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UNAWARENESS OF DEFICITS: EMOTIONAL IMPLICATIONS FOR PATIENTS AND SIGNIFICANT OTHERS

DISSERTATION

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

By

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* * * * *

The Ohio State University 1998

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ABSTRACT

Fifty persons with brain injury, along with a significant other completed questionnaires designed to assess the patient's degree of unawareness, as well as the level of emotional distress that each was experiencing. Measures included the Patient Competency Rating Scale (PCRS), the Beck Anxiety Inventory (BAI) and the Beck Depression Inventory (BDI). Information regarding the patient was obtained from hospital records. Some degree of unawareness was indicated with regard to a majority of the activities of daily living assessed by the PCRS. 54.0% of patients and 38.7% of significant others reported experiencing mild or greater anxiety, while 40.0% of patients and 34.0% of significant others reported mild or greater depression. A significant positive correlation was found between the amount of time that had elapsed since the injury and unawareness. Of the measures of emotional distress (BAI, BDI), only significant others level of depression was significantly correlated with chronicity, in the negative direction. A significant negative relationship was found between unawareness and the patient's degree of emotional distress. As unawareness increased, the patient's anxiety and depression tended to decrease. Implications for counseling and future research regarding persons with brain injury and significant others in their lives are also discussed.
Dedicated to my mother, Gail, my sister, Claire, and my grandparents, Edna and Earl
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CHAPTER 1

INTRODUCTION

Damage to the integrity of the brain may result in a number of physical, cognitive, or emotional impairments (Allen, Linn, Gutierrez, & Willer, 1994; Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Thomsen, 1974). However, it is not unusual to encounter individuals who, despite being impaired due to neurological deficits, are to some extent unaware of these impairments (Anderson & Tranel, 1989; House & Hodges, 1988). Descriptions of such persons have been noted in the literature as early as the late 17th century (Prigatano & Schacter, 1991). Interest in impaired awareness, as well as research on the topic, continues to be explored in contemporary times (Anderson & Tranel, 1989; Freeland, 1996; House & Hodges, 1988; Rebmann & Hannon, 1995).

DeLuca, Tiersky, and Diamond (1996) define impaired awareness as “a deficit in a person’s capacity for self-appraisal of his or her own abilities and/or actions” (p.14). This unawareness may be the result of neurological impairment and/or psychological denial (Altman, 1996; Rebmann & Hannon, 1995; DeLuca, Tiersky, & Diamond, 1996; Weinstein, 1991). The term neurological unawareness refers to the inability to recognize
one's deficits or impairments as a result of brain damage (DeLuca, Tiersky, & Diamond, 1996). Psychological denial, while resulting in a similar presentation of unawareness, refers to the individual's unconscious psychological need to protect himself or herself from the pain of reality (i.e., one's impairments or injuries) (Altman, 1996). Despite these distinctions, both neurological unawareness and psychological denial present a similar clinical picture, and often are not mutually exclusive. To complicate matters further, these terms are often not distinguished from one another in the literature. Therefore, in the following presentation of the literature, the terms denial and unawareness will be used to describe general unawareness and psychological denial.

Unawareness has been studied in a number of populations of individuals with neurological brain damage. Anderson and Tranel (1989) assessed awareness of cognitive and motor impairments in a population of 100 individuals suffering impairments due to either cerebral infarction, dementia, or head trauma. Unawareness was defined as a discrepancy between subjects' self-reported abilities and subjects' abilities as determined by neuropsychological and neurological evaluations (taken as an objective measure of patients' abilities). Results indicated at least some level of unawareness among all three subgroups. Denial of handicap also was evidenced in a case study of a female stroke patient (House & Hodges, 1988). Despite hemiplegia, this patient denied suffering any handicap, and the denial continued to persist even after the patient was made aware of her paralysis.

Level of unawareness was evaluated in twenty-eight persons who were seriously brain injured (Fordyce & Roueche, 1986). Ratings of abilities were completed by the
individual suffering from the injury, a relative of the patient, as well as a member of the patient’s treatment staff. Results indicated that a majority of the subjects (n=17) underestimated their impairments relative to treatment staff, thereby evidencing some degree of unawareness. Also investigating unawareness in a brain injured population was Prigatano (1991) who compared patient and relative or friend ratings to determine awareness of behavioral impairment. While patients and relatives tended to agree on the patient’s ability to conduct basic self-care activities, patients tended to underestimate their social and emotional problems when compared to friends’ or relatives’ evaluations. Similar results were obtained by Prigatano, Altman, and O’Brien (1990). These researchers found that sixty-four persons with traumatic brain injury tended to underestimate their problems in emotional control and social interaction.

Unawareness of deficits appears to have important implications for rehabilitation efforts. Individuals who are unaware that they are impaired may not be able to recognize their need for rehabilitation, or may prematurely discontinue rehabilitation efforts (DeLuca, Tiersky, & Diamond, 1996). If awareness is substantially impaired, the patient may make decisions that do not coincide with the treatment staff’s recommendations, and thus may thwart therapy efforts (Harley, 1996). For example, unaware individuals may choose work activities whose requirements exceed their capabilities (Prigatano, 1991). Relationships with friends, family members, as well as treatment staff also may become strained, as they witness the patient’s failure to comply with regimens that would improve his or her impairments (Altman, 1996). Given the serious complications that unawareness
may produce, it would seem that efforts to reduce unawareness would be a primary focus of treatment.

The need for increased attention regarding assessment of awareness as it relates to rehabilitation of the patient was stated by Anderson and Tranel (1989) who called for more investigation despite some successes in the area. Indeed, it appears that researchers are answering this call, as research in this area continues to be conducted. Feedback and contingent reinforcement have been demonstrated to decrease the discrepancy between self-rating of abilities of the individual with the brain injury, and their actual abilities, thus indicating increased awareness (Rebmann & Hannon, 1995). Guidelines for necessary components to be included in the rehabilitation of persons with unawareness were provided by DeLuca, Tiersky, and Diamond (1996). These guidelines consist of the following: a) neuropsychological evaluation of the patient, b) education for the patient as well as his or her family members, and c) psychotherapy to address patients’ emotional concerns.

The need to address patients’ emotional concerns warrants further consideration. Unawareness is frequently associated with disturbances in affect (McGlynn & Schacter, 1989). Research has indicated that the patient who is more aware of his or her impairments (as indicated by agreement with relatives and treatment staff on ability ratings) evidences more distress than individuals who are unaware of their deficits (Fordyce & Roueche, 1986). Therefore, as successful rehabilitation efforts increase the patient’s awareness of his or her deficits, the level of emotional distress is likely to increase as well (Fordyce & Roueche, 1986). Support for this claim comes from findings
by DeLuca, Tiersky, and Diamond (1996) who noted that as patients gain more insight into their behaviors, anxiety and depression may appear, or be exacerbated if already present in the patient. Additionally, Lezak (1978) found that awareness of disabilities may lead to depression or fear in the patient.

