility, fewer positive interactions, more negative affect and poorer communication. Thus, when either or both partners are emotionally distressed, the marital relationship suffers, and satisfaction decreases.

Figure 1 also illustrates that the level of relationship and sexual satisfaction for the person with brain injury tends to vary with the spouse’s relationship and sexual satisfaction. It would then seem likely that the person with injury’s satisfaction with the relationship would be influenced by the spouse’s dissatisfaction. It also appears that community integration may have a negative effect on the emotional distress of the person with injury, which then could in turn influence the couples’ marital satisfaction. Burden of care was negatively related to the relationship and sexual satisfaction of the person with injury. Other factors not included in this study may play a role in this model. For instance, role changes or loss of social interactions after brain injury may affect levels of emotional distress or relationship satisfaction.
Figure 1

Hypothetical Causal Interactions of Unawareness of Deficits, Relationship and Sexual Satisfaction, and Other Variables
for both partners. Or sexual satisfaction may be influenced by problems in the relationship before the injury. The important point illustrated by this model is that, hypothetically, unawareness of cognitive, behavioral and somatic deficits, can effect marital satisfaction, even if indirectly.

Limitations

This study sampled married individuals with brain injury (closed and open head injury, anoxia, aneurysm), who had mostly moderate to severe injuries and were treated in an acute comprehensive rehabilitation facility in the past three years, and their spouses. These results are best generalized to settings and people similar to those sampled.

A serious limitation to this study was its low return rate and the resulting small number of subjects from which to generalize. Despite repeated efforts encouraging couples to return their surveys, many did not. It may be that those surveyed have little free time, as evidenced by the individuals who told the investigator over the telephone that their spouses did not have time to complete the surveys, and had too many demands placed on them already. Alternatively, the individual with brain injury could have inhibited the couple from completing surveys, especially if he or she had severe cognitive or sensorimotor deficits. Other couples may have become separated or divorced since the injury. Possible explanations for their inability to return completed surveys are myriad, all of which may have had some effect on the outcome of the study.

While those who did not return surveys appeared to be similar to those who did return surveys based on hospital data, there may have actually been some differences between the groups which influenced the results.
Their pre-injury marital relationship may have been more or less healthy, or they may have come from different socioeconomic groups. Those who returned surveys may have been more or less reintegrated into their communities, and been different in terms of their employment status or domestic responsibilities. In addition, one important limitation to the data collected was the lack of information on racial or ethnic status. The two groups may have been significantly different on this factor, leading to a possible source of bias in the results. Another limitation was that the study only obtained the perceptions of those who were married at the time of rehabilitation, thus, the results cannot be extended to couples who are not married and heterosexual. Although this is regrettable, it would have been impossible to identify same-sex or cohabiting couples based on the data bank in use at this time.

Another limitation of the study is that it used self-report data for most of the information obtained, leading to concerns that social desireability influenced responses or that the measures were transparent. The CAGE questionnaire, and the Beck Depression Inventory (BDI) are the most notable examples, since subjects may have been unwilling to admit problems with alcohol, and the BDI may be somewhat transparent and easily manipulated (Beck, Steer and Garbin, 1988). Although they were told to complete surveys alone and not to share answers, subjects may have guessed what the study was looking for, or the spouse may have assisted their injured partner to fill out his or her survey and influenced responses.

This study did not employ a control group, possibly of married couples who had suffered another type of injury (e.g. spinal cord injury) or of couples
who were not injured (e.g. married family members who were not injured).
Thus, it is difficult to say how much impact brain injury has on the marriage in general, as compared to other types of injuries or no injuries. While it seems obvious that brain injury has a significant impact, this cannot be empirically measured.

