

Awareness of Neurobehavioral Deficits and Emotional Adjustment in
Acute- and Post-Acute Rehabilitation Following Traumatic Brain Injury

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Abstract

This dissertation examined injury-based and emotional adjustment factors that may influence an individual's self-awareness of neurobehavioral deficits following traumatic brain injury (TBI). Two studies were completed to examine these issues in acute and post-acute rehabilitation settings using the reports of TBI patients and their significant-others. In Study 1, the Patient Competency Rating Scale (PCRS) and Self-Awareness of Deficits Interview were used to assess the patients' awareness of deficit, while the Profile of Mood States and the Grief Experiences Inventory were used to assess emotional adjustment. Six patients and significant-others were followed weekly during the course of inpatient rehabilitation, and were seen approximately one month after their discharge from hospital. While individual variability was observed, most patients reported minor changes in their level of competence and limited emotional distress. The individual perceptions of patients and of significant-others were generally consistent over the course of inpatient care, and variations in patients' emotional adjustment appeared to be reasonable reactions to circumstantial factors. The emotional adjustment of significant-others varied considerably among the individuals assessed, and this variability likely influenced their ratings of the patient. Staff ratings of the patients were also collected, and identified improvements in functional abilities over time. These results suggest that patient awareness is not a prerequisite for rehabilitation success. A lack of applied or practical experiences may also influence patients' ability to accurately rate their self-competence during the acute phase following TBI.

Study 2 examined 166 individuals referred for post-acute rehabilitation, using the PCRS and the Katz Adjustment Scale (KAS-R) to assess awareness and emotional

adjustment. Patients with a history of moderate and severe TBI showed good awareness of their abilities, based on PCRS Discrepancy Scores, while patients with mild TBI were likely to report greater impairments than observed by significant-others. TBI patients showed significant emotional adjustment difficulties on the KAS-R, regardless of the severity of their injury, and there was a strong positive association between patients' acknowledgement of neurobehavioral problems and ratings of their emotional adjustment. General intellectual ability was also strongly related to patients' report of difficulties, such that low IQ and poor emotional adjustment were associated with low ratings of self-competence. On the other hand, the general location of cerebral trauma was not strongly associated with deficits in awareness. Thus, the nature and severity of TBI appeared to be less important than IQ and emotional adjustment in the post-acute rehabilitation patients, although mildly injured patients are more likely to report neurobehavioral deficits than moderate or severely injured patients. Strengths and weakness of the self-other discrepancy approach to measuring self-awareness were considered, and a robust approach to awareness assessment, based on multiple measures, is recommended. Available options include structured interviews, self-report, clinical observation, or objective testing. Furthermore, the emotional adjustment of the patient appeared to become increasingly salient in the assessment of awareness during the post-acute phase, compared to the acute phase of recovery from TBI, where significant-other adjustment may be quite relevant.

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Dedication

This dissertation is dedicated to my parents and family, the Brulot family, and especially to Magali Brulot.

Introduction

Factors affecting recovery and neuropsychological rehabilitation following traumatic brain injury (TBI) have received increasing attention in recent years. The importance of this research is highlighted by brain injury incidence estimates ranging between 500 000 and 1.9 million per year in North America (Thurman & Guerrero, 1999), and by the recent emphasis on empirically- and ecologically-valid rehabilitation interventions. Of the wide range of problems that can emerge following TBI, deficits involving patients' awareness of the nature of the injury, awareness of particular symptoms, or awareness of the implications of the injury, pose particular challenges to rehabilitation. Such deficits can negatively impact patients' participation in rehabilitation, psychosocial adjustment, and vocational outcome (Trudel, Tryon & Purdum, 1998). Clearly the personal, social, and economic implications of impaired awareness following TBI can be significant. Although there is an emerging literature on awareness issues, the relationships between injury severity, emotional adjustment factors, and awareness of deficits have not been fully appreciated or explored. Furthermore, little is known about changes in awareness over time, especially during the acute care period following head trauma.

This dissertation will briefly review the clinical and experimental literature concerning awareness deficits, and describe neurocognitive and psychological models of this phenomenon. Consideration will be given to awareness deficits as part of a dynamic recovery process following TBI, occurring in both acute- and post-acute phases of rehabilitation, with a focus on injury severity factors and emotional adjustment factors. Study 1 presents a detailed case-series of acute-care TBI patients and their significant-others, with a focus on issues of awareness of deficit and emotional adjustment. Study 2

describes a larger group of TBI patients referred for post-acute rehabilitation, contrasting the degree of injury severity with the level of awareness of deficit and emotional adjustment factors.

Clinical Syndromes of Impaired Awareness

The medical literature provides clinical and experimental descriptions of patients who either lack the ability to appraise or appreciate the significance of their neurological deficit, or who appear to be completely unaware of their deficits. Babinski (1914) initially coined the term “anosognosia” to describe a syndrome characterized by lack of knowledge, awareness, or recognition of disease. Anosognosia is most often described in stroke patients with hemiplegia who, despite contradictory evidence and who otherwise have generally intact cognitive functioning, fail to acknowledge their obvious physical deficits. Neglect is another frequently observed syndrome of impaired awareness, described as inattention to extrapersonal space, usually contralateral to the typical lesion site in the right anterior and dorsolateral portions of the occipital or parietal cortices (Heilman, Watson, & Valenstein, 1985). Fortunately, neglect is often a transient phenomenon, which diminishes over the early period of post-stroke recovery. In another syndrome, individuals experiencing Wernicke’s aphasia may be unaware of their obvious expressive language impairment. They make little attempt to correct their errors, and may become annoyed at the listener’s inability to understand. Because of their apparent lack of awareness, these individuals are often difficult to treat, and may refuse to participate in therapies. Other neurological syndromes that may be associated with deficits in awareness include the amnesic syndrome of Korsakoff’s disease, amnesia associated with hemorrhage of the anterior communicating artery, and patients with Alzheimer’s disease who experience unawareness of their memory disturbance with

disease progression. Prigatano and Schacter (1991) provide a historical review of the study of awareness deficits, while McGlynn and Schacter (1989) review contemporary neurological syndromes that include features of diminished awareness.

More recently, research has focused on alterations in awareness that can occur following TBI. Individuals with TBI have been shown to underestimate the severity of their physical, cognitive, and behavioural impairments compared to evaluations made by family members, significant-others, or clinicians; or when compared to performance on objective tests (e.g., Sherer, et al., 1998; Prigatano & Altman, 1991). Since TBI is known to produce diffuse cerebral damage, it is not easy to study the localizing contribution of this type of injury in relation to impaired awareness. However, literature reviews clearly indicate a role for the frontal lobes in disturbances of higher-order cognition, including awareness and metacognitive processes in general (e.g., Stuss, 1991; Stuss & Benson, 1986). Polar-frontal and orbitofrontal regions are particularly susceptible to the influences of TBI, suggesting a possible underlying neurological etiology for impaired awareness. Interestingly, these regions are also implicated in higher-order emotional functioning.

The study of awareness deficits has been complicated by indications that psychological processes may mediate subjective awareness following neurological insult (e.g., Weinstein & Kahn, 1955; Prigatano & Weinstein, 1996; Prigatano & Klonoff, 1998). For example, ego defense mechanisms, such as denial, have been hypothesized as powerful unconscious processes, which may be difficult to distinguish from neurologically-based deficits in awareness (Lewis, 1991; Weinstein, 1991). Furthermore, self-appraisal of cognitive processes is thought to vary over time in neurologically intact individuals, in relation to environmental stressors and sociocultural factors (Prigatano,

Ogano & Amakusa, 1997; Prigatano, Bruna, Mataro, Muñoz, Fernandez & Junque, 1998; Deaton, 1986; Barco, Crosson, Bolesta, Werts & Stout, 1991). Individuals confronted with a major life stressor such as a TBI are likely to experience psychological adjustment phenomena, which may influence awareness in a protective way. Reviews of this topic suggest that psychological factors often coexist with neurologically-based deficits in awareness (McGlynn & Schacter, 1989; Langer & Padrone, 1992), and the two may be difficult to distinguish.

Awareness Terminology

The literature does not provide a consensus definition of self-awareness. In general terms, self-awareness refers to the ability to “perceive the ‘self’ in relatively ‘objective’ terms, while maintaining a sense of subjectivity” (Prigatano & Schacter, 1991, p.13). Such definitions reflect concepts of consciousness, including basic and higher-order sensory perceptual processes, knowledge (i.e., memory), executive cognitive processes (i.e., judgement, performance-monitoring, decision making, etc.), and emotional factors. Indeed, self-awareness has been characterized as the highest of all integrated functions (Stuss & Benson, 1986; Prigatano & Schacter, 1991). More recently, Prigatano and Klonoff (1998) presented the following conceptualization of impaired self-awareness, which attempts to capture cognitive, emotional, and physiological factors:

Impaired self-awareness reflects impairments in the patient’s ability to consciously represent (perceive and experience) a disturbance in higher cerebral functioning. That impairment appears to reflect a disruption of the integration of thinking and feeling. Consequently, heteromodal cortical lesions (Mesulam, 1985) seem to be responsible for this neuropsychological impairment. Theoretically, different forms of impaired self-awareness will emerge when different regions of the heteromodal cortex are damaged (p.57).

To clarify the nomenclature, the terms “anosognosia”, “unawareness of deficit”, “imperception of disease”, and “lack of insight” have been used interchangeably to describe changes in self-awareness associated with neurological insult. “Denial of deficit or illness”, and “indifference” or “lack of concern” have also been used to describe disturbances in awareness, but more typically refer to psychological defense mechanisms (McGlynn & Schacter, 1989). Within this dissertation, the term “unawareness” will be used to refer to a patient’s neurological inability to perceive a deficit, while “denial of deficit” will be used to refer to a patient’s inability to accept or psychologically internalize the deficit. In practice it would be naive to consider physiological/organic processes and psychological/emotional processes as being entirely distinct.

Models and Mechanisms of Awareness Deficits

Neuroanatomical Considerations. It is accepted that circumscribed lesions to discrete cortical and subcortical areas can lead to predictable deficits in neuropsychological function. However, deficits in awareness have been attributed to numerous brain areas, including paralimbic structures (temporal pole, caudal orbitofrontal cortex, anterior insula, cingulate, parahippocampal and retrosplenial gyri) (Mesulam, 1985, cited in Prigatano, 1991; Cicerone & Tannenbaum, 1997); heteromodal functional areas (temporoparietal and prefrontal cortices) (Prigatano, 1991); specific frontal and prefrontal systems (Stuss, 1991; Stuss & Benson, 1986; Frith & Dolan, 1996), right hemisphere parietal regions associated with neglect (Heilman, et al., 1985), and left-hemisphere temporal-parietal regions associated with aphasia (Benson, 1985). Wagner and Cushman (1994) attempted to associate lesion site with unawareness symptoms in patients with vascular etiologies. Their findings were general, suggesting that cortical lesion sites, versus subcortical sites, were strong predictors of unawareness, while

hemispheric differences were not. Unfortunately their sample was biased against inclusion of left-hemisphere lesions because of language deficit exclusion criteria. However, there was a tendency for greater unawareness to be associated with anterior lesions. Ranseen, Bohaska & Schmidt (1990) found greater unawareness in TBI patients with focal right hemisphere injuries as compared to those with left hemisphere injuries or diffuse injury. Prigatano and colleagues did not confirm this 'laterality finding'. In a study of TBI patients, Prigatano and Altman (1990) found that patients who over-estimated their performance had a greater number of lesions in general, and had a higher incidence of frontal and parietal lesions compared to TBI patients without awareness difficulties. However, the groups did not differ in the incidence of frontal versus non-frontal lesions, or in the incidence of parietal versus non-parietal lesions. Finally, in a more recent study specifically examining laterality effects of brain damage on level awareness of deficit, Prigatano (1996) again failed to find strong differences in patients with right versus left hemisphere lesions.

As indicated above, cerebral damage associated with TBI is often non-specific, making it somewhat arbitrary to localize awareness deficits. However, initial studies of the relationship between deficits in awareness and injury severity have been reported. Current systems generally classify severity based on the depth and duration of coma, and duration of post-traumatic amnesia (PTA; for a recent review see Sherer, Madison, & Hannay, 2000). Allen and Ruff (1990), studying moderately and severely injured patients at 12-months post injury, failed to find consistent severity differences in self-awareness of various cognitive deficits. Prigatano and Altman (1990) found that initial severity of injury, based on moderate to severe admitting Glasgow Coma Scale (GCS) score, did not differentiate patients with impaired awareness from those with accurate

self-appraisal. However, those with impaired awareness demonstrated a greater number of lesions on CT and MRI; the location of lesions was similar for both groups. More recently, Sherer, Boake, Levin, Silver, Ringholz and High (1998), reported a correlation of $-.39$ between initial GCS and the clinicians' rating of patients' level of awareness several months after the injury. In a cross-cultural study, Prigatano, et al. (1998) showed that Spanish speaking TBI patients also showed a correlation of $-.39$ between awareness and admitting GCS, while a correlation of $.41$ was observed between an awareness measure and duration of PTA. Finally, Prigatano (1999) reported that individuals who had significant difficulties with awareness exhibited bilateral slowing on the Halstead finger-tapping test, which was argued to be a marker of severity of neurological impairment. A review of the literature suggests that awareness of deficit has not been specifically examined in individuals with mild TBI or complicated mild TBI (i.e., minimal or no loss of consciousness and minimal duration of PTA, but with neuroimaging evidence of brain injury). If the dose-response relationship holds between severity of injury and degree of impaired awareness, then individuals with mild injuries should not have difficulties with awareness of deficits.

In summary, the general consensus of neuroanatomical research suggests that multimodal association cortices are likely to underlie deficits in awareness, and that some types of awareness (e.g., awareness of cognitive deficits) may not be distinctly localizable in a way that impaired awareness for language or perceptual deficits may be. Neuroimaging studies have provided initial evidence for the involvement of the frontal and temporal-parietal regions in deficits in awareness, and have implicated quantity of injured tissue as important in cases involving diffuse damage (i.e., TBI). The following

discussion of neurocognitive models provides further support for frontally-based functional systems.

Neurocognitive Models. Several theories propose the existence of a supraordinate neural system that is responsible for monitoring the activities of lower level cognitive systems. In these models, damage to either the lower-level cognitive modules or to the supraordinate monitoring system can result in impaired awareness. Stuss and Benson (1986) proposed a three-level model of brain function, suggesting that self-awareness is the highest order of functioning (see also Stuss, 1991b). In this model the hierarchical levels are interdependent, each one having a feedback control system that accommodates incoming information, compares that information to the current or stored experiences of the individual, and provides a response if necessary. The first level of the model accommodates sensory/perceptual information in a domain-specific, overlearned, and automatic fashion. Posterior cortical areas are felt to be involved in these first-level processes. The second level of the model is responsible for “executive control,” adjusting and directing the behaviors of the first level. In novel, complex, or non-routine situations, conscious direction is required from this second level, which is felt to be a function of frontal and prefrontal cortical areas. Finally, self-awareness, self-reflection, or consciousness is represented in the third level of the model, which would also be associated with frontal and prefrontal association areas. Given the vulnerability of the frontal lobe in closed head injury, disturbed awareness of deficit would be expected based on this model.

McGlynn and Schacter (1989) also proposed a supraordinate “conscious awareness system” (CAS) which is responsible for monitoring changes in baseline states of individual cognitive modules (e.g., sensory-perception, memory). Domain-specific

unawareness deficits will occur if the CAS is underactivated through disconnection from, or damage to lower-order cognitive modules (e.g., as in hemiplegia). Broader deficits in awareness should result if the CAS is damaged. While McGlynn and Schacter propose that the CAS is a posterior system involving the inferior parietal lobes and the structures connecting them, they also suggest an output link to the frontal executive system, which would be involved in initiation, organization, planning, and monitoring. Thus, different types of awareness deficits could result from damage to the parietal CAS versus the anterior executive system. Unawareness of specific perceptual and motor deficits could occur with parietal damage (anosognosia in hemiplegia, hemianopia, etc.), while damage to the frontal system would be associated with unawareness of more complex deficits such as problem-solving, retrieval and integration of information, and changes in social skills, behavioural monitoring, and personality characteristics.

Clinically-based descriptions have also suggested that awareness deficits can be classified into subtypes. For example, Crossen, et al. (1989) classified awareness deficits into three interdependent types, which result from injury to various parts of the brain. At the lowest level, "intellectual awareness" reflects a basic understanding that a deficit exists. Severe deficits in abstract reasoning (associated with damage to the dorsolateral frontal lobes, or in diffuse brain injury), or severe deficits in memory (related to mesial temporal lesions, basal forebrain lesions, or diencephalic lesions) may limit intellectual awareness. "Emergent awareness" refers to the ability to recognize a problem as it is happening, and thus relies partially on intellectual awareness. Finally, "anticipatory awareness" reflects the ability to anticipate that a problem will occur as the result of a deficit. Deficits in anticipatory awareness may be associated with frontal lobe lesions, and thus also overlap with deficits in intellectual awareness.

Fleming and Strong (1995) proposed a similar model that integrates clinical descriptions into a working model oriented toward rehabilitation. The first aspect in their conceptualization refers to self-awareness of the injury-related deficits themselves (i.e., physical, cognitive, behavioural deficits). The authors note that TBI patients tend to be more aware of physical disabilities than they are of cognitive or social competence. The second aspect of their model refers to awareness of the functional consequences of the deficits. Impairments in abstract reasoning and integration of information would be expected to contribute to poor understanding of the functional implications of deficits. Finally, a third aspect of their self-awareness model refers to the ability of the patient to set realistic goals. Clinically-based models do not profess to identify neurological or psychological etiologies of awareness deficits, but rather provide a glimpse of the complexity and implications of such symptoms, which ultimately have an impact on the individual's ability to function in various domains.

Psychological Models of Impaired Awareness. As previously mentioned, there is ongoing debate regarding the role of psychological processes in impaired awareness. Psychological theories assume that denial of neurocognitive impairment may represent a defensive attempt to structure the traumatic experience by allowing time to impose personal meaning onto the unfamiliar experience of newly acquired neurological disability (Prigatano & Weinstein, 1996; Lewis 1991; Feinberg & Roane, 1997). In general, it is agreed that during the initial period following injury, denial is an expected reaction and may serve a positive function in maintaining hope and motivation (Prigatano & Weinstein, 1996; Deaton, 1986). In fact, "pushing" a patient to know what is being psychologically denied or minimized by simply repeating and reinforcing the problem to the patient, may be emotionally destructive to the psyche (Langer & Padrone, 1992), and

may be contraindicated for the rehabilitation of basic skills (Sohlberg, Mateer, Penkman, Glang, & Todis, 1998).

Weinstein has argued that psychological or symbolic representations of post-TBI disability may be influenced by several factors. These include: (1) the type, severity, rate of onset, location, and extent of the brain pathology; (2) the nature of the disability; (3) the meaning of the incapacity as determined by the patient's premorbid personality factors; and (4) the setting in which the behaviour is observed (Prigatano & Weinstein, 1996). In particular, the importance of premorbid personality features has been emphasized. For example, based on clinical observation, Weinstein & Kahn (1955) noted that deficits in awareness seemed to occur in patients who had previously regarded illness as an imperfection, who had a history of denying perceived inadequacies, and who held strong needs for prestige in the eyes of others (cited in McGlynn & Schacter, 1989). Others have not found this association (e.g., Cicerone & Kalmar, 1997), suggesting that premorbid personality and affective styles are likely intertwined with post-injury adjustment factors. Lewis (1991) reiterated that the clinical and experimental literature clearly identifies *denial* as a mechanism that is employed by a wide variety of personality types in response to a broad range of intrapsychic and external dangers. Prigatano (1992) suggested that post-injury psychosocial difficulties might simply represent a continuation or exacerbation of pre-existing disturbances.

The role of psychodynamic explanations for unawareness phenomena has been criticized on several fronts (McGlynn & Schacter, 1989). First, the specificity of anosognosia poses problems for a psychodynamic interpretation, in that individuals who use denial as a defense mechanism should be expected to apply such defenses to all serious deficits, which they do not. Second, if unawareness were purely a function of

psychological defense, the site of brain damage should be unrelated to the incidence of awareness deficits. However, as previously discussed, there may be a bias towards frontal and parietal involvement in cases of unawareness. Third, the time-course of unawareness deficits is such that impairments generally occur immediately following injury, and may diminish as patients begin to show physical recovery from their injury. The time course for denial would be such that as patients gain more experience with their deficits they exhibit increased denial. Similarly, Sohlberg and colleagues (1998) suggest that the stability of awareness deficits over longer periods of time points to a neurological etiology, rather than an emotional or motivational etiology, which would presumably involve fluctuating awareness. Fourth, it has been argued that patients may remain unaware of their deficits, despite the absence of obvious reasons for motivated denial. Finally, it has been argued that similar psychodynamic factors are present in the general population, as well as other medical populations, yet a similar prevalence of performance-appraisal deficits is not seen in other populations (Stuss & Benson, 1986).

While Weinstein and colleagues initially viewed denial as the primary process in syndromes of unawareness, others have characterized denial as a secondary behavioural symptom, employed as an adaptive mechanism to reduce anxiety or psychological distress. For example, Rosenthal (1983, cited in McGlynn & Schacter, 1989) noted that TBI patients rarely deny the actual physical defects resulting from their injury, but rather minimize or deny the cognitive implications. Levine and Zigler (1975) reached a similar conclusion in their study of stroke, cardiac, and cancer patients. These patients rarely denied the actual illness, but rather tended to minimize the functional or psychological (e.g., self-concept) implications. As such, it seems important to consider the initial

adjustment reactions in patients following TBI, to gain insight into how denial, unawareness, and minimization of symptoms overlap.

Emotional Adjustment Following TBI

Patient issues. Emotional reactions such as depression and despair, anger, isolation, loss of control, somatization, guilt, anxiety, rumination, denial, and depersonalisation are among those experienced following TBI (Zinner, Ball, Stutts, Mikulka, 1991). Compounding the range of potential emotional responses are numerous factors that can influence emotional adjustment. An inexhaustive list could include pre-injury psychosocial factors such as vocational and marital status (e.g., Brooks, Campsie, Symington, Beattie & McKinlay, 1986); changes stemming directly from neurological damage (Derryberry & Tucker, 1992; Varney & Menefey, 1993) or secondary reactions to physiological changes which involve depressive symptoms such as fatigue, confusion, or irritability; situational variables including the duration, and timing of the event in terms of other situational stresses, the age of the individual, and previous experiences with injury (e.g., Folkman, 1984; Ruff et al., 1993); personal resources such as self-esteem, locus of control, appraisal of the situation, and repertoire of effective coping strategies; and environmental resources such as availability of social supports and financial status. Kendell and Terry (1996) describe a detailed model of how these factors may interact, and their relative importance to the psychosocial adjustment of the individual.

A number of observable life-changes may spur emotional adjustment reactions following a TBI. These can include adjustments to physical impairments, changes in relationships, or changes in employability or access to recreational activities. In addition, less observable changes in cognitive and personality functioning may be perceived as

devastating by the patient or their loved ones (Kendall & Terry, 1996). Cognitive changes may include deficits in attention and memory skills, slowed speed of information processing, and alterations in decision-making or judgment. Personality changes may include emotional lability, changes in interpersonal skills, and lack of inhibition that can influence the person's ability to maintain relationships.

It is likely that the emotional status of a patient will also change in direction and magnitude over time. Interactions between the characteristics of the injury, the pre-trauma personality (Bennett & Raymond, 1997), the family dynamics (Cavallo, Kay, & Ezrachi, 1992; Fordyce & Roueche, 1986), post-trauma environment, and alterations in vocational status (Paniak, Shore, Rourke, Finlayson, & Moustacalis, 1992; Sherer, et al., 1998) can significantly influence the patient's concept of self (Persinger, 1993; Kendall & Terry, 1996). However, it is not known how these adjustment factors are related to subjective appraisals of self-competence (Haynes, 1994), nor is the chronicity of these factors well understood. Thus, it is important to consider emotional status in both the acute and post-acute phases of recovery from brain injury.

While there have been a number of studies of depression following TBI, there are relatively few studies examining general emotional adjustment following TBI, and the results are somewhat mixed. In earlier studies, Dikmen and Reitan (1977) found that depression and anxiety were highest early after TBI, but were inconclusive regarding factors that contributed to variability in emotional reactions over time. In contrast, Fordyce, Roueche, and Prigatano (1983) found that patients with chronic head trauma symptoms demonstrated increased anxiety and depression over time. The results of more recent reviews suggest that, in general, the frequency of depression over the post-injury period appears to be relatively stable (Bornstein, Miller & VanSchoor, 1989; McCleary,

et al., 1998). For example, Bornstein and colleagues reported a positive relationship between neurobehavioral deficit and emotional disruption, which did not seem to be related to the interval between injury and examination, and did not appear to be related to severity of the initial injury, or to other demographic factors. McKinley, Brooks, Bond, Martinage and Marshall (1981) had previously followed 55 patients with severe TBI and found that more than half of them displayed depressed mood at three, six, and twelve months following injury. Finally, McCleary and colleagues (1998) reported that six-months after a moderate to severe TBI, 42% of patients were identified as depressed. At 12 months 35% of the patients were identified as depressed.

In attempting to summarize this patient population, Morton and Wehman (1995) derived four general themes which illustrate the complexity of chronic emotional adjustment following TBI: (1) individuals who experience severe TBI are at high risk for a significant decrease in their friendships and social supports; (2) these individuals experience a lack of opportunity for developing new social contacts; (3) these individuals experience a decrease in the number of leisure activities in which they are involved; and (4) anxiety and depression are found at high levels for prolonged periods of time following severe TBI.

Family members. Reviews of the literature suggest that family members frequently experience long-term psychological consequences following the brain injury of a close relative (e.g., Cavallo, et al., 1992; Leach, Frank, Bouman & Farmer, 1994; Lezak, 1988; 1996; Romano, 1989; Brooks, 1984; Mintz, Van Horn, & Levine, 1995; Kreutzer, Gervasio & Camplair, 1994; Brooks, et al., 1986; Gillen, Tennen, Affleck & Steinpreis, 1998; Douglas & Spellacy, 1996; Sander, et al., 1997). Several studies have examined the role of family functioning during the post-acute phases of head injury

rehabilitation, examining such factors as severity of injury, cognitive abilities, behavioral/emotional factors and vocational and academic outcome. Typical family issues include high levels of family distress, uncertainty about the injured person's future autonomy, and increases in the personal responsibilities of individual family members (Perlesz, Kinsella, & Crowe, 2000). During the first year following the injury, a very high number of family members experience depressive symptoms, and as many as 47% of one sample of family members met diagnostic criteria for a major depressive episode (Gillen, et al., 1998). This prevalence of depression in family members fell only slightly during the first 18 months following the injury. Thus, family members are certainly not psychologically immune to the effects of brain injury, and these factors are known to be long lasting (Cavello, Kay & Ezrachi, 1992).

Family members or significant-others are inevitably called upon to make formal or informal judgements about the recovery and competency of TBI patients. However, the emotional reactions of family members are rarely considered in this process (Fordyce & Roueche, 1986; Kreutzer, et al., 1994). Family members may have difficulty appreciating subtle, or even obvious deficits if they unwittingly become involved in the patient's denial mechanisms (Fordyce & Roueche, 1986). For example, in a sample of non-TBI participants, Clarridge and Maddagli found that "informants" tend to under-report illness, symptoms, and extent of impairment or disability of those they represent (cited in Cusick, Gerhart, & Mellick, 2000). Others, however, have found that informants appear to have more negative perceptions, over-reporting problems in essentially these same areas. Additionally, the informant's closeness to the patient has been reported to impact the patient-other agreement. Close caregivers reportedly overestimate disability and underestimate independence, daily functioning, and quality of

life. This finding may be related to the burden of care that is experienced (Cusick, et al., 2000). Furthermore, the level of agreement between informant and patient has been shown to decrease with the presence of cognitive deficits, and may increase in the presence of stable, persistent symptoms, and when the symptoms are physical, functional, and observable (Leathem, Murphy, & Flett, 1998).