The emotional state of significant others in the patient’s life also may be affected by the brain injury and unawareness. According to Kraus et al. (1984), 83% of persons with brain injury return to their homes following hospitalization and rehabilitation. Therefore, the burden of care often falls upon relatives, friends, or other caregivers. Parents and partners of persons with brain injury may experience increased stress, role change issues, and health problems resulting from the burden of supporting the individual (Leathem, Heath, & Woolley, 1996). Common responses of caregivers to brain injury include denial, anger, depression, anxiety, and isolation (Brooks, 1991; Lezak, 1978). These responses may be intensified if the patient is unable to identify or recognize his or her own impairments, or does not comply with treatment regimens (Altman, 1996). Therefore, implications of unawareness for significant persons in the patient’s life should be investigated and, if possible, addressed as part of rehabilitation efforts.

The present study attempts to assess unawareness of deficits in a population of persons with brain injury. The impact of unawareness on the emotional state of the patient as well as the emotional state of significant others in the patients’ lives also will be investigated. Finally, implications for rehabilitation efforts and suggestions for future research will be discussed.
Brain injuries most often occur among teens and young adults, most frequently affecting males between the ages of 15 and 30 (Max, MacKenzie, & Rice, 1991; Sosin, Sniezek, & Thurman, 1996). Due to recent advances in medical technology, the number of survivors of brain injury has increased (Florian & Katz, 1991). As a result of these technological advances, a greater number of young persons who have sustained a brain injury survive, and must live with various physical, cognitive, and behavioral/emotional deficits (Leathem, Heath, & Woolley, 1996). These deficits may leave the person with the brain injury requiring a significant amount of long term care and rehabilitation.

The person with the brain injury may suffer a broad range of physical disabilities. The extent of the disability is dependent upon such factors as the type of damage sustained, and the severity and location of the injury (Teasdale & Mendelow, 1984). Despite the inconveniences these physical injuries may impose on the caregiver, they do not appear to cause the degree of difficulty for caretakers as do cognitive and behavioral/emotional deficits (Brooks, 1984a; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; McLean, Dikmen, Temkin, Wyler, & Gale, 1984; Oddy, Humphrey, &
Uttley, 1978). Cognitive impairments may include deficits in learning and memory, while behavioral/emotional problems may include increased irritability, attention seeking behavior, loss of insight, and inappropriate sexual behaviors (Brooks, 1984b; van Zomeren & Saan, 1990). These deficits may leave the person with the brain injury severely altered, unable to care for himself or herself, and/or unable to return to his or her previous level of social and vocational functioning. Loss of insight, or unawareness, is a deficit that has particular implications for rehabilitation efforts, as well as for the patient’s emotional functioning.

Unawareness

Descriptions of individuals who lacked awareness of their impairments can be found in the literature as early as the late 1800’s. In 1896 Gabriel Anton described a syndrome, Anton’s Syndrome, in which patients suffered profound cortical blindness, yet denied any visual impairment or difficulty (Heilman, 1991). Several other types of unawareness of deficit have been described, including Wernicke’s Aphasia and denial of hemiplegia (Heilman, 1991). Wernicke’s patients, despite having problems with both language production and comprehension, denied any language difficulties, while patients denying hemiplegia were unable to recognize their inability to control their paralyzed limb. Babinski, in 1914, coined the term “anosognosia” to refer to loss of awareness of hemiplegia (Prigatano & Schacter, 1991). Since the initial introduction of this term, anosognosia has come to be used to refer to unawareness of any deficit (Kihlstrom & Tobias, 1991).
Following a decline in the discussion of unawareness of deficits in the literature, interest in the issue reemerged, and has led to the study of unawareness in a number of populations (Anderson & Tranel, 1989; Prigatano & Schacter, 1991). House and Hodges (1988) investigated unawareness in a female stroke patient, and found that despite paralysis, the patient was unable to identify any physical deficits. Levine, Calvanio, and Rinn (1991) also found similar unawareness of hemiplegia in another population of stroke patients. Unawareness of cognitive and motor impairments was evidenced among individuals suffering from either cerebral infarction, dementia, or head trauma, as determined by a discrepancy between self-reported abilities and neurological test indicators (Anderson & Tranel, 1989). One population which has garnered considerable attention in the unawareness literature is persons with brain injury.

Brain Injury and Unawareness

Unawareness has been researched in a number of populations of persons with brain injury. Allen and Ruff (1990) investigated unawareness in persons with either severe or mild-moderate brain injury. Results indicated that regardless of level of severity, subjects tended to underestimate their cognitive limitations relative to their neuropsychological test performance. Additionally, these two groups were further divided into those patients having suffered a head injury less than or equal to one year prior to evaluation, and those patients who sustained injury greater than one year prior to evaluation. Findings suggested that subjects who had a longer chronicity (greater than one year) reported more severe impairment with regard to attention, arithmetic and memory difficulties than did
patients with chronicity of less than or equal to one year (Allen & Ruff, 1990). The increased insight that appears to be positively related to length of time postinjury also was documented in a cross-sectional follow-up study of persons who had suffered a closed head injury (Godfrey, Partridge, Knight, & Bishara, 1993). Patients were divided into three groups based on amount of time since the injury had occurred: group 1= 6 months postinjury; group 2= 1 year postinjury and; group 3= 2-3 years postinjury. Patients assessed six months postinjury tended to underestimate their behavioral problems while overestimating their social skills. However, patients assessed either one year or two to three years postinjury reported more behavioral impairment. Therefore, it would appear that awareness increases as more time elapses since the injury. However, if the individual is too severely impaired, significant unawareness may still be manifested several years postinjury (Gasquoine & Gibbons, 1994).

Fleming, Strong, and Ashton (1996) have noted that the most common method used to assess unawareness of deficits is to have both patients and either relatives or treatment staff rate the patient’s functional abilities on a questionnaire. Ratings of relatives or treatment staff are taken as an objective measure of the patient’s level of functioning. Therefore, a discrepancy between the patient’s ratings and relative or treatment staff ratings is taken as an indication of unawareness. Although relatives may tend to utilize denial themselves, they do have the advantage of spending a considerable amount of time with the patient, are familiar with his or her premorbid functioning, and therefore offer a valuable perspective (Fleming, Strong, & Ashton, 1996; Prigatano &
Several researchers have assessed unawareness in persons with brain injury via this method (Fordyce & Roueche, 1986; Prigatano & Altman, 1990). Level of unawareness was evaluated in twenty-eight persons who were seriously brain injured (Fordyce & Roueche, 1986). Patients, a relative of the patient, as well as a member of the patient’s treatment staff completed assessments of the patient’s abilities. Results indicated that a majority of the subjects (n=17) evidenced some degree of unawareness. Additionally, relatives’ ratings tended to be more in agreement with those of the treatment staff. Also investigating unawareness in a brain injured population was Prigatano (1991) who compared patient and relative or friend ratings to determine awareness of behavioral impairment. Results suggested that patients tended to underestimate their social and emotional problems when compared to friends or relatives. Similar results were noted by Prigatano, Altman, and O’Brien (1990). These researchers found that sixty-four persons with traumatic brain injury tended to underestimate their problems in emotional control and social interaction.

