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# Philadelphia College of Osteopathic Medicine Department of Psychology

# PERCEPTION OF CONTROL AND AWARENESS OF DEFICIT IN INDIVIDUALS WITH NEUROLOGICAL IMPAIRMENT IN A CLINICAL SAMPLE

Donna Marie Struck

Submitted in Partial Fulfillment of the Requirements of the Degree of

Doctor of Psychology

April 2009

## PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE DEPARTMENT OF PSYCHOLOGY

#### **Dissertation Approval**

This is to certify that the thesis presented to us by Donna Marie Struck on the on the 2<sup>nd</sup> day of April, 2009, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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#### ABSTRACT

Acquired brain injury is considered to be one of the most important public health concerns in the United States, with approximately 1.2 million adults that meet the criteria for chronic brain disease, brain disorder, or injury each year. Medical costs directly related to injury, in addition to the indirect costs related to job loss, totaled an estimated 60 billion dollars in the year 2000. Subsequent impairment following brain injury yields a complicated neurobehavioral sequelae of deficits. Anosognosia, specifically, the deficit of the patient's inability to acknowledge, or even recognize impairments, is common following brain injury. In a review of the literature, this study examined the phenomenon of anosognosia, and its relationship to an individual's perception of control Both the Perception of Control Across Domains Scale (PCADS) and the Neurological Impairment Scale (NIS) were utilized as a measure of self-report, and compared with the patient's test scores on standardized neuropsychological measures. Findings concluded that patients do not reliably report their symptoms. Although the study's findings revealed no significant correlations, implications for the field of psychology are still useful. The rising costs of healthcare have contributed to the problem of insurance companies attempting to eliminate the coverage for neuropsychological testing, in favor of conducting a clinical interview. These findings suggest that clinicians cannot rely solely on patient report to determine an accurate diagnosis.

Learning is finding out what you already know.

Doing is demonstrating that you know it.

Teaching is reminding others that they know just as well as you.

You are all learners, doers, and teachers.

- Richard Bach -

Illusions

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#### CHAPTER 1

#### INTRODUCTION

Incidence and Prevalence of Adult-Onset Brain Impairment

There are approximately 1.2 million individuals between the ages of 18 and older who meet the criteria for an adult onset of a chronic brain disease or brain disorder in the United States each year (FCA, 2001). The incidence of adults who currently live with impairments as a result of acquired brain disorders range from between 13.3 to 16.1 million (FCA, 2001). Statistics compiled by the Family Caregiver Alliance (2001) reported high and low end estimates of the major causes of brain disorders in adulthood. These include, but are not limited to, Amyotrophic Lateral Sclerosis (20,000 to 30,000); Epilepsy (1,984,000 to 2,000,000); HIV (AIDS) Dementia (14,537 to 58,150); Huntington's Disease (approximately 30,000); Multiple Sclerosis (250,000 to 350,000); Parkinson's Disease (500,000 to 1,500,000), and strokes (4,000,000 to 4,400,000).

Many of the abovementioned diseases and subsequent brain impairments are progressive, and in some cases, the incidence and prevalence increase with age (CDC, 2006b; FCA, 2001). It is estimated that 35.8% of individuals who are ages 84 or older experience moderate to severe memory impairment, and approximately 4,000,000 individuals are diagnosed with probable Alzheimer's disease (FCA, 2001). Given the increasing longevity of our growing population, it is expected that the prevalence and incidence of brain disease and disorders will increase proportionately (FCA, 2001). By

the year 2020, it is predicted that, in the state of California alone, there will be approximately one million individuals over the age of 85 who will be diagnosed with brain-related impairment; this is twice as many as there are today (FCA, 2001).

The body of literature addressing traumatic brain injury and its resultant acquired cognitive deficits continues to grow (FCA, 1998). The scope of occurrences which result in traumatic brain injuries is broad, and its resultant deficits are vast. Such occurrences include, but are not limited to, impacts related to falls, head trauma due to car accidents, penetration wounds such as gunshots, injury from surgical procedures, or oxygen deprivation (FCA, 1998). More recent statistics cited by the Center for Disease Control (2006b) reported that approximately 28% of brain injuries resulted from falls; 20% occurred from motor vehicle-traffic accidents; 19% resulted from strike or impact events and 11% resulted from assaults.

It has been stated that from 1.6 to 3.8 million individuals who sustain sports or recreational-related injuries will result in what is considered a mild traumatic brain injury, or concussion (FCA, 2001). In addition to trauma, the American Brain Tumor Association (2008) reports that more than 190,000 individuals are diagnosed with brain tumors each year. Approximately 44,000 are primary brain tumors; approximately 150,000 are metastatic. Recent statistics reported prevalence rates of individuals living with primary brain tumors are estimated at approximately 359,000 (American Brain Tumor Association, 2008).

#### Statement of the Problem

Acquired brain injury is considered to be an important public health concern because of its incidence rate, not to mention its significant impact on an individual's daily functioning (Vickery, Gontkovsky & Caroselli, 2005). During the year 2000, medical costs directly related to brain injuries, and the indirect costs related to loss of productivity, totaled an estimated 60 billion dollars in the United States (CDC, 2006b).

The resultant cognitive impairment on insult to the brain produces significant long-term consequences (FCA, 2001). According to statistics from the Center for Disease Control (2006b), an estimated 62.3 per 100,000 individuals who sustained head injuries suffered enduring functional impairment (FCA, 1998); approximately 5.3 million individuals would then require lifelong assistance with daily living activities. There are an estimated 330,000 individuals who have sustained head injuries significant enough to require hospitalization, with approximately 99,000 injuries which resulted in long-term disability (FCA 1998).

The subsequent impairment because of a brain insult contributes to a complicated array of neurobehavioral deficits (Sherer et al., 1998c; Sherer et al., 2003). Patients may exhibit any combination and magnitude of medical, physical and cognitive deficits (Flashman et al., 2005; Sherer, Oden, Bergloff, Levin & High, 1998) affecting the domains of language, thinking, learning, emotions, behaviors, and sensation (CDC, 2006b). Approximately 40 percent of individuals who are hospitalized with brain injuries require remediation for memory improvement, problem solving, managing stress and

emotional regulation, including controlling one's temper, and improving job skills (CDC, 2006b).

Prigatano (1999) found that with each successive stage after brain injury, patients often exhibited a disturbance in consciousness which altered their perceptions of their changes in personality and cognition. In addition to personality difficulties such as irritability, restlessness, and depression, the literature reports the phenomenon of impaired self-awareness (Sherer et al, 2003); this impairment in self-awareness is a common finding following brain injury (Shereer et al., 1998a).

#### Purpose of the Study

Because of the significant challenges facing rehabilitation specialists, the concept of unawareness has more recently experienced resurgence in the literature (Bogod, 2003; Flashman & McAllister, 2002; Martelli et al., 2000; Toglia & Kirk, 2000). The ability to identify whether or not the patient was able to evaluate accurately his or her level and severity of neurological functioning, and to self-appraise his or her perception of the ability to manage his or her environment following brain injury, may serve as a useful component both in clinical and in rehabilitative settings.

Despite speculation and theory over the previous century, and given the heterogeneity of the concept, there still exists a poor understanding of impaired awareness (Vuilleumier, 2004). The need for a more comprehensive understanding of the underlying mechanism of self-awareness in contributing to poor self-perception following traumatic brain injury remains a critical topic for discussion (Prigatano, 1996).

The issue of the patient's lack of awareness of deficit across a wide variety of domains is one that is dealt with daily by practicing neuropsychologists (Bigler & Clement, 1997). The purpose of this study is to explore patients' subjective self-reports on two structured checklists, in order to determine whether or not there is a relationship between 1) the accurate patient report of level of severity of symptoms; and 2) the patient's ability to perceive control over his or her behaviors and environment, when compared with actual test scores as measured by standardized neuropsychological assessment

The first checklist, (the Perceived Control Across Domains Scale [PCADS]), is a self-report measure of how well the patient perceives control over different domains in life following brain injury or following an acquired brain disease or disorder. The second checklist, (the Neuropsychological Impairment Scale [NIS]), allowed the patient to rate his or her subjective experience and severity of neuropsychological symptoms following brain injury or an acquired brain disease or disorder.

#### CHAPTER 2

#### LITERATURE REVIEW

#### Defining the concept of impaired self-awareness

Impaired self-awareness, also known commonly in the literature as anosognosia, is defined as the patient's partial or complete unawareness of an acquired deficit following neurological insult (Bogod, 2003; Borgaro & Prigatano, 2003; Carota, Staub & Bogousslavsky, 2002; Flashman, 2002; Flashman et al., 2005; Hart, Giovannetti, Montgomery & Schwartz, 1998; Martelli, Pickett & Zaller, 2000; Sherer, et al., 1998a). Up to 45 percent of individuals with moderate to severe brain injuries demonstrate either a reduced capacity for awareness, or a complete lack of awareness of their deficits (Flashman 2002).

Stuss (1991) reported that patients with unawareness deficits have difficulty with understanding the implications of their own actions, demonstrate a reduced capacity to self-monitor, and exhibit dissociation between their behaviors and their thoughts.

Although the phenomenon of impaired awareness has been reported in the medical literature for over a century (Cheng & Man, 2006), the concept has received relatively little focus compared with other manifestations of neuropsychiatric illnesses (Flashman, 2002).

Within the clinical domain, the manifestations of impaired self-awareness presents in various ways (Murphy, 2003). Patients seem unable to recognize the impairment, or to acknowledge that the impairment exists; they judge the deficit to be

inconsequential, or completely discount the existence of these deficits (Carota et al., 2002; Flashman et al., 2005), despite observable evidence to the contrary by others such as family members and therapists (Flashman et al., 2005).

Although studies have demonstrated the fact that patients have inaccurately evaluated their sensory, perceptual, motor, affective and cognitive abilities following brain injury (Orfei et al., 2007; Vuilleumier, 2004), the report of unawareness is further complicated by the inconsistency across all types of impairments, and varies in degree depending upon the severity of the neurological insult. During the acute period of brain injury, some patients were completely unaware that they had sustained any injury at all (Sherer et al., 1998b), yet other patients reported themselves to be completely normal with regard to their higher cognitive functioning and physical status (Flashman et al., 2005; Prigatano & Altman, 1990).

Other studies have found that some patients were able to report only vague behavioral symptoms, and were unable to appreciate the connection between these impairments and their brain injuries (Prigatano, 2005). Other patients reported differences in themselves, but maintained that they were not readily identifiable (Prigatano & Altman, 1990). Left untreated over time, deficits in unawareness result in a culmination of financial difficulties, decreased self-esteem, and social isolation (Murphy, 2003).

#### Complications in achieving unified terminology

In addition to being a complicated phenomenon, at this time no straightforward and unitary definition of this concept has been proposed (Cheng & Man, 2006; Flashman et al., 2005). The language used to define the absence of awareness further complicates an already intricate and complex explanation of the problem. Specifically, terminology has been frequently interchanged in the scientific literature to communicate different facets of this phenomenon (Flashman et al. 2005). Research studies have reported such terms interchangeably as anosognosia, agnosia, unawareness and denial (Flashman, 2002; Flashman, et al., 2005; Vuilleumier, 2004), lack of insight, and anosodiaphoria (Flashman et al, 2005). These terms have suggested various meanings, and seem to be dependent upon the context of the study, or the interpretation by the authors (Flashman, 2002; Flashman, et al., 2005; Vuilleumier, 2004).

Some studies have attempted to define and differentiate the terminology operationally. Studies by Agnew & Morris (1998) suggested that the lack of insight or awareness were used synonymously and reflected a change in metacognitive functioning. Some research studies have distinguished between denial and anosognosia specifically for motor impairment, and have reported different forms of unawareness, as well as different underpinnings for the impairment (Dalla Barba et al., 1999). Studies by Anderson and Tranel (1989) found that the patient's unawareness of cognitive deficits did not coincide with unawareness of motor impairments. It was reported that many patients without motor deficits demonstrated a striking unawareness only of cognitive impairment (Anderson & Tranel, 1989).

Prigatano (2005) defined the concept of impaired self-awareness and anosognosia interchangeably as "the clinical phenomena in which a brain dysfunctional patient does not appear to be aware of impaired neurological or neuropsychological function, which is

obvious to the clinician and other reasonably attentive individuals" (Prigatano, 2005, p. 20).