Before discussing assessment techniques for awareness and emotional adjustment, it should be noted that rehabilitation staff may also demonstrate biased assessments of patients due to their continuous and often stressful interaction with seriously impaired individuals (Sohlberg, in preparation; Gans, 1983; Fleming, Strong, & Ashton, 1996). Rehabilitation staff may also have an interest in seeing improvements of patients involved in rehabilitation, and may subjectively see improvements where none exist. These considerations are important, as it is family members and rehabilitation staff who are judging the patient's recovery and rehabilitation progress. While it is assumed that clinicians will be least susceptible to emotional biases (Sohlberg, in preparation) unfortunately the research on subjective factors in family and staff perspectives of patient level of functioning is sparse.

Assessment of Awareness Deficits

A number of approaches have been utilized to qualitatively and quantitatively assess awareness of deficit in patients with TBI (for reviews see Fleming, et al., 1996; Sohlberg, in preparation). These methods have typically involved comparison of the patient's subjective evaluation of their abilities with the ratings of a significant-other or clinician, or by comparing patient's evaluations with actual neuropsychological test performance. Assessment has relied upon self-report questionnaires, rating scales and structured interviews. The following section briefly reviews these methods.

Discrepancies in self-other ratings. While the self-report of TBI patients may provide useful information about deficits, clinical experience suggests that patients often underestimate their impairments, or fail to appreciate the significance of their deficit. Conversely, patients tend to overestimate their pre-injury skills when asked to provide a retrospective estimation of their abilities (Mittenberg, Diguilio, Perrin & Bass, 1992; Leathem, et al., 1998). Thus, patients may lack the objectivity required to evaluate their own performance. Lack of awareness has often been defined in terms of the degree of correspondence between ratings of clinical staff and/or significant-others, and the self-evaluation of the patient. Poor awareness is suggested by inflated ratings of patient self-appraisal, when compared to the ratings of patient performance by others (Prigatano, Altman, & O'Brien, 1991; Fleming, et al., 1996). Patients who underestimate their behavioral performance may be experiencing emotional distress, or demonstrating deliberate exaggeration of deficit in relation to some possible external gain. Several self-other rating scales have been described in the awareness literature, including the Katz Adjustment Scale (Baker, Schmidt, Heinemann, Langley, & Miranti, 1998), the Patient Competency Rating Scale (PCRS; Prigatano, Fordyce, Zeiner, Roueche, Pepping & Wood, 1986), the Change Assessment Questionnaire (Lam, McMahon, Priddy & Gehred-Schultz, 1988), the Awareness Questionnaire (Sherer, Bergloff, et al., 1998), and the Head Injury Behavior Scale (Godfrey, Partridge, Knight & Bishara, 1993). Of these scales, the PCRS appears to have been most widely cited in the awareness literature.

The PCRS is a 30-item self-report measure that evaluates patient competency on various cognitive, behavioral, and emotional tasks, without requiring the patient to actually complete the tasks. Respondents are asked to assess how easy or difficult it would be for them to perform the task, rating their evaluation on a 5-point Likert scale

(1 = "can't do" through 5 = "can do with ease"). The informant version is identical to the patient version, with the exception that questions are phrased to refer to the patient. Prigatano, et al. (1991) have compiled reliability data for the PCRS which range from $r = .97$ (patient total scores) to $.92$ (relative rating scores) in addition to significant test-retest correlations. Heilbrunner, Millsaps, Azrin and Mittenberg (1993) have supported these reliability data, and identified six relatively discrete factors of the PCRS, suggesting good content validity. While the multifactorial nature of the PCRS is desirable for capturing a range of possible difficulties (e.g., activities of daily living, interpersonal difficulties, cognitive difficulties, and emotional difficulties), Prigatano has noted that non-neurological factors, including psychological denial of deficit may contribute to patient overestimates of competency on the PCRS, particularly in the areas of interpersonal and emotional functioning (Prigatano & Weinstein, 1996). Leathem, and colleagues (1998) also found that individual items from the PCRS were problematic for both control subjects and TBI patients. These included "handling arguments," "accepting criticism," "starting conversations," "adjusting to change," and "controlling crying." Such intrapersonal issues were sometimes not recognized by the informants as being problematic. Despite these concerns, Wallace and Bogner (2000) conclude that the construct validity of the PCRS is well supported. When there is a discrepancy between the patient's and the relative's ratings, suggesting impaired awareness, the relative's perception has also been supported by high correlations between PCRS ratings, neuropsychological assessment results, and length of PTA (Prigatano, Brauna, et al., 1998, Prigatano, et al., 1997).

Fleming and Strong (1999) demonstrated the utility of the PCRS in capturing repeated self- and other-ratings of patient competencies. These authors collected data at

three-months and at one-year post-TBI. The results suggested that at three-months self-awareness was most impaired among items relating to cognitive activities (e.g., scheduling activities, understanding instructions, consistently meeting responsibilities), and activities that involved interpersonal/emotional components (handling arguments, showing affection, controlling one's emotions). On the other hand, activities of daily living (e.g., personal hygiene, dressing), retrospective remembering (e.g., names of people, daily schedule), and specific emotional items (e.g., controlling laughter and crying) were accurately appraised by the patient at three months. At one-year post TBI, significant gains were made in all areas assessed by the PCRS, with the exception of items relating to driving, personal finance, and recognizing when something one had said or done had upset someone else. The results of this study appear to support the use of the PCRS in a serial assessment fashion. However, no attempt was made by Fleming and colleagues to investigate emotional factors in patients or in significant-others, or the influence of injury severity with levels of awareness as assessed by the PCRS.

In summary, while the PCRS has been recognized as a potentially valuable instrument for collecting self- versus other-perceptions of competencies, further studies have been recommended by Prigatano and others to determine the degree to which perceptions of performance are related to actual performance. Furthermore, the relationship of PCRS scores to emotional adjustment factors, and injury-related factors has not been fully explored.

Clinician ratings. Several problems exist in using self-other ratings. For example, emotional reactions, stress, fatigue, personality type, and time since injury may bias the significant-other's level of denial or level of awareness (Fleming, et al., 1996; Seidenberg, Taylor, & Haltiner, 1994; Cusick, et al., 2000). To minimize this rater-bias,

several studies have relied on clinician- and staff-ratings of patients (e.g., Fordyce & Roueche, 1986; Herbert & Powell, 1989; Leathem, et al., 1998). One recent example is the *Clinicians Rating Scale for Evaluating Impaired Self-Awareness and Denial of Disability after Brain Injury* (Prigatano & Klonoff, 1998). This measure requires clinicians to rate patients on two dimensions, "Impaired Self Awareness" and "Denial of Disability", which are based on clinical and theoretical work suggesting that patients with impaired self-awareness will demonstrate specific behaviors. For example, the authors suggest that patients with awareness deficits lack information about themselves, experience confusion when provided with feedback about their behavioral performance, and exhibit cautious acceptance or indifference when asked to work with information about their impairments. Patients who experience denial are believed to demonstrate partial or implicit knowledge about their limitations, demonstrate resistance or outright anger when confronted with feedback about their limitations, and actively struggle when asked to work with feedback about themselves. The authors further suggest that anger and depression are common denial reactions, as compared to indifference, which typifies patients with unawareness deficits (Prigatano & Klonoff, 1998). While this scale represents a clinically useful approach to the denial versus unawareness problem, an initial report suggested that two experienced clinicians, who had thorough knowledge of the patients being evaluated, had difficulty agreeing on the degree to which patients demonstrated a particular symptom. Unfortunately the problem of identification and consistent use of behavioral referents by clinicians is common in the use of such rating scales. Clinicians typically have limited knowledge of the patient's pre-injury functioning, and could also be biased by factors such as attitude towards the patient, and expectations for recovery (Fleming, et al., 1996).

Discrepancies between self-ratings and test performance. Another approach to evaluating patient self-awareness has been to compare self-ratings of performance to performance on neuropsychological tests. For example, Allen and Ruff (1990) evaluated the accuracy with which TBI patients and controls could predict their performance on neuropsychological tests. Patients did not rate their abilities in correspondence with actual test performance, and frequently rated themselves as having no problem. Control subjects were generally better able to predict their performance. However, all groups had variable accuracy in predicting their neuropsychological test performance, depending on the cognitive domain being assessed. For example, it was found that severely-injured patients tend to be overly-optimistic when rating performance on sensorimotor and attention functioning, while mildly-injured patients tend to be pessimistic concerning their abilities in sensorimotor, language, and reasoning abilities. While contrasts between self-appraisal and actual test performance may be useful, tests of specific neuropsychological functions have been criticized for their poor relationship to difficulties experienced in everyday life (e.g., Ponsford, 1988). Furthermore, Trosset and Kazniak (1996) have suggested that discrepancies between patient self-report and test performance may be limited because it is unclear that the patients necessarily understand what abilities are required for particular tests. For example, patients may be unable to accurately assess the difficulty of a task, thus over-estimating their performance. Finally, it may not be cost- or time-effective, or clinically appropriate to administer a battery of neuropsychological tests in the interest of assessing self-awareness of deficits (Fleming, et al., 1996).

Structured interviews. Structured interview protocols have been devised to provide both qualitative and quantitative information on self-awareness following TBI.

Two structured interviews have recently been described: the Structured Awareness Interview (Giacino & Cicerone, 1998) and the Self Awareness of Deficits Interview (SADI; Fleming, et al., 1996). These scales begin with relatively open-ended questions, followed by more specific prompting of functioning in specific areas such as sensorimotor, attention, memory, visual perception, language, reasoning, and affect. The Structured Awareness Interview requires patients to provide a “conviction rating” of the certainty of their self-evaluations in order to provide insight on the “malleability” of the belief for those patients who may deny awareness of deficit. Both interviews ask patients about the functional implications of their deficits, and the SADI inquires about the ability of patients to set realistic goals. Giacino & Cicerone (1998) provide a brief description of their scoring criteria for patient responses, although to date no reliability or validity data have been published for the Structured Awareness Interview. The SADI has been used in several studies, with promising results (Fleming, et al., 1996; 1998; Bogod, 1999), and is briefly described below.

Scoring criteria for the SADI are relatively detailed for the three sections of questions relating to (1) self-awareness of deficit, (2) self-awareness of the functional implications of the deficits, and (3) ability to set realistic goals (refer to Appendix B). Inter-rater reliability among five raters of TBI patients were .78, .57, and .78 on average for the three sections of the SADI, respectively, and .82 for a summary score (Fleming, et al., 1996). Reliability data have been replicated (Fleming, Strong, & Ashton, 1998; Bogod, personal communication). Scores from the SADI have also been shown to significantly correlate with ratings from the PCRS (Fleming, et al., 1998), and with several measures of frontal lobe functioning in a sample of post-acute brain injury patients (Bogod, 1999). In addition to the psychometric properties, a clinical strength of

structured interviews may be in the qualitative information elicited through the interview format, which may reflect a broader range of awareness deficits than can be assessed through self-report rating scales.

In summary, there does not appear to be a single “gold-standard” for the assessment of awareness of neurobehavioral deficit. However, as suggested by Fleming and colleagues (1996), use of multiple measures such as discrepancy ratings from the PCRS, and structured interviews such as the SADI, represents a preferred combination of qualitative and quantitative data. These two instruments were selected for Study 1, while Study 2 focused on data gathered from the PCRS alone.

Assessment of Psychological Reactions Following TBI

Assessment of the clinical and personality features of an individual is an inherently difficult process, especially following TBI, and to date no standard methods exist for this population (McGlynn & Schacter, 1989; Lewis, 1991; Prigatano & Klonoff, 1998). However, a variety of self-report instruments have been developed or adapted for the assessment of emotional status or emotional adjustment following brain injury. Examples of such instruments include the MMPI and MMPI-2 (e.g., Walker, Blankenship, Ditty, & Lynch, 1987), the Beck Depression and Anxiety Inventories (e.g., Fleming, et al., 1998; Wallace & Bogner, 2000), the Sickness Impact Profile (e.g., Burton & Volpe, 1994), the Katz Adjustment Scale (e.g., Baker, et al., 1998) and the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1981). Lezak (1995) provides a description and brief review of each of these instruments as they have been applied to neuropsychological populations.

While a comprehensive review of measures of emotional adjustment is beyond the scope of this dissertation, a few general comments are warranted, and are followed by

brief reviews of the specific instruments used in this study. First, most scales of emotional or psychosocial adjustment have not been specifically intended for use with TBI patients, although they have been widely used and often successfully adapted for this population (Lezak, 1995). For example, correction factors and techniques for interpretation of the MMPI and MMPI-2 have been developed for the assessment of emotional functioning following TBI (e.g., Lees-Haley, 1997). Still, the use of the MMPI-2 with brain injury patients continues to be contentious because of this non-standardized manipulation and interpretation of the profiles. Second, measures of specific emotional symptoms (e.g., Beck Depression Inventory; Beck Anxiety Inventory), while straightforward in their administration and face validity, may be too specific in their content to reflect the complexity of adjustment following TBI. Third, in contrast to instruments that may suffer from lack of breadth, measures of generalized emotional and psychosocial adjustment can be lengthy in their administration (e.g., MMPI). TBI patients may not have the attentional stamina to complete such inventories. Finally, measures of psychosocial adjustment have typically been employed in the post-acute phases of recovery from brain injury (e.g., three months and beyond) to determine longer-term or persisting changes in emotional and psychosocial functioning, as well as personality disturbances. The Sickness Impact Profile and Symptom Checklist-90-Revised have been used with TBI patients, although their utility during the acute phase of recovery has yet to be firmly established.

Of the self-report instruments available for assessing psychological distress, the Profile of Mood States (POMS) has achieved acceptance as a measure of psychological distress in a variety of healthy, physically ill (e.g., cancer, TBI, spinal cord injuries, epilepsy, HIV infection), and psychiatric populations (e.g., Stambrook, Moore, Peters,

Zubek, McBeath, & Friesen, 1991; Curran, Andrykowski & Studts, 1995; Nyenhuis, Yamamoto, Luchetta, Terrien, & Parmentier, 1999). Because of its brevity, simplicity, and the variety of mood-states that it queries, the POMS has been widely used as a clinical instrument, and seems particularly well-suited to acute care TBI patients. Test-re-test reliability ranges between .65 and .75, depending on the specific scale and the population of interest, while the internal consistency has been reported between .84 and .95. Studies of the validity of the POMS are numerous, and have generally been favourable (Nyenhuus, et al, 1999; Lezak, 1995).

The Katz Adjustment Scale – Relative's form (KAS-R; Katz & Lyerly, 1963) has also assumed a role of prominence with respect to assessment of personality change following TBI (Jackson, et al., 1992). There are several advantages to the KAS-R. For example, items are phrased in such a way as to query non-professional observers (i.e., family members or significant-others) about overt behavior. The KAS-R covers a wide range of social and emotional behavior, psychiatric issues, and physical and cognitive performance issues, which at face value appear relevant to the clinical changes that follow TBI. The items have proven discriminative validity with well-adjusted and poorly-adjusted patients, and a number of studies have shown the usefulness and factor dimensions of the KAS-R among TBI respondents (Goran & Fabiano, 1993; Baker, et al., 1998). A small literature has developed regarding normative data and applications of the measure to specialized populations, including TBI (e.g., Klonoff, Snow, & Costa, 1986) and spinal trauma patients (Jackson, et al., 1992). Finally, the KAS-R is completed by family members or carers who have extensive premorbid and post-injury knowledge of the patient. Thus, while a degree of objectivity and expertise is lost by having family members rate the patient, as described previously, a thorough knowledge of the patient is

gained. This feature can be especially important in samples of post-acute TBI patients, where the significant-other has the broadest and most consistent range of experiences with the patient.

The Grief Experiences Inventory (GEI; Sanders, Mauger, & Strong, 1985) is a multidimensional, self-report measure of grief, which is applicable to both death and non-death loss/bereavement situations. Zinner, Ball, Stutts, & Philput (1997) used an adaptation of the GEI to examine the grief responses of mothers of young adults with TBI, three to 36 months post-injury. While injury severity was unrelated to mothers' grief experiences, the authors found that mothers of low-functioning TBI victims expressed greater anger, loss of control, social isolation, lack of sleep, and physical complaints than did mothers of higher functioning TBI victims. Social disinhibition, poor insight, poor planning, and mood swings were particularly concerning to mothers, and were correlated with higher levels of despair, anger and hostility, loss of control, and physical complaints by the mothers. Problems with cognitive understanding, verbal expression, speech, and physical mobility had less impact on mother's grieving patterns. Interestingly, only ratings of guilt appeared to vary over time, with the most intense guilt reported between 3 and 9 months, and later, in the 27 to 36 month period.

In a study of individuals who had sustained a mild to moderate TBI within the past year Haynes (1994) found a strikingly similar pattern of grief experience between TBI patients and bereaved respondents. However, TBI respondents scored higher on denial and atypical response scales, and reported fewer symptoms than the bereaved respondents on the loss of control scale and the depersonalization scale. This study suggests that it is possible to assess grief experiences in brain injury respondents using the GEI, although TBI patients may experience strong emotions in an atypical manner.

Despite its limited use in TBI patients, the GEI was felt to be a promising assessment instrument, in that it could provide useful breadth of information regarding the emotional adjustment reactions of both patients and significant-others.

To summarize, there is a reasonably well-developed literature on the nature and assessment of emotional adjustment reactions following TBI. More recently, rehabilitation specialists have begun to appreciate the importance of awareness issues following TBI. However, assessment techniques are inherently subjective, and the natural course of these two general factors is poorly understood, especially during the acute care phase of recovery. The following section will review literature that has attempted to reconcile awareness and emotional factors following TBI, and the natural chronicity of these factors.

Reconciling Awareness Deficits and Emotional Adjustment Issues Following TBI

It is clear that psychological and neurocognitive processes are intertwined following brain injury (e.g., MacNiven & Finlayson, 1993; Fleming, et al., 1996; 1998). While patient self-awareness of deficits and competencies is generally felt to be beneficial or even required for successful neuropsychological rehabilitation (Sohlberg, et al., 1998; Ben-Yishay & Gold, 1990), improvements in self-awareness have also been linked with emotional distress including depression, anxiety, grief, as well as “catastrophic reactions.” Two general patterns have been summarized by Herbert and Powel (1989):

First, a patient who is forced to ‘face facts’ prematurely may have hopes destroyed, which in turn may result in depression, apathy and failure to respond to treatment and rehabilitation. Alternatively, if hope is allowed to reach totally unrealistic proportions the patient may attempt to ignore or deny his/her disability and thus postpone the adjustment process by strongly maintaining that ‘everything is going to be alright’ (p.125).

From this summary, it can be seen that an understanding of the chronicity of emotional adjustment and of awareness deficits is important to understanding the interaction between the two factors.

In one of the few studies to assess awareness in the acute stages of recovery from TBI, Ranseen and colleagues (1990) measured awareness of patients, compared to staff members, within the first week of admission to an inpatient rehabilitation unit, and again at discharge. Patients demonstrated very poor initial self-awareness and did not change significantly over a one-month interval. The authors reported that there was a modest correlation between depression and awareness scores on admission, such that the patients who viewed themselves as being depressed also showed a tendency to view themselves as relatively less functionally competent. There was no attempt to measure broader emotional reactions in the patients, nor was the change in emotional status documented over the course of the study.

In terms of chronicity of awareness deficits, mixed results have been reported, all involving patients with moderate to severe brain injuries. For example, in a recent study, Newman and colleagues (2000) surveyed patients near the time of their admission to a brain injury rehabilitation program. They found a significant difference between patient and staff member ratings, reflecting patient over-estimation of their abilities. At a second evaluation, approximately one-month later, patients and staff member ratings tended to converge. The authors attributed this convergence to improved patient performance on rehabilitation tasks, rather than actual improvement in self-awareness. Other authors found that chronicity affected only the patients' insight regarding learning and memory, which showed improvements over time (i.e., approximately 12 months; Allen & Ruff, 1990). Fleming and Strong (1999) found improvements in multiple areas of self-

awareness 12 months following severe TBI. Based on their results with moderate to severe TBI patients, they suggest that experience is a crucial component to emerging self-awareness, although other factors such as the success of those experiences, and the personal meaning of competencies, were also seen to be important.

Few researchers have closely examined the natural course of awareness and emotional distress following brain injury. Heilbronner, Roueche, Everson, and Epler (1989) did not find changes over time, but did note that a group of TBI patients with good insight was ranked significantly higher on measures of depression than a group who had limited insight into their deficits. Godfrey and colleagues (1993) examined the relationship between TBI patients' level of insight about their behavioural impairment and their level of affective distress in the post-acute stages at six months, one year, and between two and three years post TBI. Their findings suggest that increased insight and awareness of impairment was accompanied by increased emotional dysfunction. Prigatano and Fordyce (1986) found that unrealistic self-appraisal, in terms of over-estimation of self-competence compared to ratings of others, was associated with emotional distress; the chronicity of this association was not clear in this study. Finally, Kendal and Terry (1996) highlight research suggesting that psychosocial adjustment after a traumatic injury or illness (e.g. spinal cord, rheumatoid arthritis) was more clearly associated with chronic daily stress that arises as a consequence of the event, than with the event itself (Sommerfield & Curbow, 1992, cited in Kendall & Terry, 1996). This research implies that negative emotional reactions may be different in quality during the acute phase of injury than in the post-acute stage, where most adjustment research has been conducted, and that emotional reactions vary with the type and severity of injury.

A very recent study examined the reactions of TBI survivors being treated as outpatients, as well as family members (Wallace and Bogner, 2000). While the severity of injury was not reported, the authors found that 40% of the TBI patients scored in the mild or greater depression range on the Beck Depression Inventory, as did 34% of the family members who completed the inventory. Fifty-four percent of the patients reported mild or greater anxiety on the Beck Anxiety Inventory, while 39% of family members reported similar anxiety. It was also found that the awareness ratings of the patients did not correlate significantly with their reported level of depression or anxiety. However, there was a moderately weak correlation between the significant others' ratings of the patients' competence, and the significant-others' reported level of depression. No relationship was found between the family members' level of anxiety and their ratings of the patients' competence. These authors found that with greater time since injury, less depression was seen in the family members, although their level of anxiety remained constant over time. As with other studies (e.g., Fleming & Strong, 1999), Wallace and Bogner found that patients' and family members' ratings of competence tended to become more aligned over time. This paper provides initial findings relating to adjustment of family members and ratings of patient competence. Unfortunately the sample was quite small and varied in terms of participant demographics (i.e., 50 patients and their significant-others, age range from 15 to 79yrs), only symptoms of depression and anxiety were queried, and no information about the severity of injury was considered.

In summary, while clinical observation and intuition suggest that emotional distress is less common in patients who lack self-awareness, further research is required to clarify this association (Fleming & Strong, 1995), especially during the acute recovery phase, where little research on these issues has been conducted. Such research will be

important because the literature also suggests that emotional reactions associated with the development of self-awareness may influence the motivational changes that are required for recovery and participation in rehabilitation (Herbert & Powell, 1989; Fleming & Strong, 1995).

Aims of the Current Study

Although there is a growing literature on awareness of neurocognitive deficit following TBI, and a distinct literature examining emotional adjustment issues following TBI, there is a much smaller literature considering the relationship between these two factors. Furthermore, while severity of injury and chronicity of deficits appear to be salient variables, few studies appear to specifically address these variables with respect to emotional adjustment and awareness of deficit. Thus, a major purpose of this dissertation was to investigate the relationship between level of self-awareness of deficit following brain injury and the emotional experiences of patients, as rated by significant-others who are required to rate patient competence. It was predicted that patients who show decreased awareness of deficits following TBI are less likely to experience strong adjustment reactions. However, it is recognized that level of awareness is likely to change over time, as neurological injuries improve and as individuals are confronted with daily difficulties in functioning. Thus, as patients become increasingly aware of their deficits, they are likely to become more emotional and, in particular, experience depressive or anxiety-related reactions. Once fully aware of their deficits, patients *may* adjust to their new condition and show a consequent stabilization in their emotional adjustment. Unfortunately this scenario is probably not the norm, as many TBI patients continue to experience neuropsychological and emotional adjustment issues over the longer term. In summary, the general aim of this dissertation was to consider the

relationships between level of awareness of neurobehavioral deficits using self-other ratings, emotional adjustment in terms of level of depression, anxiety and other emotional factors, severity of the TBI, and time since injury (i.e., considering both acute and post-acute stages of recovery).

Since, for practical reasons, it was not possible to study individual patients over prolonged periods of time, this dissertation utilized two distinct patient samples, considered in two separate studies. Study 1 focused on a small sample of individuals who had experienced a TBI of sufficient severity to require intensive acute care medical and neurocognitive rehabilitation. These individuals and their significant-others were seen weekly while in hospital, completing measures of level of awareness of deficit, and emotional adjustment. The patients were followed during their hospital stay, and were contacted for follow-up approximately one month after their discharge from acute-care rehabilitation. All of the patients were seen in acute care, which is felt to be intense and dynamic, a distinct period in recovery from TBI. While all had experienced severe traumatic brain injuries, the patients were variable in their presentation, in terms of the specific injury incurred, and in the process of recovery that followed. Similarly, the involvement of family members or significant-others was expected to vary between patients. As such, the emotional adjustment of the significant-other was felt to be of importance during this acute-recovery time frame. Based on these features, and the unavailability of large numbers of patients and family members, it was felt that a descriptive approach, using a small number of representative patients, would provide a feasible approach to the data.

An informal aim of Study 1 was to provide pilot data on the utility of assessment instruments that have been developed for assessing awareness, but have not been

employed in the early stages after TBI. In this study, results from the PCRS, SADI, and POMS were correlated with the assessment of the rehabilitation team, as measured by components of the Functional Independence Measure and the Functional Assessment Measure (FAM), which is described below in the Methods section for Study 1.

Study 1: Awareness and Emotional Adjustment in Acute Care Recovery from Severe Brain Injury

Methods

Subjects

Subjects for Study 1 were patients on the Inpatient Neurorehabilitation Unit at Foothills Medical Centre in Calgary, Alberta. This 40-bed inpatient unit services patients with brain injury, stroke, and spinal-cord injury, although only TBI patients were involved in Study 1. The rehabilitation program follows a typical multidisciplinary model involving physiatry, physiotherapy, speech therapy, occupational therapy, recreation therapy, social work, and psychology, as well as primary-care staff, including nursing and dietary services. All patients were transferred from Acute Care Neurosurgery / Neurological Services within Foothills Hospital upon medical stabilization. From this consecutive series of patients, potential participants were identified.

A number of exclusion criteria were reviewed prior to meeting with patients. First, patients were not included if they experienced significant deficits in expressive or receptive communication, which would impede the ability to provide informed consent, respond to self-report inventories, or respond to structured interview items. Objectively, patients who scored below four on the FAM scales of communication, which are

described below, were not included in Study 1. Clinically, patients were included if they were able to attend and respond to items that were read to them, with minimal elaboration or interpretation provided. Three patients were admitted to the rehabilitation unit during the course of Study 1, but were not included because the severity of their functional impairments left them severely disoriented, or with other severe cognitive deficits that precluded their ability to attend or comprehend. Second, patients who had previous histories of significant medical or mental health difficulties were not included; this criterion did not apply to any of the patients considered. Third, patients who did not have a significant-other who was willing to participate, or those who were unable to meet with the researcher weekly, were not included. Informed consent was obtained from family members and from patients. Patients were not included if they were unable to provide informed consent, as mandated by the Office of Medical Bioethics, Faculty of Medicine, University of Calgary, and by the University of Victoria Human Research Ethics Committee. Dr. Stewart Longman, Rehabilitation Psychologist and Dr. Christine McGovern, Psychiatrist, provided consultation in evaluating patient appropriateness for the study, and as necessary throughout the data collection phase. Patient progress was also followed through weekly team meetings involving the rehabilitation staff, and review of patients' medical charts.