Rehabilitation Efforts and Emotional Implications of Unawareness

Unawareness may have both beneficial as well as harmful repercussions for the patient. For example, unawareness may allow the patient to maintain self-confidence, self-esteem, and hope (Deaton, 1986). Negative aspects of unawareness may include physical injuries resulting from trying to achieve more than one is able, alienation from friends and/or family, failure to participate in rehabilitation, or premature termination (Allen & Ruff, 1990; Altman, 1996; Deaton, 1986; DeLuca, Tiersky, & Diamond, 1996).
Additionally, the patient may choose work activities whose requirements exceed his or her capabilities, or make other decisions that do not coincide with those recommended by the treatment staff (Harley, 1996; Prigatano, 1991). Despite the potential benefits of unawareness, Deaton (1986) stated that results of studies have led to the general conclusion that acknowledgment of one's impairments tends to result in a more positive outcome than does denial. Indeed, research has indicated that awareness of one's deficits leads to better treatment performance, and better rehabilitation outcomes (Deaton, 1986; Freeland, 1996; Lam, McMahon, Priddy, & Gehred-Schultz, 1988). Therefore, assessing unawareness of deficits is a critical element to include in both the planning and the execution of rehabilitation efforts (Gasquoine & Gibbons, 1994; Lam, McMahon, Priddy, & Gehred-Schultz, 1988).

Several recommendations for rehabilitation efforts to increase awareness of one's deficits can be found in the literature. DeLuca, Tiersky, and Diamond (1996) delineated general guidelines for the treatment of unawareness. These guidelines consist of the following: neuropsychological evaluation of the patient, education for his or her family members, and psychotherapy to address patients' emotional concerns. The use of concrete feedback has also been recommended (Lam, McMahon, Priddy, & Gehred-Schultz, 1988; Rebmann & Hannon, 1995). This may include the use of computers to provide feedback, videotaping the patient, supervised activities that highlight patient limitations, or group therapy wherein members may challenge one another's inaccurate perceptions (Deaton, 1986). Additionally, Deaton (1986) recommends that despite the
treatment method selected, a balance between supportive and confrontative style should be utilized, with an emphasis on specific behaviors.

Unfortunately, as awareness of one's limitations increases, emotional distress experienced by the patient also may increase (Fleming & Strong, 1995; Fordyce, Roueche, & Prigatano, 1983; Lezak & O'Brien, 1988). Malec, Machulda, and Moessner (1997) had fifty-one survivors of brain injury, significant others, and staff members rate the survivor regarding memory, executive cognitive function and depression. Survivors identified by staff members as depressed tended to show greater agreement with staff members and significant others regarding their degree of impairment than those who were rated nondepressed. Survivors who were self-identified as depressed generally overestimated their impairments relative to staff members. Nondepressed survivors tended to rate themselves as less impaired relative to treatment staff and significant other ratings. Therefore, it appears that survivors who exhibited unawareness reported a lack of depression and underestimated their level of impairment relative to significant others and treatment staff.

Unawareness and these aspects associated with it may be more prominent during certain time periods following the brain injury. Patients' level of emotional distress was examined in acute versus chronic brain injured groups (Fordyce, Roueche, & Prigatano, 1983). Acute patients were defined as those individuals examined at less than or equal to six months postinjury, while chronic patients were those examined at greater than six months postinjury. Results indicated a higher degree of emotional distress in the chronic versus the acute patient group. The authors suggest that chronic patients may have had a
longer period of time to recuperate their cognitive functioning abilities, and were therefore more capable of appreciating their deficits. A similar pattern of emotional dysfunction was noted by Fleming and Strong (1995). They identified three aspects of unawareness: unawareness of deficits; unawareness of the functional consequences of one’s deficits, and; impaired ability to set realistic goals. As awareness increases across these three domains, emotional distress may be evidenced (i.e., anxiety and depression). Additionally, it was noted that awareness often tends to increase at approximately one year following injury, as the person attempts to reintegrate himself or herself into previous vocational or social activities. Therefore, this increased awareness may also coincide with increased emotional dysfunction.

A longitudinal study of forty-two Caucasian male persons with brain injury further investigated patterns of emotional distress (Lezak & O’Brien, 1988). Subjects were placed in one of six groups depending upon the amount of time that had elapsed since their injury: 0-6 months; 7-12 months; 13-24 months; 25-36 months; 37-48 months, or; 49-60 months. Results indicated significant difficulties in temperament, emotionality, and social behaviors across all five years for one third of the subject population. Additionally, the number of subjects suffering significant difficulties with anxiety and depression evidenced an increase at approximately twelve to twenty-four months postinjury, prior to decreasing. Given that none of these subjects had participated in a rehabilitation program, recovery from emotional dysfunction may have been enhanced had proper rehabilitation efforts been utilized (Lezak & O’Brien, 1988). Given the research suggesting emotional disturbances as awareness increases, emotional disturbances may be an important focus of
rehabilitation efforts if individuals are to reintegrate themselves into former activities (Fordyce, Roueche, & Prigatano, 1983).

In addition to the patient, his or her family is often a significant contributor to rehabilitation efforts, as family members may be trained to provide appropriate feedback and support to the injured individual (Harley, 1996). However, an often overlooked aspect of this scenario is the family members’ own needs for support and their adjustment to the injury. The emotional distress of family members has been associated with the patient’s level of functioning one to four years postinjury (Lezak & O’Brien, 1988). Altman (1996) suggested that education and supportive therapy be provided to significant others in the patient’s life.

**Implications of Unawareness for Significant Others**

According to Kraus et al. (1984), 83% of persons with brain injury return to their homes following hospitalization and rehabilitation. Therefore, the burden of care often falls upon relatives, friends, or other caregivers. As mentioned previously, cognitive and behavioral/emotional deficits appear to cause the greatest degree of difficulties for significant others, and included among these cognitive deficits is unawareness (Brooks, 1984b; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; McLean, Dikmen, Temkin, Wyler, & Gale, 1984; Oddy, Humphrey, & Uttley, 1978).

Parents and partners of persons with brain injury may experience increased stress, role change issues, and health problems resulting from the burden of supporting the individual (Leathem, et al., 1996). Panting and Merry (1972) found that of thirty relatives
of persons with brain injury, 61% required some type of supportive treatment, including
sleeping tablets and tranquillizers, as a direct result of having the injured person in the
home. Common responses of caregivers to brain injury include denial, anger, depression,
anxiety, and isolation (Brooks, 1991; Lezak, 1978). In a study by Mintz, van Horn, and
Levine (1995) family members of 21 brain injury survivors were administered the Beck
Anxiety and Beck Depression inventories. Results indicated that 52% of relatives were
rated as suffering mild to moderate or greater depression, and 48% were classified as mild
to moderately anxious. Similar results were found among primary caregivers of persons
with brain injury using the Brief Symptoms Inventory. Of the 62 participants,
approximately 33% showed elevations on the Anxiety scale, and nearly 25% showed
elevations on the Depression scale. Additionally, feelings of burden and isolation were
inferred from elevations on the Paranoid Ideation and Psychoticism scales (Kreutzer,
Gervasio, & Camplair, 1994).