Other research has attempted to define how unawareness is viewed as a symptom, and separately from a biological perspective. Research by Orfei and colleagues (2007) defined the concept of anosognosia as being more closely related to neurological brain lesions. In their research on stroke patients, the authors have narrowed the fields to such key areas of stroke, anosognosia, awareness, denial, unawareness, and hemiplegia, along with corresponding neurological and neuropsychological data and clinical trial outcome. The study indicated that the concept of unawareness and its multifaceted behavioral manifestations yield a complex phenomenon that contributes to the uncertainty of conceptual definitions and diagnoses (Orfei et al., 2007).

The term anosognosia, which literally translates as "lack of knowledge of disease" (p. 309) was previously introduced by Babinski in 1914 (Agnew & Morris, 1998; Markova & Berrios, 2000; Prigatano & Weinstein, 1996; Orfei et al., 2007; Vuilleumier, 2004). Babinski's studies reported on two patients with left hemiplegia following injury to the non-dominant hemisphere (Dalla Barba, Bartolomeo, Ergis, Boisse & Bachoud-Levi, 199; Hart et al. 1998). Such examples include patients who have hemiplegia but believe their paralyzed limbs still function normally (Clare, 2003); one was unaware of her paralysis for several years (Prigatano & Weinstein, 1996).

In the late nineteenth century, studies by Anton found evidence that patients were oblivious to major neurological impairments, seemingly unaware or denying the disability despite evidence to the contrary (Markova & Berrios, 2000). These reports specifically addressed unawareness of cortical blindness (Anton's syndrome) and

deafness (Agnew & Morris, 1998; Markova & Berrios, 2000; Prigatano & Weinstein, 1996; Vuilleumier, 2000; Vuilleumier, 2004).

Flashman et al. (2005) described Anton's Syndrome as one of the most remarkable representations of impaired awareness. Patients who sustained damage to the occipital cortex or optic radiations involving the primary visual or visual association cortex suffered with cortical blindness as a result. The destruction of the ability to process visually resulted in an unobstructed display of visual imagery, but was misinterpreted by the patient as the inability to see. This may also have contributed to the patients' confabulated responses often found documented in the literature (Flashman et al., 2005).

Wernike described patients with aphasia who were unaware of their language deficits (Agnew & Morris, 1998; Flashman et al., 2005). More recent literature has demonstrated the fact that anosognosia has been reported to accompany what has been described as jargon aphasias, which includes Wernicke's aphasia, transcorticcal sensory aphasia and global aphasia (Flashman et al., 2005).

These aphasias, characterized by long, ongoing sentences, meaningless sounds, phonemic or semantic paraphasias and neologisms, appeared to go unrealized by the patient (Flashman et al., 2005). Consistent with previous reports, studies by Clare (2002) reported patients who demonstrated unawareness deficits for fluent aphasia produced numerous paraphasias and neologisms.

Based upon observable behaviors, patients seemed completely oblivious to what was being said to them, and were unaware that the listeners did not comprehend what the patients were trying to express (Flashman et al., 2005). Studies reported that although

these patients believed that they were communicating effectively, they became frustrated when they were not understood by the examiner (Clare, 2002).

In the late 1800's, Korsakoff noted the lack of concern for amnesia (Agnew & Morris, 1998). Westphal reported on a patient with hemianopia and hemiparesis who was not aware of his deficits. Sudden hemianopia and hemiplegia are most commonly associated with a vascular origin, often following a stroke, commonly occurring within the nondominant hemisphere (Flashman et al., 2005). From a functional perspective, despite the patients' inability to move or utilize the contralateral limbs (often the arm), or acknowledge stimuli in the contralateral hemifield, the patients stated that they were unimpaired (Flashman et al., 2005).

More recent studies have repeatedly demonstrated the fact that stroke patients diagnosed with anosognosia for hemiparesis denied the paresis, or acted as though the disorder did not exist (Baier, 2004). Patients tended to behave as though the limbs functioned normally, or they addressed the situation as though the limbs were simply tired (Baier, 2004).

Studies by Carota and his colleagues (2002) reported that patients with anosognosia for a hemiparesis did not spontaneously complain about their deficits. Other patients acknowledged weakness in only one limb, although there was a complete-side hemiplegia. Patient complaints were found to be either congruent, when they walked or performed activities, or incongruent, when only hesitantly accepting a wheelchair or bed (Carota et al., 2002).

In a study of patients who sustained a stroke, Hartman-Maeir, Soroker, Ring and Katz (2002) reported that thirty percent of the entire sample did not spontaneously

acknowledge having had a stroke following a general inquiry about the reasons for hospitalization. When queried, a small percentage reportedly denied having had a stroke.

#### Not limited to traumatic brain injury

Much of the literature describing anosognosia has focused on patients who have sustained moderate to severe injuries to the central nervous system (Flashman et al., 2005); Sherer et al., 1993). Although research has focused predominantly on groups with severe traumatic brain injury, little has been reported on other severity groups or in the non-traumatic brain injured population (Leathem, Murphy, & Flett, 1998).

Studies by Sawchyn, Mateer and Suffield (2005) reported that in the majority of the literature, patients have been sampled from inpatient or outpatient rehabilitation programs or settings, which included predominantly those who had experienced moderate to severe brain injury. Other studies have expanded the conceptual definition of unawareness to include physical disabilities, traumatic events, abnormality in mood, disruptions in social interactions (Prigatano & Weinstein, 1996), and neurological disorders (Flashman et al., 2005).

Research has also demonstrated the fact that deficits in awareness affect cognitive and behavioral domains more than they affect physical problems or functional activities, such as the patient's activities of daily living (Hart et al., 2004). A study by Sherer and his colleagues (1998b) found that some patients acknowledged deficits; however, many failed to understand the likely impact of these deficits on their daily activities.

Studies by Prigatao et al. (1990) found, that despite their lack of awareness for emotional and cognitive deficits, patients accurately appraised the areas of physical activity and basic self-care activities.

Research by Sherer and colleagues (2000) suggested that impaired awareness may be related to the patient's overall cognitive and emotional functioning. Patients who were unaware of changes following brain injury experienced significant depression (Sherer, et al., 1998b). Gasquoine (1992) reported that emotional dysphoria (defined in the study as anxiety, depression, and hostility) was significantly and positively correlated with the patient's unawareness of sensory and cognitive changes following head injury. Positive affect was significantly and negatively correlated with the patient's awareness of sensory and cognitive changes.

Studies by Prigatano, Altman and O'Brien (1990) found that individuals with traumatic brain injury had difficulty with emotional dyscontrol, cognitive ability, and social interaction. More recent studies have reported that patients with deficits in awareness exhibited poor self-appraisals in areas affecting their capacities for sound judgment, cognitive ability, interpersonal skills and social behavior (Flashman et al., 2005).

Findings suggested that neurological disorders including strokes, tumors, and progressive dementias also resulted in physical, cognitive and behavioral decline, post-insult (Sherer, et al., 1998c), and often rendered the patient unable to notice or acknowledge the existence of their impairments (Vuilleumier, 2004). In SPECT Studies by Venneri and Shanks (2003), findings identified marked hypoperfusion in the right

parietotemporal cortex in a patient with persistent anosognosia for hemiplegia following a stroke.

In a comprehensive review from 1990 through 2007, Orfei and her colleagues reported that studies on impaired self-awareness have been focused primarily on stroke hemiplegic patients. Studies by Bogod, Mateer and MacDonald (2003) found the phenomenon of unawareness to be present in a number of behavioral syndromes following brain injury.

In a study by Wagner, Spangenberg, Bachman and O'Connell (1997) the authors found that the Alzheimer patient group demonstrated significantly greater unawareness of cognitive deficits than did the two control groups. Their results concluded that independent of dementia severity, unawareness of cognitive ability is disease-specific.

Studies by Clare on early-stage Alzheimer's patients (2002) found that although some symptoms of unawareness could be accounted for by neurological damage, apparent unawareness was viewed as the product of psychosocial processes and their interactions with cognitive impairments.

Flashman (2002) reported that impaired awareness in Alzheimer patients ranged from the patient's acknowledging impaired memory but minimizing its severity, to the inaccurate report of very good memory skills. In a comprehensive study by Barrett, Eslinger, Ballentine and Heilman (2005), the authors concluded that patients with Alzheimer's disease estimated memory, attention, behavior, naming, visuospatial skill, limb praxis, mood and uncorrected vision before and after their abilities were assessed. Compared with controls, the patients with Alzheimer's disease demonstrated unawareness of their deficits, including overestimating visuospatial skills during

pretesting, and overestimating their memory abilities during the posttest (Barrett et al., 2005).

Studies by Selzer, Vasterline, Mathias and Brennen (2001) reported that patients with Alzheimer's disease and patients with Parkinson's disease rated themselves as being less compromised than did their caregivers. The two groups differed significantly on awareness discrepancy measures from a cognitive perspective. In the ratings of patient cognitive skills, caregivers rated Alzheimer's patients significantly more impaired than the patients were able to recognize; however, caregivers and Parkinson's patients did not significantly differ on these ratings. The authors concluded that both groups of patients displayed impaired awareness on motor-related neurologic function. Parkinson's disease patients displayed relatively preserved awareness of motor and other deficits. Impaired awareness in patients with Parkinson's was associated with poorer overall cognitive function and with performance on memory, attention, and constructional ability, than were the Alzheimer's patients.

Studies found that patients who suffered from Parkinson's disease exhibited poorer overall cognitive ability and lower performance on assessment measures of memory, attention and constructional ability; this was reported to be inconsistent with the patient's self-report of symptoms (Flashman, 2002).

Leritz and her colleagues (2004) investigated whether or not patients with Parkinson's disease exhibited the features of anosognosia. Findings indicated that patients rated themselves as significantly less impaired on two measures of activities of daily living, indicating that disruption of the basil ganglia may alter patient insight into the severity of illness (Leritz et al., 2004).

Studies by Goverover, Chiaravalloti and DeLuca (2005) reported a significant, positive correlation between cognitive abilities and self- awareness in executive dysfunction and disinhibition in patients with multiple sclerosis. However, affective symptoms of depression, and anxiety were negatively correlated with self-awareness of executive dysfunction.

Sherman, Rapport and Ryan (2008) investigated patients with Multiple Sclerosis and evaluated subjective report of awareness deficits against objective test scores on cognitive abilities. Findings concluded that one-third of patients exhibited diminished awareness of cognitive and functional deficits. Their study suggested that unawareness of deficits was more commonly found among patients with secondary progressive Multiple Sclerosis than among those with relapse-remitting Multiple Sclerosis (Sherman et al., 2008).

Studies on awareness deficits on patients with Huntington's disease exhibited denial of impairment, with unawareness of motor, cognitive and emotional changes (Goverover et al, 2005).

Deficits in awareness have also been identified in individuals with chronic alcoholism, schizophrenia, affective disorders and stress, as well as in medical disorders including breast cancer, heart disease and HIV and AIDS (Flashman, 2002). Studies by McEvoy, Freter, Merritt, and Apperson (1993) examined the correlation between frontal lobe and right hemispheric dysfunction and impaired awareness in patients with schizophrenia; however, the attempt to correlate neurological and psychiatric models of impaired awareness remains unclear (Markova & Berrios, 2000)

#### Clinical Models of Explanation

At this time, no one study has been able to provide a comprehensive model of the psychological processes that underlie the expression of unawareness of deficits (Clare, 2003) However, several models to explain impaired self-awareness have been proposed.

According to Cheng and Man (2006) most clinical models share three common components. First, there is a description of the patient's lack of objective knowledge. Second, it is difficult for patients to apply objective information or knowledge about their own impairments to daily life. Third, neuropsychological abilities such as goal setting, self-performance prediction, and self-monitoring of psychological factors influence impaired self-awareness.

Studies by Giancino and Cicerone (1998) reported a model composed of three sources of self-awareness. These included: 1) the limitation of cognitive impairment, specifically related to deficits in memory and reasoning; 2) the limitation of the psychological response or reaction to the impairment; and 3) the limitation of the inability to recognize the area of impairment.