In retrospect, several measures in this study may not have been sensitive enough or appropriate to a study of this type. Specifically, the unawareness of deficits measures did not allow for a great deal of variability, leading to limitations on statistical analyses, and may not have addressed all possible areas of unawareness. While the concept of unawareness is still being defined in the literature, it is often easily seen in clinical practice. Although the measures used in this study asked about many possible instances of unawareness of deficits, it may have been helpful to include others, such as specific physical problems (e.g. sensorimotor problems, mobility, bladder or bowel control), or personality changes (e.g. loss of sexual desire or interest in activities). It would also have been helpful to have deeper, more detailed information on relationship and sexual satisfaction. However, measures that are more detailed are also significantly longer and more complex, and depth had to be sacrificed for clarity and ease of completion for the individual with brain injury. This study did not take into account the type or location of injury when conducting analyses (as did Ranseen, Bohaska and Schmitt, 1990 who found right hemisphere injured persons had more unawareness). While this has not been assessed in most studies in the literature, it may be an important explanatory variable when examining either unawareness of deficits or marital satisfaction.
One last limitation of this study concerns the methods of statistical analyses. Analyses were conducted using simple t-tests, bivariate correlations or multiple regression. While these results illuminate relationships, they make it difficult to determine causal linkages. On a related note, investigation-wide probability of Type I error was allowed to exceed .05 to reduce the probability of a Type II error. Although it was important to seek out new information and to take the risk of rejecting true null hypotheses, it should be noted that this increased the risk that some of the findings here are due to chance. Further research is needed to determine if that is so.

Notwithstanding all of the limitations described above, this study can be useful for professionals working in rehabilitation of individuals with brain injury.

Implications for Rehabilitation and Counseling

Several results of this study have implications for rehabilitation and counseling. Most importantly, it appears that rehabilitation professionals and counselors must be attentive to the needs and perceptions of both members of the couple, not just the person with brain injury or the spouse. Too often, it seems that in both research and clinical work, the needs of either the person with injury or the spouse alone are the focus of attention, and their needs as a couple are ignored. This could take the form of asking only one member of the couple for their perceptions (i.e. having the spouse speak for the person with brain injury, or having the person with injury speak for him or herself and ignoring the spouse’s input). It is also evident that the focus on the individual minimizes the effect of brain injury on the couple. The results of this study indicate rehabilitation professionals and counselors
should be attentive to, and ask directly about both the needs and perceptions of the individual, and the changes and problems for their relationship as a couple.

Counselors working with individuals with brain injury and their spouses would also benefit from addressing possible difficulties with unawareness of deficits. This study shows that unawareness is related to spousal depression, and may indirectly be related to marital satisfaction. Several other studies (Prigatano, 1991; Linn and Willer, 1992) noted unawareness has negative effects on interpersonal relationships, rehabilitation, and emotional status of patient and spouse. Thus, it is important to monitor the person with brain injury's unawareness of deficits, and the effects this may have on the spouse and their relationships, marital and otherwise. This may be difficult, however, especially if the person with brain injury is an outpatient, since unawareness is most readily seen in activities of daily living and the rehabilitation professional cannot observe him or her. Observations of the spouse or other family member become important, and should always be explored during interviews. If possible, it may be most helpful to ask separately for the perceptions of both the person with injury and the spouse regarding the same problems, so their responses can be compared and unawareness can be assessed.

Another result of this study which could be applied in counseling persons with brain injury and their spouses is that the sexual satisfaction of the couple is negatively affected in some ways by brain injury. Rehabilitation professionals need to specifically ask and address sexual relations in preparing couples for discharge from the hospital, and in follow-up counseling. Many
couples may get discouraged, or may be too embarrassed to ask or talk about their problems. In this study, the level of depression of both members of the couple was related to the spouse's sexual satisfaction, and the burden of care for the person with injury at discharge was related to his or her sexual satisfaction. If possible, counselor's should address these issues with a couple before they leave the hospital, in hopes that preparation and increased awareness will help them cope.

Although the depression levels for both partners in this study were low overall, some individuals with brain injury and their spouses reported moderate to severe levels of depression. In addition, spouses in this study were more dissatisfied than their partners with the overall and sexual relationships. Since depression may be one of the best predictors of marital dissatisfaction, the emotional distress of both partners should be consistently monitored by counselors. In this study, spouses tended to be less satisfied or more aware of their dissatisfaction. Rehabilitation professionals need to be highly attentive to this, since spouses often have a great deal of responsibility for their partner with brain injury after discharge. If the spouse is depressed and dissatisfied, he or she may not cope with or function as well in the caretaking role. Spouses would benefit from preparation for what may happen at home (i.e. education, information, trial home visits). While most rehabilitation facilities do a good job of supporting and preparing spouses before discharge, services for the spouse after the person with injury is home could most certainly be increased. Support groups for spouses, and more frequent contacts with counselors or with others who have had a partner injured would decrease the isolation some spouses feel. These resources
could also help guide spouses in coping with their partner's injury. More support for couples after rehabilitation is important because of the likely increased risk of divorce, separation or strain on relationship. Problems in the marital relationship after brain injury are not only costly to the individual, they can also be costly to society. An individual with brain injury can require costly medical, social and rehabilitative services, many of which spouses are able to perform more productively and inexpensively.