Instruments:

Awareness measures. The PCRS was used to evaluate the patient's self-appraisal of competence. Total Scores were attained by tabulating the self-rating scores of the patient, and ratings of the patient provided by the significant-other (described in Fordyce & Roueche, 1986). The highest possible Total Score on the PCRS is 150, with scores over 120 suggesting that the patient can manage tasks "fairly easily." In contrast, a Total

Score of 90 reflects “some difficulty” completing activities. The discrepancy between patient and significant-other scores is considered to be a reflection of awareness on the part of the patient. Patients who overestimate their competence, compared to significant-other ratings, are considered to have impaired awareness. Four factor scores were also examined, based on work described by Heilbronner and colleagues (1993). Appendix A contains a description of the PCRS items, categorized by the four major factor components.

The wording of the SADI was slightly modified for use in assessing acute-care patients’ self-appraisal in a less structured manner than permitted by the PCRS. Appendix B provides a description of the SADI, with modifications in wording provided in brackets. Scoring of the SADI utilized a four-point rating system described by Fleming and colleagues (1996). In this system a score of zero reflects no deficit in awareness, while a score of three reflects a severe disturbance in awareness. Scores are provided for the domains of current ability, functional implications, and future implications. A combined score between zero and nine is derived, with higher values indicating greater deficits in awareness. To date, no normative data exist for the SADI, rather the scoring criteria provide a method of quantifying the qualitative responses of patients. From this perspective, scores of one or greater in any of the three domains could suggest impaired awareness.

Psychological adjustment measures. The POMS consists of 65 words or brief statements that participants rate on a 5-point Likert scale, ranging from one (Not at all) to five (Extremely), based on how they had been feeling during the preceding week. The POMS typically required five to ten minutes to administer. Six factor scores (i.e., Fatigue-Inertia, Anger-Hostility, Vigor-Activity, Confusion-Bewilderment, Depression-

Dejection, Tension-Anxiety, Friendliness), and a Total Distress Score can be calculated. However, because of poor reliability observed in previous studies, items from the Friendliness subscale are usually omitted, resulting in a 55-item scale. In Study 1, a Total Mood Score was computed by summing the factor scores, with "Vigour" scored negatively. Standard scores were calculated, compared to a normative sample of 400 community dwelling adults with a mean age of 44 years and mean education of 14.3 years (Nyenhuis, et al., 1999).

Grief Experience Inventory: Forms B and BI. The GEI consists of 135 self-report items that contribute to nine bereavement scales (i.e., Despair, Anger/Hostility, Guilt, Social Isolation, Loss of Control, Rumination, Depersonalization, Somatization and Death Anxiety) and three validity scales (Denial, Atypical Responses, and Social Desirability). Several research scales are available, based on a limited number of items (sleep disturbance, loss of appetite, loss of vigour, physical symptoms, optimism/despair, and dependency). Form B was developed by the authors to assess grief experiences in non-death situations, and Form BI was later developed to assess grief in persons who experience losses relating to brain injury (Zinner, et al., 1991). Reliability estimates suggest internal consistency ranging between .52 and .84, while test-retest reliability coefficients for respondents at least one-year post bereavement range between .61 and .87 (the inter-test interval was not provided).

Study 1 respondents indicated 'True' or 'False' to individual items on the GEI (Sanders, et al, 1985). Raw scores were converted to standard scores, using a normative sample of 693 respondents drawn from a general reference group (see Sanders, et al., 1985). Because of the complexity of the factor structure, and the large number of scores on the GEI, only the standard scores from the Despair, Anger/Hostility, and Loss of

Control scales were calculated for comparison against the scores derived from the POMS. During the administration of this measure, it was noted that many of the patients required clarification of the items, raising concerns about the reliability and validity of this inventory in an acute-care TBI population.

Functional assessment rating. The FAM is a 30-item instrument that allows multidisciplinary rehabilitation staff to evaluate patient abilities on motor items (self-care, bladder and bowel control, transfers, locomotion), and cognitive/psychosocial items (communication, psychosocial adjustment, cognitive functioning) (Donaghy & Wass, 1998; Corrigan, Smith-Knapp & Granger, 1997). FAM scores were derived through the consensus of the rehabilitation team at intake and discharge. Individual therapists used a variety of objective and subjective techniques to evaluate the patient, prior to providing their input to the team. Detailed rating criteria are provided by the test authors, and are summarized in Appendix C. For the purposes of Study 1, scores from the cognitive/psychosocial scales of the FAM were used as indicants of functional levels. In general, scores of five or less on a particular scale represent significant changes that should be apparent to untrained observers. However, patients rated as 'completely independent' may not necessarily function at premorbid levels. Rather, they have been judged to be capable of functioning independently with any acquired deficit that may be present.

Procedure

During the initial meeting with each patient, the nature and purpose of the study was explained, a suitable significant-other was identified, and informed consent was obtained. Patients and significant-others were seen independently, and encouraged not to share the details of their responses to the various questionnaires with one another. During the initial session with patients, the SADI was completed. This was followed by

completion of the patient form of the PCRS. In most cases the items were read to the patient, with large-print response options made clearly visible throughout the administration. Explanations or elaboration of item content were infrequently required. Next, the POMS was completed in a similar manner. That is, items were read to the patient, with large-print response options always visible. This method of presenting the material in multiple modalities appeared to minimize the influence of attention, comprehension, or other communication difficulties that may have been present. Finally, during the initial session, patients completed the GEI. Items were read to the patient, with true or false responses provided verbally by the patient.

During the initial session with the significant-other, the same protocol was followed, with minor changes. First, the significant-other was asked to complete the relative's version of the PCRS, responding as they perceived the patient to be prior to the injury. Next, the significant-other was asked to complete the PCRS as they perceived the patient to be in the present. The significant-other then completed the POMS, reflecting on their own personal mood state. Finally, significant-others completed the GEI, again reporting their personal experiences. Significant-others completed the self-report forms independently of the researcher; in some instances, specific questions regarding wording or context were clarified for the significant-other.

Members of the rehabilitation team made an initial intake evaluation of each patient within five days of transfer to the rehabilitation unit, and a consensus FAM was completed. Because the input of multiple rehabilitation specialists was utilized, scores on the FAM were felt to provide a relatively robust and reliable assessment of the patient's functional abilities and deficits. A second FAM score was obtained, again by team consensus, during the final week of inpatient rehabilitation. FAM scores were available

from the patient's chart, which was available for review upon consent of individual patients and from their significant-other. Additional information gathered from the chart included demographic data such as age, sex, time since injury; type and severity of injury data, including GCS scores, estimates of duration of loss consciousness, and estimated duration of PTA; relevant treatment information was also obtained, including treatment set-backs, medical issues and medication reviews, and similar information.

Participants were seen on a weekly basis during their stay on the inpatient rehabilitation unit. Patients and significant-others were seen on the same day in most cases, or within one day when same-day observations were not possible. During each weekly session patients and significant-others completed the PCRS and the POMS. Questions or concerns were answered, although specific information about the study was not provided. The duration of each patient's stay on the unit varied between three and seven weeks, depending on individual treatment needs. Data were gathered on an individual basis, from the time that patients met the basic communication requirements and weekly thereafter until their discharge.

During the discharge phase, patients completed the SADI, PCRS, POMS, and the GEI. Similarly, the significant-others repeated the intake protocol of PCRS, POMS, and the GEI. A discharge FAM score was recorded from the team conference, and arrangements for follow-up were made. In all but one case, patients continued in therapy as outpatients. These individuals and their significant-others were met for follow-up within the hospital. The remaining patient arranged to complete the follow-up materials by mail. Follow-up data included the PCRS and the POMS for patient and significant-other.

Results

Results for Study 1 are presented in the form of case-vignettes for each of the six patients studied. Following the vignette, a graph summarizes the PCRS awareness data and POMS scores for both patient and significant-other. Specific comments are offered for each patient. Finally, a summary section presents correlational and descriptive data of the awareness measures, PCRS discrepancy profiles and factor scores, and data gathered from the measures of emotional adjustment.

All patients in Study 1 were young males, ranging in age from 18 to 39 years, which is the typical demographic for TBI survivors. There was minimal variability in GCS scores, and considerable variability in patient duration of loss of consciousness. Although there was variability in the nature of the specific injuries, all patients were classified as having a severe brain injury, based on neuroimaging results and the lengthy duration of PTA observed in each case. Table 1 displays a summary of demographic and injury characteristics for each of the six patients. From this table it can be seen that the patients were reasonably consistent in terms of the length of time between injury and the onset of their involvement in the study. There was, however, variability in the duration of stay of the individuals, ranging from seven to twelve weeks. Thus, while Patient 1 was followed over the course of his eight-week stay on the rehabilitation unit, Patients 4 through 6 were seen on three occasions during their rehabilitation care, and once for follow-up. All six patients selected a female family member or spouse to provide significant-other ratings.

Table 2 summarizes the intake and discharge scores on selected FAM indices described within each case vignette, and Table 3 summarizes the intake and discharge

Table 1. Summary of Patient Demographic Information for Study 1.

Patient	Age	Initial GCS	LOC	PTA	Neuroimaging data	Days to First Evaluation	Length of Hospital Stay	Relationship of Sig. Other
1	38	7	2 hrs	>20 days	right frontal contusion, right internal carotid artery dissection	39	88	Common law Spouse
2	31	7	5-10 min	>20 days	left-sided skull fracture, bilateral subdural haematomas with minimal mass effect, fractures of cervical spine	45	71	Sister
3	18	5	17 days	>20 days	multiple hemorrhages involving the left temporal lobe and basal ganglia, indicative of diffuse axonal injury; basal skull fracture, lumbar spinal fracture	56	76	Mother
4	29	10	10 days	>20 days	left temporal contusion and posterolateral ventricular hemorrhage; right midbrain shear hemorrhages; small diffuse hemorrhages, generalized cerebral edema	58	75	Mother
5	39	7	10 days	>20 days	small epidural hematoma of the left temporal pole, minimal mass effect; left lateral orbital wall fractures; sphenoid fractures; small right frontal subdural hematoma	34	50	Wife
6	26	3	12 days	~25 days	right thalamic hemorrhage; bilateral frontal contusions, temporal bone fracture; multiple infarcts associated with diffuse axonal injury	48	59	Mother

Note: GCS = Glasgow Coma Scale; LOC = duration of loss of consciousness; PTA = duration of post-traumatic amnesia.

Table 2. FAM Scores for patients in Study 1.

Patient	FAM - Intake				FAM - Discharge			
	Total	Cognitive	Psychosocial	Communication	Total	Cognitive	Psychosocial	Communication
1	3.12	2.4	1.7	5.2	4.60	4.4	4.0	5.4
2	4.52	3.6	3.7	6.2	6.12	6.2	5.7	6.4
3	1.75	1.6	1.2	2.4	4.97	5.4	4.5	5.0
4	3.28	2.4	3.2	4.2	4.97	4.6	4.5	5.8
5	4.47	3.2	5.0	5.2	5.02	5.2	4.2	5.6
6	4.00	3.0	3.0	3.33	4.83	4.6	4.5	5.4

Note: Total FAM scores represent the mean score across cognitive, communication, and psychosocial adjustment items. Higher scores represent better adjustment, as described in Appendix C.

Table 3. SADI Scores for patients in Study 1.

Patient	SADI - Intake				SADI - Discharge			
	Total Score	Appreciation Of Deficits	Functional Implications	Ability to Set Goals	Total Score	Appreciation of Deficits	Functional Implications	Ability to Set Goals
1	4	1	1	2	4	0	2	2
2	7	2	2	3	3	0	1	2
3	8	3	3	2	6	1	3	2
4	4	1	1	2	4	0	2	2
5	8	2	3	3	7	1	3	3
6	6	0	3	3	3	0	1	2

Note: Higher scores represent greater deficits in awareness. Scoring criteria are described in Appendix B.

scores on the SADI. Details of these scores are provided within the following individual case vignettes.

Patient 1

Patient 1 was a 38-year-old professional chef who was hit by a vehicle while changing a tire at the roadside. Initial GCS was 7 and emergency neuroimaging revealed a right frontal contusion, with local mass effect, but no midline shift. Dissection of the right internal carotid artery was also noted. Approximately four days after his accident the patient was conscious, but unable to appropriately answer simple questions, demonstrating confusion about where he was, and neglect of his left side. His behavior became increasingly inappropriate, with angry outbursts and continuing evidence of confusion. He was transferred to the inpatient rehabilitation unit approximately four weeks after his injury. At that time he was noted to have difficulties with attention, cognitive organization, and self-monitoring. He demonstrated mild word-finding problems, excessive confabulation, and continuing neglect of his left side. His intake FAM scores revealed moderate problems in Communication, and significant problems in Psychosocial Adjustment, and Cognitive Functioning.

Patient 1 slowly became more cooperative, but remained impulsive, with limited attention and persisting signs of confabulation. He was perseverative in his topics of conversation, discussing his intention to return to cooking, and the difficulties that he was having with his marriage.

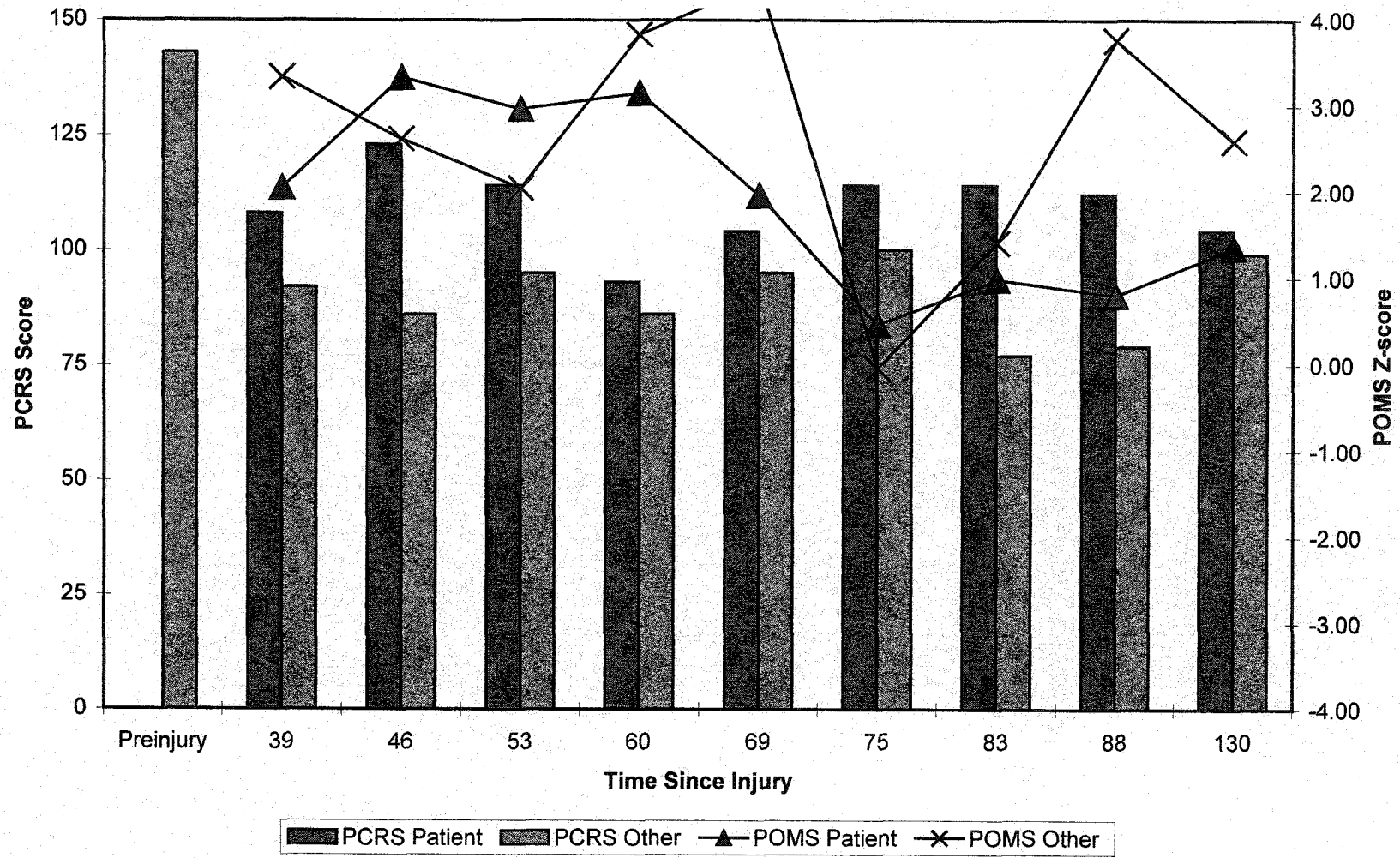
Patient 1 had a vague, but relevant premorbid history. He was separated from his wife, and lived with his girlfriend at the time of the accident. His girlfriend, the significant-other in this case, expressed considerable emotional distress in relation to a number of issues: first, she questioned the potential for a continuing relationship with the

patient; second, she was under considerable financial strain; third, she had a number of personal health concerns. Her POMS scores reflected a variable, but generally high level of emotional distress throughout the rehabilitation period. Nonetheless, she attended the hospital on a daily basis during the patient's stay, and planned to stay with him for the foreseeable future.

Patient 1 demonstrated consistent improvements in his physical ability, and in his ability to monitor his social interactions. However, staff commented that he displayed limited insight and an inability to appropriately plan for his future. He remained highly focused on a plan to immediately return to his job, despite the fact that he had failed a simple kitchen assessment with the occupational therapist. Furthermore, the relationship with his girlfriend continued to be turbulent, and psychological counseling was initiated for both individuals during the eighth week following the accident. Levels of emotional distress dropped for both individuals over the following weeks. The patient was eventually discharged to the care of his significant-other, with preparations made for him to attend an intensive outpatient rehabilitation program for TBI survivors.

Figure 1 displays the PCRS and POMS scores for Patient 1, and suggests that the patient was seen to be quite competent prior to his accident. This rating dropped substantially following the accident, at day 39 post-injury, and the discrepancy of 16 points between the patient and significant-other ratings on the PCRS was large in comparison to values previously reported for TBI patients (Prigatano, 1996). The initial SADI scores showed that Patient 1 was able to acknowledge "some" deficits, and "some" functional implications of his deficits. However, his abilities in setting goals and his foresight about long-term implications were limited. During his first weeks in the study, the patient reported increasing levels of competence, while the ratings of his significant-

Figure 1. PCRS and POMS Scores for Patient 1 and Significant-other



other remained relatively consistent. As the time of discharge approached, the significant-other decreased her ratings of the patient's competence, and her level of emotional distress increased. The patient's discharge FAM scores suggested that, although his functional abilities had shown significant improvement from intake, he continued to experience cognitive and psychosocial problems that would influence his ability to complete daily activities independently. Emotionally, both the patient and the significant-other appeared to benefit from the counseling intervention that was initiated during the eighth week post-injury. However, the patient continued to report a relatively low level of psychological distress, while the significant-other reported quite high levels of distress at the time of discharge.

Patient 2

Patient 2, a 31-year-old roofer, fell approximately 14 feet, landing on his head. He experienced a brief loss of consciousness and was highly combative at the scene and in the emergency room. His initial GCS was 14, although his deteriorating cognitive status precipitated an emergency CT scan, which showed a left-sided skull fracture, bilateral subdural hematomas with minimal mass effect, and fractures of his cervical spine. In addition to his head and neck injuries, this patient suffered fractures of his ribs. His lowest unmedicated GCS was 7.

Patient 2 remained in PTA for approximately 30 days, at times becoming agitated and requiring physical restraint. He was medicated with Cloxipol, Haldol, and Ativan during his acute medical recovery, with progressive improvements noted in his physical and mental agitation. He was transferred to the inpatient rehabilitation unit approximately six weeks post-injury, where he was oriented to person and place, but not to time or to the circumstances of his hospitalization. His FAM scores suggested good

comprehension and expressive language abilities, but cognitive and psychosocial scores were areas of moderate impairment. He displayed deficits in attention, memory for new information, and endurance. He was generally considered to be a difficult patient because of his poor compliance with treatments.

Patient 2 elected for his sister to act as his significant-other. She reported a disruptive family history, marked by frequent arguing, and strained relations between the adult family members. She also indicated that the patient had a moderate problem with alcohol prior to his injury. Despite these comments, her premorbid PCRS rating suggested that Patient 2 had been quite competent. The significant-other specifically noted that the patient's frustration tolerance was lower than premorbidly, that his anger was more severe than it had previously been, and that he was quite sensitive to criticism or feedback about his behavior. During the course of this patient's care, the significant-other voiced her own frustration about not being included in, or informed about the rehabilitation process. In addition, she regularly commented about her difficulties with personal and work-related stress. Her POMS score showed elevated levels of emotional distress at the beginning of Study 1, with some moderation over time.

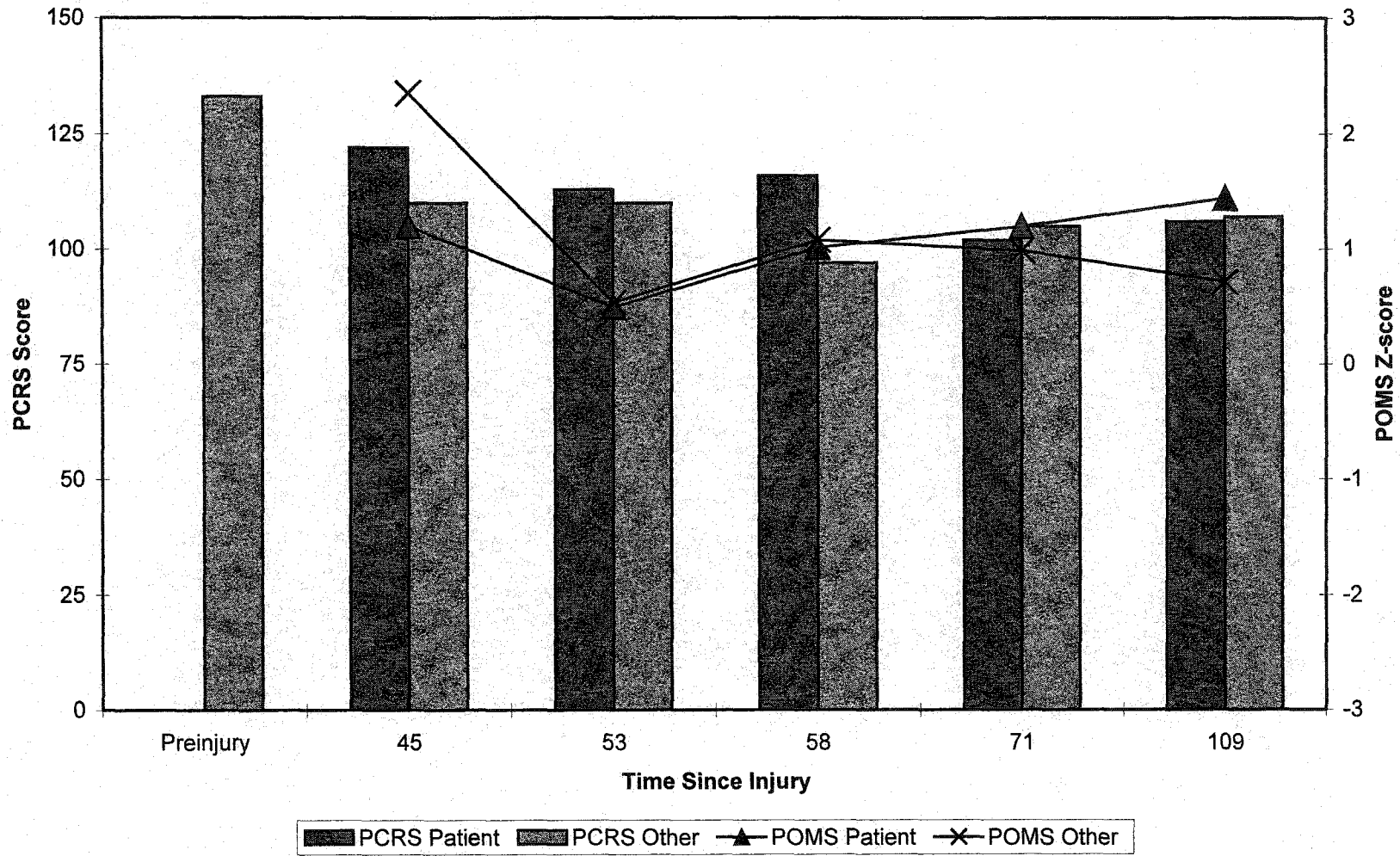
Patient 2 made steady physical recovery, and was judged to be making good progress in cognitive therapies. In addition to his TBI, injuries involving his neck clearly restricted his physical activity, although the patient did not seem to appreciate the importance of guarding his neck movements. This issue was a source of tension between medical staff and the patient. He was discharged to the care of his sister, and was generally independent in his activities of daily living. At that time, his insight was rated as mildly impaired by staff members, although it was noted that he was increasingly better at receiving feedback from therapists. Specifically, his discharge FAM showed

substantial improvements in Cognitive abilities and few concerns with Communication skills. Psychosocial scores on the FAM suggested moderate impairment. On release he was referred for outpatient therapies at a local facility for brain injured adults.

Examination of Figure 2 suggests that Patient 2 was perceived to be quite competent prior to his injury. Forty-five days after the injury, there was a 23-point drop in the significant-other rating of the patient's competence, reflecting her concerns about the patient's frustration tolerance. However, the actual discrepancy between the PCRS-Patient and PCRS-Other scores was minimal, suggesting that this patient had a good appreciation of his deficits. This finding was not in keeping with the SADI scores, which identified that the patient was denying or minimizing his deficits, and that he had few realistic plans for his future. Initial FAM scores also suggested that Patient 2 was not as skilled as he and his significant-other believed. There was very little variation in the patient and significant-other ratings during his rehabilitation, although the patient showed a trend toward increasing emotional distress the longer he remained in care. This pattern held at the follow-up evaluation, approximately five weeks after his discharge. Based on his SADI scores, this patient showed an increasing level of awareness of his abilities, and of the functional implications of his difficulties, although he maintained a poor ability to predict how his limitations would influence his future. Asked about his goals for the next six months, the patient replied that he wanted to "find peace in life", that he did not care about the injury, and did not want to return to work.

In summarizing this patient's course in rehabilitation it appeared that, the SADI and FAM were consistent in identifying the patient's continued psychosocial difficulties, and failure to appreciate the implications of these difficulties. However, scores from the PCRS did not identify a significant deficit in awareness. This may have been because of

Figure 2. PCRS and POMS Scores for Patient 2 and Significant-other



the relatively lower "baseline" level of competence perceived by the significant-other in this case (i.e., premorbid family issues, alcohol use, etc.). Emotionally, both the patient and significant-other were relatively stable across the rehabilitation time-frame.

Patient 3

Patient 3 was an 18-year-old undergraduate student who was involved in a motor vehicle accident, in which the car being driven by his girlfriend left the road, rolled several times, and ejected him from the passenger compartment. His initial GCS was 5 to 6, and CT scans showed hemorrhages in the left temporal lobe and basal ganglia, as well as diffuse axonal injury. A cranial drain was placed to relieve cerebral edema. He also suffered peripheral injuries, which included a lower spinal fracture. Two weeks after the accident he was described as having "low-level" consciousness, and was able to spontaneously open his eyes. He made slow but steady medical progress, and was transferred to the acute-care rehabilitation unit approximately one month after his accident.