Crosson et al. (1989) proposed a three-tier model, identifying three distinct types of self-awareness, including intellectual awareness (described as the ability of the patient to comprehend that a particular function is impaired), emergent awareness (the ability of the patient to recognize that there is a functional problem as it occurs), and anticipatory awareness (the patient's ability to anticipate the problem that will occur as a result of the deficit).

Studies by Allen and Ruff (1990) created a comprehensive, three-level clinical model of self-awareness. The first level required the patient to attend to, to be able to encode information, and to retrieve information concerning the self. The second level required the patient to be able to compare existing information with premorbid, self-evaluative information. The third level required the patient to be able to describe self-perception to another individual.

Fleming, Strong and Ashton (1996) proposed a comprehensive, three-level model of awareness, comprising awareness of objective knowledge, of functional implications and ways in which these impairments related to the patient's daily activities, and the patient's ability to establish realistic goals.

In more recent studies by Toglia and Kirk (2000), the authors expanded upon Crosson's hierarchal model. According to this later model, awareness was divided into two major areas: metacognition, and what the authors described as online awareness (Toglia & Kirk, 2000). The authors described metacognitive knowledge as declarative knowledge concerning one's abilities. Online awareness was described as the ability to demonstrate ongoing monitoring of an individual's actual performance during the task (Dirette, 2002; Toglia & Kirk, 2000).

#### Underlying Neuronal Mechanisms

Currently, knowledge of the possible mechanisms underlying deficits in unawareness is still very poor (Dalla Barba et al., 1999). The neuronal pathways of anosognosia are still debated (Orfei et al., 2007), and few systematic studies have been

accomplished because the focus of these more effectively characterizes the clinical features of unawareness and its underlying cognitive mechanisms (Vuilleumier, 2004). More recent studies have been descriptive in addressing various lesion types and severity of neurological impairments, whereas studies focusing on experimental design have been limited or accomplished in only a few single cases (Vuilleumier, 2000).

Earlier studies by McGlynn and Schacter (1989) concluded that anosognosia resulted from concurrent lesions within several areas of the brain, thereby creating varying degrees and combinations of producing different presentations of the disorder (Agnew & Morris, 1998).

Research by Anderson and Tranel (1989) found that unawareness of hemiparesis was found only in subjects with right-hemisphere damage, suggesting that knowledge associated with right hemisphere neuronal networks (predominantly the primary and early association cortices where sensory and motor processes occur) necessary for the perception of an impaired function, was disrupted.

In the most recent comprehensive evaluation of hemispheric specialization, findings concluded that the right cerebral hemisphere is dominant for the awareness both of physical and of emotional self (Devinsky, 2008). Body image, relationship to the environment, and social function are mediated by neuronal pathways associated with right hemisphere involvement (Devinsky, 2008).

Consistent with research, studies found that patients who sustained lesions to the right hemisphere resulted in left-sided neglect, and anosodiaphoria (emotional indifference). In this case, motor problems were acknowledged, but without concern (Ossola, Ladavas, Stracciari, Giannarelli & Ossola, 1993). In studies by Devinsky (2008),

lesions to the right hemisphere were also associated with topographical disorientation, social disorders, and anosognosia.

Although deficits in unawareness have often been associated with neurological disorder involving cortical brain regions, relatively few studies have examined the role of subcortical structures (Leritz, Loftis, Crucian, Friedman & Bowers, 2004). Because subcortical structures (such as the thalamus, caudate nucleus and internal capsule) are connected extensively to larger cortical regions including the frontal lobes, one can expect that deficits in awareness would be similar to patients with cortical lesions (Leritz et al., 2004).

The most recent neuropsychological models also suggested that problems with the feed-forward system and neuro-anatomical research consistently report right cerebral hemisphere (specifically, the prefrontal and parieto-temporal cortex, insula and thalamus) involvement (Orfei et al., 2007).

Studies by Andelman and colleagues (2004) found that patients with intractable epilepsy experienced significant distortions in their awareness of memory. Findings suggested that patients with epileptogenic right-hemisphere brain lesions overestimated their memory abilities, but patients with left-hemisphere lesions more equally overestimated and underestimated their abilities, similar to normal control subjects (Andelman et al., 2004).

Damage to the overarching control system mediated by the frontal lobes would result in a generalized disturbance of awareness for cognitive disorders (Agnew & Morris, 1998; Ossola et al., 1993). This is consistent with earlier theories of anosognosia which postulated that the disorder was due to impairment within the central monitoring

systems, or to damage to the system governing conscious awareness (McGlynn & Schacter, 1989).

Stuss, Picton, and Alexander (2002) proposed a theory of consciousness encompassing four distinct theories, summarized as: 1) awareness occurs as a result of cerebral processes that create models of the world; 2) the brain's ability to create these models are arranged in a hierarchal fashion; 3) within any one division of this hierarchy, the processes operate in a modular fashion, and 4) At the highest level of conscious processing, the frontal lobes are significant in the role of conscious processing.

Specifically, the right frontal lobe is critical for an individual to be self-aware (Stuss et al, 2002).

In a study by Johnson et al. (2002) utilizing functional imaging, the authors concluded that the medial prefrontal cortex and posterior cingulate were identified as important structures for accessing a sense of self, and were consistent with previous brain lesion studies in patients diagnosed with impaired self-awareness.

McGlynn and Schacter (1989) reported that patients with amnesic disorders due to frontal lobe impairment tended to be unaware of their memory deficits; this is in comparison with patients whose amnesic disorders were due to temporal lobe damage.

Markova and Berrios (2000) reported that many studies investigating these associations with frontal lobe involvement have not measured awareness in a systematic way and that findings concluded either a presence of or an absence of the disorder.

Because many of these studies are single-case designs, from an empirical standpoint, it is difficult to generalize the findings concerning the relationship between unawareness and frontal lobe deficits (Markova & Berrios, 2000).

Studies have demonstrated that damage to the parietal lobes would result in impairment to the brain's center responsible for monitoring more peripheral difficulties, such as motor and sensory impairment (Ossola et al., 1993).

Studies by Andersson, Gundersent and Finset (1999) reported reduced self-awareness to be associated with low autonomic reactivity. Their results concluded that reduced psychophysiological reactivity in patients who present as apathetic were associated with a decrease in emotional response, disengagement, and lack of concern for their current situation (Andersson, et al., 1999).

#### Measuring Impaired Awareness

The concept of impaired self-awareness remains a complicated and intricate phenomenon, and research on the nature and course of impairment following traumatic brain injury is still at an early stage (Sherer, et al., 1998b). Disturbances of self-awareness following neuropsychological insult are difficult to measure (Prigatano & Klonoff, 1998).

The need for the accurate assessment of impaired awareness plays a critical role in contributing to patients' overall independent functioning (Bogod et al., 2003; Prigatano, 1999; Sherer, et al., 1998a; Sherer, Madison & Hammay, 2000; Toglia & Kirk, 2000), the need for continued health care, the patient's ability to live independently, and whether or not the patient will be able to return to work or to former activities (Sherer et al., 2000). Correct identification also assists in the development of a treatment or remediation plan to address the patient's need for supervision, medical care, rehabilitation, and related costs (Sherer et al., 2000).

Findings by Sherer and colleagues (1998b) suggested that impaired awareness was not a global deficit, and was related not only to the severity of impairment, but also related to the measure utilized to make the diagnosis. Not only was this due to the scope of what was included within the concept of awareness (Toglia & Kirk, 2000), but also may conceivably be the result of the variety of ways in which the construct of awareness has been defined across studies (Sherer, et al., 1998b; Toglia & Kirk, 2000).

There is a shortage of specific instruments and interventions to improve deficits in unawareness (Appelros, Karlsson, Seiger & Nydevik, 2002). Although a number of strategies have been implemented to obtain a quantitative evaluation, there is no single method to measure impaired awareness (Appelros et al., 2002; Flashman & McAllister, 2002; Fleming, Strong & Ashton, 1996), and no gold standard for what it is that constitutes this phenomenon (Bogod et al., 2003).

The use of self-report questionnaires, one method of gathering quantitative information, is scored by the interviewer, and compared with a rating scale (Flashman & McAllister, 2002). In order to make inferences concerning impaired self-awareness, the patient's report must differ from another external measure, such as performance on neuropsychological assessment measures (Anderson & Tranel, 1989). The general assumption is that patients who exhibit impairment in self awareness will rate their abilities as better than the standard; the discrepancy between the self-perception of abilities and actual scores is said to be the measure of the level of unawareness (Hart et al., 2004; Sherer, et al., 1998b).

Self-report questionnaires are often used to gather both quantitative and qualitative information about patients' self-perceptions of their abilities (Hart et al.,

2004). Over the years, research has focused on the patient's self-report with the intent to study its effect on rehabilitation outcome, and to assess the efficacy of treatment modalities which focus on improving awareness (Sherer, et al., 1998a, 1998b).

The Patient-Competency Rating Scale (PCRS) is a measure that provides self-and informant-ratings of every day memory and gives an overview of the patient's awareness of their difficulties (Leathem, Murphy & Flett, 1998). In a study utilizing two measures of awareness, (clinician rating versus PCRS), Fischer, Trexler and Gauggel (2004) confirmed the fact that brain injured patients tended to overestimate their abilities when these patients are compared with orthopedic controls. Borgaro and Prigatano (2003) modified the rating scale for neurobehavioral rehabilitation (PCRS-NR) and found that the psychometric properties of this briefer version of the rating scale were found to be psychometrically sound for the use in an acute neurorehabilitation unit.

In a study by Leathern et al. (1998), the traumatic, brain injured patients overrated their pre-accident competencies when they were compared with normal controls. Patients with moderate and mild brain injuries were consistent in their reports on cognitive and emotional domains.

The findings, in study by Duke and his colleagues (2002), concluded that Alzheimer's patients tended to estimate their own memory abilities to be as good as that of the controls, over predicting their self-performance. Additionally, patients inaccurately underestimated their difficulties in carrying out daily functioning tasks, in comparison with caregiver reports (Duke & Seltzer, 2002). Although Alzheimer's patients demonstrated intact, immediate awareness of their memory difficulties, they failed to

incorporate incidents of memory failure into a generalized self-belief system (Duke & Seltzer, 2002).

In a study utilizing the Self-Awareness of Deficits Interview (SADI), Simmond and Fleming (2003) investigated the reliability of the measure. Their results indicated high inter-rater reliability for the SADI, and reported that the measure is a reliable means of evaluating the level of self-awareness.

Few cross-cultural studies have been reported in the literature. In a cross-cultural study comparing New Zealand Maoris and non-Maoris brain injured patients, Prigatano and Leathem (1993) compared patients' scores, utilizing the PCRS. Their research indicated that both groups showed no correlation between actual neuropsychological status and their self-report of behavioral competency. In contrast, the ratings of their relatives concerning their behavioral competency were correlated with the patients' neuropsychological test performance.

The authors concluded that Maori patients reported less behavioral competency than non-Maori patients; non-Maori patients' performances on the PCRS replicated findings which were compared with American brain-injured patients. Their research concluded that brain damage contributes to patients' misperceptions of their own behavioral abilities; however, cultural factors also played a critical role (Prigatano & Leathem, 1993).

Although questionnaires and structured interviews have been most frequently utilized, some limitations concerning these instruments have been reported in the literature. The use both of questionnaires and of structured interviews relies heavily on the patient's ability to understand oral and written questions verbally, and to convey their

understanding of their deficits verbally (Flashman & McAllister, 2002). A study by Appelros and his colleagues (2002) indicated that self-report instruments cannot be effectively utilized when a patient's level of consciousness is reduced; this may have added a degree of uncertainty to the findings of their study.

Comparisons of self-appraisal may be measured against that of a family member's, a clinician's, or a rehabilitative staff's rating (Flashman & McAllister, 2002; Sherer, et al., 1998a, 1998b; Toglia & Kirk, 2000), although it can invite caregiver and relative biases that may influence the patient (Fleming et al., 1996; Hart et al., 2004). However, when ratings are obtained by clinical and rehabilitative staff, the patient's premorbid information prior to the brain injury may not be available to the raters, thereby confounding a complete and accurate assessment (Flashman & McAllister, 2002).