Social services for the person with brain injury and his or her spouse also appear to be important. Results of this study showed that the level of community integration of the person with injury is related to his or her level of emotional distress. Getting the person with brain injury and his or her spouse connected to either post-acute rehabilitation or vocational rehabilitation programs and resources enables the couple to return to as much of a "normal" social or family life as possible. Although this study did not find statistically significant results related to the financial strain experienced by a couple, financial changes after brain injury may still be practically significant. Many couples reported the loss of a significant percentage of their yearly income. It may be important that counselors look at the situation of each couple holistically, and be aware of things like the likelihood of financial problems. Counselors should familiarize themselves with services available in their area, and be able to connect couples with other rehabilitation professionals who can get them other services they may need.

**Directions for Further Research**

Future research could take several lessons from this study. Most importantly, the return rate of surveys and number of subjects must be
increased in order to make valid conclusions from studies in this area. While attempts to encourage subjects to return surveys were varied (reminder post cards, phone calls, second mailing of surveys), they were, on the whole, ineffective. When working with a population where individuals may not have the time or be inclined to participate in research, investigators may need to use some other kind of incentive (i.e. enter the name of those who return surveys in a lottery for a savings bond or other reward). Although other methods may affect the randomness of the sample, they would most likely increase the return rate. It also would be helpful if a method of finding out which subjects are divorced or separated could be devised, so that those couples would not be included in the sample, or their differences from those who were still married could be studied.

Another serious limitation of this study which should be rectified in future studies is the lack of data on the racial and ethnic makeup of couples. No published studies reported this variable either, which leads to questions about possible bias in the literature or in the findings. A change which might be helpful for future studies is the inclusion of different information about the brain injury, including location (e.g. CT scans, neuropsychological assessment results) and multiple measures of severity (e.g. Glasgow Coma Scale scores, length of post-traumatic amnesia, as well as onset to admission). In addition, it was difficult to determine causality from this study, mainly because it was observational and exploratory in nature, and because of the statistical analyses used. Future studies would benefit by developing more experimental designs, possibly by borrowing more from the relationship research of clinical, social and counseling psychology.
Several findings from this study deserve further attention in future research. One is the importance of the perceptions of the person with brain injury. Much of the literature on brain injury and family adjustment ignores the perspective of the person who is most affected, and this study shows that his or her input is valuable and contributes to our understanding of what happens within the marriage and family. This is especially obvious in terms of unawareness of deficits, as we must ask the person with injury what he or she is aware of in order to determine the level of unawareness and how it influences the marriage and family. Further study is warranted on the multimodal aspects of unawareness, since strong conclusions cannot be made based on these results, even though unawareness appears to be somewhat multimodal. The level of emotional distress of the person with injury and spouse appeared to be important influences on the marital relationship of individuals with brain injury, and so deserve further investigation. While this study found few significant differences between men and women with brain injury, it would seem their experiences would be divergent and may need further study.

This study points out several new directions for research. Many authors have written about the process of adjustment for families and spouses of the person with injury (c.f. Muir and Haffey, 1984; Lezak, 1986; Kay and Cavallo, 1991; Williams, 1991). Further research would help determine how families and couples adjust to brain injuries, and, more importantly, how their perceptions and needs change over time. The literature in this area would also be more complete if couples who were successful in their adjustment to brain injury were studied more in depth. These "success
stories” would be extremely helpful to those still struggling to adjust and cope with the consequences of brain injury.

Although the results of this study show a possible indirect connection between relationship satisfaction and unawareness of deficits, they are not conclusive. Future research might best examine other influences on marital and sexual satisfaction after brain injury. If unawareness as measured here does not directly affect satisfaction, what does? Though it may be depression as shown in this study, the question then becomes: what contributes to the depression? Although unawareness contributed to the spouse’s depression, there may be other variables which are as important or more important. In addition, the results of this study are inconclusive in determining what contributes to the person with injury’s depression.