Patient 3 remained agitated following his transfer, and was barely able to follow 1-step commands or to respond to yes/no questions. He soon began to show problem-solving skills, but with minimal spontaneous verbalization, and a limited span of attention; frequent cuing to task and to inappropriate behavior was required. He demonstrated a right-sided visual field deficit, and was unable to complete ADLs because of his physical limitations, including left-sided hemiparesis. Emotional distress was evident when his parents were not available to calm him, although he had begun to show signs of increasing orientation and awareness of his situation. His low level of functional ability was reflected in the intake FAM score, which identified severe deficits in Cognitive, Psychosocial, and Communication abilities.

Despite his significant deficits, Patient 3 was highly motivated and cooperative in therapies. He continued to demonstrate word-finding difficulties, and his comprehension was limited to simple words and phrases. He showed progress in physical and cognitive activities, and was able to walk at seven weeks post-injury. He was involved in Study 1 during the eighth week following his accident, identifying his mother and girlfriend as appropriate significant-others. In fact, his parents and his girlfriend remained heavily involved in all aspects of this patient's rehabilitation, to the extent that rehabilitation staff discussed potential negative implications of family over-involvement. The family maintained a strong religious faith, and did not readily discuss the patient's deficits, instead preferring a highly optimistic view for full recovery. They began to inquire about discharge options very early in the rehabilitation process.

Patient 3 showed gains in attention and concentration, but remained impulsive in problem solving and judgment. He failed to continuously attend to his right side, and demonstrated continued word-finding problems. Concerns about higher-order cognition, expressive language (i.e., fluency, articulation, word-finding), abstract reasoning, and limitations in his appreciation of these deficits continued until his discharge. With respect to awareness, Patient 3 demonstrated a mild degree of confabulation, reported by the therapists.

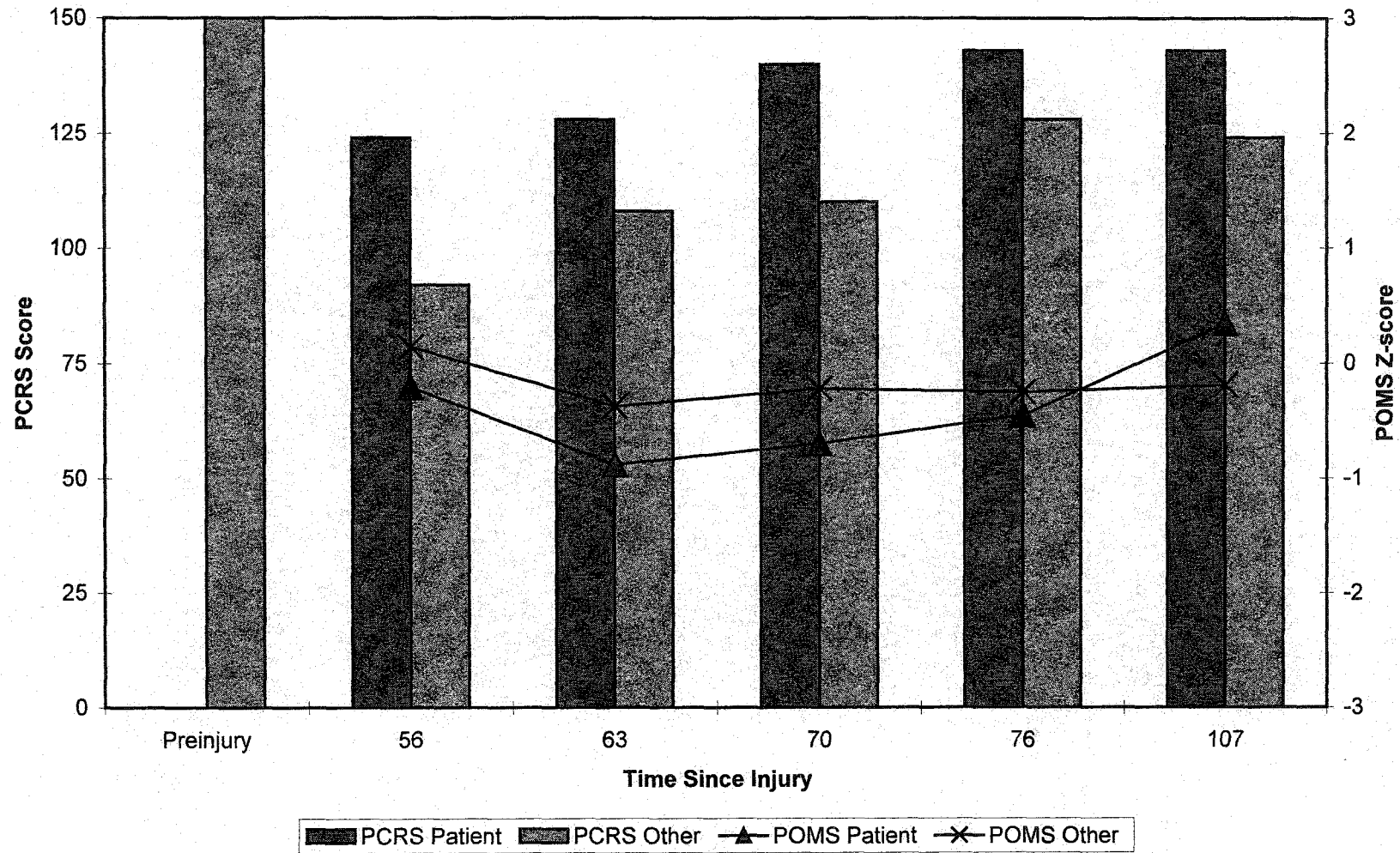
By the tenth week post-injury, the patient's family requested that he be discharged home. The patient was anxious to return to his home community, but had agreed to return for outpatient therapies on a weekly basis. He showed frustration with continuing areas of weakness, such as abstract reasoning, memory, and expressive language (word-finding, fluency, articulation), although the team did not feel that he had a full appreciation of these deficits. He reacted negatively to testing or challenge of his

deficits. His limited insight into his deficits, and into the functional implications of these deficits were areas of concern.

At follow-up, approximately one-month following his release from hospital, Patient 3 was increasingly unwilling to be involved in any rehabilitation or therapy activities. His parents remained highly supportive of his wishes, perhaps not fully appreciating the range of his deficits. Patient 3 expressed determination to return to his pre-accident life-style, regardless of the recommendations of others.

Figure 3 identifies that Patient 3 was seen as being highly competent prior to his injury, his significant-other (mother) rating him at the highest level possible on all abilities. However, eight weeks after the injury, significant-other's PCRS showed a 58-point drop in level of competence. A substantial discrepancy of 32-points was also seen between the patient's judgement of his abilities, and the significant-other's ratings. This discrepancy was consistent with ratings on the SADI, which classified Patient 3 as having a very limited appreciation of his level of deficit, or the functional implications of his deficits. Despite these noteworthy impairments, Patient 3 and his significant-other reported no psychological distress. In fact, they tended to report fewer stressors than the normative sample of the POMS. Clinically, in the case of the significant-other, a very high level of optimism was maintained during the patient's stay in rehabilitation. Indeed, his mother's absolute rating of the patient's competence (i.e., PCRS = 92), was probably an overestimate of his actual ability level at that time, as the initial FAM ratings had not been favourable. Thus, while the significant-other's PCRS score identified a problem with awareness in this case, the PCRS discrepancy score likely underestimated the degree of the problem.

Figure 3. PCRS and POMS Scores for Patient 3 and Significant-other



In examining changes in Patient 3's scores during his rehabilitation, it was apparent that both he and his significant-other perceived slow, but steady improvements in his overall level of competence. The relative discrepancy in competence ratings remained consistent at approximately 15-points. The rehabilitation staff continued to see a host of cognitive difficulties, as indicated by the discharge FAM scores. Although the scores had shown improvement, the patient was seen as having moderate deficits in the areas of cognitive, psychosocial, and communication skills. Finally, discharge scores on the SADI suggested that Patient 3 was beginning to admit that he had deficits, but remained unable to infer the functional implications of his difficulties, and had a limited ability to set realistic goals. Interestingly, at the one-month follow-up, the patient was beginning to acknowledge psychological symptoms, although they remained within the normal range. His self-report of emotional difficulties was also inconsistent with the reports of rehabilitation workers, who had seen the patient become increasingly unwilling to complete rehabilitation tasks, or to consider that there was a need for his continued treatment.

Patient 4

Patient 4 was a 29-year-old who was involved in an accident during a professional moto-cross race. He lost control of his motorcycle while jumping, landed on his head, with the motorcycle falling on top of him. His initial GCS was 10 and CT scans revealed a temporal contusion and posterolateral ventricular hemorrhage on the left, and midbrain shear hemorrhages in the right hemisphere. Small hemorrhages were noted diffusely, with significant cerebral edema. In addition to his head injuries, Patient 4 had a collapsed lung and a stable fracture of the right acetabulum. Chemical paralysis and hypothermia were induced, and maintained for approximately one week. CT scans during this time

revealed few changes, but when the paralysis was lifted Patient 4 could move all four limbs spontaneously, with some decerebrate posturing to pain stimulation. He showed no spontaneous eye opening, and no visual tracking. Thus, his lowest GCS would have been considerably lower than the GCS of 10 reported initially.

This patient's initial progress was slow. Two weeks after the accident he was able to partially open his eyes, and to nod in response to very basic questions. He showed signs of spontaneous visual tracking and recognition for familiar faces. He made steady improvements, with no medical difficulties, and was transferred to the acute-care rehabilitation service approximately six weeks after his injury.

At the time of admission to Unit 58, Patient 4 could reliably answer simple yes/no questions. However, he had difficulty with vision, and was only able to attend for 10 to 15 minutes. His FAM scores reflected a moderate to severe level of impairment across Cognitive, Psychosocial, and Communicative domains. It was decided that his participation in Study 1 would be delayed until his comprehension and attention abilities improved.

By eight weeks post-injury, Patient 4 was showing increasing use of humor, sometimes excessively, and was gaining in terms of physical and cognitive stamina. His ability to recall information after a short delay was minimal, and he remained prone to distraction. He initiated speech more regularly and appropriately, but had difficulty with word-finding and in making inferences, he was perseverative in his topics, and he had difficulty with processing of multiple pieces of information, sequencing and planning. While he demonstrated some awareness of his specific difficulties, he showed no awareness for the implications of these difficulties. Physically, he required minimal

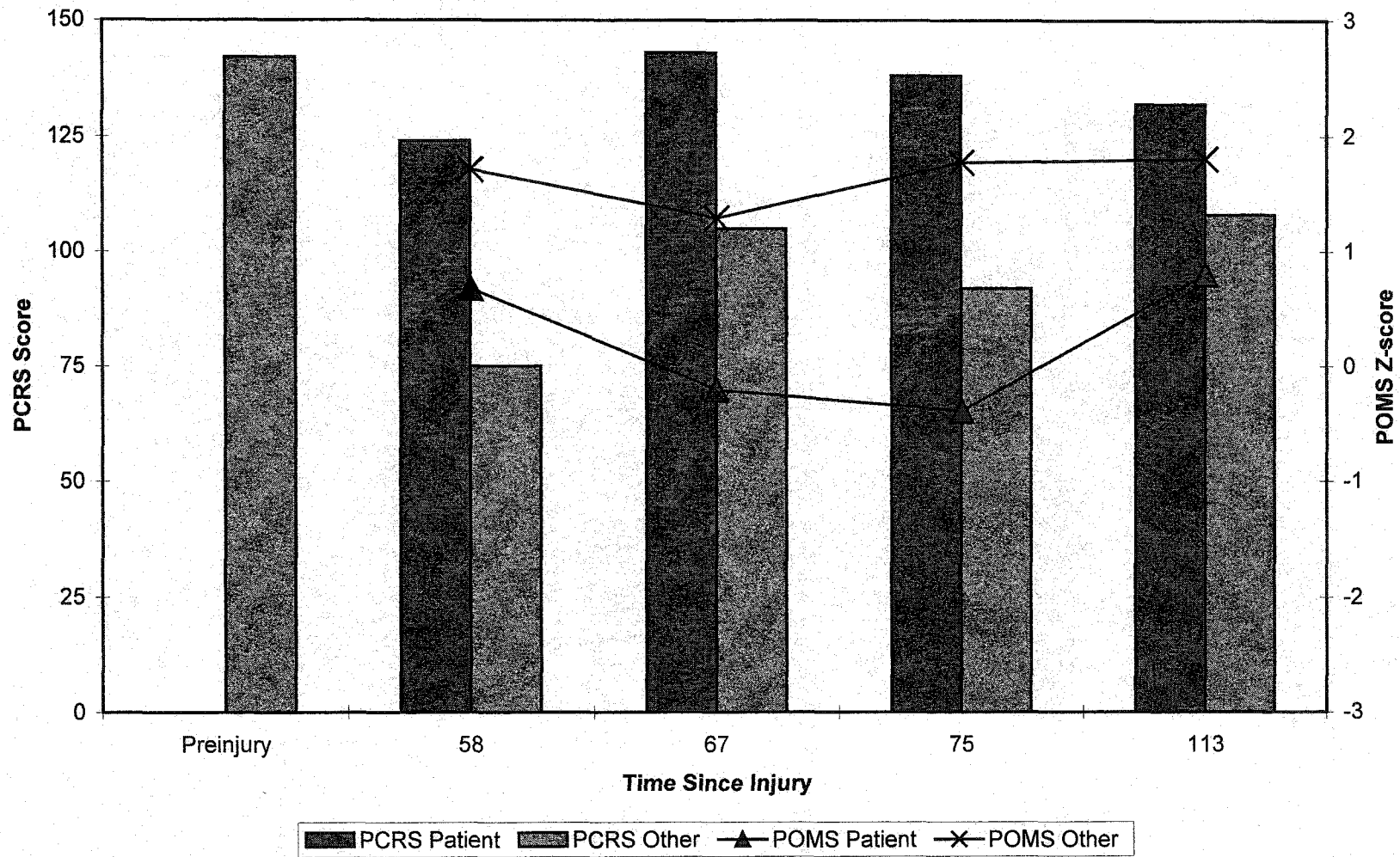
assistance with his wheelchair, but remained inattentive to his left side. He and his mother were involved in Study 1 at this time.

By eleven weeks post-injury Patient 4 was increasingly cooperative and pleasant, at times showing excessive laughter, but generally appropriate. He continued to be frustrated with challenges, and displayed weaknesses in sequencing information, attention to visual detail, divided attention and concentration, verbal reasoning, and memory for recent events. His tendency to confabulate had diminished, but no appreciation of his difficulties was shown. His comprehension was felt to be 75% for passages of two to three sentences, and his expressions tended to be delayed, with persisting word-finding. Physically, he was able to transfer with cuing, but still neglected his left side in motor and sensory realms. He was able to manage ADLs with setup.

Patient 4 was discharged to the care of his parents during the eleventh week post injury. His parents remained highly supportive of him, although they demonstrated an explicit under-appreciation of the severity of his residual functional deficits. For example, Patient 4's father indicated that his son "would be back to racing in no time." Patient 4 continued in outpatient therapies, demonstrating little change in his overall level of awareness.

Figure 4 shows that the significant-other had perceived the patient as being quite competent prior to the accident, but also reported a considerable decrease in competence at the first observation in Study 1 (i.e., a 67-point drop between the premorbid estimate and eight weeks post-injury). Furthermore, the 49-point discrepancy in patient-other PCRS ratings reflected considerable limitations in the patient's awareness of his deficits. These ratings were consistent with staff ratings of the patient's functional abilities, which identified moderate to severe cognitive and psychosocial issues, and moderate

Figure 4. PCRS and POMS Scores for Patient 4 and Significant-other



impairments in communication abilities. The initial SADI scores were moderate in this case, suggesting that the patient had insight about his deficits, with some denial or minimization. He was unable to infer how these deficits would impact his lifestyle. This patient generally acknowledged few symptoms of emotional distress. His significant-other, on the other hand, endorsed a number of symptoms which were appropriate to the circumstances. There was little change in the POMS ratings over the course of rehabilitation, and no notable change in PCRS discrepancies. By the time of his discharge, the patient's functional ratings (i.e., FAM) remained in the moderately impaired range, and his SADI scores reflected poor appreciation of deficits, and poor ability to comprehend the significance of his deficits. Both the patient and his mother had reported some gains in competence, although the large PCRS discrepancy remained, suggestive of impaired awareness on the patient's part. Clinically, the patient remained insistent on a return to his previous routine, regardless of his potential deficits. At the follow-up session, Patient 4 showed increasing signs of emotional distress. His mother rated him as continuing to have "some difficulty" in completing activities.

Patient 5

Patient 5 was a 39-year-old man who was involved in a single vehicle accident, possibly having fallen asleep at the wheel while driving home from work. His GCS at the scene was 7, and had improved to 10 by the time he was airlifted to the emergency center. His coma duration was less than 24 hours, but the duration of PTA was lengthy. CT scans revealed a small left temporal pole epidural hematoma with no mass effect, facial fractures, and a small right frontal subdural hematoma. Subsequent CT scans identified collections of intracranial air, bifrontal collections of blood, and fractures of the left orbit. Patient 5 made a slow medical recovery, which was complicated by respiratory

infection. At two-weeks post-injury he displayed mild ataxia, with poor coordination on the left side. He was oriented to person and place, but not to time. He was noted to have significant deficits in concentration, judgment, attention, short-term memory and prospective memory (i.e., memory to complete a task in 5-minutes). When transferred to acute-care rehabilitation, three weeks after his accident, he remained in a state of post-traumatic amnesia.

On the rehabilitation unit, Patient 5 was able to initiate various activities of daily living with minimal cuing, and minimal setup. He was able to self-ambulate, but required a wheelchair for longer distances. His FAM scores reflected mild to moderate impairments in Psychosocial and Communication skills, with more significant deficits in Cognitive tasks. Although he was able to verbalize his needs effectively, he was not oriented to time or to the reason for his hospitalization. He had significant short-term memory difficulties, consistent with PTA. Emotionally, he was polite but easily agitated. Staff noted that he was not distressed about his deficits, and that he appeared to have limited insight into his situation or functional deficits.

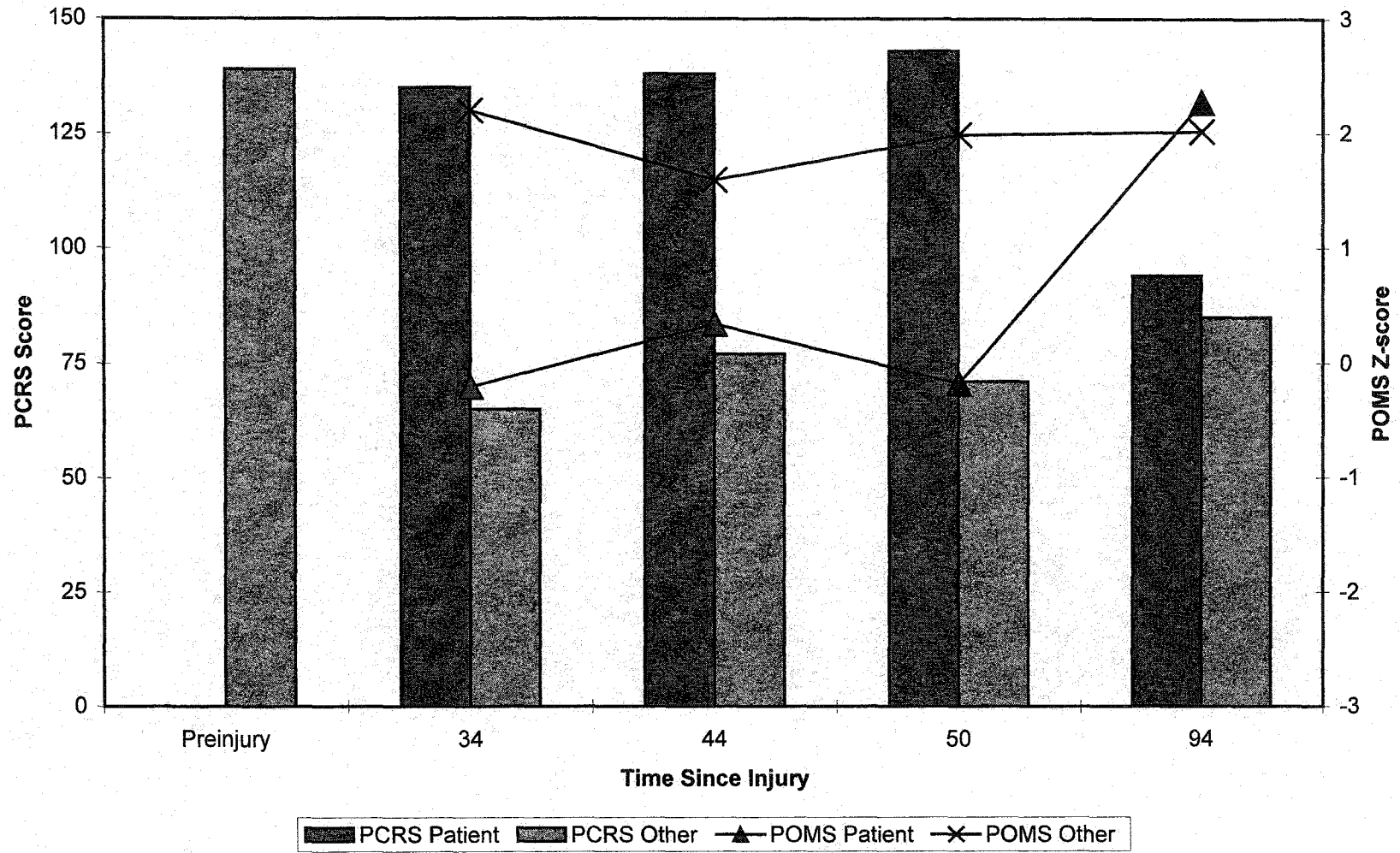
By the fifth week following his accident Patient 5 still had communication deficits, but was able to comprehend simple multi-step commands. He showed evidence of mild confabulation, decreased attention and concentration, poor deductive reasoning, and poor planning and awareness in general. He was able to communicate sufficiently to meet Study 1 inclusion criteria. Informed consent was obtained from the patient and from his wife. By this time his wife acknowledged that she was less concerned with Patient 5's medical recovery, and increasingly concerned with the family's financial status. She was fully aware that it would be very difficult for Patient 5 to return to employment, and she discussed her concerns openly with therapists.

By his seventh week post-injury, Patient 5 continued to show promising physical recovery, and was able to ambulate independently, without a wheelchair. He often appeared tearful during challenging cognitive tasks, but was generally able to control his emotions. He showed attention deficits and decreased processing speed, and was persistently inaccurate regarding the date and time of day. He showed poor awareness of errors, mild word-finding difficulties, and concrete thinking. Although he completed rehabilitation tasks with enthusiasm, his wife voiced concerns that he was more depressed than usual. Interestingly, she noted that the patient also showed an *increased* tolerance to frustration and a stabilization of his previously moody disposition.

At discharge, Patient 5 essentially had shown complete physical recovery, but with persistence of his cognitive deficits. He experienced confusion about issues relating to his injury, and confabulated on a regular basis. He paid inadequate attention to the details tasks, and showed poor appreciation of his errors. He was discharged to the care of his family, and showed little change in his cognitive status over the following month. However, consistent with the data displayed in Figure 5, his wife anecdotally described an increasing level of depression, which was evident on the PCRS and on the patient's POMS. She noted that Patient 5 did not appear to react negatively to his many cognitive difficulties. Home-care was implemented such that his wife was able to seek employment.

From Figure 5 it can be seen that Patient 5 demonstrated a significant drop in his level of competence, as perceived by his wife. Figure 5 also displays that the patient remained persistently unwilling to admit to his deficits, resulting in very large discrepancy scores on the PCRS. These scores were consistent with scores on the SADI, which showed severe limitations in awareness, and with FAM ratings. In fact, the

Figure 5. PCRS and POMS Scores for Patient 5 and Significant-other



rehabilitation staff saw Patient 5 as having significant cognitive deficits, but less severe deficits in the areas of psychosocial and communication skills. In terms of emotional adjustment, the patient did not acknowledge specific emotional concerns, compared to his wife, who endorsed numerous symptoms of emotional distress. Her POMS scores were consistently two standard scores above those of the normative sample. Figure 5 shows that there were no dramatic fluctuations in the ratings of the patient, or of the significant-other in this case. By discharge, the patient was grossly over-estimating his competence, as rated on the PCRS and the SADI. His functional ratings (i.e., FAM scores) had improved somewhat, but remained within the moderate impairment range across the Cognitive, Psychosocial, and Communication domains.

At the time of follow-up, 44-days after his discharge, a distinct change in the PCRS and POMS profiles appeared. The patient's rating of competence had dropped significantly, convergent with the reports of the significant-other. On the other hand, Patient 5's POMS scores had increased to match his wife's ratings. This pattern suggested increased awareness and increased emotional distress. Clinically, the significant-other reported that Patient 5 had begun to show signs of depression, but she did not perceive changes in his general level of cognitive ability. Unfortunately, since the patient was no longer an inpatient, FAM scores were not available to ascertain his actual level of functional ability. It could be hypothesized that Patient 5 had attempted to engage in functional activities in his home environment, leading to a realization of his limited competence. It was not possible to confirm this hypothesis clinically.

Patient 6

Patient 6 was a 26-year-old undergraduate student who was broad-sided as he drove his car through an intersection. He sustained severe head injuries, with an initial

GCS of 3. CT scans showed a basilar skull fracture, a frontal bone fracture, and pneumocranium. Systemic injuries were surgically treated, including a liver laceration, splenic contusion, renal pelvis injury, and ruptured diaphragm. Neuroimaging completed several days after his accident identified focal damage of the right thalamus, shear injuries involving the corpus callosum, and bilateral contusions of the frontal lobes. Thus, the impressions of the radiologist were consistent with diffuse axonal injury. Several days after the accident, Patient 6 showed signs of neurological recovery, including purposeful movement, but with abnormal posturing on the left side. He experienced medical complications arising from an infection, but was conscious and cooperative by two weeks post-injury. At three weeks he was able to respond to yes/no questions through nods, eye-blinks, and other non-verbal means but could utter only reflexive verbal sounds. He demonstrated a flattened affect, and the number of visitors was reduced to prevent over-stimulation.

Prior to the accident this patient had been quite physically active, living independently, and working part-time while attending school. He was described as an avid reader. His highly supportive parents were in continuous attendance throughout his emergency medical care, and acute neurorehabilitation. Unlike Patient 3, there was no concern that parental involvement was hindering the patient's recovery.

Patient 6 was transferred to the rehabilitation unit four weeks after his injury. He was able to repeat single words in a weak, aphonic voice, and with very slow output. He demonstrated significant left-sided weakness, altered sensations on the left side, significant word-finding problems, poor confrontational naming with perseverations, and poor attention and memory performance on simple tasks. His comprehension was adequate for three-step commands, and he was functionally able to communicate his

needs. On cognitive testing he showed poor discriminative attention, poor orientation, and poor recall.

By the fifth week post-injury, Patient 6 was inconsistently oriented to time, he continued to have deficits in attention, memory, and sequencing, and he was increasingly aware of his speech errors. He experienced difficulty with initiation of speech and his utterances were marked by paraphasias and word-finding difficulties. However, he responded well to cuing and was able to express his needs. At this time the patient and his mother were enrolled in Study 1. His SADI scores indicated that he had excellent awareness of his deficits, but had very limited insight about the functional limitations that his deficits would pose.

Over the course of Study 1, Patient 6 continued to show improvements in physical abilities, including walking, and general endurance. Socially, he was engaging with the therapists, showing good initiation. Cognitively, his weaknesses included difficulties with short-term memory, word-finding, and decreased attention with some distractibility during conversation. He was still not oriented to year, but was beginning to show effective problem-solving abilities, and some awareness of errors in speech, memory, and attention.

By the time of his discharge, Patient 6 was appropriately engaging in conversation, but remained rather concrete in his thinking. Therapists identified continuing improvements in comprehension, word-retrieval, and ADLs. He was discharged to the care of his parents, and continued with outpatient therapies within Foothills Hospital. His parents reported reasonable adjustment at home, although he had not attempted many of his previous activities. Patient 6 acknowledged that he experienced increased frustration with his deficits following his release from inpatient

care. He felt that he managed these problems effectively, and that friends and family continued to be highly supportive of him.