Studies by Bair and Karnath (2005) investigated whether or not patients mentioned their impairments spontaneously rather than when prompted. Their study concluded that individuals who did not mention their paresis spontaneously, but acknowledged the deficits when questioned directly, should not be diagnosed as having anosognosia. In a case study by Berti et al. (1998), the authors found that the patient demonstrated severe agnosia for motor impairment when reporting symptoms; however, only implicit knowledge of her condition was demonstrated. A contrast was noted between being unaware on a verbal report when compared with awareness on self-evaluation tests (Berti et al., 1998).

The most common way to measure a patient's awareness level is through comparison of the individual's self-appraisal against the individual's scores on another standardized or objective measure (Flashman & McAllister, 2002; Fleming et al., 1996)

such as the use of a self-report measure in comparison with a patient's performance on neuropsychological tests, or other performance measures (Flashman & McAllister, 2002; Toglia & Kirk, 2000).

# The challenge for rehabilitation

Rehabilitation professionals agree that deficits in awareness continue to present major challenges so that a successful treatment outcome may be achieved (Flashman et al., 2005; Sherer et al., 2000; Toglia & Kirk, 2000). The role of physical rehabilitation has been the predominant form of rehabilitation following brain injury, and it has been only in the past two decades that psychologists, rehabilitation specialists, and neuropsychologists refocused their efforts on psychosocial and cognitive rehabilitation (Cheng & Man, 2006).

Within the domain of cognitive rehabilitation, research efforts have predominantly concentrated on the rehabilitation of cognitive abilities including memory, attention, orientation, comprehension, problem-solving and perception deficits. Other studies have found that rehabilitative programs were typically designed and implemented based on physical and neuropsychological assessment; however, they often neglected an assessment of the patient's motivational state (Andersson et al., 1999).

Although there are some research studies that have reported on the benefits of improving the patient's self-awareness, there is presently no consensus on models to guide intervention, or identification about which interventions are the most effective (Lucas & Fleming, 2005). It is imperative for brain injury rehabilitation specialists to

comprehend this phenomenon and to implement appropriate treatment approaches which may conceivably improve patient self-awareness (Sherer et al., 1998c). Establishing the framework for self-awareness in rehabilitation has been developed gradually, but it remains in its infancy (Cheng & Man, 2006).

Additionally, because many patients who sustain brain injury are partially or fully unaware of this impairment, the treatment and rehabilitation is often hindered by this very deficit (Anderson & Tranel 1989). Although patients who demonstrated deficits in awareness exhibited a sense of self-regard of their own abilities and traits, they were not congruent with what others observed (Stuss, 1991). Sherer and his colleagues (1998b) found that although patients acknowledged deficits, many failed to understand the likely impact of these deficits on their daily activities.

Studies have found that not only does the correct identification of deficits in awareness have important implications for rehabilitative outcome (Bogod et. al., 2003; Flashman, 2002; Sherer et al., 1998b; Toglia & Kirk, 2000), the ability to identify these impairments accurately is implicated in diagnostic treatment, and independent functioning (Flashman, 2002; Sherer, Bergloff, Boake, High & Levin, 1998b; Orfei et al., 2007; Toglia & Kirk, 2000). Studies by Prigatano (2005) found that impaired self-awareness was related to treatment outcome, length of stay, treatment compliance, and the establishment of a working alliance in therapy (Anderson et al. 1999; Prigatano 2005).

The successful assessment and management of traumatically brain injured adults requires that the patients have insight into their own functional limitations, including how awareness deficits impact their activities of daily living (Prigatano, Alman & O'Brien,

1990). At the basic level, implementing compensatory strategies requires the patient initially to be aware that a problem needs to be addressed, and participation in remediation involves the recognition that these problem areas need to be strengthened or improved (Toglia & Kirk, 2000). Self-awareness requires that the patient compare information from an external, objective source, with the patient's own inner experience (O'Callaghan, Powell & Oyebode, 2006).

Studies reported that the inability of the patient to recognize deficit areas that need improvement prevented the participation in even the most remedial activities (Toglia & Kirk, 2000), and often resulted in the patient's refusal, or even total resistance to treatment efforts (Hart et al., 2004). Studies have found that patients were less likely to implement compensatory strategies when the need for these strategies was not apparent (Sherer et al., 1998a; Toglia & Kirk, 2000).

Studies have repeatedly demonstrated that deficits in awareness negatively impacted rehabilitation efforts because they significantly disrupted the patient's participation in rehabilitation, impeded motivation for treatment (Hart et al., 2004; Sherer et al., 1998a; Sherer et al., 1998c; Toglia & Kirk, 2000), decreased involvement in therapy tasks, and reduced compliance of behavioral change suggestions (Fleming, Strong & Ashton, 1998).

With unawareness comes the lack of motivation, a common sequelae following brain injury. Many patients lack the motivation to comply with rehabilitative treatment protocols (Sherer, et al., 1998a; Anderson et al., 1999; Toglia & Kirk, 2000). Studies by Anderson and his colleagues (1999) reported that a major problem both in physical and

in neuropsychological rehabilitation following brain injury was the ability to engage patients in rehabilitation activities.

In a study by Andersson et al. (1999), the authors investigated the relationship between patient apathy and emotional reactivity, measured by the change in electrodermal and cardiovascular activity during therapeutic involvement. Their findings concluded that reducing apathy and increasing self-awareness would promote patient motivation both in rehabilitation, and within the therapeutic relationship. Anderson et al. (1999) reported that ignoring such emotions as patient apathy could easily create unrealistic expectations both in the patients and in the rehabilitation staff.

The incompatibility between a patient's unrealistic goals, family expectations, and goals posed by the treatment team presents additional challenges to rehabilitation professionals (Toglia & Kirk, 2000). Awareness and self-monitoring require the ability to evaluate the level of difficulty involved in a task as it relates to the person's individuals strengths and weaknesses, as well as an ability to plan ahead and to incorporate appropriate strategies (Goverover, 2004).

Studies have found that there was a tendency for patients to choose activities beyond their perceived abilities, with little recognition of deficit, or the recognition that they required any assistance at all (Toglia & Kirk, 2000). Sherer et al. (1998b) reported that the functional outcome of treatment objectives was impeded by the patient's inability to choose appropriate long-term goals accurately. As a result of incompatible goals, patients often experienced repeated failures over time, increasing their levels of frustration (Prigatano, 2005).

In a study by Fischer, Gauggel and Trexler (2004), the authors examined the relationship between awareness, the ability to set realistic goals, and outcome for rehabilitation. Their findings demonstrated the fact that patients with less realistic awareness of their limitations set less realistic goals. Hence, rehabilitative outcome was found to be lower for these patients when compared with patients who demonstrated more realistic views of their impairments. Their studies concluded that self-awareness was related to higher goal setting ability and positive outcome in long-term rehabilitation; however, it was found to be less so for short-term experimental tasks.

Studies by Goverover (2004) examined the relationship between the patient's executive function, self-awareness and every-day functional competence in patients who sustained brain injury. The study indicated that categorization, deductive reasoning (defined as an ability to formulate a hypothesis, make inferences and rationalize a conclusion), and self-awareness were good predictors of functional performance of activities of daily living, and could direct more appropriate planning of treatment interventions.

Studies by Katz, Fleming, Keren, Lightbody and Hartman-Maeir (2002) reported that deficits in awareness should be viewed on a continuum which will differ between and within patients. Because patients exhibit varying degrees of this syndrome complete with psychological and neurological factors, occupational therapists need to evaluate the extent to which unawareness is present. Furthermore, the authors asserted that the severity of awareness impairment should guide the treatment team in selecting between structured awareness training versus compensatory strategies (Katz et al., 2002).

In a comprehensive literature review by Lucas and Fleming (2005), the authors outlined models to guide therapists' interventions and created key factors to consider while implementing these tasks. Factors included the client-therapist relationship, goal setting, task selection, and emotional issues. From an educative point of view, the authors reviewed feedback techniques, behavioral therapy techniques, individual and group psychotherapy, strength-and-weakness lists, and task-rating strategies. A multi-contextual treatment approach, as well as an occupation-based intervention program was reviewed (Lucas & Fleming, 2005).

# The concept of perceived control

The ability to comprehend the perception and attribution of control has long been a major goal in the field of psychology (Declerck, Boone & De Brabander, 2006).

To date, the majority of studies addressing the phenomenon of control have provided no conceptual definition of control; rather, the meaning is left to the reader's understanding, or is given an operational definition to communicate meaning (Thompson, 1981).

According to Thompson (1981), control is defined as "the belief that one has at one's disposal a response that can influence the aversiveness of an event" (p. 89). She further asserts that although the definition is broad enough to address different types of control, it also emphasizes the idea that "the control does not need to be exercised for it to be effective and that it does not even need to be real, just perceived for it to have effects" (p. 89).

Of the literature addressing control, the largest body of research focuses on analyzing individual differences in perceived control (Wegner & Bargh, 1998).

Psychological disorders ranging from depression or learned helplessness, to addiction and psychosis are invariably accompanied by a sense of loss of control (Declerck et al., 2006).

Schroder et al., (2007) examined the perception of behavioral control in patients with chronic idiopathic axonal polyneuropoathy. Their findings concluded that perceived behavioral control, in part, mediated the impairment (identified as muscle strength) and the patient's activity limitations. They found that the patient's impairment affected the

individual's perceived control, and in turn, these perceptions contributed to the patient's activity limitations.

Hasson-Ohayon, Walsh, Roe, Kravetz and Weiser (2006) differentiated between perceived personal control (defined as control of self) and perceived interpersonal control (defined as control of others) on different domains of quality of life for patients with severe mental illnesses. Their results demonstrated the fact that personal control was more positively related to the achievement of personal subjective goals, than to the achievement of environmental and objective goals (Hasson-Ohayon et al. 2006).

A sense of cognitive control has been found to have overall positive effects on the experience of an unpleasant event; knowing one has a cognitive strategy reduces anticipatory anxiety, reduces the impact of the presenting issue, and improves the subsequent effects (Thompson, 1981). Patients who feel a sense of control in the health care environment demonstrated more positive adaptive outcomes, and tended to exhibit more favorable emotional and behavioral responses to disease and aversive procedures (Tangsrud & Smith, 2000). The authors suggested that high control perception contributed to physical well-being through (a) avoidance of negative physiological results associated with control loss and (b) the increased likelihood that that patients will participate in appropriate health and maintenance behaviors (Tangsrud & Smith, 2000).

Studies by Fuhrer, Rintala, Hart, Clearman and Young (1992) found that perceived control has the strongest association with life satisfaction. The authors asserted that, theoretically, the concept of perceived control may be important as a psychological variable that mediates the relationship between life satisfaction on the one hand and handicap on the other. Chase, Cornille and English (2000) examined the extent to which

life satisfaction in patients with spinal cord injuries was linked to perceived control. Exploratory findings suggested that the variables of perceived control (along with marital status) were significant predictors of life satisfaction (English, 2000).

In a longitudinal study, Windsor, Anstey, Butterworth, and Rogers (2008) investigated the relationship between negative life events in midlife and perceived control. The study highlighted the importance of approach-avoidance traits both in influencing control beliefs and in controlling the effects of stressful events on control. Their results indicated that the experience of negative life events was associated with weaker control beliefs. Additionally, a behavioral approach was positively related to control which was found to be protective against negative life events that undermine control beliefs.

Vallerand, Templin, Hasenau, & Riley-Doucet (2007) reported that a patient's perceived control over pain was a subjective phenomenon that played an important part in how an individual reacted to pain. Their findings concluded that the patients' knowledge and attitudes about pain and symptom management affected their participation in and acceptance of a particular pain management program, as well as their adherence to therapy regimes (Vallerand et al., 2007).

Other studies by Haythornthwaite, Menefee, Heinberg and Clark (2000) found that patients' perceptions on control over pain, in addition to utilizing specific pain coping strategies, were positively correlated with a positive outcome in chronic pain conditions and in better adjustment. In a study by Vallerand et al., (2007) it was found that perception of control over pain had a significant effect on pain-related distress.

Williams, Golding, Phillips and Towell (2004) investigated the effects of differences in a pre-procedure briefing related to perceived control, and preparatory information on the perceptions of the second of two identical pain situations. Their results concluded that differences between participant groups were related to individual locus of control, and that perceived control should be engendered in clinical situations in which painful procedures were involved (Williams et. al., 2004).