This study measured depression at only one point in time. Depression or other factors in adjusting to brain injury may vary over time within the same person. Further research should explore whether factors such as emotional distress, unawareness of deficits, and relationship satisfaction do vary over time, and if so, how they vary. For instance, they may follow a linear stage model, or they may be more changeable, as in the mobile mourning or episodic loss models. To explore adjustment to brain injury, further research would ideally be prospective in nature (i.e. would have valid information on the person/couple/family before and after the injury and rehabilitation). Since this may not be feasible, it may at least need to ask for a retrospective estimation of the person’s, couple’s or family’s situation before the injury, to determine if this has changed.
Although the findings from this study were tentative, it does appear unawareness of deficits has some effect on the spouse and marital relationship of the person with brain injury. Future studies may need to use different methods to assess unawareness. Behavioral or observational assessments would be useful. It is important to continue to explore unawareness of deficits, particularly the effect it might have on other aspects of life for the person with brain injury and his or her spouse (e.g. social life, vocational life, relationships with children or other family members). Empirical knowledge of these effects can only add to the clinical and practical knowledge in the area.
APPENDIX A

Cognitive Disability Scale (CDS)
(Linn and Willer, 1992)

For Person with Injury:
Please circle the appropriate response, either yes or no, to the following questions:
1. Do you have any trouble following simple written directions? yes no
2. Do you get lost easily outside the home? yes no
3. Do you often find it difficult to make decisions? yes no
4. Do you have problems remembering important things you must do? yes no
5. Do you have any trouble following oral (verbal/spoken) directions? yes no
6. Do you have difficulty remembering events that happened during the past 24 hours? yes no
7. Do you get tired easily? yes no
8. Do you tend to repeat a behavior for no apparent reason? yes no

For Spouse:
Please circle the most appropriate response, either yes or no, to the following questions:
1. Does your spouse have any trouble following simple written directions? yes no
2. Does your spouse get lost easily outside the home? yes no
3. Does your spouse often find it difficult to make decisions? yes no
4. Does your spouse have problems remembering important things he or she must do? yes no
5. Does your spouse have any trouble following oral (verbal/spoken) directions? yes no
6. Does your spouse have difficulty remembering events that have happened during the past 24 hours? yes no
7. Does your spouse get tired easily? yes no
8. Does your spouse tend to repeat a behavior for no apparent reason? yes no
APPENDIX B

Social Aggression Scale (SAS)
(Linn and Willer, 1992)

For person with injury:
Please circle the appropriate response, either yes or no, to the following questions:
1. Do you sometimes let frustration lead to anger? yes no
2. Do you occasionally have verbal outbursts? yes no
3. Do you sometimes have physical outbursts? yes no
4. Do you sometimes use obscene gestures? yes no
5. Do you use swear words excessively? yes no
6. Do you occasionally make threatening gestures? yes no
7. Do you talk too much? yes no
8. Do you sometimes intimidate (frighten) others? yes no

For Spouse:
Please circle the most appropriate response, either yes or no, to the following questions:
1. Does your spouse sometimes let frustration lead to anger? yes no
2. Does your spouse occasionally have verbal outbursts? yes no
3. Does your spouse sometimes have physical outbursts? yes no
4. Does your spouse sometimes use obscene gestures? yes no
5. Does your spouse use swear words excessively? yes no
6. Does your spouse occasionally make threatening gestures? yes no
7. Does your spouse talk too much? yes no
8. Does your spouse sometimes intimidate (frighten) others? yes no
APPENDIX C

Somatization Subscale of Trauma Complaints List (TCL)
(van Zomeren and van den Burg, 1985)

For Person with Injury:
In the next section, you will find descriptions of symptoms that are sometimes experienced by people who have had a head injury. Please circle the number that best describes each statement as applied to you, either 0 (no does not apply), 1 (applies somewhat) or 2 (definitely applies).