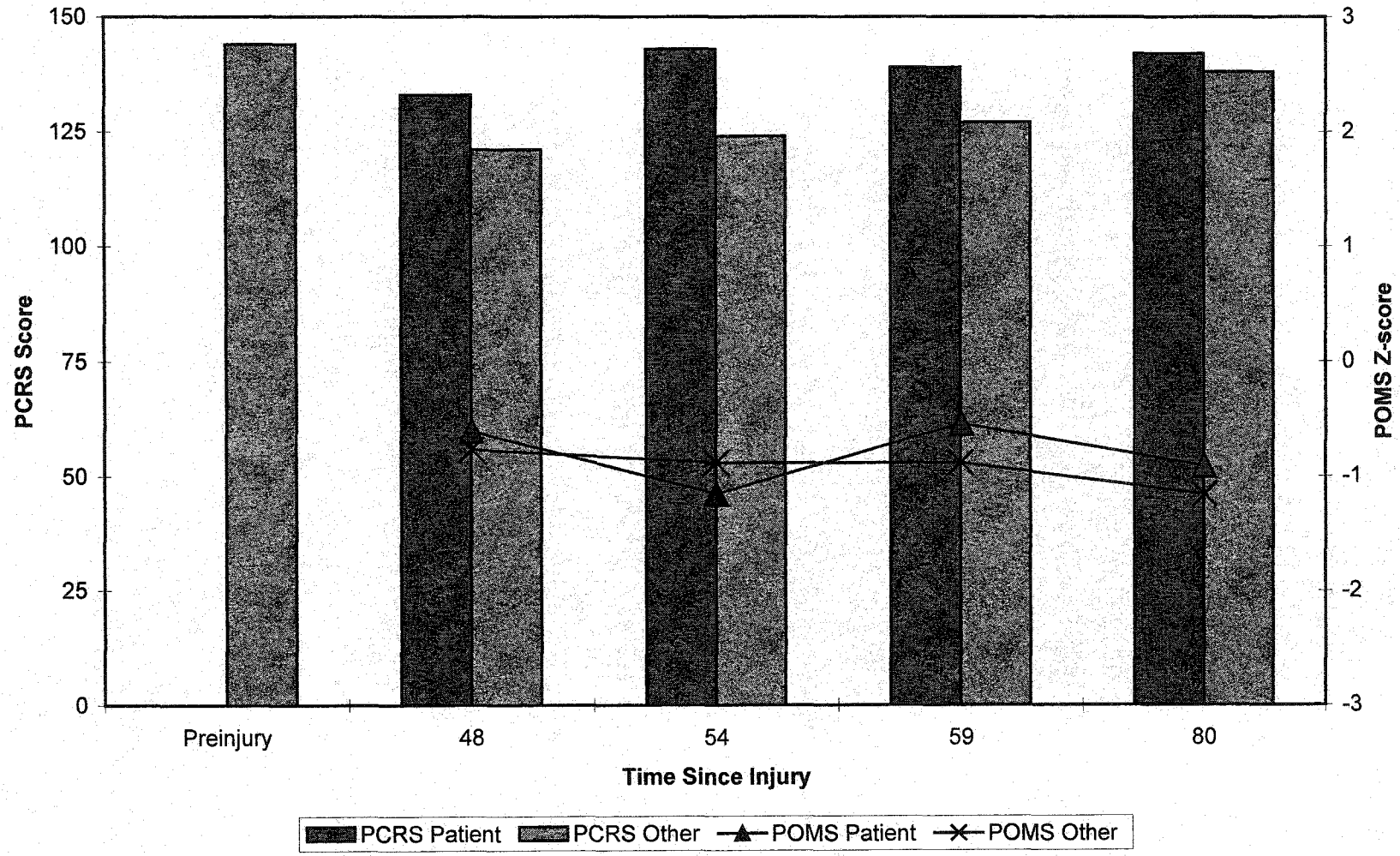
The PCRS data for Patient 6 was not particularly consistent with the results of the SADI, which had identified good appreciation of current deficits, but poor appreciation of the implications of those deficits. As depicted in Figure 6, the patient's ratings of self-competence suggested that he perceived few changes in his abilities. While the significant-other admitted changes from pre-injury competencies, noted by a 23-point drop in the significant-other PCRS score, the discrepancy between the patient's rating and the significant-other's rating was minimal, 12 points overall. Similarly, there was very little fluctuation in the absolute ratings of either the patient or the significant-other during the course of rehabilitation. While the PCRS is not intended to examine the patient's ability to predict future competence, this patient appeared to minimize his specific deficits on the PCRS, while he was more willing to discuss deficits on the SADI.

The emotional adjustment scores from the POMS suggested that both the patient and the significant-other *denied* specific psychological concerns, scoring approximately one standard deviation below the general population in terms of degree of experienced emotional distress. By the time the patient was discharged from hospital, the FAM scores identified moderate impairments in cognitive and psychosocial abilities, with mild to moderate impairments in communication abilities.

Group Considerations

Data from the six patients of Study 1 were combined to allow for examination of summary results. Although it was not possible to complete traditional statistical analyses because of the small number of participants, Figure 7 shows that there was a mean drop of 48.5 points on the PCRS-R (relative's version) when comparing the significant-others'

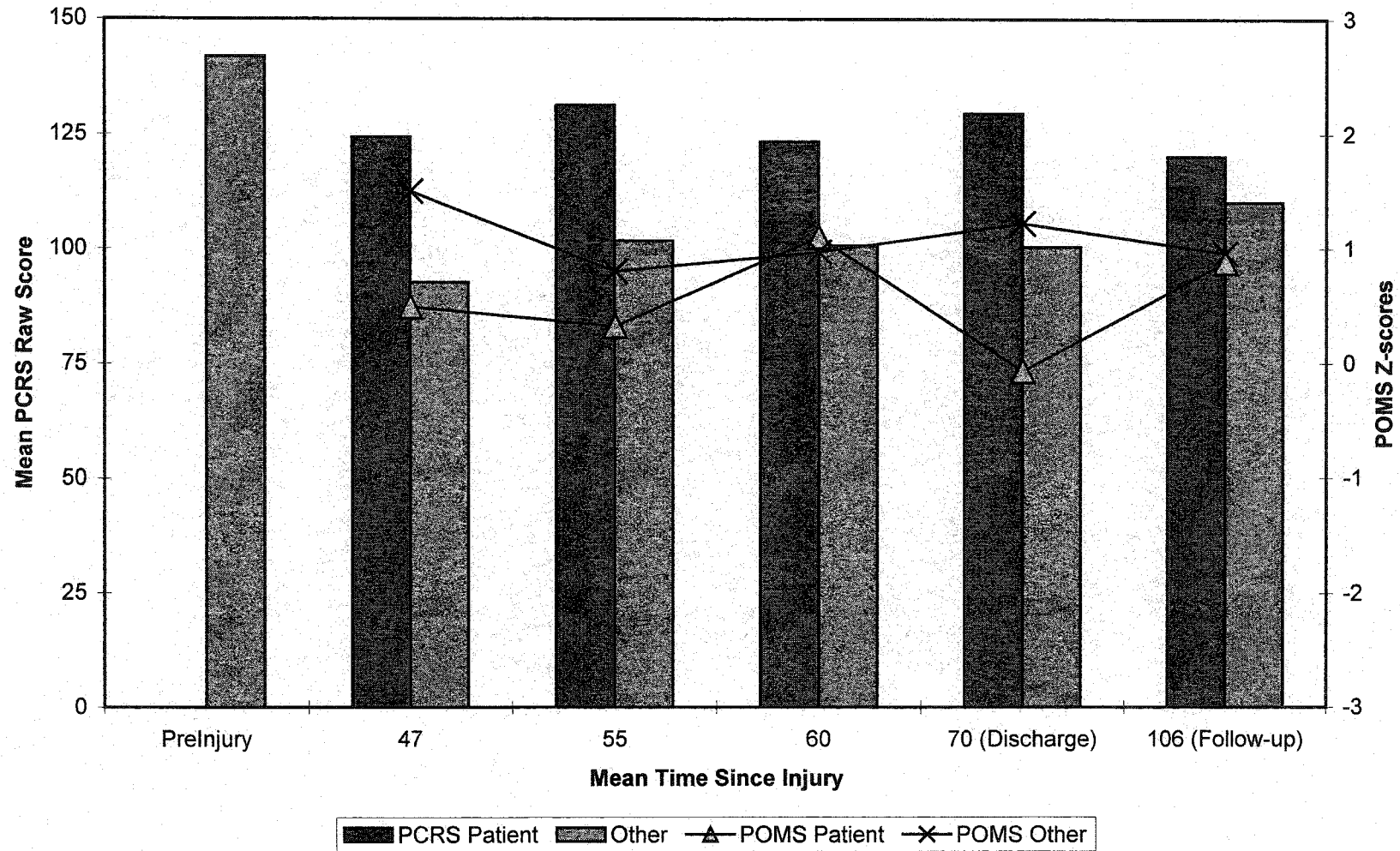
Figure 6. PCRS and POMS Scores for Patient 6 and Significant-other



perceptions of the patient prior to the injury, to the perceptions of the patient in the earliest post-injury period. Furthermore, there was a large mean discrepancy of 31.8 points between patients' ratings of their own competencies, and the significant-others' ratings of competencies during the first assessment, occurring an average of 47 days post-injury. This discrepancy showed little variability over the course of four weeks of rehabilitation. Some patients remained in hospital longer, but in considering all six patients at their respective follow-ups, which occurred an average of 106 days post-injury, the discrepancy between the patients' ratings and the significant-others' ratings had diminished from approximately 29 points at discharge, to just 10 points at follow-up. Inspection of Figure 7 suggests that, at follow-up, moderation had occurred in the ratings of both the patient and the significant-other, such that competency ratings were more closely aligned. Thus, the patients, as a group, came to see themselves as being somewhat less competent, while the significant-others came to see the patients as being more competent.

Figure 7 shows the summary POMS self-rating scores, suggesting that as a group the patients tended not to report emotional adjustment issues on the POMS, while the significant-others did. At discharge, four of the six patients actually scored below the mean of the community dwelling standardization sample in the POMS, and no patient scored higher than one standard score above the mean. At follow-up, the patients were approximately one standard score above the normative mean on the POMS. However, as described in the individual case vignettes, the group was not consistent in their experience of emotional adjustment difficulties. Three patients scored above one standard score, two patients scored within the average range, and one patient scored one standard score below the normative mean. These results strongly suggest that the

Figure 7. Summary PCRS and POMS Data Averaged Across Patients

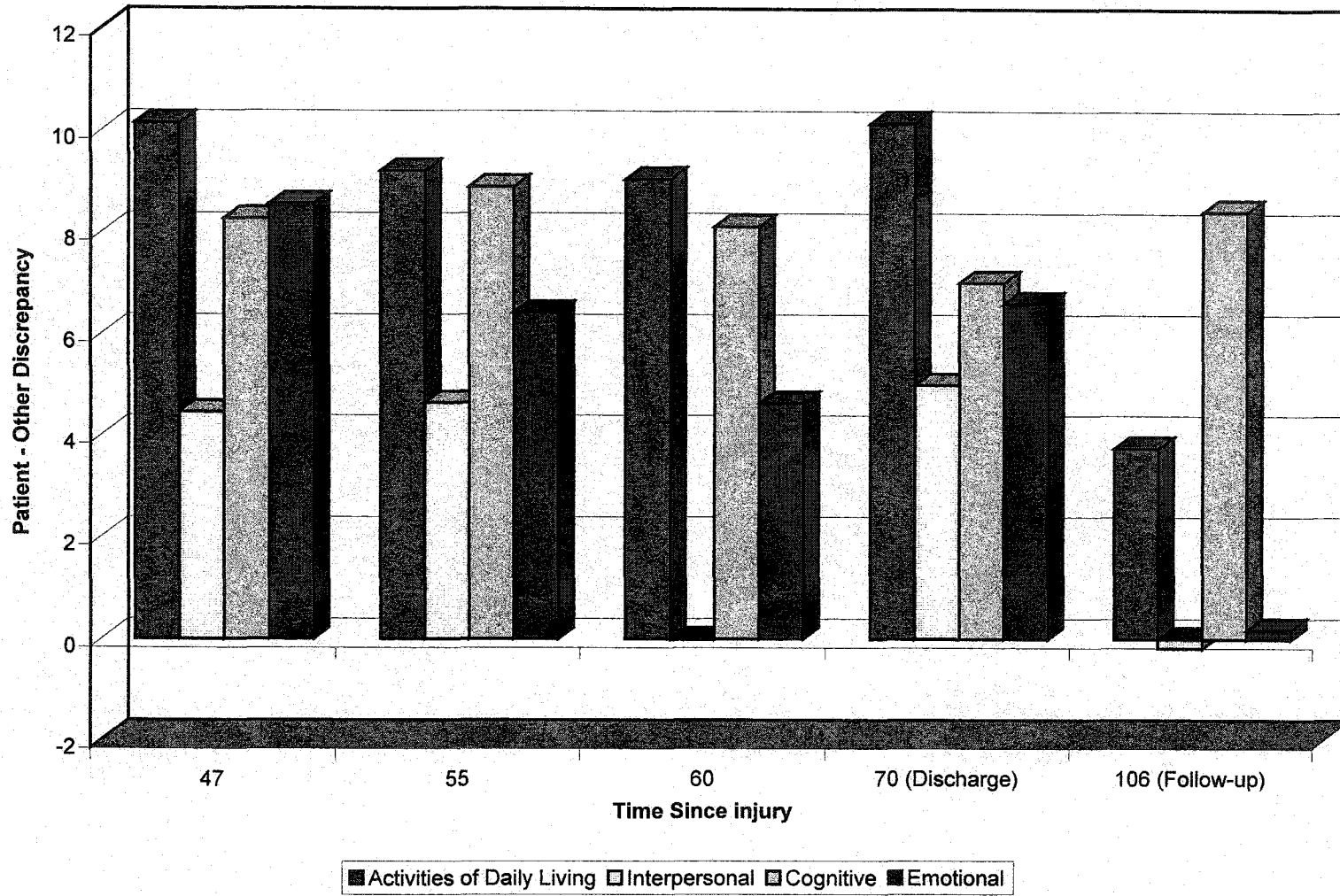


emotional adjustment of patients with severe TBI may vary widely and should be considered individually, especially in relation to their level of cognitive deficit, their personal ability to acknowledge deficits, and staff-member's perspectives of deficits. The results also suggest that the emotional adjustment reactions of significant-others can vary widely, and family members may report as much, or more subjective emotional distress than the patient. In other cases, family members expressed minimal levels of emotional distress, scoring considerably below the standardization mean. This "keep it together" presentation of some significant-others appeared to be associated with higher PCRS ratings of patient competence.

The results of the PCRS were explored in terms of the previously identified factor structure (Heilbronner, et. al, 1993). Items were grouped into ADLs, Interpersonal, Cognitive, and Emotional issues. While in hospital the patients and significant-others showed strong discrepancy scores on items relating to ADLs (see Figure 8). Patients also rated themselves as being competent in activities involving cognitive and emotional skill, while significant-others saw the patients as being less competent. The discrepancies between patient and significant-other ratings on the Interpersonal factor were generally lower than on other factors. These results are contrary to what has been reported for post-acute patients, who typically have poor awareness of their interpersonal and emotional competencies. These findings could suggest a need for "togetherness" following a traumatic injury, thereby resulting in strong feelings of interpersonal connection.

At the time of follow-up, the patients showed reasonable agreement with the significant-others on the PCRS Total Discrepancy, a finding displayed in Figure 7. However, when examining the discrepancies in factor scores in Figure 8, it appeared that

Figure 8. Patient-Other Discrepancies on PCRS Factor Scores



the patients rated themselves as being more competent in the area of Cognitive ability, than did the significant-other. In contrast, no discrepancy was observed between patient and significant-other ratings of Interpersonal or Emotional competencies, and ratings on Activities of Daily Living were only slightly discrepant.

To address issues relating to the utility of the test instruments used, and the relationship between emotional distress and ability to report competence, correlations between test scores were examined. Because of the small number of observations, the results were interpreted as tendencies, rather than valid correlations, even when correlations reached statistical significance. A number of correlations are presented in Table 4. With respect to the two measures of awareness, the total score on the SADI, combining awareness of deficit, ability to recognize the functional implications of the deficit, and the ability to set realistic goals for the future, was not strongly correlated with PCRS scores. The two awareness summary scores, the PCRS-Total Discrepancy and the SADI Total score were non-significantly correlated at $r = .43$ ($p = .16$). Looking more closely, the strongest correlation was between the patients' PCRS Total score and the SADI rating of the patients' ability to recognize the functional implications of their difficulties ($r = .57$, $p = .055$).

The Psychosocial, Cognitive, and Communicative ratings of impairment from the FAM were combined to create a FAM Summary Score. This general rating of neurocognitive impairment showed a moderately strong correlation with the SADI "deficit score", which is designed to assess the patient's awareness of *specific* deficits ($r = -.68$, $p = .02$). Thus, greater impairment reported by the staff, was associated with a higher likelihood that the patients would report their deficits. However, the lack of correlation between the FAM Summary Score, and the SADI "implications score", which

queries a patient's ability to identify potential implications of their deficit, suggests that while in hospital, patients may have difficulty gauging the functional implications of their problems, regardless of how they are perceived by staff. This finding may be due to the limited opportunities for the patient to actually engage in functional activities that they are asked to rate.

Table 4. Correlations Among Tests in Study 1.

	POMS Patient	PCRS Other	PCRS Patient	PCRS Discrepancy	SADI Deficits	SADI Implications	SADI Total	FAM Summary
POMS Other	.74**	-.69**	-.57**	.18	.08	-.21	-.05	-.47
POMS Patient		-.41*	-.77**	-.24	.04	-.61**	-.32	-.10
PCRS Other			.35	-.65**	-.29	-.09	-.24	.25
PCRS Patient				.49**	.05	.57**	.39	.11
PCRS Discrepancy					.29	.40	.43	-.15
SADI Deficits						.41	.80**	-.68**
SADI Implications							.84**	-.11
SADI Total								-.35

* significant at $p < .05$; ** significant at $p < .01$

The relationship between POMS scores and awareness measures was also considered. Strong correlations were observed between the patients' and significant-others' self-report of emotional distress on the POMS ($r = .74$, $p < .001$). The emotional status of the patient was also correlated with their self-report on the PCRS ($r = -.77$, $p < .001$), such that low levels of emotional distress were associated with higher ratings of competence. In this small sample, the patients appeared to deny both functional and

emotional concerns. The pattern of correlations implies that, as patients endorse more functional concerns, they will also endorse emotional adjustment issues. In examining the scores for the significant-others, a similar pattern was observed. That is, a correlation of $r = -.69$ ($p < .001$) was seen between the significant-others' report of emotional distress, and their ratings of the patients' competencies. The suggestion is that higher levels of significant-other emotional distress are associated with lower ratings of patients' competence.

GEI Results. The GEI was administered to patients and significant-others at the onset of the study, and again at the time of their discharge from inpatient rehabilitation. During the administration of this instrument, it was observed that patients frequently requested clarification of particular items, which may have excessively influenced their responses. Patient 1, for example, showed a high number of atypical responses, suggesting that he may not have fully understood some of the questions on this inventory. No other respondents demonstrated elevations on the Atypical Response Index. Administration of the GEI was also cumbersome with this group of patients, due to the length of time required. The scores were nonetheless examined on a case-by-case basis, evaluating patient and significant-other responses at the time of intake into Study 1. Summary scores were computed for the various GEI factors and converted to standard scores, based on data provided in the manual (Sanders, et al., 1985; GEI Form B, Non-Death Version). Patients 2, 3, 4 and 5 all showed elevations on the Denial scale, which utilizes responses to common emotional reactions to gauge how openly an individual expresses their adjustment reactions. Additionally, the significant-others of patients 2 and 3 showed mild elevations on the denial scale of the GEI.

Examining selected factors of the GEI, only one patient showed a slight elevation on a factor related to Depression and Despair, and three patients reported fewer feelings of depression than the mean of the bereavement standardization sample. Significant-others did not show elevations on the Depression and Despair factor, and two significant-others reported fewer of these feelings than the standardization sample. No patient showed an elevated anger score, and most of the significant-others reported less anger than observed in other non-death bereavement situations. On the Loss of Control Index, patients and significant-others tended to report fewer such feelings than the standardization sample. In comparing the GEI to the POMS, the Despair factor and the Anger/Hostility factor were highly correlated with the POMS total score (.94 and .90, respectively) although the small number of observations limits the interpretability of these correlations. Patients tended to endorse a variety of somatic and physical concerns, such as sleep disturbance, changes in energy, and changes in appetite. However, it would be difficult, in this sample, to make the case that such symptoms are emotionally-based, and not related to the physical rehabilitation factors.

Discussion, Study 1

Study 1 presents a descriptive case-series approach to the study of level of awareness and emotional adjustment following severe TBI. Six adult males were followed through their acute-care rehabilitation. All had experienced a range of injuries, requiring an average of approximately 70 days hospitalization. There was moderate variability in the patients' initial GCS scores, and substantial variability in the duration of loss of consciousness for each patient. All patients had periods of posttraumatic amnesia that exceeded 20 days, and all had brain damage identified by either CT or MRI.

The first general prediction of Study 1 proposed that patients with decreased levels of awareness would be less likely to show emotional adjustment difficulties, compared to individuals with good awareness. Thus, the first task was to identify impairments in awareness of deficit. The rehabilitation staff rated each patient using cognitive, psychosocial, and communicative items from the FAM, identifying impairments ranging from mild to severe. In this regard, all patients had clear deficits in one or more cognitive domains upon admission to the rehabilitation program. During the initial evaluation, the significant-other was first asked to recall the patient's abilities from before the injury, and then to report those abilities since the injury. All significant-others reported a decrease in the patient's overall level of competence. Furthermore, all patients reported their level of competence to be higher than that viewed by the significant-other, and in no case did the patient see himself as being more impaired than perceived by the significant-other. Thus, discrepancies between the patients and relatives PCRS appeared to reflect the patients' perception of deficits, but also the significant-others' ability to perceive changes. This discrepancy is felt to represent a level of patient unawareness of deficit.

The SADI also proved useful in providing semi-objective ratings of deficits in awareness in this sample of patients. Initially, almost all patients scored positively on all three indices of the SADI, suggesting difficulty in recognizing specific deficits, functional implications, and long-term consequences of their injury. The SADI scores identified that the greatest weakness of the patients was in their ability to predict the implications of their deficits. Even those patients who were able to identify one or more specific deficits had trouble predicting how those deficits would limit current or future activities. For example, Patient 6 had little difficulty discussing his deficits "in the

moment,” apparently demonstrating very good “intellectual awareness”. However, when asked to predict the impact of his deficits, his SADI scores reflected very poor “anticipatory awareness”. Furthermore, the strongest correlations between SADI and PCRS scores suggested that the more competent the patients reported themselves to be on the PCRS, the higher their SADI “Implications” score (i.e., suggesting poor anticipatory awareness). The structured interview approach provided less specific information than the PCRS in terms of querying particular areas of deficit, although the SADI allowed greater clinical flexibility in terms of the open-ended responses. This observation was supported by the moderate correlation between SADI scores and staff perceptions of the patient. Thus, with regard to the first hypothesis, although the SADI and PCRS were only moderately correlated, the SADI was felt to provide useful information regarding the patients’ level of awareness, particularly their anticipatory awareness, which was somewhat different from the information provided by the PCRS.

The second task was to assess each patient’s level of emotional adjustment. This was accomplished using the POMS, which was felt to be an appropriate measure because of its ease of administration, face validity, and simplicity. These features were found to be especially appropriate for the acute-care rehabilitation patients considered in Study 1. Interestingly, in the initial assessment, only two of the patients acknowledged symptoms of emotional distress on the POMS, two patients endorsed subclinical levels of emotional distress, and two patients actually reported fewer emotional symptoms than endorsed by the standardization sample for the test. Based on these mixed findings one could conclude that the POMS was not specific in measuring the level of emotional distress in acute-care TBI patients. On the contrary, when considering how individual patients responded to the POMS over the course of their stay, in most cases a high level of

consistency was observed. In one case where large fluctuations in POMS scores were observed (Patient 1), the fluctuations appeared to be related to the patient's actual lability in mood, based on clinical interactions and chart notes, rather than to idiosyncratic factors or problems with the POMS (see Figure 1).

Next, in examining the group data, a strong correlation was observed between the patients' likelihood of acknowledging emotional distress on the POMS, and their likelihood of reporting problems on the PCRS. Patients who admitted few changes in their specific competencies were also unlikely to acknowledge emotional problems. Patients 3 and 6 illustrate this point, as both had clear difficulties based on their clinical presentation and FAM scores, yet neither patient reported notable declines in their level of competence, and neither acknowledged emotional distress. Based on these data, the POMS appeared to provide a useful estimate of the patient's emotional adjustment.

The GEI was administered to explore its potential among acute care patients, and in an effort to capture a greater range of emotional reactions of the patients. The GEI was more complex than the POMS in terms of the language used, and in the level of abstraction that was required from the respondents. In each case, the GEI was read to the patient, and in many instances the questions required clarification. However, only one patient scored highly on the Atypical Response Index, potentially calling the validity into question for this individual. Several patients and significant-others showed elevated scores on the Denial Index, which captures emotional reactions that are typical following a traumatic loss such as divorce, or other separation from a loved one. Other patients and significant-others showed modest elevations in scales relating to anger and depression. In addition patients endorsed a variety of concerns that could be directly associated with their physical rehabilitation status (e.g., decreased energy, appetite, sleep disturbances).

The GEI has previously been used to assess grief and bereavement reactions among brain injury survivors (Haynes, 1994; Zinner, et al., 1991), showing similar profiles to those who had experienced the death of a loved one. However, the GEI proved to be impractical for acute-care rehabilitation patients. Issues relating to the administration and the appropriateness of comparison samples were felt to limit the utility of the GEI in this study.

In considering the relationship between emotional adjustment and level of awareness of neurobehavioral deficit, it appeared that at the time of initial evaluation, patients tended not to report changes in their level of competence, and generally reported no strong emotional distress. Patient 1 was alone in reporting substantial changes in his abilities, and this patient also reported emotional adjustment issues. Patient 2 acknowledged a moderate drop in his level of competence, and showed a slight elevation in emotional concerns. The remaining patients showed little or no emotional concern. The patients also tended to be quite poor at identifying the potential implications of their deficits.

The second general prediction of Study 1 was that patients' level of awareness would change over the course of their acute-care rehabilitation, and during the follow-up interval. To address this issue, patients and significant-others were followed on a weekly basis, completing the PCRS and the POMS. The patients' self-ratings tended to be quite stable during the time that they remained on the inpatient unit. Patient 1 showed the most variability, both in terms of his self-rated competencies, and in his emotional adjustment. In general, as his self-perceived competence increased, his emotional reactions decreased. As a group, the significant-others' ratings also appeared to be quite stable during the period of inpatient rehabilitation, with a very slight tendency toward increased ratings of

competence as the weeks passed. The significant-other of Patient 1 proved to be the anomaly, with fluctuations in her ratings of the patient's level of competence noted over an eight week period. This significant-other also showed tremendous weekly variability in her emotionality. In summarizing, the patient self-perceptions and the significant-other perceptions of patients' competence did not tend to change over the course of inpatient rehabilitation. These results are consistent with those of Ranseen and colleagues (1990), who saw no improvement in patients' awareness over a one-month interval.