Studies by Jones, Mandy, and Partridge (2000) examined the effect of empowering stroke patients, and found that the extent to which patients perceived they were in control of their own recoveries encouraged them to contribute to their rehabilitation. Bollini, Walker, Hamann, & Kestler (2004) concluded that interventions to enhance perceptions of control and personal control expectancies served to protect individuals from exposure to stressful situations.

In a study by White, Brown, Somers, and Barlow (2006) the authors examined the relationships among anxiety sensitivity, perceived control, and agoraphobia. Their findings indicated that anxiety sensitivity and perceptions of control (both threat and emotional control) were correlated with agoraphobia. Those individuals who perceived themselves to have little control over threatening situations and emotions, and who were fearful of the physical symptoms associated with anxiety, exhibited more phobic avoidance (White et al., 2006).

Moser et al. (2007) examined the relationship between anxiety and perceived control with in-hospital patients who had experienced an acute myocardial infarction. Findings suggested that perceived control had a moderating relationship; when they perceived that control was high, the association between anxiety and in-hospital

complications was weak. When they perceived that control was low, the association between anxiety and in-hospital complications was strong (Moser et al., 2007).

In a study by Velissaris, Wilson, Saling, Newton, and Berkovic (2007), findings concluded that patients who experienced a first-time seizure experienced threats to their sense of control, which, in turn, resulted in changes to their cognitive and behavioral processes. These included feelings of a pervasive loss both of physical and of psychological control as a result of exposure to vulnerability. Findings concluded that at one month, pervasive loss of control, as well as depression and anxiety, were associated with subsequent seizures (Velissaris et al., 2007).

The study also found that gender was most strongly related to perceived loss of control, and suggested that women were more vulnerable to stress following a traumatic event (Velissaris et al., 2007). Additionally, the authors noted that those patients with a previously diagnosed psychiatric history reported a pervasive loss of control, which suggested that patient responses were influenced by susceptibility to stress. Pervasive loss of control was reported more often by older patients (Velissaris et al., 2007).

Studies by O'Donnell, De Soto, & De Soto (1993) suggested that those patients' tendencies to over report symptoms on the NIS may have been more reflective of an affective disturbance, or have been associated more closely with nonorganic impairment. Although the underreporting of symptoms on the NIS may be the result of such psychological and motivational factors (such as a desire to leave treatment, or the reluctance to admit deficits), the tendency to underreport was associated with the more significant, neurologically based anosognosia (Prigatano & Schacter, 1991).

## Impaired awareness and the perception of control

The question remains about whether or not an individual's awareness, impaired or not, affects his or her appraisal of how he or she is able to perceive control over the environment following brain injury. Restated differently, is there a relationship between an individual's ability to acknowledge neurological deficits and the ability to perceive control over one's behavior and his or her environment? Prigatano and Schater (1991) define the concept of self-awareness as the ability to "perceive a situation, object or interaction in a manner similar to others' perceptions, while at the same time maintaining a sense of a private, subjective, or unique interpretation of the experience." (p. 12).

Few research studies have examined the interrelationship between impaired self-awareness the perception of control. From a conceptual standpoint, it is easy to view impaired self-awareness simply as the consequence of cognitive dysfunction that interrupts processes of perception, memory, and a comprehension of the changes in oneself (Hart, 2005). Prigatano (1998) reported that for patients who sustained moderate to severe traumatic brain injury, cognitive dysfunction emerged with an overall disturbance of consciousness and day-to-day recall that manifested in obscuring the patient's self-perception and perception of external reality.

Johnson et al. (2002) discussed the importance of a patient's ability to reflect consciously on one's sense of self as a significant feature of self-awareness and defines a sense of self as "a collection of schemata regarding one's abilities, traits and attitudes, that guides our behaviors, choices and social interactions; the accuracy of one's sense of self will impact ability to function effectively in the world." (p. 1808).

Therefore the question remains, if the sense of self is impaired, rendering the patient unaware, can the patient accurately perceive control over the abovementioned abilities? The importance of determining whether or not the patient exhibits a deficit in awareness would reflect impairment in the ability to perceive accurately his or her ability to guide behavior, choices, and social interactions.

#### CHAPTER 3

#### **METHODOLOGY**

# Participant Data Files

Individuals who were identified for this pilot study were selected from existing archival patient data files located within a private psychological practice in Mechanicsburg, Pennsylvania. The patients were originally recruited by way of self-referral, through family members, physical therapists, physiatrists, psychiatrists, neurologists, primary care physicians, schools, and attorneys. Each archival data file represented an individual patient who participated in an assessment battery with the intention of evaluating his or her current status of neurocognitive functioning.

### Inclusion and Exclusion Criteria

For purposes of this study, each data file consisted of demographic information obtained from the patient's clinical interview, as well as a compilation of his or her neuropsychological assessment measures and resultant diagnosis. Only patient charts that met the criteria for a completed neuropsychological data set were selected. The completed data set included two self-report independent checklists; selected neuropsychological measures addressing specific cognitive domains were identified. Those patients who did not complete both checklists, who completed only one, or who

did not complete the neuropsychological assessment measures identified for this study were excluded from selection.

#### Measures

## Comprehensive Neuropsychological Assessment Battery

Patients who met criteria for the completion of assessment measures outlined for this study were previously administered a neuropsychological battery addressing the cognitive domains of intellect, verbal and visual memory, attention and concentration, visuo-spatial ability, language, and executive functioning. In addition, self-report checklists addressing personality and emotional functioning were also administered. These inventories were selected, based upon the patient's presenting complaint or the referral question. All patients were administered the Perceived Control Across Domains Scale (PCADS; Davis, Freeman & Royer, 2004) and the Neuropsychological Impairment Scale (NIS; O'Donnell, DeSoto, DeSoto & McQ Reynolds, 1993) as a measure of their subjective report of symptoms.

# Perceived Control Across Domains Scale (PCADS)

The Perceived Control Across Domains Scale (PCADS; Davis, Freeman & Royer, 2004) was developed as an untimed, 36-item self-report scale, intended to measure the amount of the patient's perceived control across 17 common areas. Such domains include

food intake, family relationships, work and school relationships, social and close relationships, emotional expression, substance use, self care and health maintenance, activities of daily living, aggressive behavior, self-injurious behavior, finances, thought processes, compulsive and obsessive behaviors, mood state, future, goals, personal influence over his or her environment, and the perceived control of physical discomfort (Davis, Freeman & Royer, 2004).

The PCADS is administered as an untimed, self-report assessment measure, taking approximately 15 minutes to complete. This measure, written at a seventh grade reading level, is composed of six factors encompassing 17 items. The total scoring ranges from zero to a total of 51. A cut-off score of 14 for the average college student would indicate that the individual is within the average range within the population for college students. In addition to an individual score, examination of individual item responses allows the clinician to identify specific areas in which the individual may feel either adequate or feel a loss of control across both cognitive and behavioral domains (Davis, Freeman & Royer, 2004).

#### Psychometric Properties of the PCADS

Test-retest reliability. Statistical analysis demonstrated the fact that items were reliable over time. The PCADS was administered in conjunction with the SOC-3 during its initial administration. During the test-retest which occurred one week later, the participants were administered only the PCADS. Test-retest reliability utilizing Spearman's rho correlation coefficient between total PCADS scores and the total PCADS

retest score was r=.898, p<.000, indicating strong test-retest validity. Correlations between individual items and the corresponding retest scores were found to be statistically significant for all items, with a range from .471 to 1.0 (p<.01).

Face Validity. The items are designed to be face-valid, with each domain clearly identified (i.e., "Goals"). Under each item the individual is able to choose which one of four levels, ranging from zero (almost never having problems within this area) to three (almost always having problems within this area) applies to him or her (Davis, Freeman & Royer, 2004).

# Neuropsychological Impairment Scale (NIS)

The NIS, a self-report, paper-and-pencil inventory consisting of 50 items, is intended to screen and measure the patient's neuropsychological symptoms (NIS; O'Donnell, DeSoto & DeSoto, 1993). There is a long version and short version of the NIS, each designed to rate the patient's subjective complaints on a five-point scale. These range from zero (not at all) to four (extremely). For purposes of this study, the shorter, research edition of the NIS was administered as a screening measure of the patient's neuropsychological complaints and as a supplement to the clinical interview.

The NIS is administered to adults ages 18 and older, and can be read at a fifth-grade reading level or above. Its purpose is to be utilized as an addition to the clinical intake, or to supplement a comprehensive psychological or neuropsychological assessment battery (O'Donnell et al., 1994). Development and the standardization of the NIS is based upon the earlier research and development of the Cognitive Deficit Scale of

the Symptom Checklist 90-Revised (SCL-90-R; Derogatis, 1977) which led to the initial and subsequent versions of the NIS (Leark, 1994). The most recent version of the NIS was developed, based upon a group of patients who were cognitively impaired, postacute, and participating in cognitive rehabilitation. The nonclinical standardization sample (N = 1,000) obtained was grouped demographically according to race, gender and age, based upon the 1995 US Bureau of Census (Leark, 1994).

#### Psychometric Properties of the NIS

Reliability. Split half, internal consistency Cronbach alpha coefficients and test-retest reliability were used to assess reliability. For the neuropsychiatric sample, a coefficient of .93 was found when correcting for attenuation (Leark, 1994). For nonclinical samples, Cronbach alpha internal consistency coefficient values for each scale range from .66 to .95. For the clinical sample, the values range from .67 to .97. Median values for the scales are .79 for the nonclinical group and .86 for the clinical group (Leark, 1994).

Test-retest reliability. Test-retest reliability was achieved by utilizing four different subject groups: Group 1 (college-age subjects) with an average correlation of .90 (ranging from .64 to .98); Group 2 (neuropsychiatric outpatients) yielded an average coefficient of .91 (ranging from .78 to .94); Group 3 (neurological patients) from which reliability coefficients were not reported, and Group 4 (outpatient rehabilitation participants) which averaged .83 (ranging from .72 to .88). The patients were

administered the NIS on two separate occasions, with a time interval of approximately two weeks between each administration.

Construct validity. Construct validity assessed the scale correlations and factor structure of the NIS, and was examined with respect to its internal structure, as well as its convergence with measures asserted to measure constructs of similar areas. The factor structure compares both clinical and nonclinical standardization samples, with relationship patterns found to be similar for both groups (Leark, 1994).

Criterion validity. Criterion validity was measured by looking at convergent measures, screening ability and discriminant analysis. Findings concluded that the NIS is sensitive to cognitive impairments. The NIS's screening effectiveness, encompassing hit rate, sensitivity and specificity compared the GMI (Global Measure of Impairment) scores (≥70) with Halstead Reitan Battery Impairment Indexes (≥ .5). Given this criteria, a .80 hit rate, a sensitivity of .91 and a specificity of .76 was achieved. The classification table outlining the discriminant analysis yielded an overall 90% accurate classification (Leark, 1994).

#### Cognitive Measures

In addition to the two measures of subjective self-report, a comprehensive neuropsychological assessment battery had been administered in order to address the following domains of neurocognitive functioning.

### Measures of Intellect

Wechsler Adult Intelligence Scale—Third Edition (WAIS-III, Wechsler, 1997).

The WAIS-III provides Verbal (subtests include Information, Vocabulary, Similarities, Comprehension, Arithmetic and Digit Span), Performance (subtests include Picture Completion, Block Design, Matrix Reasoning, Picture Arrangement, Digit Symbol and Object Assembly) and Full Scale IQ measures. Factor Scores include Verbal Comprehension, Perceptual Organization, Working Memory and Processing Speed.

Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999). The WASI is designed as a reliable, brief measure of general cognitive ability (Hebben & Milberg, 2002). The WASI provides a Verbal IQ score (subtests of Vocabulary and Similarities), a Performance IQ score (Block Design and Matrix Reasoning) and a Full Scale IQ score.

Because both intelligence measures were selected and administered, depending upon referral question and presenting symptoms, only the Verbal, Performance and Full Scale IQ scores will be utilized as a measure of intellectual ability.

#### Measures of Attention

Symbol Digit Modalities Test (SDMT; Smith, 1991). The SDMT is a task requiring visual scanning and tracking under time demands (90 seconds). The examinee is required to match specific numbers to specific geometric figures, utilizing a reference key as a guide (Hebben & Milberg, 2002). The measure is administered in written and oral format, and has a cut-off time demand of 90 seconds.