It appears that caregivers continue to experience stress related to caring for the
person with the brain injury well after the brain injury has occurred. Gervasio and
Kreutzer (1997) investigated the psychological distress of relatives of persons with brain
injury at 10 months to greater than 48 months post-injury. Of the 116 participants, 44%
reported clinically significant problems including, but not limited to, alienation, isolation, a
tendency to blame others for personal problems, self doubt, anxiety, and depression.
These indicators of psychological distress were present regardless of the amount of time
since the injury.
Similar results were found in a study conducted three months following the brain injury, at which time relatives continued to experience psychiatric and social disturbances (Livingston, Brooks, & Bond, 1985a). Relatives of persons with brain injury were interviewed at intervals of less than one month, six months, and twelve months following the accident. Relatives’ levels of stress was measured using the Wakefield Depression Scale and interview questions (Oddy, Humphrey, & Uttley, 1978). Results indicated that within one month following the injury 39% of relatives studied were suffering from depression. Although the level of stress had decreased by the six month follow-up, stress was still present, and continued to be reported at twelve months post injury. Similar findings were obtained by McKinlay, et al. (1981), as well as Livingston, Brooks, and Bond (1985b) who found that relatives’ stress remained constant at three, six, and twelve months post injury. Additionally, the sample of patients used by McKinlay, et al., was followed up at five years post injury, and results indicated that relatives were under significantly more strain than at one year (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986).

Given the degree of emotional distress that significant others in the patient’s life may experience, further investigation appears warranted. One factor that may contribute to this distress is the patient’s unawareness of his or her deficits. As noted by Altman (1996), relationships with friends and family members may become strained as they witness the unaware patient’s failure to comply with treatment regimens. This strain may contribute to increased anxiety and/or depression in significant others.
Problem Statement

Further investigation into the emotional ramifications of unawareness for both the patient and significant others in his or her life is necessary to enhance the planning and implementation of rehabilitation efforts. The present study attempts to assess the degree of emotional dysfunction experienced by persons with brain injury and significant others in their lives. Specifically, unawareness of deficits and amount of time since the injury (chronicity) will be examined as they relate to emotional distress.

Hypotheses

Specific hypotheses are presented in this section in the order in which they will be presented in the results section.

Hypothesis 1: The patient’s degree of unawareness will be significantly negatively correlated with the amount of time that has elapsed since the injury (i.e., as the amount of time since the injury increases, unawareness will decrease).

Hypothesis 2: Patients’ degree of emotional distress will be significantly negatively related to their level of unawareness (i.e., as unawareness increases, patients’ degree of emotional distress will decrease).

Hypothesis 3: Significant others’ emotional distress will be significantly positively correlated with the patient’s unawareness (i.e., as unawareness increases, significant others’ emotional distress will increase).
CHAPTER 3

METHODS

Participants

Subjects for this study were drawn from individuals who have had an inpatient stay, indicative of moderate to severe brain injury, at the brain injury rehabilitation center of a large Midwestern medical center. Individuals who were receiving follow-up treatment at the same facility, as well as an accompanying significant other, were approached, at the clinic, to participate in the study. Additionally, only those individuals who had ample time to complete the questionnaires during the duration of their appointment were included in the study. A total of 56 patient and significant other pairs were approached to participate in this study. Of the 56 pairs approached, five refused to participate, and one set of questionnaires was returned incomplete and unusable. Therefore, a total of 50 complete and usable questionnaires were attained, yielding an 89% completion rate. This is comparable to the number of subjects used in similar studies of persons with brain injury (Fordyce & Roueche, 1986; Lam, McMahon, Priddy, & Gehred-Schultz, 1988; Prigatano & Altman, 1990; Prigatano, Altman, & O’Brien, 1990).
Instruments

Participants were asked to complete questionnaires designed to determine the participant’s level of unawareness, and the degree of emotional distress being experienced by both the patient and the significant other. Level of impairment was assessed using the Patient Competency Rating Scale. This instrument was completed by both patients and significant others, and a comparison of ratings was used as an index of patient unawareness. Both the patient’s and the significant other’s emotional distress was measured via the Beck Depression Inventory and the Beck Anxiety Inventory. Demographic information was obtained from the patient’s medical records.

Patient Competency Rating Scale

The Patient Competency Rating Scale (PCRS) (Fordyce & Roueche, 1986) is a 30-item questionnaire designed to assess unawareness of deficits. There are two versions of the PCRS, a patient form, and a relative form. The patient’s ability to perform activities of daily living is assessed using a 5-point Likert scale with the following range: 1 = “can’t do”; 2 = “very difficult to do”; 3 = “can do with some difficulty”; 4 = “fairly easy to do”, and; 5 = “can do with ease”. Unawareness was determined by subtracting the significant other’s ratings from the patient’s ratings, with a positive score indicating unawareness (Prigatano, Altman, & O’Brien, 1986). Test-retest reliability for the PCRS has been noted at .97 for patients, and .92 for relatives (Prigatano & Altman, 1990).
**Beck Depression Inventory**

The Beck Depression Inventory (BDI) (Beck, Rush, Shaw, & Emery, 1979) is designed to detect and measure depression. Twenty-one depressive symptoms are rated on a 4-point scale. The BDI has been utilized for over twenty-five years to assess a variety of populations (Beck & Steer, 1993a). A meta analysis of six normative outpatient samples yielded reliability coefficients ranging from .79 to .90 (Beck & Steer, 1993a). Additionally, a meta analysis of nine psychiatric samples yielded internal consistency coefficients ranging from .73 to .95, and concurrent validity coefficients of .60 to .76 (Kramer & Conoley, 1992). This demonstrates high internal consistency in both clinical and nonclinical populations (Beck & Steer, 1993a). The BDI also has demonstrated stability of ratings, with test-retest correlations ranging from .48 to .86 in psychiatric populations and from .60 to .90 in nonpsychiatric populations (Beck & Steer, 1993a). Additionally, the BDI has demonstrated concurrent validity, yielding a correlation coefficient of .73 with the Hamilton Psychiatric Rating Scale for Depression (Beck, Steer, & Garbin, 1988).

**Beck Anxiety Inventory**

The Beck Anxiety Inventory (BAI) (Beck, Brown, Epstein, & Steer, 1988) is a 21-item self-report inventory designed to measure clinical anxiety. Subjects rate the degree to which they are bothered by symptoms of anxiety using the following rating scale: “not at all”; “mildly”, “moderately”, or; “severely”. Ratings are assigned a weight of 0 through 3 respectively, and summed to yield a total anxiety score. Research on the BAI has yielded
an internal consistency of .92, test-retest reliability of .75, and a correlation with the Hamilton Anxiety Rating Scale of .51 (Beck, Brown, Epstein, & Steer, 1988).

Procedures

Individuals who met criteria for participation in this study were approached while they were in the examining room between visits with physicians, nurses, and psychologists (several individuals on the treatment staff are routinely seen during one visit). Individuals were asked by the researcher whether they were willing to participate in the study (See Appendix A). The PCRS was administered first, followed by either the BAI or the BDI whose order was randomized. In the event that the patient’s disabilities were such that he or she was unable to complete the questionnaires on his or her own, the questionnaires were administered orally by the researcher (this applied to 3 patients and to one significant other).