While patients and significant-others appeared to see things quite consistently from week to week, staff perceptions of the patients' functional abilities identified improvement between the initial assessment and the time of patient discharge to post-acute care. FAM summary scores showed improvement in all cases, including Patient 1. One conclusion is that, despite the observation that patients were not recognizing problems in their own neurocognitive ability, they were actually benefiting from rehabilitation interventions. This finding in the acute-care patient population is similar to the finding of Newman and colleagues (2000) who reported that, although patients and staff member ratings showed convergence with ratings of the patients' level of awareness, the convergence may have been largely due to change in staff perceptions of the patients' ability to complete rehabilitation tasks. In Study 1, the changes in staff perceptions did not specifically carry over to the assessment of awareness. For example, while some improvements were seen in the SADI scores over the course of inpatient rehabilitation, all patients were viewed as having continuing problems in their ability to predict the functional implications of their deficits (emergent awareness), and potential long-term consequences of their deficits (anticipatory awareness). Since the SADI was

completed only for the purpose of Study 1, and the FAM was completed as a regular part of rehabilitation, different raters completed each instrument. It could be argued that rehabilitation staff were biased toward seeing improvements. However, the chart notes for several patients also commented that limited awareness of functional status was a problem. Thus, the data seem to support the notion that awareness is not necessarily required for rehabilitation gains to be observed.

In considering changes in emotional status over the course of rehabilitation, individual patients were relatively consistent in their self-report of emotional difficulties, although there was variability between the patients. As indicated, Patient 1 reported considerable variability in emotional distress from week to week. This fluctuation was probably due to external factors, such as the unstable relationship with his significant-other. Further confirmation of the general emotional stability of patients was observed through the PCRS Emotional factor scores, which did not fluctuate by more than four points (out of a possible total of 38) over the course of the study. Thus, while consistency of self-perceptions of competence and emotional adjustment appeared to be the rule for these patients, exceptions were seen.

Considering patients at the one-month follow-up evaluation, most patients perceived little change in their level of competence. One patient experienced a significant drop in his perceived abilities, with a coincident jump in his report of emotional distress. One hypothesis derived by Fleming and Strong (1999) is that over longer periods of post-acute rehabilitation, experience is a key element for increasing levels of patient awareness. While such a hypothesis may apply to the current results, experience is probably not a strong factor in the very acute time period following rehabilitation. At one-month post-discharge, patients and significant-others were largely

in agreement about the patient's level of competence. Patients and significant-others agreed most strongly in the areas of interpersonal skills and emotional functioning, with patients perceiving themselves as having less competence in these areas. The largest discrepancy at one-month post-discharge was in ratings of cognitive ability, followed by activities of daily living, where patients continued to see themselves as being quite competent. The "experience hypothesis" may partially account for this pattern of results, but in a different way than previously considered. Specifically, while in hospital, patients have relatively few opportunities to test their skills in true functional activities. Thus, little change in their perception of deficits was seen over the course of their inpatient stay. However, by one-month post-discharge, patients had begun to engage in a variety of activities. Patients continued to see themselves as being quite competent in activities of daily living, and in cognitive abilities. These types of tasks tend to be rather concrete and require external validation or feedback. Furthermore, feedback given to patients in the acute stages of rehabilitation tends to be very positive, in order to encourage progress. In this regard, some of the significant-others remained very optimistic and supportive. Thus, individuals with impairments in emergent awareness might not be sensitive to their performance in such activities. However, interpersonal and emotional skills tend to be internally gauged, with impairments less easily tolerated by significant-others. Thus, it is possible that the patient received less direct environmental feedback, but more frequent "internal feedback," and honest feedback from the significant-others. This type of experience could conceivably result in the patients' being more "aware" of their skills in these areas, and more willing to report that they do not feel as competent as in activities of daily living.

The “experience factor” should also be considered in the interpretation of the SADI scores. After a one-month period of community living, patients were slightly better able to identify specific problem areas. However, they remained quite poor at predicting how their acquired deficits would bear out in everyday experience. Thus, at one month, the patients did not appear to have sufficient experience to test their abilities, and change their predictions for success.

The third general prediction of Study 1 was that the emotional status of the significant-other would be related to their reported perceptions of the patient’s competence. This appeared to be the case, based on correlations between the significant-others’ self-reported emotional status, and ratings they provided on the PCRS. First, the significant-others reported more emotional distress than the patients, and this was true throughout the study. While some significant-others reported no strong concerns with emotional symptoms, possibly even denying feelings of emotional distress, others consistently reported higher than normal levels of emotionality. In general, higher ratings of emotional distress in the significant-others were associated with lower ratings of patient competence. Causality cannot be inferred from this correlation, as other factors were noted to be relevant for some patients. For example, relationship issues for Patient 1 and financial concerns for Patient 5 were considered to be important components in their individual presentations. However, even the limited data available from this case-series suggests that emotional factors for the significant-other rater are important in how significant-others report patient competence, or vice versa.

Several additional comments regarding Study 1 are warranted. First, when significant-others were asked to reflect on the patient’s competence as it was prior to the accident, all patients were seen as being highly competent. Substantial reductions in

patient competence were perceived by most significant-others following the accident. These individual findings should probably be tempered by previous observations that individuals tend to see premorbid abilities through "rose-colored glasses." Mittenberg and colleagues (1992; 1997) found that patient's expectations about brain injury play a strong roll in how they perceived their abilities before and after a TBI. Although this feature was not examined in significant-other reports of premorbid and post-injury ability, it is likely that a similar effect influences the ability to retrospectively rate the patient's pre-injury abilities. This biasing process could have inflated the premorbid competence ratings, and deflated the ratings of the patients post-injury. Admittedly, it would be difficult to obtain unbiased estimates on the patient's true premorbid competencies, and one major prediction of this study related to the influence of emotional bias on the ability of significant-others to rate patient competence.

A second general comment relates to the potential influences of laterality of brain injury. In evaluating the nature of patients' injuries, it was possible to identify them as having generally right-hemisphere, left-hemisphere, or bilateral involvement. A number of previous studies have examined the laterality of brain damage in relation to awareness of deficit (e.g., Ranseen, et al., 1990; Wagner & Cushman, 1994; Prigatano, 1996). Mixed results have been found, generally implicating the right hemisphere in awareness deficits. However, it was felt that an examination of laterality effects would not be particularly meaningful in such a small sample of TBI patients. Although the patients in this study may have had specific focal lesions identified through neuroimaging, their injuries typically involved damage to multiple areas, and diffuse axonal damage throughout both cerebral hemispheres. To more carefully address the issue of laterality

and deficits in awareness, stroke patients with specific lesions might be appropriate for study. However, even in stroke, focal neurological damage is not always the norm.

A third comment relates to the benefits and drawbacks in using a case-study approach to neuropsychological populations. Shallice (1979) identified that one reason for the resurgence of case-studies has been that group studies in neuropsychology face the problem of heterogeneity of neurological factors in a group over which results must be averaged. Enormous ranges in age, premorbid skills, lesion sizes and location, and the interactions amongst these factors are problems that are difficult to eliminate. These issues were certainly raised within this small sample of individuals. For example, while the emotional responses of the patients and significant-others tended to be quite stable across the duration of the research, there was notable variability between the patients.

There are also some fundamental weaknesses with the case-study approach to neuropsychological research. First, there can be practical problems with specific methods employed in the investigative process. For example, there may be problems associated with establishing how well a patient fits into a specific syndrome category. This problem may be especially true of diffuse injuries associated with TBI. There are also problems associated with conducting lengthy experimental investigations in a clinical setting, because the patient's clinical condition and adaptation to deficits are not static. Third, the problem of analysis and interpretation of the data is made quite difficult, unless a standardization sample is available for comparison. Similarly, there are problems relating to the generalization of results, both to other patients, and to theories about the processes being studied.

In the current series of patients, the variability of injury incurred was evident from the variety of results obtained from neuroimaging data, even though all were classified as

severe injuries. The psychosocial context of the individual appeared to play a strong role in rehabilitation and recovery, possibly stronger than the neurological injury itself. Thus, a case-series approach seemed justified with these acute-care TBI patients. At the same time the limited generalizability of the results is problematic. All of the patients in this series were male, and all of the significant-others in this case were females. While this pattern was representative of individuals who presented in the acute-care rehabilitation unit at Foothills Medical Centre, there are undoubtedly gender differences to be found in the way that both patients, and significant-others react following a traumatic injury. This issue remains to be explored.

Literature reviews failed to identify previous research using the PCRS to study awareness in an acute-care brain injury sample, and no research has used the PCRS repeatedly to follow these patients through their rehabilitation. The results of Study 1 suggest that the PCRS and SADI can be effective in this population, with relatively consistent results obtained throughout the acute-care phase. The emotional status of the patient appears to be intertwined with their level of awareness, such that those individuals who display limited insight into their level of competence, also tend not to report emotional distress. Assessment of emotional status should probably be constrained to highly specific instruments, rather than instruments such as the GEI, which are broad, but much more abstract in their language. The current case examples suggest that the emotional status of the significant-other can also play a role in the evaluation of patient awareness, particularly in that significant-others are required to rate the patients' competencies. Thus, if the PCRS is to be used in acute-care rehabilitation, close attention should be paid to the emotional status of the significant-other.

Study 2: Awareness and Adjustment in Post-Acute Recovery

Study 2 examined the relationship between emotional adjustment and level of awareness of deficit in a large sample of individuals who had sustained a brain injury of mild, moderate, or severe degree, and had been referred for post-acute assessment and/or treatment of their neurocognitive deficits. It was felt that this sample would permit an examination of severity of injury, level of awareness of deficit, and emotional adjustment factors after the acute effects of the injury had abated. A number of specific hypotheses were generated:

1. Based on the work of Prigatano, et al. (1991) and others, TBI patients were expected to show limitations in awareness, as demonstrated by discrepancies in the competency ratings of patients and significant-others. In particular, discrepancies have been noted in the areas of emotional control and interpersonal interaction.
2. Severity of injury, as indicated by GCS scores, duration of PTA, and presence of neuroimaging abnormalities, was predicted to be directly related to the patients' level of awareness, as measured by the PCRS. This finding has not been consistently demonstrated in the literature. Specifically, individuals in the mild injury group were predicted to have lower discrepancy scores on the PCRS (i.e., better awareness) than individuals in the moderate and severely injured groups. However, this relationship was also expected to be influenced by emotional adjustment factors, as described below.
3. In terms of specific areas of emotional maladjustment, Klonoff and colleagues (1986) have previously found that post-acute TBI patients showed adjustment difficulties on a number of scales of the KAS-R. In particular, Belligerence, Verbal Expansiveness, Negativism, Suspiciousness, Withdrawal and Retardation, General Psychopathology,

and Confusion scales showed elevations in TBI patients, compared to normal control participants (see Appendix D). It was predicted that levels of emotional maladjustment would not vary significantly between the severity groups. This prediction was based on the assumption that since these post-acute patients may continue to experience difficulties (i.e., precipitating their referral for follow-up assessment), they would also continue to experience emotional adjustment problems. Patients with mild TBI might even report greater emotional maladjustment, because their relatively preserved awareness of persisting difficulties would allow emotional insight. The relationship between severity, awareness, and emotional adjustment is considered below.

4. In general, emotional distress was expected to be inversely related to level of awareness. Specifically, individuals with large discrepancy scores on the PCRS (demonstrating limited awareness of deficit) were expected to show low levels of emotional distress on the KAS-R indices.
5. The complex interactions between awareness of deficit, severity of injury of neurological injury, and the emotional adjustment of the patient are poorly understood. In general, severity of TBI was felt to be a relatively weaker predictor of level of awareness, when the emotional adjustment of the patient was also considered. This prediction was based on the assumption that the longer TBI patients attempt to cope in their daily activities, with limited successes (either due to neurocognitive deficits themselves, or to psychological factors), the more emotional distress would be experienced from repeated negative outcomes of such attempts.
6. The relationship between the location of neuroimaging findings and the degree of impaired awareness was explored. Although previous research has yielded mixed

results, it was expected that individuals with right-sided lesions would show poorer awareness than those with left-sided lesions. Individuals with diffuse bilateral lesions were expected to show the greatest deficits in awareness. An analysis of frontal versus non-frontal lesions was also planned, with the expectation that anterior lesions would be associated with lower awareness, compared to individuals with posterior lesions.

Methods

Subjects

Study 2 involved patients with a history of TBI, who had been referred to a post-acute rehabilitation facility for assessment and/or treatment. The majority of these patients were Workers Compensation Board referrals, with approximately 20% of the individuals referred by other agencies, such as insurance companies or private rehabilitation requests. Most patients received neuropsychological testing as part of their evaluation, all completed the PCRS, including the ratings of a designated significant-other, and all significant-others completed the KAS-R.

Data were gathered from the files of 185 individuals and their significant-others seen between 1992 and 2000. 166 individuals were selected, based on the completeness of their PCRS, KAS-R data, and demographic information. Injury severity data included an estimate of duration of LOC, estimated duration of PTA, initial GCS score, and comments regarding neuroimaging data. The patient's age, sex, handedness, occupation, and time since injury were also recorded. The relationship with the significant-other was documented, as was the significant-other's level of familiarity with the patient.

Procedure

Summary statistics were completed for the entire sample of patients. Patients were assigned to one of three groups, based on the severity of their brain injury. Table 5 presents the criteria used, based on the current literature (e.g., Lezak, 1995; Esselman & Uomoto, 1995; Binder, et al., 1997). Individuals who experienced duration of LOC of less than 60 minutes, GCS of 13 or greater, or duration of PTA less than 60 minutes were classified as having a mild TBI. Those individuals who were classified as having a mild injury, but who had positive neuroimaging data, not including basal skull fracture, were automatically classified as moderate. Similar individuals have also been classified as having a "complicated mild TBI" and are felt to be categorically different from individuals with a mild TBI (Binder, et al., 1997). Individuals with duration of LOC between 1 and 24 hours, GCS between 9 and 12, or PTA between 1 and 24 hours were classified as having a moderate TBI, regardless of their neuroimaging status. Finally, individuals with LOC greater than 24 hours, GCS less than nine, or PTA greater than 24 hours were classified as having a severe TBI, again regardless of their neuroimaging status. In practice, most patients classified as severe had positive neuroimaging data. All severity estimates were based on a review of the patient's medical chart when it was available. In other cases, patients or significant-others provided estimates of the duration of LOC or PTA. While the utility of such estimates has been questioned, McMillan, Jongen and Greenwood (1996) found that retrospective and prospective estimates of PTA are equally correlated with other measures of brain injury severity. Failing the availability of a GCS score, retrospective estimates of LOC or PTA are often the only severity indices available.

Table 5. Head injury severity classification system

Severity	LOC	GCS	PTA	Imaging
Mild	< 60 minutes	≥ 13	< 60 minutes	Negative
Moderate	1 – 24 hours	9-12	1 – 24 hours	Negative or Positive
Severe	> 24 hours	< 9	> 24 hours	Negative or Positive

Note: LOC = Duration of loss of consciousness; GCS = Glasgow Coma Scale Score; PTA = Duration of post-traumatic amnesia.

Regarding neuroimaging classifications, the CT and/or MRI reports from the neuroradiologist were used, when available. Findings were summarized as “no imaging completed”, “negative imaging results”, “primarily right-sided damage”, “primarily left-sided damage”, or “diffuse/bilateral damage”. An additional classification was created for “primarily frontal injury” versus “primarily non-frontal injury”.

Estimates of general intellectual ability were based on the Full Scale IQ from the WAIS-R or WAIS-III. In some cases, a North American Reading Test Score was used to compute an estimate of WAIS-R Full Scale IQ.

Results

Summary statistics for the entire sample of patients showed the mean age of the patients to be 39 years ($sd = 11.21$), with a mean of 11.4 years ($sd = 2.87$) of education. Eighty-eight percent of the patients were males, and 79 percent were right-handed. The sample of patients was highly representative of labourers and semi-skilled labourers, 22 and 48 percent, respectively. Twenty-one percent of the patients were classified as skilled labourers or professionals. Forty-three percent of the patients had sustained their injuries in a fall, 21 percent had incurred an impact trauma, and 23 percent had sustained an injury in a motor-vehicle accident. The remaining patients had sustained their injury

through assault, crush-type mechanism, or other trauma. Thus, the patients in this sample were slightly older than the typical 15-24 year-old demographic of males, who tend to be over-represented in the general population of TBI survivors. This bias may be associated with the employment-related nature of the injuries sustained by many of the patients in this sample. The types of injuries were generally consistent with reports of the literature, although the motor-vehicle category was somewhat under-represented, while the number of injuries sustained through falls was over-represented (Lezak, 1995). The mean time since injury for the entire sample was 705 days, reflecting the post-acute nature of the sample, and there was a large degree of variability in the time since injury ($sd = 817$ days).

Of the entire sample of significant-others, approximately 55 percent were spouses, 10 percent were parents, 10 percent were siblings, and 7 percent were friends of the patient. Of those who reported, 96 percent of the significant-others stated that they felt they knew the patient "Pretty Well" or "Very Well." Thus, it was felt with a high degree of confidence that the behaviours reported by the significant-others were representative, in so far as measured by the PCRS and KAS-R.

Hypothesis 1 predicted that the patients' PCRS scores would be higher than the significant-others' ratings. In other words, the patients were predicted to rate themselves as being more competent than others saw them to be, indicative of poor awareness of their actual abilities. In particular, it was predicted that issues relating to emotional and interpersonal competencies would show the largest discrepancies on the PCRS. To examine this issue paired-samples t -tests were used, contrasting PCRS Total Scores, and each of the four PCRS factor scores between patients and significant-others for the entire sample. The mean scores are presented in Table 6. Because of the number of contrasts,

alpha was set at .01 was considered to be statistically significant, while a p-values less than .05 identified tendencies toward statistical significance. Contrary to expectation, the patients tended to rate themselves as being less competent than the ratings of the significant-others, although in no instance was the self-other discrepancy statistically significant.

Table 6. Mean PCRS scores for the entire sample of Study 2.

	Self		Other	
	M	(sd)	M	(sd)
Total	107.63	18.79	110.24	20.51
ADL	29.85	5.64	30.13	5.83
Interpersonal	26.24	5.52	27.22	5.90
Cognitive	25.16	5.88	26.47	6.33
Emotional	26.22	5.16	26.21	5.74

To follow-up on Hypothesis 1, a number of specific PCRS items were examined. Prigatano, et al. (1991) identified 8 items on which patients and significant-others are likely to agree and 10 items on which they are likely to disagree (see Appendix A). As seen in Table 7, this predicted pattern was not seen in the current sample when the severity of the injury was not considered. In fact, the patients and significant-others significantly disagreed on items that they were predicted to agree upon ($t(165) = 2.24, p = .03$).

Before considering Hypothesis 2, the influence of general intellectual ability on the patients' PCRS scores was considered. While this was not a planned analysis, it was suggested that higher levels of intellectual ability might be associated with increased ability to be insightful about neurobehavioral deficit (Mish 2001, personal

communication; Anderson & Tranel, 1989). Correlations between the patients' PCRS Total and factor scores, and their level of education and general intellectual ability (FSIQ estimate) were computed. The patients' level of education was found to be weakly, but significantly correlated with their self-rating on the PCRS Total Score ($r = .19, p < .05$), ADL factor ($r = .20, p < .05$) and Interpersonal factor ($r = .23, p < .01$), but not on the Cognitive or Emotional factors. General intellectual ability (FISQ) was not significantly correlated with the patients' ratings on any factor of the PCRS.

Table 7. Mean ratings on PCRS items on which Patients and Significant-others typically agree and disagree, for the entire sample of Study 2.

	Self		Other	
	M	(sd)	M	(sd)
Agree Items	4.05*	.63	4.20*	.64
Disagree Items	3.39	.70	3.39	.81

Note: asterisk represents statistical significance at the $p < .01$ level.

To consider Hypothesis 2, relating to the influence of severity of brain injury on self-awareness of deficit, patients were classified as having a mild, moderate, or severe injury based on the criteria in Table 5. A Univariate Analysis of Variance (ANOVA) was conducted to identify group differences on demographic variables of age, education, time since injury, and general intellectual ability. As seen in the upper panel of Table 8, no group (i.e., severity) differences were identified on these variables. Chi-square tests were conducted to determine if the groups were equivalent in terms of sex, handedness, occupational status, type of injury, and imaging findings. As can be seen in the lower panel of Table 8, the mild brain injury group contained a slightly higher proportion of females (Pearson $\chi^2(2, N = 166) = 13.46, p = .01$). Localization of neuroimaging

Table 8. Demographic variables for the three groups of Study 2.

	Mild ($n=83$)		Moderate ($n=25$)		Severe ($n=58$)	
	M (sd)	M (sd)	M (sd)	M (sd)	M (sd)	M (sd)
Age	40.23	9.73	37.44	10.70	38.01	13.23
Education	11.41	2.96	11.36	2.69	11.52	2.87
Time Since Injury	687	814	665	506	745	930
General Intellectual Ability	96.33	9.7	95.58	13.61	92.6	9.68
Males	79.5 % ^a		96.0 % ^b		98.3 % ^b	
Right Handed	84.3 %		68.0 %		75.9 %	
Occupational Status						
Labourer	21.1 %		22.7 %		28.3 %	
Semi-Skilled	53.9 %		54.5 %		50.9 %	
Skilled	23.7 %		22.7 %		17.0 %	
Professional	1.3 %		0.0 %		3.8 %	
Imaging						
None	51.8 %		12.0 %		10.3 %	
Negative	47.0 %		8.0 %		22.4 %	
Right	0.0 %		16.0 %		22.4 %	
Left	0.0 %		24.0 %		17.2 %	
Diffuse	0.0 %		40.0 %		50.0 %	
Injury Type						
Fall	34.9 %		44.0 %		55.2 %	
Impact	28.9 % ^a		28.0 % ^a		6.9 % ^b	
Assault	4.8 %		0.0 %		1.7 %	
Accel/Decel	26.5 %		16.0 %		22.4 %	
Other	4.8 %		12.0 %		13.8 %	

Note. The upper panel of Table 8 depicts means and standard deviations, while the lower panel depicts percentages. "a-b" identifies significant Chi² at the $p < .05$ level.

findings was balanced across the moderate and severe injury groups, as was the mechanism of injury, with the exception of impact trauma, which was under-represented in the severe brain injury group ($\text{Chi}^2(8, N = 166) = 17.9, p < .05$). Finally, in terms of imaging results, by definition the mildly injured group had no positive imaging results. Examining the moderate and severe groups, the presence and lateralization of neuroimaging findings was balanced across the two groups ($\text{Chi}^2(1, N = 83) = 5.82, p > .10$).

Table 9 presents the patient and significant-other PCRS Total and Factor scores for each of the three severity groups. PCRS Total Scores of patients and significant-others were considered for each of the three severity groups using a Multivariate Analysis of Variance (MANOVA); a multivariate main effect for group (i.e., severity) was identified ($F(4,324) = 4.204, p < .01, \eta^2 = .05$). To control for the violation of Type I experimentwise alpha error, a more conservative $p < .01$ was adopted to interpret significant results at the univariate level, when looking at patients and significant-other ratings individually. Differences were seen in the patients' Total Scores across the three severity groups ($F(2,163) = 8.18, p < .001, \eta^2 = .09$), with Tukey's post hoc analyses revealing that the mildly injured patients reported lower competence in comparison to the moderate and severe groups, which did not differ from each other. Examining the significant-others' scores, presented in the right panel of Table 9, there were no differences in the PCRS Total Scores across the three severity groups.

Because of colinearity between the PCRS Total Scores and the PCRS factor scores, the first MANOVA did not include the factor scores. Thus, a second MANOVA was completed to consider the group effect on the factor scores, and this analysis was also significant at the multivariate level ($F(8, 156) = 1.71, p < .05, \eta^2 = .08$). Looking at the

Table 9. Mean PCRS Total and Factor Scores for Patients and Significant-Others Across Three Severity Groups.

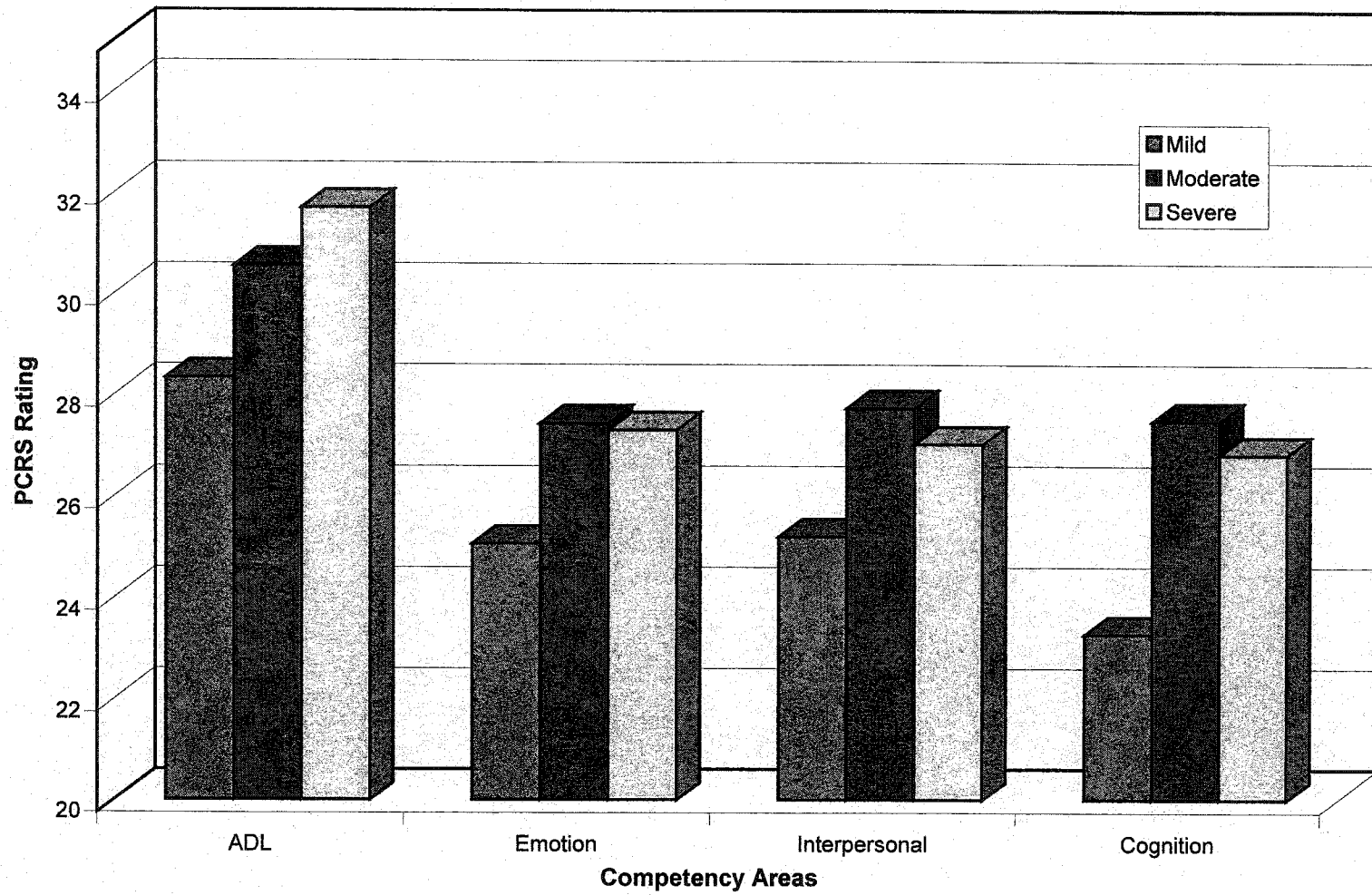
	Patient			Significant-Other		
	Mild M (sd)	Moderate M (sd)	Severe M (sd)	Mild M (sd)	Moderate M (sd)	Severe M (sd)
Total	101.97 _a (17.18)	113.26 _b (19.87)	113.21 _b (18.38)	111.40 _c (20.88)	107.14 (19.17)	109.93 (20.74)
ADL	28.33 _a (5.81)	30.56 (5.68)	31.71 _b (4.79)	30.04 (5.86)	30.19 (5.11)	30.23 (6.15)
Interpersonal	25.21 (5.64)	27.75 (4.78)	27.05 (5.44)	27.82 _c (6.04)	26.18 (5.98)	26.80 (5.65)
Cognitive	23.28 _a (5.44)	27.50 _b (5.77)	26.83 _b (5.75)	26.71 _c (6.32)	25.43 (5.77)	26.59 (6.65)
Emotional	25.07 _a (4.83)	27.45 (5.43)	27.32 _b (5.22)	26.69 (5.76)	24.97 (5.40)	26.07 (5.87)

Note: "a-b" signifies clinically significant differences at the $p < .01$ level, within the three patient samples; "c" signifies clinically significant differences at the $p < .01$ level, between significant-other and patients, within a particular severity group.

univariate level for the patients' ratings, differences were seen among the PCRS factor scores for ADL ($F(2, 163) = 6.79, p < .001, \eta^2 = .08$), Cognitive ($F(2, 163) = 9.45, p < .001, \eta^2 = .11$), and the Emotional factors ($F(2, 163) = 4.27, p < .01, \eta^2 = .05$), and a tendency was identified for the Interpersonal factor ($F(2, 163) = 3.06, p = .05, \eta^2 = .04$). The means for the patient self-reports were examined using Tukey's *post hoc* tests. As seen in the left panel of Table 9, the mild patient group reported less competence than both the moderate and severe groups on the Cognitive factor, and less competence than the severe group on the ADL and Emotional factors. There was no difference between the patient groups on the Interpersonal factor. The moderate and severe patient groups reported similar levels of competence across all four factor scores. These results for the patients are depicted graphically in Figure 9. Considering the univariate tests for the significant-other factor scores, there were no differences in how the significant-others saw the patients on any of the factor scores across the three severity groups (displayed in the right side of Table 9).

