Outcome In The First Year Following Severe Traumatic Brain Injury: A New Zealand Study Of The Impact On Patients And Their Primary Caregivers

A thesis submitted in partial fulfilment

of the requirements for the degree of

Doctor of Philosophy

at the University of Waikato

by

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University of Waikato

Te Whare Wananga O Waikato

1999

Abstract

This research project describes the first year following severe traumatic brain injury (TBI) for 84 adults and their primary caregivers. Study 1 examines the utility of a measure of severity of injury, somatosensory evoked potentials (SEP), in predicting the 1 year outcome for 76 patients. Study 2 describes both the 6 month and 1 year outcome for 65 patients. Finally, Study 3 details the status of 52 primary caregivers 6 months and 1 year following the injury of their family member.

An examination of the utility of SEPs, obtained within 24 hours of injury, in predicting outcome at 1 year showed that SEP 3 was associated with an unfavourable outcome (death, persistent vegetative state, or severe disability) in 100% of cases, and with death in 77% of cases. The absence of SEPs bilaterally was associated with death in 90% of cases. SEPs were more effective at predicting outcome as measured by the Glasgow Outcome Scale than the Glasgow Coma Scale score. The level of accuracy required for making triage decisions is discussed.

Severe TBI resulted in pervasive impairments in cognitive, emotional, and behavioural abilities and significant disruption to social functioning. Despite an improvement in cognitive functioning between 6 months and 1 year, deficits in many aspects of cognitive functioning were still evident at 1 year postinjury. However, the prevalence of emotional and behavioural disturbance and disrupted social functioning remained consistent through the first year postinjury. The TBI patient's levels of cognitive and behavioural impairments were significant indicators of the patient's social functioning, including employment, independence, and social contact, at 1 year postinjury.

Primary caregivers reported high levels of psychosocial difficulties and various forms of burden as a result of caring for the TBI patient. Despite some improvement in the caregivers' social adjustment, their levels of anxiety and depression remained relatively constant in the first year postinjury. The caregivers appraisal of the TBI patient's level of functioning significantly predicted caregiver level of burden at both 6 months and 1 year. However, those aspects of TBI patient functioning that were most predictive of caregiver burden changed between 6 months and 1 year postinjury. This suggested that caregivers adapted over time to some aspects of TBI patient impairment, while other aspects may become more salient at later stages postinjury. Overall, it was the TBI patient's loss of social contact that was the most consistent predictor of caregiver level of subjective burden.

The implications of these findings for rehabilitation are outlined. Measures of severity of injury were found to predict only gross categories of outcome following severe TBI. Despite this, they can be used to estimate approximate rehabilitation needs and prepare the family for the likely level of disability in the TBI patient. The findings from this research project also suggest the need for a comprehensive neuropsychological assessment prior to vocational rehabilitation. Programmes designed to assist family caregivers of people with severe TBI need to be flexible enough to adapt to the needs of caregivers, which change over time. It is the TBI patient's loss of social contact that the caregivers find consistently distressing. While appropriate vocational rehabilitation may go some way towards reintegrating the TBI patient back into the social world, programmes aimed at reducing the impact of cognitive deficits and the frequency of behavioural problems are also required to reduce both TBI patient and caregiver distress.

Acknowledgements

I would like to thank the TBI patients and their caregivers for taking part in this study. Many patients and their caregivers said that they were happy to participate in the study, hopeful that one day this research would benefit others like themselves. I hope this is true. I would also like to thank the patients and families that I have work with as a clinician over the past few years whose stories are implicit in this study.

I would like to express my gratitude to Dr Jack Havill and Dr Jamie Sleigh at Waikato Hospital. Their interest in their patients even after their patients had left their care in the Intensive Therapy Unit prompted the extensive follow-up of this study. Thank-you also to Dr Nigel Marsh. It was a pleasure to work on this project with you.

Many thanks go to my supervisors Professor Ian Evans and Dr Malcolm Stewart who have continued to be involved, and have maintained an interest in this seemingly never-ending task.

Thank-you to Jane Gill and Karen Schneller for their understanding and long suffering support. I promise the party won't take as long to organise as the thesis did to complete. Also to Shirley Hosking for her diligent and obsessive proof reading.

Thank-you to Nigel for his endless energy and enthusiasm in wanting to see this project completed. It couldn't have been done without you.

Finally to Jason and Martin. Their struggles and commitment to their own study never failed to provide me with inspiration and encouragement to complete this piece of work. (Despite their resounding overt support, "You'll never finish it Mum, give up now".) As ever I love you both kids.

This thesis is dedicated to the memory of

Eileen Rose Kersel
and
Kenneth Henry Kersel

And to Kim
Such a good friend, so sadly missed

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Chapter 1

Introduction

This chapter describes the general context for the current research project. The nature, causes, and definition of the disorder known as traumatic brain injury are outlined. A brief background to each of the three studies that comprise the project is also presented. These studies deal with the role of the assessment of severity in the prediction of outcome, outcome for the patient who receives the injury, and outcome for their primary caregiver, respectively.

Traumatic brain injury (TBI) is reported to be the most common cause of brain damage (Lezak, 1995). In New Zealand, death and disability resulting from road traffic crashes, the most common cause of TBI, are key health issues for males and females between 15 and 65 years of age and for children. While the number of road traffic crashes involving death decreased between 1992 and 1994, the number of accidents involving serious injury has increased (K. Brough, New Zealand Land Transport Safety Authority, personal communication, June 3, 1999). Advances in medical techniques and management in the acute stages has improved survival rates following TBI, however the psychological consequences for the person sustaining the TBI and their family remain.