Questionnaires were completed by the patient and significant other in an interview room. Questionnaires were coded, and code numbers were matched to a code list containing only the patient’s name. Therefore, subjects were not required to put their names on any of the questionnaires. Following the completion of the questionnaires, subjects were debriefed, and given the opportunity to address questions and concerns (See Appendix B). Additionally, subjects were offered the opportunity to receive notification of the results of the study. Notification of results was requested by 44 subject pairs. All information was stored in a locked file cabinet to which only the researcher had access.
Additionally, once data collection was completed, the list containing participant names and code numbers was destroyed.
CHAPTER 4

RESULTS

Questionnaire results and information from medical records were coded and data analyzed using the Statistical Analysis System (SAS) (1985). All hypotheses were analyzed using Pearson Correlations. Hypotheses two and three were further analyzed using an Analysis of Variance procedure.

Demographics

Completed and usable questionnaires were returned by 50 patient and significant other pairs. Persons with brain injury ranged in age from 15.7 years to 79.0 years (mean=34.8, SD=14.8), and the length of time since the injury occurred ranged from 0.2 years to 9.4 years (mean=2.0, SD=2.1). The majority of patients were male (78%, n=39), and Caucasian (90%, n=45). The primary cause of injury was moving vehicle related accidents (60%, n=30) (see Table 1), and all brain injuries were in the moderate to severe range. The most frequent relationship of the significant other to the person with the brain injury was parent (46%, n=23), followed by spouse, other, friend, sibling, grandparent and
<table>
<thead>
<tr>
<th>Reasons</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gun Shot</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Moving Vehicle Accident</td>
<td>30</td>
<td>60</td>
</tr>
<tr>
<td>Object Fell On Head</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Blow To Head From Fall</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Assault</td>
<td>7</td>
<td>14</td>
</tr>
</tbody>
</table>

Table 1: Causes of Brain Injury
in-law (see Table 2). The majority of significant others were female (78%, n=39), and reported knowing the patient very well (82%, n=41) (see Table 3).

**Items Indicative of Unawareness**

For each of the thirty items of the PCRS, significant other ratings were subtracted from patient ratings to yield a difference score. The mean difference score across subjects was calculated for each item, with a positive score indicating unawareness. These findings are presented in Table 4. Items about which patients indicated the highest degree of unawareness were their ability to drive, to handle finances, to handle arguments, to schedule daily activities, and to recognize when they have upset someone else. Items about which patient’s tended to underestimate their abilities compared to significant others were dressing themselves, starting conversations, remembering names, and controlling their laughter.

**Degree of Emotional Distress**

Scores on the Beck Anxiety Inventory range from 0 to 63. Using scoring recommendations of Beck and Steer (1993b) four levels of anxiety were determined based upon the following scoring system: (1) minimal anxiety=0-7; (2) mild anxiety=8-15; (3) moderate anxiety=16-25; and (4) severe anxiety=26-63. In the current study mean anxiety (BAI) scores were 10.27 (SD=9.00), and 7.96 (SD=9.81) for patients and significant others, respectively. Thus, patients mean score fell in the mild anxiety range, while significant others mean score placed them in the minimal anxiety range.
<table>
<thead>
<tr>
<th>Relationship</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>23</td>
<td>46</td>
</tr>
<tr>
<td>Spouse</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Sibling</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Grandparent</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Friend</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>In-law</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Other (ie., step-daughter, girlfriend, brother’s fiancee)</td>
<td>6</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 2: Significant Other’s Relationship to Person with Brain Injury
<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Know Very Well</td>
<td>41</td>
</tr>
<tr>
<td>Know Pretty Well</td>
<td>6</td>
</tr>
<tr>
<td>Know Fairly Well</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 3: Significant Other’s Familiarity with Patient
<table>
<thead>
<tr>
<th>Item</th>
<th>Number of Pairs</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparing meals</td>
<td>49</td>
<td>0.16</td>
<td>0.75</td>
</tr>
<tr>
<td>Dressing oneself</td>
<td>49</td>
<td>-0.14</td>
<td>0.65</td>
</tr>
<tr>
<td>Personal hygiene</td>
<td>50</td>
<td>0.04</td>
<td>0.73</td>
</tr>
<tr>
<td>Washing dishes</td>
<td>49</td>
<td>-0.16</td>
<td>0.92</td>
</tr>
<tr>
<td>Doing laundry</td>
<td>49</td>
<td>0.35</td>
<td>1.01</td>
</tr>
<tr>
<td>Finances</td>
<td>49</td>
<td>0.71</td>
<td>1.40</td>
</tr>
<tr>
<td>Keeping appointments</td>
<td>49</td>
<td>-0.31</td>
<td>1.37</td>
</tr>
<tr>
<td>Starting conversation</td>
<td>48</td>
<td>-0.08</td>
<td>1.07</td>
</tr>
<tr>
<td>Staying involved in activities</td>
<td>47</td>
<td>-0.40</td>
<td>1.28</td>
</tr>
<tr>
<td>Remembering what they ate last night</td>
<td>50</td>
<td>-0.10</td>
<td>0.97</td>
</tr>
<tr>
<td>Remembering names</td>
<td>50</td>
<td>-0.18</td>
<td>1.02</td>
</tr>
<tr>
<td>Remembering daily schedule</td>
<td>50</td>
<td>-0.20</td>
<td>0.97</td>
</tr>
<tr>
<td>Remembering important things</td>
<td>50</td>
<td>-0.38</td>
<td>1.23</td>
</tr>
<tr>
<td>Driving</td>
<td>47</td>
<td>0.81</td>
<td>1.39</td>
</tr>
<tr>
<td>Getting help when confused</td>
<td>48</td>
<td>-0.10</td>
<td>1.29</td>
</tr>
<tr>
<td>Adjusting to changes</td>
<td>49</td>
<td>0.43</td>
<td>1.23</td>
</tr>
<tr>
<td>Handling arguments</td>
<td>50</td>
<td>0.54</td>
<td>1.27</td>
</tr>
<tr>
<td>Accepting criticism</td>
<td>50</td>
<td>0.46</td>
<td>1.45</td>
</tr>
<tr>
<td>Controlling crying</td>
<td>49</td>
<td>-0.08</td>
<td>1.24</td>
</tr>
<tr>
<td>Acting appropriately</td>
<td>50</td>
<td>-0.30</td>
<td>0.95</td>
</tr>
<tr>
<td>Showing affection</td>
<td>49</td>
<td>-0.23</td>
<td>0.96</td>
</tr>
<tr>
<td>Participating in activities</td>
<td>49</td>
<td>-0.29</td>
<td>0.96</td>
</tr>
<tr>
<td>Recognizing upsetting someone</td>
<td>50</td>
<td>0.50</td>
<td>1.38</td>
</tr>
<tr>
<td>Scheduling activities</td>
<td>49</td>
<td>-0.53</td>
<td>1.37</td>
</tr>
<tr>
<td>Understanding instructions</td>
<td>50</td>
<td>-0.24</td>
<td>1.17</td>
</tr>
<tr>
<td>Meeting daily responsibilities</td>
<td>50</td>
<td>-0.26</td>
<td>1.16</td>
</tr>
<tr>
<td>Controlling temper</td>
<td>49</td>
<td>-0.43</td>
<td>1.21</td>
</tr>
<tr>
<td>Avoiding becoming depressed</td>
<td>49</td>
<td>-0.29</td>
<td>1.17</td>
</tr>
<tr>
<td>Keeping emotions from affecting activities</td>
<td>50</td>
<td>-0.34</td>
<td>1.21</td>
</tr>
<tr>
<td>Controlling laughter</td>
<td>50</td>
<td>-0.24</td>
<td>1.38</td>
</tr>
</tbody>
</table>

* Items expected to display unawareness (as identified by Prigatano et al.)
+ Items expected to display patient and relative agreement (as identified by Prigatano et al.)