Because education had been weakly, but significantly correlated with the patients PCRS Total Score, ADL Score, and Interpersonal Score, an unplanned MANCOVA was completed to determine the influence of education on the observed findings. Looking at the PCRS Total Scores for both the patient and the significant-other, there was a significant multivariate effect of level of education ($F(2, 153) = 3.44, p < .05, \eta^2 = .04$). At the univariate level, education was a significant covariable for the patients' PCRS Total Score ($F(1, 154) = 5.95, p < .05, \eta^2 = .04$), but not for the significant-other ratings. Severity of brain injury remained a significant factor at the multivariate level ($F(4, 306) = 3.88, p < .01, \eta^2 = .05$), and was also significant at the univariate level for the patients' PCRS Total Score ($F(2, 154) = 7.53, p < .01, \eta^2 = .09$). This result suggests that a patient's level of education is related to their ability to rate themselves on the PCRS.

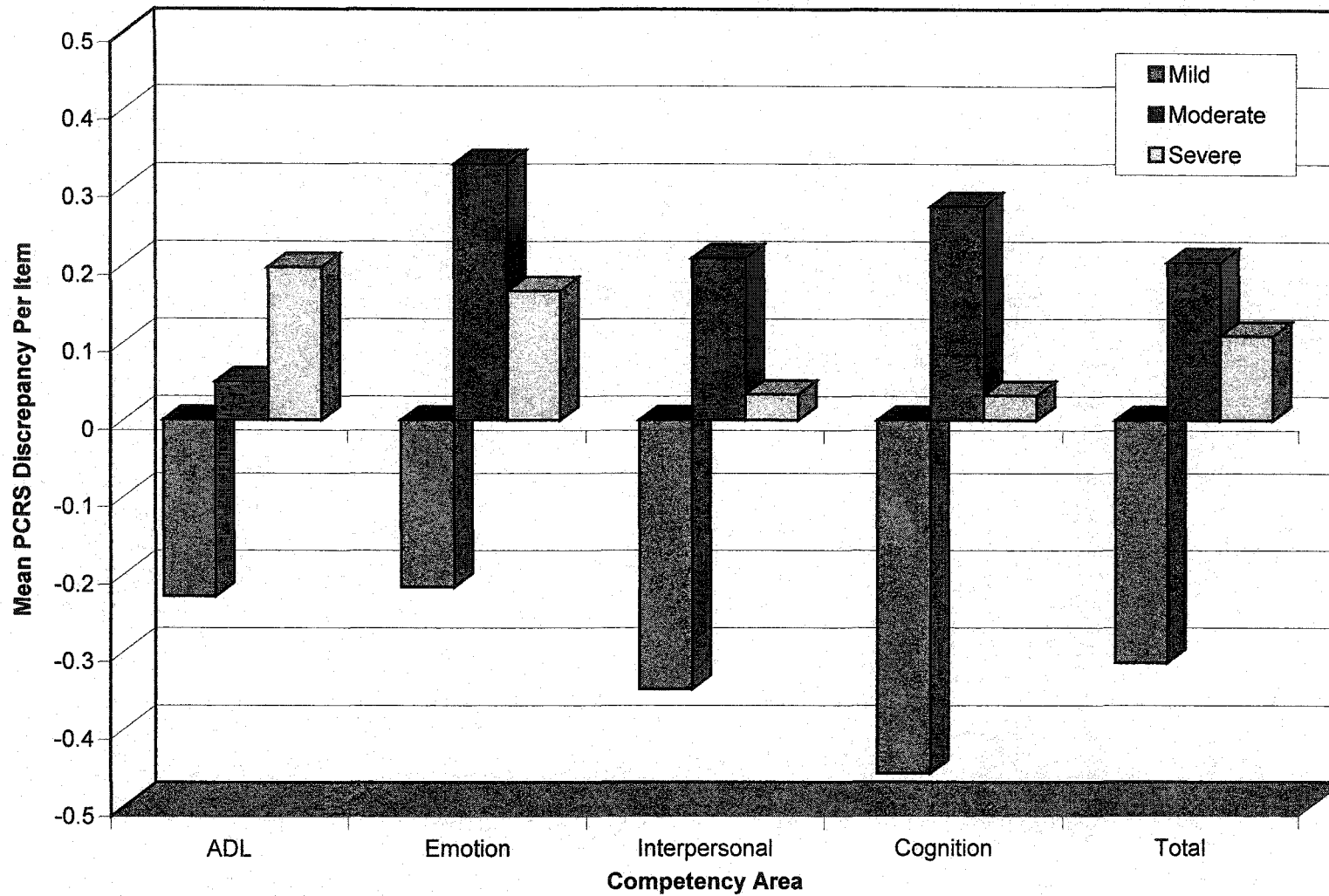
Figure 9. Patient Competency Ratings



Whether this association is related to basic features such as their ability to read and comprehend the PCRS items, or a more complicated explanation such as the person's ability to be insightful or abstract in their self-judgments is unknown. In a similar analysis, however, the patients' level of general intellectual ability, as measured by the Wechsler scales or by estimates based on reading level, was not related to their scores on the PCRS.

Turning next to the discrepancies in patients and significant-other ratings, a number of paired *t*-tests were computed to determine if discrepancies in PCRS ratings were greater or less than zero. Again, the acceptable alpha level was set at .01, to minimize the risk of Type I error. Significant patient-other discrepancies on the PCRS Total Score only appeared in the mildly-injured group, with the patients consistently identifying more problems than identified by their significant-other ($t(82) = -3.24, p < .01$). The same pattern was identified on the Interpersonal factor ($t(82) = -3.02, p < .001$), and the Cognitive factor ($t(82), p < .001$), while tendencies were identified on the ADL factor ($t(82) = -1.88, p = .064$) and on the Emotional factor ($t(82) = -1.96, p = .05$) (see Table 9). While the mean Discrepancy Score for the PCRS Total was in the predicted direction for the moderate and severe groups, the discrepancy between patient and significant-other PCRS Total Scores did not reach statistical significance. This observation was also true for the each of the factor scores of the PCRS in the moderate and severe groups. These data are depicted in Figure 10, which displays discrepancies between patient and significant-others across the three severity groups, and by severity of injury classification. In this figure, the discrepancy score displayed is the mean discrepancy per item on the particular factor or on the total score.

Figure 10. Average Discrepancy Score Per Item on PCRS Factors and Total Score



To examine the pattern of discrepancy scores between the severity groups, a univariate ANOVA was completed to compare the PCRS Total Discrepancy Score across the three severity groups. The group effect was significant ($F(2,163) = 5.35, p < .01, \eta^2 = .06$), and post hoc tests identified that the Total Discrepancy Score of the mild group was significantly lower than that of the moderate or severe group, which as identified above, were not significantly different from zero. A MANOVA was used to examine the PCRS factor scores. The multivariate group effect approached significance ($F(8, 320) = 1.88, p = .06$). Although this multivariate statistical test was not passed, the effects of severity on each factor score were nonetheless considered for exploratory purposes. Consistent with the t -tests reported above, the mild group displayed the largest self-other discrepancies, particularly for the Cognitive items, followed by the Interpersonal and Emotional factors. All of the discrepancies in the mild group were in the negative direction. These data are displayed in Figure 10.

In summary then, the PCRS Discrepancy Scores did not appear to identify deficits in awareness in the moderate and severe post acute brain injury samples. On the other hand, in the mild TBI patients, the PCRS Discrepancy Scores suggested that the patients rated themselves as less competent than viewed by their significant-others, particularly for the cognitive items, less so for items of interpersonal and emotional competence, and non-significantly for items relating to activities of daily living.

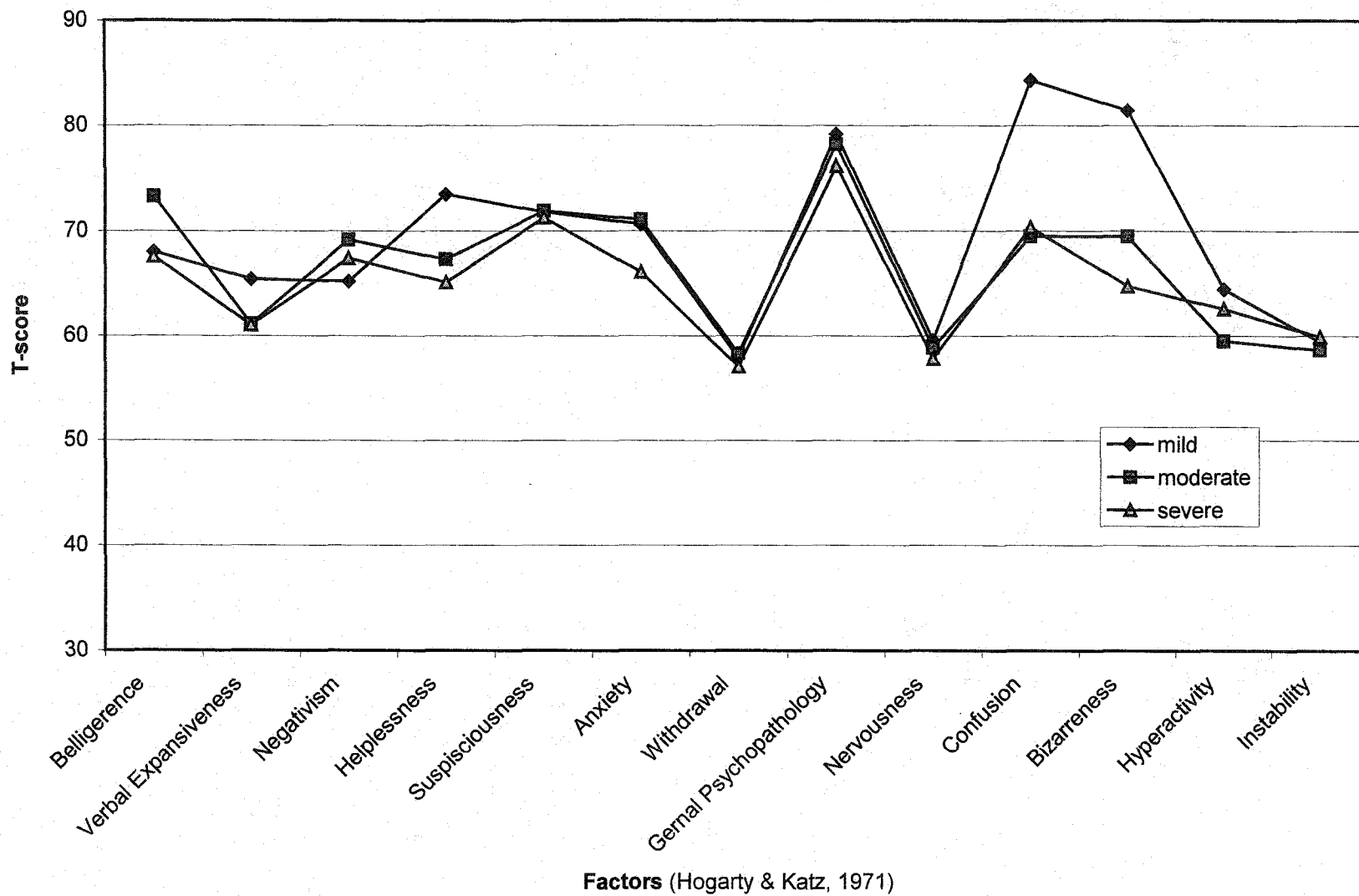
Because the Discrepancy Scores revealed an unexpected pattern, the agree/disagree items identified by Prigatano, et al. (1991) were also considered for their ability to identify patient-other discrepancies between the three severity groups. Looking first at the mild cases, the patients reported lower competencies on both the agree items ($t(82) = -3.21, p < .01$) and the disagree items ($t(82) = -2.31, p < .03$) of the PCRS, compared to

the ratings of the significant-others. For the moderate and severe cases, the ratings of the patients and of the significant-others were similar on items that were predicted to show agreement, and on items that were predicted to show disagreement. Thus, in this sample of moderate and severely injured cases, the agree/disagree method of scoring did not reveal the predicted pattern of results. Furthermore, in the mild brain injury cases, patients showed a robust tendency to report more difficulty than seen by significant-others.

Hypothesis 3 related to the pattern of emotional adjustment in the post-acute brain injury sample, as rated by significant-others on the KAS-R. Figure 11 displays the KAS-R factor scores graphically, to allow comparison of the three severity groups. As can be seen by the elevated T-scores, all three groups were seen as having a range of psychological adjustment difficulties, when compared to the normative sample of the test (Hogarty & Katz, 1971; Stambrook, Moore & Peters, 1990). For several factors, the TBI patients scored greater than 1.5 standard deviations above the normative mean, and overall elevations were greater than two standard deviations above the normative mean on factors of General Psychopathology, Suspiciousness, Confusion, and Anxiety. Elevations were not limited to the factors identified by Klonoff, et al. (1986) in their TBI sample, although there was some overlap. The mean T-score elevation across all KAS-R factor scores, for all three severity groups was 67.44 ($sd = 16.32$).

Hypothesis 3 also predicted that there would not be a substantial difference in the emotional adjustment of the three severity groups. Considering the overall means of the three severity groups on the KAS-R, there was no difference in the level of emotional adjustment (respective means: Mild = 69.29 ($sd = 15.57$), Moderate = 66.63 ($sd = 19.2$), Severe = 65.14 ($sd = 16.01$)). The individual factor scores were also considered using a

Figure 11. KAS-R Scores for Three Severity Groups



mixed ANOVA to examine the effect of severity of injury across the KAS-R factor scores. There was a small but significant main effect of group ($F(26, 302) = 1.56, p < .05, \eta^2 = .12$). Examining the individual factor scores, only the Helplessness factor ($F(2, 163) = 3.54, p < .05, \eta^2 = .05$), the Confusion factor ($F(2, 163) = 3.60, p < .05, \eta^2 = .04$) and the Bizarreness factor ($F(2, 163) = 5.61, p < .01, \eta^2 = .06$) were significantly different between the groups. In each of these instances, Tukey's tests identified that the mild injury group was rated as having more adjustment difficulties than either the moderate or severely injured groups.

Turning next to the relationship between KAS-R scores and scores on the PCRS, as addressed in Hypotheses 4 and 5, a correlation analysis was completed to examine emotional and awareness scores for the entire sample. Selected results are shown in Tables 10 and 10a. First, considering the correlation between the significant-others' ratings on the PCRS (i.e., PCRS significant-other Total Score) and the KAS-R Total Score, there was almost no correlation between these variables (largest $r = .04$; Table 10, right panel). This was somewhat surprising considering that both the KAS-R and PCRS scores were provided by the significant-other. The KAS-R and the PCRS were completed on the same day, and by the same individual (i.e., the significant-other). Each of these measures utilized observable behaviors in the rating of patients, although the KAS-R focused largely on emotional behaviors, while the PCRS focused on a variety of general behaviors, including emotional behaviors. It is possible that the PCRS and the KAS-R measure distinct constructs.

A strong correlation was seen between the patients' self-rating on the PCRS (PCRS patient Total Score) and the KAS-R Total Score ($r = -.51, p < .01$; Table 10, left panel). Moderate to strong correlations were also observed between the KAS-R Total

Score and the PCRS factors scores (patient's ratings), and importantly, the strongest correlation was between the KAS-R Total Score and the patients' score on the PCRS Emotional factor ($r = -.52, p < .01$). Examining the correlations between the KAS-R Total Score and the Discrepancy Scores of the PCRS, moderate correlations were seen across the Total Discrepancy, and the discrepancies in the four factor scores of the PCRS. These data are presented in Table 11.

Table 10. Correlations between KAS-R Total Score and PCRS Total and Factor Scores for Patients and Significant-others.

	Patient					Significant-other				
	Total	ADL	IP	Cog	Emot.	Total	ADL	IP	Cog	Emot.
KAS-R Total	-.51*	-.34*	-.41*	-.46*	-.52*	.04	.04	.10	-.01	.01

Note: * significant at the .01 level.

Table 11. Correlations between KAS-R Total Score and PCRS Discrepancy Scores.

PCRS Discrepancies	Total	ADL	Interpersonal	Cognitive	Emotional
KAS-R Total	-.37*	-.27*	-.36*	-.32*	-.33*

Note: * significant at the .01 level.

Exploring the KAS-R and PCRS scores further, there were very low correlations between the significant-others' PCRS factor ratings and their ratings of patients on the KAS-R factors. However, stronger correlations appeared between the patients' PCRS factor ratings and the KAS-R factor scores. The highest correlations were in the $r = -.40$ to $r = -.50$ range, between the PCRS Emotional Score and KAS-R factors of Anxiety, General Psychopathology, Helplessness, and Belligerence. Similar correlations were also noted between the PCRS Cognitive Score for the patients and the KAS-R factors of Confusion and Helplessness. Lower correlations (i.e., $r < .40$) were noted between the KAS-R factor scores, and the PCRS patient scores for Activities of Daily Living and

Interpersonal behaviors. Thus, the predicted pattern of correlations was seen between the KAS-R factor scores and the PCRS patient scores. These correlations were always in the negative direction, such that reports of greater difficulties with emotional adjustment were associated with lower ratings of competence, as reported by the patients.

Hypothesis 5 addressed the relationship between the patients' awareness of neurobehavioral deficits, patient emotional adjustment, and severity of injury. To examine this relationship, a multiple regression analysis was completed using the PCRS Total Discrepancy Score as the dependent variable, with the KAS-R Total Score and severity of injury (i.e., mild, moderate, or severe) as simultaneous predictor variables. This analysis resulted in a significant model ($F(2,168) = 16.42, p < .01, R^2 = .17$), with both the severity of injury ($t = -4.68, p < .01$) and the level of emotional adjustment ($t = 2.45, p = .02$) contributing to the prediction of level of awareness of deficit. When the patients' PCRS Total Score was used as the measure of awareness, the model was also significant ($F(2, 168) = 36.15, p < .01, R^2 = .31$), again with severity of injury ($t = -7.33, p < .001$) and emotional adjustment ($t = 3.42, p < .001$) contributing to the prediction of PCRS patient Total Scores.

A partial correlation matrix was computed to examine the relative strength of correlations between the PCRS Total Discrepancy Score, the KAS-R Total Score and the severity of injury variables. First, the correlation between the PCRS Discrepancy Score and the Severity of Injury, controlling for KAS-R Total Score was $r = .18 (p = .01)$. The correlation between the PCRS Discrepancy Score and the KAS-R Total, with the effect of Severity removed was $r = -.36 (p < .001)$. This pattern appears to confirm that the emotional adjustment of TBI patients is more strongly related to their level of awareness than is the severity of their injury.

Next, to examine the influence of various potential moderating variables on the patients' general level of awareness, a second multiple regression analysis was completed, again using the PCRS Total Discrepancy Score as the dependent variable. Predictor variables were blocked (Block 1: KAS-R Total, Severity of Injury, and Block 2: Education, Sex, FSIQ, TSI, and Response Bias) and entered into a stepwise multiple regression with the criteria to include variables set at $F \leq .05$. Of these variables, only the KAS-R Total Score, and FSIQ were identified as significant predictors of patients' level of awareness ($F(2, 85) = 10.87, p < .001, R^2 = .19$).

Following up on the apparently strong influence of the FSIQ variable, correlations were computed between the PCRS Total Discrepancy, the KAS-R Total, severity of injury and FSIQ. Table 12 displays these correlations, which suggest that the patients' level of awareness is more strongly associated with their intellectual ability than it is with the severity of their injury. This finding is important, because although the FSIQ may decrease as a function of severity of injury, the "contemporary" general intellectual ability of patient appears to be a strong feature in how insightful patients may be about their deficits. When the influence of severity of injury was removed from the correlation between the KAS-R Total Score and the PCRS Discrepancy Score, the influence of FSIQ remained statistically significant, although it was less strong ($r = -.28, p < .01$). The partial correlation between KAS-R Total Score and the PCRS Discrepancy Score remained in the moderately strong range ($r = -.34, p < .001$).

A number of questions were raised by the results of Tables 10 and 10a, pertaining to the relationship between FSIQ and the PCRS Discrepancy Scores. Specifically, the correlation between the KAS-R score (emotional adjustment) and awareness (based on the PCRS Discrepancy Score) might be largely due to the patients' responses to the PCRS,

Table 12. Relationship between intellectual ability emotional adjustment and awareness.

	KAS-R Total	FSIQ	Severity
PCRS Discrepancy	-.37 **	-.31**	.22*
KAS-R Total		.30	-.12
FSIQ			-.16

Note. Correlation is significant at the * $p < .01$ or ** $p < .001$ level.

versus the significant-others' responses. On the other hand, in exploring Hypothesis 1, it was found that the correlation between FSIQ and the patients' PCRS self-ratings were quite low. These findings suggested that the patient's FSIQ might be associated with the significant-other's ratings on the PCRS. Indeed, moderate correlations were observed between the patient's FSIQ and the significant-others' PCRS ratings on the Interpersonal factor ($r = .38, p < .001$) and the Emotional factor ($r = .35, p < .001$), respectively. One interpretation of this finding is that the patients' general intellectual ability influences the behaviors that they are rated on by the significant-others (i.e., as on the PCRS). However, as reported previously, the ratings of the patients' emotional behaviors on the PCRS were not related to the patients' FSIQ. Thus, the behaviors queried by the PCRS appear to be differentially susceptible to the effects of the patients' level of general intellectual ability.

In considering that the PCRS Patient Score is a "clean" measure of their perspective, independent of the variables that could bias the significant-others' ratings, an additional multiple regression analysis was computed. In this analysis the patients' PCRS Total Score was used as the dependent variable, instead of the PCRS Discrepancy Score. The set of predictor variables was again blocked and entered stepwise into a multiple regression model. Block 1 included the KAS-R Total and the severity of injury, while Block 2 included the various demographic variables (education, sex, FSIQ, TSI,

and response bias). In this case, only the KAS-R Total Score and the severity of injury entered the significant model ($F(2, 96) = 29.21, p < .001, R^2 = .38$). The patients' general intellectual ability, educational level, sex, time since injury, and measures of response bias did not contribute to the prediction of their ratings on the PCRS.

Hypothesis 6 considered the influence of the approximate location of the injury, as determined through neuroimaging reports. Since there were no significant differences between the moderate and severe injury groups on either the emotional or the awareness measure, these two groups were combined for consideration of Hypothesis 6. For the anterior/posterior injury location factor, cases were classified as being predominantly anterior (i.e., involving the frontal lobes), predominantly posterior (i.e., non-frontal), or diffuse injury. Similarly, for the lateralization factor, injuries were considered to be predominantly right-hemisphere, predominantly left-hemisphere, or bilateral diffuse. The factors were not mutually exclusive, such that a single patient could, for example, be included in both the "anterior" category, and the "right" category.

73 patients were classifiable, resulting in the following distribution on the two factors:

Lateralization		Anterior/Posterior	
Right	17	Anterior	17
Left	17	Posterior	18
Diffuse	39	Diffuse	36

Correlations between the lateralization factor, the anterior/posterior factor, the awareness measures, and the emotional measures were quite low, with no significant results observed. A univariate analysis examining the combined influences of the anterior/posterior factor and the laterality factor on the PCRS Total Discrepancy Score

was not significant, although there were very small Ns in each of the cells being compared. The influences of the location factors were examined in separate analyses to increase the number of observations in each cell. Again, the Total Discrepancy Score did not vary by either the laterality or the anterior/posterior location of the lesion. However, the Patients' Total Score did vary by location of the lesion. A univariate analysis examined the effect of the lateralization and anterior/posterior factors on the patient's Total PCRS Scores. A near significant effect of the anterior/posterior lesion location was found ($F(2, 62) = 3.06, p = .05, \eta^2 = .09$), but there was no main effect of lateralization of the lesion ($F(2, 62) = .02, p = .98, \eta^2 = .001$). Tukey's post-hoc analyses identified a tendency for patients with frontal lesions to report more difficulties than either patients with posterior lesions, or patients with diffuse lesions.

Discussion Study 2

Study 2 presents an examination of the relationship between awareness and emotional adjustment factors in a relatively large sample of patients in the post-acute phase of recovery following TBI. While the PCRS has been used in several studies to examine awareness factors, an examination of the influence of severity of injury and the emotional adjustment of the patient has not been made. It is clear from the findings of Study 2 that the relationships between awareness, injury, and emotionality are complex.

In the current sample of TBI patients, the severity of the injury had a clear effect on the PCRS Discrepancy Scores. However, this effect was not as expected, based on previous work with this instrument (e.g., Prigatano, et al., 1991; Leathem, et al., 1998). While previous studies have reported PCRS scores from samples of moderate and severe TBI patients, the current study also included patients with mild TBI. These mildly

injured patients under-rated their abilities compared to ratings provided by significant-others, particularly on those items relating to cognitive and interpersonal abilities.

Clinical interpretations of these results might suggest a response style that exaggerates deficits or is highly deficit-focused. It has also been suggested that this pattern is clinically associated with emotional distress and functional (i.e., psychiatric) sequelae (Prigatano, et al., 1991). Patients who had experienced moderate to severe injuries showed PCRS discrepancies in the expected direction, rating themselves as having more competence than perceived by the significant-other. However, the discrepancy scores observed for the moderate and severely injured patients not reach statistical significance.

In comparing the current PCRS Discrepancy findings with other research, Prigatano (1996), who studied a sample of TBI patients with moderate to severe injuries, also found that the mean discrepancies between patients' and significant-others' ratings were quite small, on the order of .30 per item, on a scale of 1-5. Similarly, the data of Leathem and colleagues (1998), who also studied moderate to severely injured patients, showed a mean item discrepancy of .27. In the current study, comparable figures revealed a mean item discrepancy of .20 for the moderately injured group, and .11 for the severely injured group. Based on these results, the PCRS Total Discrepancy Scores may be of limited clinical utility, especially without due consideration given to the injury severity of the sample or individual being considered. Furthermore, discrepancy scores are influenced not only by patient variables, but also by features of the significant-other (Fleming, et al., 1996; Cusick, et al., 2000), which are not usually considered in awareness research due to the complexity of such features. For example, Wallace and Bogner (2000) reported that the significant-other's report of depression and anxiety was not directly related to PCRS Discrepancy Scores, although these factors were related to

ratings provided on the PCRS by the significant-other. Other research has suggested that significant-other adjustment is a function not only of changing perspective of the individual with the brain injury, but more importantly, the extent to which the significant-other utilizes coping strategies and available supports (Douglas & Spellacy, 1996; Sander, et al., 1997). A systematic consideration of such factors will increase the interpretability of patient-other discrepancy scores in future research.