1. Have more trouble now in following a conversation with several people? 0 1 2
2. Generally speaking, now do things more slowly? 0 1 2
3. Less tolerant of loud noises or racket than before the accident. 0 1 2
4. Feel more depressed or defective now than before the accident? 0 1 2
5. Bothered by dizziness more than before the accident? 0 1 2
6. Have more headaches? 0 1 2
7. Feel more indifferent now, or just don't care about things as much as before the accident? 0 1 2
8. Bothered by bright lights now more than before the accident? 0 1 2

For Spouse:
Below you will find descriptions of symptoms that are sometimes experienced by people who have had a head injury. Please circle the number that best describes each statement as applied to your spouse, either 0 (no, does not apply), 1 (applies somewhat) or 2 (definitely applies).

1. Has more trouble now in following a conversation with several people? 0 1 2
2. Generally speaking, now does things more slowly? 0 1 2
3. Less tolerant of loud noises or racket than before the accident? 0 1 2
4. Feels more depressed or defective now than before the accident? 0 1 2
5. Bothered by dizziness more than before the accident? 0 1 2
6. Has more headaches? 0 1 2
7. Feels more indifferent now, or just doesn't care about things as much before the accident? 0 1 2
8. Bothered by bright lights now more than before the accident? 0 1 2
APPENDIX D

Relationship Assessment Scale
(Hendrick, 1988)

Please rate your relationship with your spouse on the following questions. Please circle the correct response on the scale of 1 to 5, where 1 indicates not at all, and 5 means very much.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at All</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How well does your partner meet your needs?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. In general, how satisfied are you with your relationship?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. How good is your relationship compared to most?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. How often do you wish you hadn’t gotten into this relationship?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. To what extent has your relationship met your original expectations?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. How much do you love your partner?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. How many problems are there in your relationship?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
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84,
Appendix E

85,
Appendix F

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APPENDIX G

Community Integration Questionnaire
(Willer, Linn and Allen, 1991)

1. Who usually does shopping for groceries or other necessities in your household?
   ___ yourself alone
   ___ yourself and someone else
   ___ someone else

2. Who usually prepares meals in your household?
   ___ yourself alone
   ___ yourself and someone else
   ___ someone else

3. In your home, who usually does normal everyday housework?
   ___ yourself alone
   ___ yourself and someone else
   ___ someone else

4. Who usually cares for the children in your home?
   ___ yourself alone
   ___ yourself and someone else
   ___ someone else
   ___ not applicable/no children under 17 in the home.

5. Who usually plans social arrangements such as get-togethers with family and friends?
   ___ yourself alone
   ___ yourself and someone else
   ___ someone else

6. Who usually looks after your personal finances, such as banking and paying bills?
   ___ yourself alone
   ___ yourself and someone else
   ___ someone else
Community Integration Questionnaire (cont.)

How many times a month do you now usually participate in the following activities outside your home?

7. SHOPPING
   ____Never _______1-4 times _______5 or more

8. LEISURE ACTIVITIES SUCH AS MOVIES, SPORTS, RESTAURANTS...
   ____Never _______1-4 times _______5 or more

9. VISITING FRIENDS OR RELATIVES
   ____Never _______1-4 times _______5 or more

10. When you participate in leisure activities, do you usually do this alone, or with others?
    ____mostly alone
    ____mostly with friends who have head injuries
    ____mostly with family members
    ____mostly with friends who do not have head injuries
    ____with a combination of family and friends

11. Do you have a best friend with whom you confide?
    ____yes
    ____no

12. How often do you travel outside the home?
    ____almost every day
    ____almost every week
    ____seldom/never (less than once per week)

13. Please choose the answer below that best corresponds to your current (during the past month) work situation:
    ____full-time (more than 20 hours per week)
    ____part-time (less than or equal to 20 hours per week)
    ____not working, but actively looking for work
    ____not working, not looking for work
    ____not applicable, retired due to age

14. Please choose the answer below that best corresponds to your current (during the past month) school or training program situation:
    ____full-time
    ____part-time
    ____not attending school or training program

15. In the past month, how often did you engage in volunteer activities?
    ____never
    ____1-4 times
    ____5 or more
PLEASE NOTE

Copyrighted materials in this document have not been filmed at the request of the author. They are available for consultation, however, in the author's university library.

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Appendix H

University Microfilms International
APPENDIX I

Demographic Information

Please answer the following questions in the blanks provided.