Table 4: Degree of Unawareness by Category
Similarly, Beck Depression Inventory scores range from 0 to 63, with four levels of depression determined using scoring recommendations by Beck and Steer (1993a): (1) minimal depression = 0-9; (2) mild depression = 10-16; (3) moderate depression = 17-29; and (4) severe depression = 30-63. In this investigation mean depression scores were 10.63 (SD=9.49) for patients and 7.46 (SD=6.84) for significant others. These means place the patients in the mild depression range, and the significant others in the minimal depression range.

Therefore, sample means appears to be on the lower end of the anxiety and depression scales, however, the high standard deviations illustrate a wide spread of scores, demonstrating that several participants were classified in higher anxiety and depression categories. As shown in Table 5, 54% of patients (n=27) reported experiencing mild or greater anxiety (mean=10.3, SD=9.0), and 40.0% (n=20) reported experiencing mild or greater depression (mean=10.6, SD=9.5). Additionally, as indicated in Table 6, 38.7% of significant others (n=19) reported mild or greater anxiety (mean=8.0, SD=9.8), while 34.0% (n=17) reported mild to moderate depression (mean=7.5, SD=6.8).

**Chronicity**

A Pearson correlation was conducted to determine whether there was a relationship between unawareness and the amount of time that had elapsed since the injury. Analysis indicated a significant positive relationship (r=0.29, p=0.045), indicating that as the time since injury increased, unawareness increased. However this relationship was not in the direction predicted in Hypothesis One (see Table 7). Pearson correlations
<table>
<thead>
<tr>
<th>Degree of Anxiety</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Anxiety</td>
<td>23</td>
<td>46.0</td>
</tr>
<tr>
<td>Mild Anxiety</td>
<td>12</td>
<td>24.0</td>
</tr>
<tr>
<td>Moderate Anxiety</td>
<td>12</td>
<td>24.0</td>
</tr>
<tr>
<td>Severe Anxiety</td>
<td>3</td>
<td>6.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Degree of Depression</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Depression</td>
<td>30</td>
<td>60.0</td>
</tr>
<tr>
<td>Mild Depression</td>
<td>9</td>
<td>18.0</td>
</tr>
<tr>
<td>Moderate Depression</td>
<td>9</td>
<td>18.0</td>
</tr>
<tr>
<td>Severe Depression</td>
<td>2</td>
<td>4.0</td>
</tr>
</tbody>
</table>

Table 5: Anxiety and Depression Reported by Patients
### Degree of Anxiety

<table>
<thead>
<tr>
<th>Degree of Anxiety</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Anxiety</td>
<td>30</td>
<td>61.2</td>
</tr>
<tr>
<td>Mild Anxiety</td>
<td>11</td>
<td>22.4</td>
</tr>
<tr>
<td>Moderate Anxiety</td>
<td>3</td>
<td>6.1</td>
</tr>
<tr>
<td>Severe Anxiety</td>
<td>5</td>
<td>10.2</td>
</tr>
</tbody>
</table>

Frequency missing=1

### Degree of Depression

<table>
<thead>
<tr>
<th>Degree of Depression</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Depression</td>
<td>33</td>
<td>66.0</td>
</tr>
<tr>
<td>Mild Depression</td>
<td>11</td>
<td>22.0</td>
</tr>
<tr>
<td>Moderate Depression</td>
<td>6</td>
<td>12.0</td>
</tr>
<tr>
<td>Severe Depression</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Table 6: Anxiety and Depression Reported by Significant Others
<table>
<thead>
<tr>
<th></th>
<th>Chronicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unawareness</td>
<td>0.285*</td>
</tr>
</tbody>
</table>

n=50, *p<.05

Table 7: Results of Pearson Correlation of Unawareness with Chronicity
also were conducted to assess whether a relationship existed between chronicity and anxiety and depression of patients and significant others. As Table 8 indicates, chronicity was not found to be significantly correlated with the patient’s \( r = -0.05, p = 0.72 \) or significant other’s \( r = -0.23, p = 0.12 \) level of anxiety, nor the patient’s level of depression \( r = -0.26, p = 0.08 \). However, a significant negative relationship was found between chronicity and significant other’s level of depression \( r = -0.29, p = 0.04 \), indicating that as time since the injury increased, significant others’ level of depression decreased.

**Unawareness and Emotional Distress**

All thirty items of the PCRS were added to yield a total score. The significant other’s total score was then subtracted from his or her respective patient’s total score to yield an overall unawareness score. Pearson correlations were used to investigate whether a relationship existed between unawareness and emotional distress of patients and significant others. Results indicated a significant negative relationship between unawareness and patients’ anxiety \( r = -0.32, p = 0.02 \) and depression \( r = -0.41, p = 0.01 \); thus, as unawareness decreased, patients’ anxiety and depression tended to increase. These findings provide support for Hypothesis Two (see Table 9). Results did not indicate significant relationships between unawareness and significant other anxiety \( r = 0.09, p = 0.55 \) and depression \( r = 0.15, p = 0.30 \).

A further analysis was conducted to investigate the relationship between unawareness and emotional distress. Three scores were computed based on the differences between patient and significant other ratings on the thirty PCRS items:
### Table 8: Results of Pearson Correlations of Patient and Significant Other Anxiety and Depression with Chronicity

<table>
<thead>
<tr>
<th></th>
<th>Chronicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Patient Anxiety</td>
<td>-0.05</td>
</tr>
<tr>
<td>2 Patient Depression</td>
<td>-0.26</td>
</tr>
<tr>
<td>3 Significant Other Anxiety</td>
<td>-0.23</td>
</tr>
<tr>
<td>4 Significant Other Depression</td>
<td>-0.29*</td>
</tr>
</tbody>
</table>

^1n=49, n.s.  
^2n=46, n.s.  
^3n=50, n.s.  
^4n=50, *p<.05
<table>
<thead>
<tr>
<th></th>
<th>Unawareness</th>
</tr>
</thead>
<tbody>
<tr>
<td>^Patient Anxiety</td>
<td>-0.32*</td>
</tr>
<tr>
<td>^Patient Depression</td>
<td>-0.41**</td>
</tr>
<tr>
<td>^Significant Other Anxiety</td>
<td>0.09</td>
</tr>
<tr>
<td>^Significant Other Depression</td>
<td>0.15</td>
</tr>
</tbody>
</table>

1^n=49, *p<.05
2^n=46, **p<.005
3^n=50, n.s.
4^n=50, n.s.