Digit Span (DS; Wechsler, 1987; Wechsler, 1997). The Digit Span subtest is a task of short-term auditory sequential memory. The Digit Span subtest is one of the subtests both of the WAIS-III and of the WMS-R. Numbers are read aloud to the examinee who is required to repeat the sequence of digits back to the examiner in the order presented. The amount of repeated numbers increases as the task progresses. The task is also administered in a reverse format, during which the examinee is required to recite numbers of progressively increasing length in a backwards format when presented in a forward order by the examiner. Forward digit span is a measure of elementary attention or span of apprehension; backward digit span is the ability to manipulate information mentally, and requires the additional component of working memory (Hebben & Milberg, 2002).

Trail Making Tests (TMT; Reitan & Wolfson, 1993). Trails A and B are a measure of sustained visual attention, visual scanning, sequencing and cognitive flexibility (Hebben & Milberg, 2002). The first task, Trails A requires the examinee to scan a page and to connect the numbers in numerical sequence accurately, under a time demand. The second task, Trails B, requires the examinee to differentiate between two types of symbols (both numbers and letters), and to alternate from one set of symbols to the other consistently (maintaining attention on two aspects of stimulus situation). This task is also a measure of executive ability.

#### Measures of Executive Function

Wisconsin Card Sorting Test (WCST; Heaton, et al., 1981). The WCST is a measure of the examinee's ability to demonstrate concept formation and abstract reasoning involving flexible problem-solving, the capacity to learn from experience, and perseverative responding.

Category Test (CT; Reitan & Woflson, 1993). For purposes of this study the booklet version of the Category Test was administered by the examiner. The task measures complex concept formation encompassing the ability to note reoccurring similarities and differences in stimulus material, postulate reasonable hypotheses about the similarities and differences, test hypotheses by receiving positive or negative feedback, and to adapt hypotheses based upon the reinforcement following each response. This is also a measure of abstraction, reasoning and logical analysis essential for organized planning. For purposes of this study, individuals were administered either the WCST, CT or both, depending upon referral questions and levels of education.

#### Measures of Verbal Memory Function

Wechsler Memory Scale-Revised (WMS-R; Wechsler, 1987). Both verbal and visual memory tasks were administered. As a measure of verbal memory, the subtest of Logical Memory I requires the examinee to listen and encode paragraph-length information which consists of a few short sentences read aloud, and then to recall the

story to the examiner immediately after it is read. A second story of different content is also read aloud, and the examinee again, is required to encode and recall the information presented orally. Logical Memory II is a measure of verbal retention; the examinee is required to recall both passages after a 30-minute delay. This task yields a score for verbal encoding, recall and retention.

Hopkins Verbal Learning Test—Revised (HVLT-R; Brandt & Benedict, 1991). The HVLT-R is a word-list learning and memory task which consists of a list of 12 nouns, with four items taken from each of three semantic categories (Brand & Benedict, 1991). The task yields a score of total number of words encoded over three trials. A 20-25 minute delay yields a recall and recognition score.

# Measures of Visual Memory Function

Wechsler Memory Scale-Revised (WMS-R; Wechsler, 1987). As a measure of visual memory, the subtest of Visual Reproduction I requires the examinee to examine and encode four stimulus cards presented one at a time for a brief 10-second exposure. The examinee is then required to reproduce each card following exposure of the card. Visual Reproduction II is a measure of visual retention; the examinee is required to reproduce the four cards from memory after a 30-minute delay. This task yields a score for visual encoding, recall and retention.

Rey Complex Figure Test and Recognition Trial (RCFT; Meyers & Meyers, 1995). The RCFT incorporates four trials consisting of a Copy trial, immediate recall (administered at a three minute delay) of the figure, a delayed recall (administered after

30 minutes) and a recognition trial administered directly after the 30-minute delay. The task measures visuospatial recall and recognition memory, processing speed and visuo-constructional skill (Hebben & Milberg, 2002). The components of the three-minute delay, 30-minute delay, and recognition trial were used as a measure of visual memory.

#### Measures of Language Function

Controlled Oral Word Association Test (COWAT; Benton & Hamsher, 1989). The COWAT is a task that measures the examinee's ability to produce individual words which belongs to a particular class identified by a letter (Hebben & Milberg, 2002). The task requires the individual to generate as many words as possible within a one-minute interval. Two forms are used; one utilizes the letters of F, A, and S; the second form utilizes the letters C, F, and L. As a measure of categorical and semantic fluency, the examinee is required to generate as many words as possible that belong to a particular category under a one-minute time demand. For this data, the category of Animals was utilized. The COWAT is also a measure of executive ability.

#### Measures of Spatial and Constructional Skills

Judgment of Line Orientation (JOLO; Benton, et al., 1994). The JOLO is a measure of spatial perception, orientation and visual-spatial judgment. The examinee is required to identify and match angled lines to a stimulus card which details a multinumber radii arranged in a semicircle (Hebben & Milberg, 2002).

Rey Complex Figure Test and Recognition Trial (RCFT; Meyers & Meyers, 1995). The copy trial was utilized as a measure of complex visuospatial and constructional skills. The delay components of the RCFT included a three-minute delay, a 30-minute delay, and a recognition trial; these were used as a measure of visual memory for the study.

## Measures of Emotional and Personality Functioning

Because the presenting concerns and referral question dictated the measure of emotional functioning to be utilized, the following self-report checklists were administered to examinees:

Beck Depression Inventory—II (BDI; Beck, Steer & Brown, 1996). The BDI is a face-valid, self-report inventory consisting of 21 statements which identify common symptoms of depression and severity of symptoms (Hebben & Milberg, 2002).

Beck Anxiety Inventory (BAI; Beck & Steer, 1993). The BAI is a face-valid, self-report inventory consisting of 21 statements which identify common symptoms of anxiety and their level of severity (Hebben & Milberg, 2002).

Minnesota Multiphasic Personality Inventory—2 (MMPI—2; Butcher, Dahlstrom, Graham, Tellegen, & Kaemmer, 1989). The MMPI—2 is a broad-range personality inventory comprising 567 true-false statements. The measure is intended to screen for psychopathology and assess the major symptoms of social and personal maladaptive behaviors in individuals age 18 and older (Hebben & Milberg, 2002).

Millon Clinical Multiaxial Inventory—III (MCMI—III, second edition; Million, Davis & Million, 1997). The MCMI—III is a broad-range 175 item inventory assessing personality and Axis I disorders, in individuals 18 and older. The test is designed to assess the patient's long-term personality characteristics and his or her interaction with the patient's presenting clinical symptoms (Millon, Davis & Millon, 1997).

#### Procedures

#### Data collection

Data utilized for this study was collected from identified archival patient files that had been assessed at a private practice during a period of four years. Each data file met the criteria for the complete neuropsychological assessment battery identified for this study. A letter of permission from the Clinical Director allowed the researcher access to patient files, including demographic information and a summary of the completed assessment data. For purposes of inter-rater reliability, the facility's Clinical Director reviewed each patient's chart to ensure that each individual met the criteria for the complete data set identified for the research study.

A summary sheet located in each archived patient file outlined raw scores, T-scores and percentile ranks for each neuropsychological measure and checklist, and was photocopied by a staff assistant who worked within the facility. For ease of comparison, only T-scores were entered for statistical analyses. All data was entered by the researcher.

All identifiable information such as the patient's name, date of birth, referral source, and occupation were blacked out from the photocopied page for each file.

Unidentifiable demographic information including presenting complaint, age, education, gender, and diagnosis was entered into a statistical program for data analysis.

Each summary sheet was assigned a subject number before data was entered to ensure confidentiality.

For those patient files which had two sets of assessment scores (test-retest), only the initial set of data from the first assessment was utilized for this study. All archival patient charts were returned to their original file cabinet after use. All charts were secured in order to ensure confidentiality of all patient data and assessment materials.

## The assessment process for archival data files

For each archived data file, a clinical interview had been previously conducted by a licensed psychologist, who determined the assessment measures that would be appropriate to address the patient's presenting complaints and referral questions.

Following the clinical interview, a doctoral-level psychology intern administered the neuropsychological assessment battery as outlined by the supervising psychologist.

At the onset of the test administration, patients routinely and independently filled out two standardized self-report measures. These allowed them to identify and evaluate the severity of neuropsychological symptoms, as well as to self-appraise their perceptions of overall functioning across several domains of daily living.

Following the completion of these checklists, a comprehensive neuropsychological assessment was administered to appraise cognitive domains. These included an evaluation of intellect, attention and concentration, executive functioning, visual and verbal memory, memory retention, visual-spatial ability and language, as well as selected emotional and functional self-report checklists.

Following completion of the assessment, all protocol scoring was completed by a doctoral-level intern and outlined on a summary sheet. The final scores were reviewed

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by the licensed psychologist who determined the patient's diagnosis and outlined treatment recommendations.

#### CHAPTER 4

#### RESULTS

A total of N=85 participant files selected (in chronological order) from archival data were identified for this study. The demographic breakdown for the study follows below.

## Demographics

A total of 44 males represented 51.8 percent of the data. A total of 41 females represented 48.2 percent of the data files. Selected participants ranged in age from 18 years to 71 years. The mean age was 45.2 with a standard deviation of 8.6. The mean education for the data set was 14.83 with a standard deviation of 3.00. The minimum level of education in years was 8 years. The maximum level of education for the data set was 22 years.

Participant files (n = 25) that contained the WAIS-III assessment measure yielded a mean Full Scale IQ score of 105.7 with a standard deviation of 15.5. The minimum Full Scale IQ was 80; the maximum Full Scale IQ was 136. Participant files (n = 58) that contained the WASI assessment measure yielded a mean IQ score 105.9 with a standard deviation of 15.1. The minimum Full Scale IQ was 65; the maximum Full Scale IQ was 128.

# Presenting Complaints

Approximately one-third of patient data files selected presented with complaints of different severity levels of traumatic brain injury. Table 1 outlines the breakdown of patient complaints at the time of the referral.

Table 1
Frequency Distribution of Patient Presenting Complaints

	The state of the s	
Presenting Complaint	Number	%
Traumatic Brain Injury	33	38.8
Acquired Brain Injury	21	24.7
Memory/Dementia	14	16.5
Developmental	12	14.1
Psychiatric	5	5.9
Total	85	100

# Diagnoses

Following a neuropsychological evaluation, approximately one-third of patient data files that were identified met the criteria for traumatic brain injury. Table 2 outlines the breakdown of patient diagnoses (derived from the neuropsychological report).

Table 2
Frequency Distribution of Patient Diagnoses

Presenting Complaint	Number	%
Traumatic Brain Injury	30	35.3
Acquired Brain Injury	10	11.8
Memory/Dementia	22	25.9
Developmental	14	16.5
Psychiatric	9	10.6
Total	85	100

## Hypotheses and Findings

In assessing a patient's ability to report symptoms accurately (as measured by the Neuropsychological Impairment Scale), as they relate to domains of neurological impairment (as measured by neuropsychological tests) and the ability to accurately evaluate accurately how well there is (sense of) control over (behavior and) environment (as measured by the Perceived Control Across Domains Scale), the following hypotheses were outlined.

Because of multiple comparisons, a Bonferroni Correction was run to guard against inflation of the experiment-wise alpha (a/n, where n denotes the number (maximum number) of comparisons; for this study, 15). Thus, .05 alpha divided by 15 = 0.003 or (rounded to) 0.01. Thus, the alpha level was set at .01 as a threshold for significance.

#### Hypothesis # 1

Lower scores on self-report of neurological impairment (as measured by the Neuropsychological Impairment Scale) will be associated with higher levels of global cognitive ability as measured by standardized assessment. An ANOVA addressed the relationship between the NIS total score and cognitive assessment measures of Trails A (F = .311), (and) Trails B (F = .678). A Pearson Product Moment Correlation addressed perseverative responses on the Wisconsin Card Sorting Test (r = .038), Symbol Digit

Modalities Test Oral (r = -.128) and Written (r = .170), and Full Scale IQ (r = .030). No significant relationship was found between these variables, p > .01.