A consideration of the patients' and significant-others' ratings, independently of one another, determined that patients with moderate and severe injuries tended to rate themselves as being less impacted by deficits than the patients who had sustained mild injuries. However, there was no difference in how the significant-others rated the patients, across the three severity levels. Thus, the discrepancy ratings discussed above appeared to be largely due to variations in the patients' perspective, and not necessarily to changes in how the significant-others were seeing the patients. Interestingly, when considering patients' and significant-others' responses on the four PCRS factor scores, the mild injury group saw themselves as being more impaired on items relating to cognitive ability, interpersonal, and emotional issues. There was no difference in how the mild, moderate, and severely injured patients reported their ability on items relating to ADLs. Again, the significant-others rated the patients similarly on the four PCRS factors, regardless of the severity of the injury.

The finding that significant-others do not vary in their perception of patients with varying TBI severity is of importance, and raises questions as to the utility of the significant-other as an unbiased rater. Prigatano and Altman (1991) suggested that actual competency after TBI should be based on neuropsychological test scores combined with the reports of significant-others. In theory, this would allow an objective assessment of

the patient's actual cognitive abilities, but may not provide an objective assessment of the other PCRS factors. Furthermore, using test scores as the reference point may not adequately address the pattern encountered in Study 2. Specifically, it is often found that TBI patients who report difficulties in their daily routine, can perform normally on many standardized measures. This is especially true of individuals with mild TBI. Thus, use of neuropsychological tests might work best for individuals with severe TBI, who demonstrate clear difficulty on objective tests, but not as well for mild or moderate TBI patients, who may do well on such measures, but who nonetheless report difficulties in everyday activities. The most comprehensive approach should therefore incorporate patient ratings, significant-other ratings, clinician ratings, and quantitative assessment of the abilities being rated.

The emotional adjustment of the patients was assessed using the KAS-R, which relies on the behavioural observations of significant-others. Each of the three severity groups in Study 2 had clinical elevations on a variety of factors of emotional adjustment, compared to the normative sample of the KAS-R. In particular, TBI patients scored highly on factors relating to general psychopathology, suspiciousness, confusion, and anxiety, which is consistent with previous findings using this instrument (Klonoff, et al., 1986; Stambrook, et al., 1990). The degree to which significant-others reported emotional behavior to be problematic for the TBI patients was striking, and consistent with the accepted finding that these behaviors are a significant feature of the post-acute rehabilitation picture (Morton & Wehman, 1995). The finding that patients with TBI have been rated as socially and behaviourally impaired as psychiatric patients also raises the possibility that the significant-others of the TBI patients experience considerable

social stigma. It therefore seemed likely that emotional factors would influence the awareness ratings of both the patients and the significant-others.

As predicted by Hypothesis 3, there was little discrepancy between the emotional ratings of the three TBI groups. One explanation for this finding is that since these individuals had been referred for neuropsychological assessment in the post-acute phase, the assumption could be made that even the mildly injured patients were experiencing residual symptoms. Furthermore, patients had been coping with, or adjusting to their symptoms for a minimum of several months, and as long as several years. Thus, the chronicity factor, combined with any residual deficits, would be predicted to result in difficulties with coping and emotional adjustment. While the groups did show similar KAS-R profiles, patients with mild injuries were rated significantly higher on factors relating to helplessness, confusion, and bizarre behavior, compared to patients with moderate and severe injuries. The reasons for this finding are not clear. It is possible that in the context of an otherwise mild TBI, the significant-other deemed the mildly injured patients' persisting behavioural and emotional difficulties as unusual or unexpected. For the significant-others of patients with more serious injuries, persisting difficulties might be expected, and thus rated as being less problematic. On the other hand, the emotional ratings of the mildly injured patients might reflect a sampling bias. Specifically, individuals with mild TBI are generally expected to fully recover within a period of days to weeks following an injury. Those individuals who experience persisting difficulties may be more psychologically vulnerable, a factor that has been implicated in the sustenance and exacerbation of the effects of mild TBI (e.g., Binder, et al., 1997). Thus, mildly injured patients presenting for assessment in the post-acute stage are atypical in that their deficits have not subsided. While the emotional status of the

patients was not sampled directly through self-report measures, the findings appear to be consistent with those of previous studies, which indicate a high level of emotional adjustment difficulties following TBI.

Exploration of the relationship between the emotional adjustment of the patient, and scores on the awareness measure revealed a perplexing pattern. The low correlation between the significant-others' ratings on the PCRS and their ratings of the patients on the KAS-R was unexpected. Although the PCRS taps a comparatively small number of emotional behaviors (see appendix A), it was expected that there would be a strong correlation between the significant-others' ratings on the PCRS and the ratings on the KAS-R, which queries a large array of emotional behaviors. It seems unlikely that significant-others would rate the patients so differently on two instruments that utilize a similar style of questioning, with items of similar content. This low correlation questions the reliability or validity of using significant-other ratings of patient behavior, although these issues have been addressed previously in other studies using the KAS-R (Baker, et al, 1998). It is also possible that the KAS-R and the PCRS are measuring truly independent constructs (i.e., adjustment versus awareness). In either case, one would predict that when the significant-other perceives the patient to be emotionally maladjusted, they would also rate the patient as having difficulties in other areas, as measured by the PCRS.

While the correlations between the KAS-R and significant-other PCRS ratings were low, the correlations between the KAS-R and the patients' rating of self-competence were moderately strong. For example, the negative correlation between the patients' PCRS Emotional factor score and the KAS-R Total (-.52) supports the notion that patients who display greater emotional distress are likely to report greater difficulties

in a variety of areas. This result applied across the three severity groups, but was particularly strong for individuals with milder injuries, as discussed below.

In considering the relationship between awareness, severity, and emotional adjustment in this post-acute sample of patients, the results suggested that the level of emotional adjustment is a stronger predictor of a patient's awareness than the severity of their initial injury. However, taken together, these factors accounted for only 17% of the variance. Given the identified concerns in using the Discrepancy Score as the measure of patient awareness, it was noted that severity of injury and scores on the KAS-R were much stronger predictors of how the patients rated themselves on the PCRS, accounting for approximately 31% of the variance. While the patient's score on its own may not be a good index of level of awareness, the results do identify that emotional adjustment and severity factors are strongly related to how a patient perceives their ability. Again, the pattern of correlations suggested that mildly injured patients were most likely to display emotional adjustment problems, and most likely to report a variety of other neurobehavioral difficulties.

In *post hoc* explorations it became clear that additional factors were relevant to how individuals rated their ability. Mish (2001, personal communication) considered the influence of level of education on the ability of children with a history of TBI to report their awareness of deficit. In that study, it was found that education was not related to the child's score on a modified version of the PCRS. In the current study, *post hoc* explorations suggested that IQ was strongly related to an individual's self-ratings of competence, while the patients' level of education, their sex, and the time since injury were not. In this sample, a combination of low intellectual ability, combined with poor emotional adjustment, was associated with low self-report scores for the patient on the

PCRS. The patients' general intellectual ability was also related to how the significant-other rated them on the PCRS. Two implications of these findings are that (1) TBI patients can experience cognitive decline, which can be identified both through measures of intelligence and through significant-other observations of the individual (it is of interest that interpersonal and emotional behaviors, as seen by the significant-other, were most strongly associated with FSIQ, while cognitive and ADL factors showed weaker associations with FSIQ); (2) the patient's ability to be insightful about the neurobehavioral impact of the TBI is influenced by their general intellectual ability. These findings make it clear that, in the post-acute phase, emotional adjustment factors of the patient, and the patient's general intellectual ability are central to their ability to be insightful about neurobehavioral difficulties. While the severity of the injury is also a factor, it appears to be less important in the post-acute phase of recovery.

Several previous studies have examined the influence of the location of neurological damage, and the level of awareness of deficit (e.g., Prigatano, 1990; Ranseen, et al., 1990; Prigatano, 1996). The findings have been mixed, with some researchers failing to find strong support for the predicted pattern of increased awareness problems associated with damage to the right hemisphere. The current sample showed no left- versus right-hemisphere bias in terms of lesion location and level of awareness of deficit. Both the PCRS Discrepancy Scores and the Patients' self-ratings were examined in this regard, and the findings are consistent with those of Prigatano (1996), and others (e.g., Wagner & Cushman, 1994). The results suggest that impaired perceptions of neurobehavioral deficit cannot be explained on the basis of the laterality of the injury alone.

In examining frontal versus non-frontal lesions, there were no differences in the PCRS Discrepancy Scores. However, patients who had frontal lesions, versus non-frontal lesions, had a tendency to report more difficulties on the PCRS. This finding does not imply that impaired awareness is associated with frontal damage, but does show that patients with frontal injuries experience and report a greater incidence of neurobehavioral difficulties in the post-acute phase of their recovery. Previous studies have found an association between awareness problems and lesions involving the frontal lobes (e.g., Wagner & Cushman, 1994; Cicerone & Tanenbaum, 1997; Prigatano, 1991). Some of these reports are based on clinical examples or case studies (e.g., Prigatano, 1991; Giacino & Cicerone, 1998), while others are based on integration of theory and reviews of the clinical research (e.g., Stuss & Benson, 1986). The research does identify that individuals with frontal lobe injury are more susceptible to deficits in high-order cognition, which theoretically includes self-awareness. The current results do support the finding that patients with damage to the anterior regions of the brain are more likely to report difficulties in a variety of functional activities. However, the current results do not associate impairments in awareness with damage to the frontal lobes, suggesting that damage involving other heteromodal areas can be related to impairments in awareness. Thus, as indicated with respect to laterality of lesions, the frontal versus non-frontal location of neurological damage does not predict the presence of awareness deficits with a strong degree of certainty.

In considering these localization analyses, methodological problems must be considered. First, the original neuroimaging scans were not reviewed in this study. Rather, classifications were based on radiologists' reports, allowing for approximate categorization of the patients. In reality, the inherent problem in localizing the damage

associated with TBI is that the damage is often diffuse. For example, even if the principle damage is localizable to the right hemisphere, there is a high probability that damage has occurred in other areas of the brain, including the shearing and tearing effects of rotational and impact forces applied to the skull. The frontal and anterior temporal lobes may be particularly susceptible to such effects, which can be difficult to appreciate through neuroimaging. The second problem associated with these analyses was that there were a limited number of observations contained within each cell. Only moderate and severely injured patients had neuroimaging results available. Of these individuals, roughly 20% were classifiable as having a right versus left hemisphere injury, 23% were coded as having a diffuse injury. Similar classification rates applied to the anterior/posterior localization factor. Third, in examining the awareness scores of those individuals whose lesions were classifiable, a high level of variability was observed, which may have washed out the effects of lesion location. Finally, the data did not allow for an analysis of the quantity of tissue involved in the injuries sustained by this sample of patients, which may be a critical factor (Prigatano, 1996). Thus, the conclusions drawn from the localization analyses suggest that the brain regions responsible for impaired awareness are not easily localizable in post-acute TBI patients. While it is likely that multiple cortical areas are responsible for deficit awareness, particularly the heteromodal association areas, it is clear that other factors play a strong role in awareness in the post-acute phase of neuropsychological recovery from TBI.

Additional considerations for further research. A number of methodological concerns may have influenced the interpretability of the results of Study 2. Although the patient sample represents a post-acute rehabilitation sample, it may be biased in several ways. First, those individuals who experienced a mild TBI yet continued to experience

neurocognitive and emotional difficulties are not typical of the fast-recovering, mildly injured patient. It appears that these patients continued to experience an array of difficulties, which may be emotionally driven. It would be of clinical and empirical interest to study the patient and significant-other ratings of individuals who had not been referred for assessment. It is possible that such individuals return to the community, continue to struggle, and remain unaware of their deficits. In such cases, it would likely be the significant-other, or a third party carer who would identify a problem, and refer the patient for neuropsychological investigation. Thus, such patients, regardless of the severity of their initial injury, would be inherently difficult to recruit for study, but could add valuable information to the question of the role of emotional reactions in impaired awareness.

Second, the technique of comparing patients' ratings to the significant-others' ratings has face validity, but there are certainly methodological problems associated with this technique. One problem observed in the current study pertains to the reliability and validity of both the patients' and the significant-others' self-reports. In particular, there was no satisfactory explanation for the differences in significant-others' rating of patients on different instruments. The influences on the significant-others' ratings appear to be complex, and are not clearly understood (e.g., Douglas & Spellacy, 1996). The current results suggest that a patient's general intellectual ability is related to how the patient is rated by the significant-other. Whether this association is due to direct neurological changes that are measured by intelligence tests, or to secondary changes in the patients' behavior remains unclear, and warrants further exploration. Similarly, no consistent database addresses the reliability and validity of the observations of the patient by significant-others. Caregivers may report better psychological and neurobehavioral

functioning in the patient than the patient reports in themselves, particularly in the late post-acute phase of recovery from moderate to severe TBI (Brown & Nell, 1992). If the relative overestimates the patients' competence, then both patient and significant-other ratings may reflect a lack of insight, and there is no way to determine which is correct. In clinical practice, there is often considerable variability in relatives' perspectives of the patient.

From the patient side of the equation, some studies have argued that the self-ratings of the TBI patient are fairly reliable (Prigatano, et al., 1990), but there are few data on the validity of their ratings. It could be that the patients' daily routine is quite different from the one portrayed on a self-report inventory. Standardized neuropsychological assessment does not necessarily correct for this problem, as patients with mild TBI, for example, often perform well on standardized measures, but experience difficulty in certain environments. Patients may generalize negative experiences or positive experiences from their everyday experience, and provide inaccurate ratings of their abilities. Since the present study did not independently assess the reliability and validity of the self-ratings of the participants, there is no way to determine if the patients' ratings reflect a true lack of insight into their disability. Thus, additional quantitative measures of functioning, such as neuropsychological assessment, and objective documentation of patients' behavior in a variety of settings should be incorporated into a method of evaluating patients' insights about their neurocognitive deficits. Clinically, such an approach would be costly and prohibitive for practical reasons. However, a comprehensive approach could be adopted for patients who are participating in a rehabilitation program, where they are observed by multiple therapists across a variety of rehabilitation tasks.

General Discussion

Prigatano (1996) identified that there is a growing appreciation that disorders of brain function can produce disturbances in awareness of neuropsychological deficits, and that for some patients such disturbances can be the single greatest impediment to successful neuropsychological rehabilitation or recovery. Therefore, a better understanding of the mechanisms and factors that relate to poor insight or self-awareness after TBI is crucial. The central aim of this dissertation was to explore the relationship between awareness factors and emotional adjustment issues in TBI patients.

Commenting first on the primary measures utilized in the current study, the PCRS was useful in assessing patient's and significant-other's perspectives in the acute phase of recovery from TBI, and in the post-acute phase of rehabilitation from TBI. The results of this study suggest that a standardized scoring protocol for the PCRS is warranted, one that does not rely exclusively on discrepancies between PCRS Total scores. An empirical comparison of the various scoring techniques, including discrepancy scores, factor scores, agree/disagree items, or individual item analysis will be an important undertaking for future research. Similarly, although the PCRS has seen increasing use as a research instrument, a normative base against which to compare the ratings of patients and significant-others would permit it to be used as a clinical tool. Such a normative base is currently lacking. In lieu of a costly and time-consuming standardization study, a meta-analysis of available data could supply a provisional database for the purposes of clinical evaluation.

While the PCRS has the advantage of being a relatively specific and structured measure, the SADI was useful in the relatively open-ended nature of the questions. The

SADI requires that the clinician have some knowledge of the patient, which is more likely to be the case in the acute-care rehabilitation setting than in a post-acute assessment environment. Thus, the SADI may be more appropriate in the acute-care setting, while the PCRS more appropriate for post-acute assessment purposes, and with careful consideration given to the scoring technique used, and the variety of additional factors that can influence both patient and significant-other perceptions. For a robust assessment of a patient's awareness of deficit, a combination of self-other discrepancies, staff-ratings, neuropsychological examination, and structured clinical interviews should be considered.

Both Study 1 and Study 2 identified that there are numerous potential sources of bias that may influence patient and significant-others' ability to gauge awareness. Discrepancy scores, in particular, are likely to be influenced by the combined effects of such variables. This study identified that the patient's general intellectual ability can be a significant factor in how patients rate their abilities. Patients' general intellectual ability was also related to the perceptions of the significant-other. While general intellectual ability was not examined in the acute-care study, in the post-acute phase of rehabilitation both intellectual ability and emotional adjustment were stronger predictors of the scores on the PCRS, than the initial severity of the patients' injury. The influence of general intellectual ability on patients' level of awareness of deficit has not previously been a focus in the awareness literature surrounding TBI, and warrants further investigation.

The combined results of Study 1 and Study 2 suggest that emotional adjustment can significantly influence ratings of patients' behavior. For the patient, this factor appears to be strongest during the post-acute phase, and for individuals with mild TBI. For significant-others, variations in emotional adjustment are likely to be greatest in the

early stages of recovery. Although the post-acute emotional adjustment of the significant-others was not examined in the current research, this factor has been considered previously. Both the patient and significant-other are likely to experience a change in strength and quality of their emotional experiences from the acute phase of recovery to the post-acute phase of recovery.

In considering the nature of impaired awareness following TBI, the current results suggest that limited awareness early after injury is likely to be a reflection of the neurological injury itself, versus psychological denial on the part of the patient. Clinicians should, however, be conscientious in the assessment of patients who have fluctuating emotional supports, as these external factors can influence the patient's self-perspective. Laterality or location of the injury is theoretically relevant, but in practice, injuries are probably diffuse, involving multiple areas. At the same time, "awareness", as a higher-order cognitive function, undoubtedly involves multiple cortical areas, and heteromodal integration. Assuming that patients are generally oriented at the time of their assessment, with the basic capacity to respond to questions, their level of awareness or insight does not appear to change dramatically during the course of inpatient rehabilitation, or in the early stage of their community-based recovery. Patients also appear to remain quite emotionally stable during their inpatient recovery.

A lack of applied experience for the patient may be a major obstacle for patients, family members, and clinicians in rating neurocognitive abilities. While the significant-other may have a vast repertoire of pre-injury behaviors on which to base their ratings, the limited amount of post-injury behavioral experience can be a significant limiter in the ability of all involved to provide usable ratings of the patient. However, by the time patients are referred for post-acute assessment, it is likely that the patient has been able to

experience the range of their neurocognitive ability, and to respond emotionally to changes in their skill set. The current study is among the first to provide an analysis of impairment ratings of mildly injured patients, using the PCRS. The reports of these patients strongly suggest that factors other than the neurological injury are related to the experience of symptoms. In fact, the group of patients with moderate to severe injuries displayed relatively good insight, as determined from self-other discrepancies, while individuals with mild injuries reported more neurobehavioral difficulties, and greater emotional maladjustment. Previous research suggests that these adjustment difficulties are not likely to be related to pre-injury affective or personality issues, but may relate to the individual's ability to cope with post-concussion type symptoms (Cicerone & Kalmar, 1997). Mildly injured patients may do quite well in cognitive rehabilitation, although these services are often denied to this group of patients (Raskin & Mateer, 2000).

In conclusion, Prigatano has argued that human awareness is an emergent brain function that integrates both cognitive and affective states. Human consciousness emerges from the integration of these two dimensions (Prigatano & Weinstein, 1996). The inherent difficulty in assessing level of awareness of neurobehavioral deficit, and in assessing emotional adjustment, is that the "technology" available to psychologists relies on subjective ratings. This issue is not specific to TBI research, but to a varying degree applies to clinical psychology in general. In addition, "awareness" reflects a complex interaction of cognitive processes, with substrates such as attention, memory, judgement, and so on. Similarly, the term "emotional adjustment" belies the complexity of human emotional experience. Through the study of TBI rehabilitation patients, one has the opportunity to observe these characteristics pushed to limits. The continuing study of

these issues will be important to maximize the benefits of rehabilitation practices, and patients' opportunities for return to optimum daily functioning.

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Appendix A. Patient Competency Rating Scale Items

Item content listed by Factors described by Heilbronner, et al. (1993)

Activities of Daily Living		Cognitive	
1. Preparing meals	=	7. Keeping appointments	
2. Dressing	=	9. Staying involved in work	≠
3. Personal hygiene	=	10. Remembering dinner	
4. Washing dishes	=	11. Remembering names	=
5. Doing laundry	=	12. Remembering schedules	
6. Managing finances	≠	13. Remembering important things	
14. Driving a car		24. Scheduling activities	≠
26. Daily responsibilities		25. New instructions	
Interpersonal		Emotional	
8. Group conversations		16. Adjusting to change	≠
15. Getting help		18. Accepting criticism	
17. Handling arguments	≠	19. Controlling crying	=
20. Acting appropriately		27. Controlling temper	≠
21. Showing affection		28. Controlling depression	≠
22. Group activities		29. Emotions and activity	≠
23. Recognizing if upset	≠	30. Controlling laughter	=

Note: "=" identifies items on which patients and significant others are predicted to be in agreement; "≠" identifies items on which patients and significant-others are predicted to disagree (Prigatano, et al., 1991).

Appendix B. Self-Awareness of Deficits Interview (SADI)

I. Self-awareness of deficits.

Are you any different now compared to what you were like before your accident? In what way? Do you feel that anything about you, or your abilities has changed?

Do (*would*) people who know you well notice that anything is different about you since the accident? What might they notice?

What do you see as your problems, if any, resulting from your injury? What is the main thing you need to work on / would like to get better?

Prompts

Physical abilities (e.g., movement of arms and legs, balance, vision, endurance)?

Memory / confusion?

Concentration?

Problem solving, decision making, organizing and planning things?

Controlling behavior?

Communication?

Getting along with other people?

Has your personality changed?

Are there any other problems that I haven't mentioned?

2. Self-awareness of functional implications of deficits?

Does (*will*) your head injury have any effect on your everyday life? In what way?

Prompts

Ability to live independently?

Managing finances?

Looking after your family / managing the home?

Driving?

Working / Studying?

Leisure / social life?

Are there any other areas of life which you feel have [*will*] changed or may change?

3. Ability to set realistic goals

What do you hope to achieve in the next 6 months? Do you have any goals? What are they?

In 6 months time, what do you think you will be doing? Where do you think you will be?

Do you think your head injury will still be having an effect on your life in 6 months time?

If yes, how?

If no, are you sure?

SADI Scoring

I. Self-awareness of deficits.

- 0 Cognitive / psychology problems (where relevant) reported by the patient / client in response to general questioning, or readily acknowledged in response to specific questioning.
- 1 Some cognitive / psychological problems, but others denied or minimized. Patient / client may have a tendency to focus on relatively minor physical changes (e.g., scars) and acknowledge cognitive / psychological problems only on specific questioning about deficits.
- 2 Physical deficits only acknowledged; denies, minimizes, or is unsure of cognitive / psychological changes. Patient / client may recognize problems that occurred at an earlier stage by denies existence of persisting deficits, or may state that other people think there are deficits, but he/she does not think so.
- 3 No acknowledgement of deficits (other than obvious physical deficits) can be obtained, or patient / client will only acknowledge problems that have been imposed on him/her, e.g., not allowed to drive or drink alcohol.

II. Self-awareness of functional implications of deficits.

- 0 Patient / client accurately describes current functional status (in independent living, work/study, leisure, home management, driving), and specifies how his/her head injury problems limit function where relevant and/or any compensatory measures adopted to overcome problems.
- 1 Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient/client may not be sure of other likely functional problems, e.g., is unable to say because he/she has not tried an activity yet.
- 2 Patient / client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient / client.
- 3 Little acknowledgement of functional consequences can be obtained; the patient/client will not acknowledge problems: except that he/she is not allowed to perform certain tasks. He / she may actively ignore medical advice and may engage in risk-taking behaviors, e.g. driving, drinking.

III. Ability to set realistic goals.

- 0 Patient / client sets reasonably realistic goals, and (where relevant) identifies that the head injury will probably continue to have an impact on some areas of functioning, i.e., goals for the future have been modified in some way since the change.
- 1 Patient / client sets foals which are somewhat unrealistic, or is unable to specify a goal, but recognizes that he/she may still have problems in some areas of function in the future, i.e., sees that goals for the future may need some modification, even if he/she has not yet done so.
- 2 Patient/client sets unrealistic, or is unable to specify a goal, and does not know how he/she will be functioning in 6 months time, but hope he/she will return to pre-trauma, i.e., no modification of goals has occurred.
- 3 Patient/client expects without uncertainty that in 6 months time, he/she will be functioning at pre-trauma level (or at a higher level).

Appendix C. Components of the FIM + FAM

Motor Items for Self Care	Scoring Levels for Independence
1. Eating	7. Complete Independence (timely, safely)
2. Grooming	6. Modified Independence (device; more than reasonable time, safety considerations)
3. Bathing	Modified Dependence
4. Dressing Upper Body	5. Supervision or Set-up
5. Dressing Lower Body	4. Minimal Contact Assistance (subject expends more 75% or more effort)
6. Toileting	3. Moderate Assistance (subject expends 50% or more of the effort)
7. Swallowing	Complete Dependence
Sphincter Control	2. Maximal Assistance (Subject expends 25% or more of the effort)
8. Bladder Management	1. Total Assistance (subject expends less than 25% of the effort)
9. Bowel Management	
Transfers	
10. Bed, chair, wheelchair	
11. Toilet	
12. Tub or Shower	
13. Car transfers	
Locomotion	
14. Walking/wheelchair	
15. Stairs	
16. Community access	
Cognitive/Psychosocial Items	
Communication	
17. Comprehension	
18. Expression	
19. Reading	
20. Writing	
21. Speech intelligibility	
Psychosocial adjustment	
22. Social interaction	
23. Emotional status	
24. Adjustment to limitations	
25. Employability	
Cognitive Functioning	
26. Problem Solving	
27. Memory	
28. Orientation	
29. Attention	
30. Safety judgement	

Appendix D. Factor Components of the KAS-R (Katz and Lyerly factor structure).

	Normal Controls (age 20-29)
1. Belligerence*	4.86 (1.03)
2. Verbal Expansiveness*	5.99 (1.48)
3. Negativism*	11.84 (2.61)
4. Helplessness	4.78 (1.16)
5. Suspiciousness*	4.39 (0.92)
6. Anxiety	6.59 (1.21)
7. Withdrawal and retardation*	8.09 (1.84)
8. General Psychopathology*	21.73 (4.69)
9. Nervousness	6.41 (1.66)
10. Confusion*	3.18 (0.51)
11. Bizarreness	5.41 (1.05)
12. Hyperactivity	4.37 (1.21)
13. Stability	30.99 (4.75)

Note: * represents factors on which TBI patients were rated significantly higher than controls ($p = .01$ level of significance; Klonoff, et al., 1986).

Appendix E. Profile of Mood States Factor Scales and Normative Data

POMS Subscale	Men		Women	
	Mean	sd	Mean	sd
Tension	7.1	5.8	8.2	6.0
Depression	7.5	9.2	8.5	9.4
Anger	7.1	7.3	8	7.5
Vigour	19.8	6.8	18.9	6.5
Fatigue	7.3	5.7	8.7	6.1
Confusion	5.6	4.1	5.8	4.6
Total Mood	14.8	32.7	20.3	33.1

Note: Total mood score is computed by summing the factor scores with vigour scored negatively. These data are derived from a sample of 400 community dwelling adults with a mean age of 44 years and mean education of 14.3 years (Nyenhuis, et al., 1999).