Table 9: Results of Pearson Correlations of Patient and Significant Other Anxiety and Depression with Unawareness
(1) number of items in which the patient score was greater than the significant other score (reflecting patient unawareness) (2) number of items in which the patient score was equal to the significant other score (reflecting an accurate assessment) (3) number of items in which the patient score was less than the significant other score (reflecting an overestimation of limitations). Based on which score was most frequent across the thirty items, patients were classified into three groups: Group 1: patient rating was greater than significant other rating on the majority of PCRS items (unaware of limitations); Group 2: patient rating was equal to significant other rating on the majority of PCRS items (accurate assessment of limitations); Group 3: patient rating was less than significant other rating on the majority of PCRS items (overestimation of limitations) (see Table 10).

Those individuals who had equal frequencies in one or more groups were dropped from the analysis (n=1).

An Analysis of Variance procedure was conducted to assess whether the three groups differed with regard to patient and significant other anxiety and depression. Results indicated that no significant differences were found among the groups (see Table 11).
<table>
<thead>
<tr>
<th>Group</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient rating greater than significant other rating</td>
<td>20</td>
<td>40.0</td>
</tr>
<tr>
<td>Patient rating equal to significant other rating</td>
<td>21</td>
<td>42.0</td>
</tr>
<tr>
<td>Patient rating less than significant other rating</td>
<td>8</td>
<td>16.0</td>
</tr>
</tbody>
</table>

Table 10: Classification of Patients Based on PCRS Ratings
<table>
<thead>
<tr>
<th>Group 1 (P&gt;S.O.)</th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total N=20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Anxiety</td>
<td>20</td>
<td>11.50</td>
<td>8.79</td>
</tr>
<tr>
<td>Patient Depression</td>
<td>19</td>
<td>10.32</td>
<td>11.08</td>
</tr>
<tr>
<td>S.O. Anxiety</td>
<td>20</td>
<td>8.30</td>
<td>9.99</td>
</tr>
<tr>
<td>S.O. Depression</td>
<td>20</td>
<td>8.20</td>
<td>6.54</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group 2 (P=S.O.)</th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total N=21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Anxiety</td>
<td>21</td>
<td>9.81</td>
<td>8.78</td>
</tr>
<tr>
<td>Patient Depression</td>
<td>19</td>
<td>11.58</td>
<td>8.76</td>
</tr>
<tr>
<td>S.O. Anxiety</td>
<td>21</td>
<td>8.10</td>
<td>10.62</td>
</tr>
<tr>
<td>S.O. Depression</td>
<td>21</td>
<td>7.19</td>
<td>8.09</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group 3 (P&lt;S.O.)</th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total N=8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Anxiety</td>
<td>7</td>
<td>9.29</td>
<td>11.28</td>
</tr>
<tr>
<td>Patient Depression</td>
<td>7</td>
<td>9.29</td>
<td>8.40</td>
</tr>
<tr>
<td>S.O. Anxiety</td>
<td>8</td>
<td>6.63</td>
<td>8.82</td>
</tr>
<tr>
<td>S.O. Depression</td>
<td>8</td>
<td>6.88</td>
<td>4.39</td>
</tr>
</tbody>
</table>

Table 11: Mean Anxiety and Depression Scores by Group
Summary

The majority of the patient sample in this study were males, which is consistent with demographics reported in studies of similar populations (Florian & Katz, 1991; Max, et al., 1991; Sosin, et al., 1996), and Caucasian. The age of patients ranged from 15.7 years to 79.0 years (mean=34.8, SD=14.8), representing a broad range of the brain injured population with regard to age. The mean age of participants involved in other, similar studies, ranged from 29.7 years (Prigatano & Altman, 1990) to 28.0 years (Gasquoine & Gibbons, 1994) to 37.6 years (Malec, Machulda, & Moessner, 1997). Therefore, participants in this study appear to be within normal limits regarding age.

The most common cause of brain injury was moving vehicle related accidents, and all participants had sustained brain injuries in the moderate to severe range. This classification may not be representative of the typical brain injury survivor, as most brain injuries are classified as mild (Max, et al., 1991). Therefore, results of this study should be applied with this caveat in mind.
Significant others of patients were primarily female, with the most frequently reported relationship to the patient being parent. Additionally, the majority of these significant others reported knowing the patient very well.

Prigatano, Altman, and O'Brien (1990) identified ten PCRS items in which they expected unawareness to be evident, and eight items on which they expected no difference between patients and relatives ratings. Of the five items in this study on which the greatest degree of unawareness was found, four were included among the ten items identified. Similarly, all five of the items on which the least amount of difference was found between patient and significant other ratings were included among the eight items predicted to show no difference. Therefore, it appears that the current findings are consistent with what would be expected for this population.

Of the thirty items used to assess unawareness, those items with which patients seemed to be least aware of their limitations were their ability to drive, to handle their finances, to handle arguments, to schedule daily activities, and to recognize when something they have done or said has upset someone else. Therefore, it may be beneficial to work towards increasing patients' awareness of deficits in these areas, as well as in other areas in which unawareness was indicated.

Measures of emotional distress indicated that 54% of patients and 38.7% of significant others reported experiencing at least mild anxiety (BAI scores >=8). Additionally, 40.0% of the patient sample and 34.0% of the significant other sample reported mild or greater depression (BDI scores >=10). Similar studies have reported 52% of significant others experiencing mild or greater depression and 48% reporting mild
to moderate anxiety (n=21) (Mintz, vanHorn, & Levine, 1995). Reporting of patients'
emotional distress has tended to either be made by others, or by using other measures,
thereby not allowing direct comparison. Therefore, it appears that patients and significant
others may benefit from programs designed to address their emotional needs relating to
the brain injury.

The amount of time elapsed since the injury, chronicity, was found to have a
significant positive relationship with unawareness. Therefore, as more time elapsed since
the injury, unawareness appeared to increase. This finding was opposite to that predicted
in Hypothesis One (unawareness would decrease with the passing of time). This result
may be due, in part, to the fact that the injury severity of the sample ranged from moderate
to severe. Some patients may have experienced injuries so severe that they in fact have
not gained insight into their limitations, even with the passage of time.

Chronicity was not found to have a significant relationship with the level of anxiety
being experienced by patients or significant others, nor with patients’ degree of
depression. However, a significant negative relationship between chronicity and
significant others’ level of depression was noted. The direction of this relationship
suggests a tendency for significant others’ depression to decrease as time since the injury
increases.

Both the anxiety and depression measures of patients’ emotional distress were
significantly correlated with unawareness. As unawareness increased, patients’ anxiety
and depression tended to decrease. This relationship lends support to Hypothesis Two,
and is consistent with other findings suggestive of the tendency for patients who are
unaware of their deficits to experience less emotional distress than those who are able to identify their limitations (Fleming & Strong, 1995; Fordyce, Roueche, & Prigatano, 1983; Lezak & O’Bien, 1988; Malec, Machulda, & Moessner, 1997). A significant positive relationship was not observed between unawareness and significant others’ emotional distress, therefore Hypothesis Three was not supported.

Patients were classified into three groups based upon whether the majority of their self-ratings were greater than, equal to, or less than the ratings of their significant other. Analyses did not reveal any significant differences between groups with regard to emotional distress being experienced by patients and significant others. However, given the limited sample size, results of this analysis should be interpreted with caution.

Relation of Findings to Other Literature

The findings of this study were relatively consistent with findings based on similar populations found in the literature. The majority of the patient sample was male and appeared to be within normal limits regarding age. Those items which were identified as indicating the greatest amount of unawareness and those indicating the greatest accuracy of patient self-assessment were comparable to what has previously been predicted (Prigatano, Altman, & O’Brien, 1990).