How old are you? _____
How old is your spouse? _____
How long have you been married? ______

Have you been married before? ______
   If so, how many times? ______
Has your spouse been married before? ______
   If so, how many times? ______

If you have children, how many, and what are their ages?
_________________________________________________________________________
_________________________________________________________________________

What is your estimate of your yearly family income prior to your spouse’s injury? ______________
What is your estimate of your yearly family income currently? ______________

Did someone else help you or your spouse to fill out this survey? ______
   If so, what is their relationship to you or your spouse? ______
APPENDIX J

CAGE Questionnaire
(Ewing, 1984)

Please circle the correct response to the next four questions, either yes or no:

1. Have you ever felt you should cut down on drinking? yes no
2. Have people annoyed you by criticizing your drinking? yes no
3. Have you ever felt guilty about your drinking? yes no
4. Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hang over? yes no
Dear Participants,

We are conducting a study regarding the possible effects of brain injury on the marital relationship. We are collecting information from individuals who have had an acquired brain injury and their spouses to gain a better understanding of the problems they sometimes experience and how they adjust to them.

Since you have been through the experience, you are in the best position to help us in this study. Participation would require that each of you complete one of the enclosed booklets of questions. This survey asks for some general information and includes questions about problems that may have resulted from the injury. The entire questionnaire takes from **15-30 minutes** to complete. All of your responses will be kept confidential. Some of the questions may ask about sensitive information, but **ALL OF YOUR RESPONSES WILL BE KEPT CONFIDENTIAL.** Your participation is voluntary, and you are free to stop at any time.

If you would like to volunteer to share your perceptions and experience, please fill out the questionnaires and return them in the enclosed stamped envelope. **It is very important that you fill out the surveys separately, not together.** If you or your spouse need assistance in any way, please have someone else (another family member or close friend) help to answer the questions. Do not compare answers. Notice one booklet is marked to be filled out by the individual who had the injury, and the other is for the spouse.

This study can give helpful information about the experiences of people who have been injured and their spouses. Hopefully, this information will allow us to better help others in the future. If you would like further information about this research or the overall results of this survey, we would be happy to provide it.

We truly appreciate your participation in this study.

Richard K. Russell, Ph.D.  Linda C. Tipton, M.A.  John D. Corrigan, Ph.D.
Associate Professor of  Doctoral Candidate  Associate Professor of
Psychology  Ohio State University  Physical Medicine
Ohio State University  and Rehabilitation
Ohio State University

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APPENDIX L

Post Card Reminder

Dear Participants,

Your recently received a set of questionnaires asking about your experiences with brain injury. We hope to receive completed surveys from as many people as possible, so that we can better help persons who are injured and their spouses in the future. If you have not already returned your completed surveys, please take a few moments (approximately 15-30 minutes) to do so. If you have already returned them, we appreciate your time. If you need another set of surveys or have other questions, do not hesitate to contact us at (614) 293-3830.

Thank you very much.

Richard K. Russell, Ph.D.  Linda C. Tipton, M.A.  John D. Corrigan, Ph.D.  
Associate Professor of  Doctoral Candidate  Associate Professor of  
Psychology  Ohio State University  Physical Medicine  and Rehabilitation  
Ohio State University  Ohio State University
APPENDIX M

Telephone Solicitation Script

My name is Linda Tipton and I am calling from Ohio State University in regard to the letter and surveys you recently received about participating in a study about adjustment to acquired brain injury. If you have a few minutes I would like to talk to you about the study and what it involves.

First, let me state again that whether or not you participate in this study will in no way effect your ability to receive treatment from personnel at University Hospitals or Dodd Hall. Your participation is voluntary. You may decide not to participate at any time.

Participation in the study would involve filling out the brief questionnaires you received in the mail. As mentioned in the letter, the surveys are concerned with you and your spouse's adjustment and reactions. From this information, we feel we'll be able to get a better idea how acquired brain injury affects marriage and what helps in adjusting to it. Using this information, we may be able to improve services to patients and their spouses. Your name or any personal identification will not be used in any reports of the findings.

The total time to complete the surveys is usually 15-30 minutes each, depending on how quickly you work. If you need another set of surveys, we would be happy to send them.

Do you have any questions? Thank you for your time and consideration.
LIST OF REFERENCES


Panting, A., and Merry, P.H.. (1972). The long term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family. Rehabilitation, 38, 33-37.