### *Hypothesis* # 2

Higher scores on self-report of neurological impairment (as measured by the Neuropsychological Impairment Scale) are associated with greater memory impairment. A Pearson correlation addressed the relationship between the total NIS score and memory subtests of the WMS-R: both Verbal Retention (r = .071), and Visual Retention (r = .069), and recall scores of the RCFT: both three-minute (r = .180) and thirty-minute (r = .089) delay tasks. No significant relationship was found between these variables, p > .01.

#### Hypothesis # 3

Higher scores on self-report of neurological impairment (as measured by the Neuropsychological Impairment Scale) are associated with greater language impairment. A Pearson correlation addressed the relationship between the NIS total score and verbal memory subtests of the HVLT-R: Retention (r = -.059) and Recall(r = -.145) tasks and scores on the verbal tasks of the COWAT (r = -.094) and Semantic Fluency (r = -.057). No significant relationship was found between these variables, p > .01.

# Hypothesis # 4

Higher scores on self-report of neurological impairment (as measured by the Neuropsychological Impairment Scale) are associated with greater visual spatial and constructional impairment. A Pearson correlation addressed the relationship between the NIS total score and spatial tasks consisting of the RCFT Copy task (r = -.057), Judgment of Line Orientation (r = -.017) and the WASI Performance IQ score (r = .062). No significant relationship was found between these variables, p > .01.

## *Hypothesis* # 5

Intellectual functioning moderates self-report symptoms of neurological impairment and overall global cognitive ability. A Partial Correlation was performed for the number of perseveratory responses on the WSCT (r = .0082), Symbol Digit Modalities Test: Written (r = -.0503) and Oral (r = -.0700) while controlling for WASI Full Scale IQ scores. All were found to be non-significant (p > .01).

# Hypothesis # 6

Lower scores on self-report on domains of perceived control (as measured by the Perceived Control Across Domains Scale) will be associated with higher levels of global cognitive ability as measured by standardized assessment. An ANOVA addressed the relationship between the PCADS total score and cognitive assessment

measures of Trails A (F = .311), Trails B (F = .678). A Pearson correlation addressed perseverative responses on the Wisconsin Card Sorting Test (r =.-.142), Symbol Digit Modalities Test Oral (r = -.046) and Written (r = .058), and Full Scale IQ (r = .083). No significant relationship was found between these variables, p > .01.

# Hypothesis #7

Higher scores of self-report on domains of perceived control (as measured by the Perceived Control Across Domains Scale) are associated with greater memory impairment. A Pearson correlation addressed the relationship between the PCADS total score and memory subtests of the WMS-R: both Verbal Retention (r = .099), and Visual Retention (r = .033), and recall scores of the RCFT: both three-minute (r = .080) and thirty-minute (r = .082) delay tasks. No significant relationship was found between these variables, p > .01.

# *Hypothesis* #8

Higher scores on self-report on domains of perceived control (as measured by the Perceived Control Across Domains Scale) are associated with greater language impairment. A Pearson correlation addressed the relationship between the PCADS total score and verbal memory subtests of the HVLT-R: Retention (r = -.001) and Recall

(r = -.076) tasks, and scores on the verbal tasks of the COWAT (r = -.067) and Semantic Fluency (r = -.018). No significant relationship was found between these variables, p > .01.

# Hypothesis #9

Higher scores on self-report on domains of perceived control (as measured by the Perceived Control Across Domains Scale) are associated with greater visual spatial and constructional impairment. A Pearson correlation addressed the relationship between the PCADS total score and spatial tasks consisting of the RCFT Copy task (r = -.141), Judgment of Line Orientation (r = -.025), and the WASI Performance IQ score (r = -.001). No significant relationship was found between these variables, p > .01.

# Hypothesis # 10

Intellectual functioning moderates self-report symptoms of perceived control and overall global cognitive ability. A Partial Correlation was performed for the number of perseveratory responses on the WSCT (r = -.0277), Symbol Digit Modalities Test: Written (r = -.0350) and Oral (r = -.0456) while controlling for WASI Full Scale IQ scores. All were found to be non-significant (p > .01).

# Hypothesis # 11

There is an association between higher scores of self-report on the Neurological Impairment Scale and higher scores on the Perceived Control Across Domains Scale, indicating that patients would accurately perceive themselves as having little personal control over their lives, concurrently with brain injury. A One-Way ANOVA indicated no significance between total scores of the PCADS and NIS (F = .183, p > .01). The two scales were positively correlated (r = .635, p < .01).

#### CHAPTER 5

#### DISCUSSION

# Summary

This study examined a sample of patients from archival data files, who previously presented with brain diseases and disorders of varying magnitudes of impairment. Each patient had been referred to a clinical practice for an evaluation of his or her neuropsychological functioning. A total of 85 patient files were selected, based upon a completed data set for the study.

Patients were divided according to presenting complaints and final diagnoses. The first group was composed of individuals who had sustained traumatic brain injuries as results of being involved in a motor vehicle accident, pedestrian accidents, falls resulting in head injury, and mild, to moderate and severe TBI. The second group was composed of patients who were referred for vague neurological complaints and neurocognitive difficulties including seizure disorders, anoxic events, aphasia, tumors and cerebral vascular accidents.

The memory and dementia group were referred for general and vague memory concerns and complaints, patients who had multiple sclerosis, and cognitive complaints because of possible dementia due to significant and previous alcohol abuse. Those adults, who were categorized as having problems associated with developmental concerns, reported problems with attention, concentration and focus, or had a prior diagnosis of

attention disorders or disorders within the autistic spectrum. The remaining patients were those who presented with psychiatric complaints, including Bipolar, Schizophrenia (medication managed), anxiety and depression.

The purpose of the study was to explore whether or not a relationship would be found between the patients' self-reports of perceived control (as measured by the Perceived Control Across Domains [PCADS]), and their self-appraisals of neuropsychological symptom severity (as measured by the Neuropsychological Impairment Scale [NIS]), when compared with their actual assessment scores following brain injury.

The author was interested in investigating the relationship between patients' subjective self-reports as predictors of neuropsychological functioning. Findings concluded the patients' self-appraisals on measures of self-report of neurological symptoms and levels of severity, as well as the patients' perceptions of control over behaviors and their environments, did not allow the predictions of patient performances on standardized assessment measures. No consistency was found on checklists scores and test performances within groups. Although some patients achieved better scores than they expected, despite their self-reports to the contrary, others achieved poorer results when compared with their own standardized assessment scores.

Total scores from the patients' self-endorsed checklists were compared with their actual test scores across several cognitive areas of neuropsychological functioning, including memory and attention, executive ability, and visual spatial constructional abilities. From a statistical standpoint, because of multiple comparisons, a Bonferroni

Correction was run to in order to guard against the inflation of the experiment-wise alpha; hence the alpha level was set at .01 as a threshold for significance.

# Hypotheses Findings

The first hypothesis investigated whether or not lower scores (indicating that the patient reported little to no impairment) on a self-report measure of neurological impairment (as measured by the NIS), would be associated with higher levels of overall cognitive ability. An ANOVA was performed to compare the patients' assessment scores on Trails A, Trails B. A correlational analysis was performed on the number of perseverative responses on WCST, and the SDMT (both written and oral). The results found no significant relationship between the patients' self-reports of little to no impairment in neurological symptoms as predictors of higher levels of overall global cognitive impairment.

The second hypothesis investigated whether or not higher scores on the NIS (indicating the patient reported greater levels of neurological symptom severity) would be correlated with greater memory impairment. A Pearson Correlation was performed to compare patients' self-reports with assessment scores as measured by the visual and verbal memory retention scores of the WMS-R, and the 3-minute, and 30-minute recall scores of the RCFT. The results found no significant relationship between patients' reports of greater neurological difficulties as predictors of greater memory impairment.

The third hypothesis investigated whether or not higher scores on the NIS (indicating greater levels of neurological symptom severity) would be associated with

greater impairment in language. A Pearson Correlation was performed to compare patients' self-reports with assessment scores retention and recall tasks of the HVLT-R, and the scores on the COWAT, FAS and semantic fluency tasks. No significant relationship was found between patients' self-reports of greater neurological difficulties as predictors of greater language impairment.

The fourth hypothesis addressed the relationship between patients' higher scores on self-reports of neurological impairment, and whether or not their reports of greater impairment would be associated with greater impairment on tasks measuring visual spatial and constructional ability. A Pearson Correlation was performed to compare patients' subjective reports of greater impairment, and the RCFT copy task, JOLO, and the Performance IQ scores on intellectual measures. Results found no significant relationship between patients' self-reports of greater neurological impairment as predictors of greater impairment in visual spatial and constructional ability.

The fifth hypothesis examined patients' overall self-reports of neurological impairment and the relationship to overall global cognitive ability when controlling for education. A Partial Correlation was performed while controlling for IQ. Results indicated that the patients' responses were not moderated by IQ when partialed-out.

The sixth hypothesis investigated whether or not lower scores (indicating that patients' perceived themselves to have more control) on the PCADS would be associated with higher levels of global cognitive ability when compared with standardized assessment scores. An ANOVA was performed to compare the patients' assessment scores on Trails A, Trails B. A correlation was performed on the number of perseverative responses on WCST and on the SDMT (both written and oral). Our results found no

significant relationship between the patients' self-reports of little to no control over their environments as predictors of higher levels of overall global cognitive impairment.

The seventh hypothesis investigated whether or not higher scores on the PCADS (indicating that patients felt less control over their behavior and environment) were associated with greater memory impairment. A Pearson Correlation was performed to compare patients' self-reports of the amount of control that was perceived with assessment scores, as measured by the visual and verbal memory retention scores of the WMS-R, and the 3-minute, and 30-minute recall scores of the RCFT. The results found no significant relationship between patients' reports of minimal to no control reports as predictors of greater memory impairment.

The eighth hypothesis investigated the relationship between higher scores on the PCADS and greater language impairment. A Pearson Correlation was performed to compare patients' self-reports with assessment scores retention and recall tasks of the HVLT-R, and the scores on the COWAT, FAS and semantic fluency tasks. No significant relationship was found between patients' self-reports of little to no control as predictors of greater language impairment.

The ninth hypothesis investigated whether or not a relationship would be found between higher scores on the PCADS and greater impairments in visual spatial and constructional abilities. A Pearson Correlation was performed to compare patients' subjective reports of greater impairment, and the RCFT copy task, JOLO, and the Performance IQ score on intellectual measures. Results found no significant relationship between patients' self-reports of minimal to any control as predictors of greater impairment in visual spatial and constructional abilities.

The tenth hypothesis addressed whether or not intellectual functioning moderated self-report symptoms and global cognitive abilities. Partial correlations were accomplished to determine the relationship between for the PSV total on the WCST, the SDMT (Written and Oral) and the NIS total scores when controlling for IQ. All were non-significant (p > .01).

The eleventh and final hypothesis investigated whether or not the difference in self-reports addressing the domains of perceived control would differ, based upon gender, age or diagnosis. No significant differences were found, based upon these findings.

## Limitations of the study

Because this was an exploratory study utilizing existing data, the most obvious limitation to the study was the sample size. We were not able to achieve sufficient statistical power. A larger number of subjects may have contributed to a larger statistical power; however, not all patient charts met the completed data set when selected for the study. This was due predominantly to the individualized assessment protocol designed according to patient complaint and age; therefore, some measures were not utilized.

Additionally, it should be noted that the correlations were found to be extremely low. Had adequate power been achieved, the correlations may have been statistically significant, but not clinically significant (for example, r = .20 would account for approximately 4% of the sample).

Another limitation was the heterogeneity of the sample. Diagnostic categories representing the patients' presenting complaints and final diagnoses were representative

of that which one would expect to find in a clinical practice. However, there was considerable heterogeneity within each category. Additionally, not all disorder were represented equally within each category. For example, some clients were involved in litigation involving lawsuits related to job injuries. Studies report that malingering is an important factor of concern for patients involved in personal injury litigation, or other scenarios in which benefits for compensation or disability are awarded (Nicholson & Martelli, 2007). For this reason, generalizability of results would also a factor.

Different ethnicities were not identified in the study. This was due predominantly to the use of existing data, on which ethnic demographics were not noted on the assessment protocols.

# Implications for research in the field of psychology

Although the findings of this study were reported as not being significant, some implications for the future research in the field were noted. First, the representative sample clientele examined for this study is a more representative group of the kind of patients that many neuropsychologists might encounter in private practice, unless there is a specialization of a particular disorder or disease.