Patients and significant others appeared to be experiencing anxiety and depression levels slightly lower than those attained by the norm samples; however, the large standard deviations of both groups indicate a likelihood that patients and significant others were experiencing a wide range of emotional distress.
Findings in the current study revealed a significant relationship between chronicity and unawareness; as chronicity increased, unawareness tended to increase. This finding is contrary to what would be expected. According to the literature, unawareness generally tends to decrease as chronicity increases (Allen & Ruff, 1990; Godfrey, Knight, & Bishara, 1993). However, as noted by Gasquoine and Gibbons (1994), if the patient is too severely impaired significant unawareness may persist several years following the injury.

The literature has indicated that as patients become more aware of their limitations, their emotional distress tends to increase (Fleming & Strong, 1995; Fordyce, Roueche, & Prigatano, 1983; Lezak & O’Brien, 1988). Findings from the current study were consistent with this literature, as a significant relationship was found between unawareness and patients’ emotional distress; as unawareness decreased, anxiety and depression increased. Unawareness was not found to be significantly related to significant others’ emotional distress. However, as focus on the significant other with regard to unawareness has not been frequently documented, no comparisons may be made.

Limitations

A limitation of this study is the restricted population on which the investigation was conducted. Only those individuals who had sustained a moderate to severe brain injury were approached for participation. Therefore, generalization of this study does not necessarily extend to individuals with less severe injuries. Additionally, significant others of persons with brain injury were not compared to caregivers of individuals who had sustained other types of injuries (e.g., stroke, spinal). Similarly, there were no other injury
groups investigated against which to compare persons with brain injury. Therefore, it cannot be stated with certainty that the results obtained were unique to persons with brain injury and significant others in their lives. It should also be noted that patients are only required to receive follow-up treatment at the clinic up to one year postinjury. Therefore, those individuals whose injury occurred more than one year prior and who are still receiving treatment, are doing so by choice. This self-selection factor may influence the constitution of the sample, and thereby limit the ability to generalize findings.

The measures used in this study present further possible limitations. The Beck Anxiety Inventory, used to assess patient and significant other anxiety, may be sensitive to other problems. For example, persons may experience trembling due to a physical problem unrelated to anxiety. Therefore, an instrument more refined at distinguishing symptoms may have been more effective. There were neither neurological measures nor ratings of staff members with which to assess the accuracy of patient and significant other ratings. Without these objective measures of the patient’s abilities, it cannot be stated with certainty that patients’ unawareness has been accurately measured. Additionally, no measures of social desirability were used, thus it is possible that the results obtained may have been influenced by this factor.

Additionally, due to the fact that existing databases on these patients are limited, there may be other variables influencing patient and significant other emotional distress that were not included in this study (i.e., substance abuse history, affective disorders, psychological disorders).
Implications for Counseling

The presence of unawareness of deficits in persons with brain injury has been documented in the literature, and the results of this study indicate that the sample population expressed unawareness with regard to many activities of daily living. Additionally, these patients appear to experience increased emotional distress as their awareness of their limitations increases.

Rehabilitation efforts have focused on the treatment of unawareness. General guidelines, including neuropsychological evaluation, education for patient and family, and psychotherapy, were delineated by DeLuca, Tiersky, and Diamond (1996). Additionally, the use of concrete feedback has been recommended (Lam, McMahon, Priddy, & Gehred-Schultz, 1988; Rebmann & Hannon, 1995). Although the emotional implications of unawareness for the patient have been documented, less emphasis has been placed on addressing these issues in a rehabilitation setting. This study serves to highlight the need to focus on attenuating emotional distress as the patient’s awareness of his or her limitations increases.

In addition to the patient, significant others in his or her life are often significant contributors to rehabilitation efforts. Consistent with other studies on similar populations, a good number of significant others in this study reported experiencing emotional distress (anxiety and depression). Rehabilitation efforts need to focus on alleviating the emotional distress experienced by significant others. Significant others may benefit from individual and family counseling, as well as support groups designed to educate them regarding expectations of the patient’s abilities and recovery. It has been suggested that persons
close to the person with the brain injury need to hear things such as: anger, frustration and sorrow are normal reactions; caretakers must put themselves first; role changes can be emotionally distressing for all involved and; family members can do little to change the injured individual and should not feel guilty if they are unable to do so (Lezak, 1978).

**Implications for Further Research**

Further research is needed in this area to facilitate the implementation of appropriate rehabilitation efforts, counseling, and support services for persons with brain injury and significant others in their lives. Based upon limitations identified in this study, future researchers should strive to obtain objective measures of patients' limitations, such as neuropsychological measures and ratings of staff members. Additionally, the use of more sensitive instruments may aid in the prevention of false indicators of emotional distress.

In future studies, more variables that may contribute to emotional distress should be included (ie., substance abuse history, coping styles, affective disorders, psychological disorders). This may be facilitated by the establishment of longitudinal databases, and more systematic assessment of patients and significant others. A large database may allow for more thorough comparisons among different significant other groups (ie., spouse, parent, friends). Additionally, the large standard deviations in the current sample suggest that at least some patients and significant others were experiencing considerable anxiety and/or depression. It may be beneficial to examine individuals with high scores on these
variables compared to those with low scores in order to investigate what possible differences might emerge.

The influence of unawareness among other, less severe, brain injured populations should also be investigated, as well as among populations of other injured persons who have not sustained brain injury. Finally, outcome studies should be conducted in order to evaluate the efficacy of treatments in alleviating emotional distress in patients and significant others.
APPENDIX A

Oral Solicitation Script
Hello, my name is Cynthia Wallace. I am a graduate student in the Department of Psychology at The Ohio State University. As part of my PhD dissertation research, I, along with my advisor, Dr. Richard Russell, am conducting a study to investigate the impact of brain injury on the patient, as well as on significant others in the patient’s life. This research will allow recommendations to be made regarding rehabilitation efforts and support for both persons with brain injury and their significant others. If you are willing to participate in this research effort, there are three questionnaires I will ask each of you to complete, and the time required to do so is approximately twenty minutes. The questionnaires are coded, and those code numbers will be matched to a code list containing only the patient’s name. Therefore, you will not be required to put your name on any of the questionnaires. All of the information that is collected will be stored in a locked file cabinet, to which only I will have access. Whether or not you choose to participate will in no way affect the treatment that you will receive at this facility. Additionally, should you choose to participate, you may discontinue at any time without penalty. If you would like to participate, but feel that you need assistance to complete the questionnaires, I will read the questions to you and record your answers.
APPENDIX B

Debriefing Script
Thank you for your participation in this study. The questionnaires that you completed will allow me to investigate the effects of brain injury on the patient, as well as significant others in the patient’s life. Specifically, I am interested in how the patient’s lack of awareness regarding his or her deficits relates to the emotional state of the patient and persons close to him or her. I am also interested in how the amount of time that has elapsed since the injury effects this relationship. If you would like to know the results of the study when it is completed, please provide me with an address where you would like this information sent. Do you have any questions or concerns regarding the study?
LIST OF REFERENCES