The study did not find an expected discrepancy in scores as a predictor of the patient's perception of cognitive impairment. Rather, the study found that patients did not reliably predict their own level of cognitive impairment on self-report measures. This was surprising, given the literature on the assessment of patients with deficits following neurological insult. Research indicates that the most conventional manner in which to

measure patient awareness of self is through the comparison of the patient's self-report with standardized neuropsychological measures (Flashman & McAllister, 2002; Fleming et al., 1996; Toglia & Kirk, 2000). Findings concluded that patients with deficits in awareness tend to rate their abilities as better than the standard, and the discrepancy between the self-perception of abilities and actual scores is said to be the measure of the level of unawareness (Hart et al., 2004; Sherer, et al., 1998b).

More studies utilizing the PCADS in different sample populations would be beneficial. There is also the possibility that the construct of perceived control in assessing a patient's level of impairment may be minimally associated or completely unrelated.

Also, the question arises about whether or not the presence of severe cognitive impairment is or is not related to how intensely a patient is able to perceive a sense control over behaviors and personal environments. Studies by Thompson on perceived control (1981) emphasized the fact that control needs only to be perceived in order to be effective. Given these patients' inability to predict their own levels of impairment reliably, this fact may not hold true for patients with neurological insult.

Toglia and Kirk (2000) described metacognitive knowledge as declarative knowledge concerning one's own abilities. Disruption of these functions have been found to interrupt the ability to appraise one's abilities accurately, including the ability to obtain a sense of control over his/her behaviors and the environment Therefore, it is also possible that the PCADS would be more appropriately utilized as a more sensitive evaluative measure for complex metacognitive processes. This might include such higher-level metacognitive functions as the ability to self-appraise one's feelings about one's own behaviors and across domains of everyday living.

The need for accurate psychological assessment is imperative, given the importance of evaluating not only the patient's level of functioning, but also the patient's perception of his or her ability to control and manage the environment. This discrepancy between a patient's perception of his or her behaviors, abilities and management of the environment compared with his or her actual ability has been seen, for example, in individual who have been referred for neuropsychological assessment to return to work or resume driving activities.

With the rising cost of insurance, companies have encouraged modified assessment protocols which focus on a minimal number of assessment measures, relying heavily on clinical interviews. The use of structured interviews relies heavily on the patients' abilities to comprehend questions verbally, and to convey their understanding of their deficits verbally (Flashman & McAllister, 2002). Given the findings of this study, if patients are unable to report symptoms reliably, or to perceive their levels of control over daily functions unreliably, the question remains about how clinicians can reliably diagnose them. The need for structured self-report measures and a robust neuropsychological battery accessing domains of cognitive abilities is imperative for the accurate assessment, diagnosis, identification of functional limitations and recommendations for rehabilitation and treatment.

# Cognitive Behavioral Therapy

Although no relationship was found for the NIS and the PCADS to predict scores on cognitive measures, both checklists could easily be utilized within the assessment

setting to assist not only with reporting neurological symptom severity, but also with reporting the patients' thoughts about the amount of security they feel in controlling their environments following neurological insult. Within the assessment setting, not only would the checklists provide additional information to supplement the clinical interview, but also give a subjective overview to supplement patient complaint not otherwise mentioned or questioned by the clinician.

Research suggests that impaired self-awareness was related to treatment outcome, length of stay, treatment compliance, and the establishment of a working alliance in therapy (Anderson et al. 1999; Prigatano 2005). Sherer and his colleagues (1998b) reported that the functional outcomes of treatment objectives were impeded by the patient's inability to choose appropriate long-term goals accurately because of deficits in awareness. As a result of incompatible goals, patients often experience repeated failures over time which increases their level of frustration (Prigatano, 2005).

Within the therapeutic arena, the establishment of a strong therapeutic alliance during psychotherapy could be established more quickly when patients have the chance to fill out checklists that address subjective experience and complaint This would also provide a segue into conversation about such thoughts that may not readily be apparent during the first few sessions.

In both cases, the information garnered from these checklists would assist in creating effective treatment plans that are specific to the problematic domains reported by the patient. Beyond the treatment plan, both checklists could be utilized for periodic

reevaluation in order to determine whether or not patients were making progress over time, both in their subjective evaluations of symptom reports, and in the perceptions of their regained control over their environments.

### Future Directions

The current study examined some of the issues involved in this type of exploratory study within a clinical practice. It would be beneficial to design a study that would incorporate a larger sample size. Further, it may be more advantageous to study one group at a time, in which patients were equally represented across groups. This, in turn, this would promote more effective generalizability. Additionally, because demographics for age, gender and education were incorporated, more cross-cultural studies are needed; therefore, it would be beneficial to observe different ethnic groups within the various groups of patients who sustain neurological insult.

#### **PCADS**

# (Perceived Control Across Domains Scale)

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Instructions for completing the Perceived Control Across Domains Scale: After carefully reading each group of statements, circle the response (0,1,2, or 3) that best describes the way you feel.

#### 1. Activities of daily living: I almost never have problems doing things for myself such as eating, 0 dressing, or bathing. I sometimes have problems doing things for myself such as eating, 1 – dressing, or bathing. I often have problems doing everyday activities for myself such as eating, 2dressing, or bathing. I almost always have problems doing everyday activities for myself such 3 – as eating, dressing, or bathing. 2. Self care: -0I am always careful about my health. I am often careful about my health. 1 – I sometimes am careful about my health. 2-I am never careful about my health. 3 -3. Goals: 0 -I almost never have problems achieving my goals. I sometimes have problems achieving my goals. 1 -I often have problems achieving my goals. 2-3 – I almost always have problems achieving my goals. 4. Food intake: I never have problems with the amount of food I eat. 0 -

- 1 I often have problems with the amount of food I eat.
- I sometimes have problems with the amount of food I eat. 2-
- I almost always have problems with the amount of food I eat. 3 –

#### 5. Substance use:

- 0 I never have problems with drug or alcohol use.
- 1 I sometimes have problems with drug or alcohol use.
- 2 I often have problems drug or alcohol use.
- 3 I almost always have problems with drug or alcohol use.

#### 6. Thought processes:

- 0 I almost always change the way I think, if doing so would help me.
- 1 I often change the way I think, if doing so would help me.
- 2 I sometimes change the way I think, if doing so would help me.
- 3 I never change the way I think, even if doing so would help me.

# 7. Aggressive behavior:

- 0 I never think of myself as aggressive.
- 1 I sometimes think of myself as aggressive.
- 2 I often think of myself as aggressive.
- 3 I almost always think of myself as aggressive.

#### 8. Future:

- 0 I always think of myself as optimistic.
- 1 I often think of myself as optimistic.
- 2 I sometimes think of myself as optimistic.
- 3 I almost never think of myself as optimistic.

## 9. Emotional expression:

- 0 I never have problems like yelling or throwing things when I'm angry or frustrated.
- 1 I sometimes have problems like yelling or throwing things when I'm angry or frustrated.
- 2 I often have problems like yelling or throwing things when I'm angry or frustrated.
- 3 I almost always have problems like yelling or throwing things when I'm angry or frustrated.

## 10. Family relationships:

- 0 I never have problems with family relationships.
- 1 I sometimes have problems with family relationships.
- 2 I often have problems with family relationships.
- 3 I almost always have problems with family relationships.

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- 0 I never have thoughts, images, or impulses that I can't put a stop to.
- 1 I sometimes have thoughts, images, or impulses that I can't put a stop to.
- 2 I often have thoughts, images, or impulses that I can't put a stop to.
- 3 I almost always have thoughts, images, or impulses that I can't put a stop to.

# 12. Work/school relationships:

- 0 I almost never have problems with people at work or school.
- 1 I sometimes have problems with people at work or school.
- 2 I often have problems with people at work or school.
- 3 I almost always have problems with people at work or school.

# 13. My environment:

- 0 I almost always think I am able to influence people around me.
- 1 I often think I am able to influence people around me.
- 2 I sometimes think I am able to influence people around me.
- 3 I never think I am able to influence people around me.

# 14. Self-injurious behavior:

- 0 I never have problems with wanting to harm myself.
- 1 I sometimes have problems with wanting to harm myself.
- 2 I often have problems with wanting to harm myself.
- 3 I almost always have problems with wanting to harm myself

# 15. Social relationships:

- 0 I almost never have problems with people when I'm in a social situation.
- 1 I sometimes have problems with people when I'm in a social situation.
- 2 I often have problems with people when I'm in a social situation.
- 3 I almost always have problems with people when I'm in a social situation.

## 16. Physical sensations:

- 0 I always am able to relieve physical discomfort when I have it.
- 1 I often am able to relieve physical discomfort when I have it.
- 2 I sometimes am able to relieve physical discomfort when I have it.
- 3 I rarely am able to relieve physical discomfort when I have it.

#### 17. Finances:

- 0 I never have problems with spending too much money.
- 1 I sometimes have problems with spending too much money.
- 2 I often have problems with spending too much money.
- 3 I almost always have problems with spending too much money.

Name:	Date:	

#### N.I.S.

Below is a list of problems which some people have. Some of them describe their experiences during the past few days or weeks. Others refer to their life-time experiences. Please read each one carefully and ask yourself how much that statements applies to you. Then, to the left of that statement, circle the number that shows how much the statement applies to you, from "Not At All" to "Extremely." Answer every item to the best of your ability. Do not spend a great deal of time on any one item.

Responses: 0 = Not at all; 1 = A little bit; 2 = Moderately; 3 = Quite a bit; 4 = Extremely.

0	1	2	3	4		1. I am forgetful.
0	1	2	3	4		2. I bump into things.
0	1	2	3	4		3. I get tired easily.
0	1	2	3	4	~	4. My mind works slowly.
0	1	2	3	4		5. My hearing has become worse.
0	1	2	3	4		6. I have trouble writing sentences.
0	1	2	3	4		7. I often feel sad and blue.
0	1	2	3	4		8. My words get mixed up.
0	1	2	3	4		9. I have trouble following conversations.
0	1	2	3	4		10. I like everyone I know.
0	1	2	3	4		11. I check and double check everything I do.
0	1	2	3	4		12. I faint sometimes.
0	1	2	3	4	_	13. Part of my body is paralyzed.
0	1	2	3	4		14. I drop things frequently.
0	1	2	3	4		15. I have serious memory problems.
0	1	2	3	4		16. I have trouble walking.
0	1	2	3	4		17. I feel quite discouraged about my future.
0	1	2	3	4		18. My eyesight has become worse.
0	1	2	3	4		19. I have trouble getting organized.
0	1	2	3	4		20. I am always right.
0	1	2	3	4		21. I forget what I'm saying.
0	1	2	3	4		23. My thinking becomes blocked.

# PERCEIVED CONTROL AND SELF-AWARENESS 80

0 1 2 3 4	24. I fall down sometimes.
0 1 2 3 4	25. I have forgotten many things which happened in my childhood.
0 1 2 3 4	26. My hands shake and tremble.
0 1 2 3 4	27. I tend to worry all the time.
0 1 2 3 4	28. My muscles twitch and jump.
0 1 2 3 4	29. I am very clumsy.
0 1 2 3 4	30. I am always happy.
0 1 2 3 4	31. I have trouble with the left side of my body.
0 1 2 3 4	32. I have trouble learning new things.
0 1 2 3 4	33. I get confused easily.
0 1 2 3 4	34. I often lose things.
0 1 2 3 4	35. I have forgotten much of what I have learned in school.
0 1 2 3 4	36. My mind frequently goes blank.
0 1 2 3 4	37. I think about death and dying often.
0 1 2 3 4	38. My health is getting worse.
0 1 2 3 4	39. I have difficulty making decisions.
0 1 2 3 4	40. I always do the right thing.
0 1 2 3 4	41. My speech has become worse.
0 1 2 3 4	42. I feel frustrated quite often.
0 1 2 3 4	43. I have trouble spelling.
0 1 2 3 4	44. I have a hard time remembering people's names.
0 1 2 3 4	45. I have been knocked unconscious.
0 1 2 3 4	46. Part of my body feels numb.
0 1 2 3 4	47. I often feel lonely and isolated.
0 1 2 3 4	48. I have had a head injury.
0 1 2 3 4	49. My handwriting has become worse.
0 1 2 3 4	50. I always tell the truth.

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