Definition of Traumatic Brain Injury

The National Head Injury Foundation in the USA has defined TBI as "an insult to the brain caused by an external force that may produce diminished or altered states of consciousness which results in impaired cognitive abilities or physical functioning" (National Head Injury Foundation, 1989). TBI can be divided into two categories, open TBI and closed TBI. An open TBI occurs when an object fractures the skull and the brain is penetrated (e.g., bullet). These injuries tend to produce more localised damage and generally result in a more focal pattern of neurological deficit.

More commonly occurring is closed TBI. This type of injury occurs as a consequence of a blow to the head from a relatively blunt object or from the impact of the head with a stationary object. Primary damage to the brain is determined by the nature, direction, and magnitude of the force of impact, and tends to result in either cerebral contusions or diffuse axonal injuries. Cerebral contusions and/or lacerations occur when the brain impacts against the wall of the skull and are most frequently found on the orbital surfaces of the frontal lobes, the temporal poles, the lateral and inferior surfaces of the temporal lobes, and the cortex above and below the sylvian fissures. These lesions can swell and be subject to haemorrhage, causing an intracranial mass lesion (Rimel, Jane, & Bond, 1990; Teasdale & Mendelow, 1984). Diffuse axonal injuries occur more frequently and are caused by a shearing mechanism produced by a rotational acceleration movement between different components of the brain. This often causes widespread damage to the nerve fibres in the white matter (Rimel et al; Teasdale & Mendelow). Unless otherwise stated, the remainder of this work will use the term TBI to refer to closed head injuries.

A distinction can be made between the occurrence of primary and secondary brain damage following TBI. Primary damage occurs at the moment of impact and is therefore not reversible. Secondary damage occurs as a result of later complications.

Secondary damage can be prevented, or if treated early, the extent of damage can be greatly minimised.

Table 1.1. Causes of Secondary Brain Damage following Traumatic Brain Injury

Extracranial factors	respiratory failure
	hypoxia
	hypotension
	anemia
	pyrexia
	hyponatremia
	hypoglycemia
Intracranial factors	haematomas
	brain swelling
	infection
	subarachnoid haemorrhage
	hydrocephalus
	epilepsy

Secondary damage (Table 1.1) can be due to intracranial complications such as raised intracranial pressure, oedema, infection, and intracranial haematoma, or to systemic insult such as hypoxia, hypercarbia, hypotension, or hyponatremia (Hume Adams, 1990; Rimel et al., 1990). Secondary insult of systemic origin is commonly related to the presence of multiple injuries affecting other parts of the body. Multiple injuries frequently occur when a person sustains a TBI. Jennett (1990) reported that 60% of 113 cases of severe TBI and 40% of 193 cases of moderate TBI admitted to the Head and Spinal Unit in Edinburgh in 1986 also had one or more additional systemic injuries. Similarly, Groswasser, Cohen, and Blankstein (1990) reported that 58% of 328 people admitted with a severe TBI had associated trauma. People who sustain a TBI with associated multiple trauma are reported to remain in coma for a longer period of time and have more difficulties in overall psychosocial functioning than those who sustain only a TBI (Groswasser et al., 1990; Moore, Stambrook, Peters, Cardoso, & Kassum, 1990).

Epidemiology of TBI

While there are numerous epidemiological studies of TBI comparisons between those studies is difficult due to methodological inconsistencies between the studies. Such inconsistencies include the use of different definitions for TBI, different methods for classifying the severity of injury, and different sampling techniques. In a comprehensive review of epidemiological studies carried out in North America, Frankowski (1986) reported the incidence rate of TBI as between 200 and 300 per 100,000 per year. While most of these injuries were mild to moderate, approximately 30% were estimated to be severe and 10% were fatal. Estimates of admission to hospital and death rate resulting from TBI in Australia suggest similar figures (Frankowski). In contrast, the death rate from TBI in the United Kingdom is estimated as much lower at 9 per 100,000 population (Jennett & Frankowski, 1990).

While many studies focus on the number of deaths resulting from TBI, few report the number of people who remain disabled from such injury. In the United Kingdom, Jennett (1990) estimated that TBI results in 150 people experiencing disability per 100,000 population, per year. In North America it is estimated that of the 500,000 people admitted to hospital with TBI each year 10 - 20% survive with severe impairments that affect independent living, and more than 40% experience some kind of difficulty that interferes with activities of daily living (Jacobs, 1988; Jennett, Snoek, Bond, & Brooks, 1981).

Information regarding the incidence of TBI in New Zealand is scarce. The most frequently cited figure is the New Zealand Head Injury Society (1993) estimate that New Zealand hospitals admit approximately 257 per 100,000 people each year with TBI. Gronwall, Wrightson, and Waddell (1990) have suggested that as many as 297 per 100,000 people are admitted to hospital in New Zealand each year following a blow to the head, and a further 594 per 100,000 are treated but not admitted each year. A study by Caradoc-Davies and Dixon (1995) reported the incidence rate of TBI in New Zealand as 298 per 100,000 in 1980 and 228 per 100,000 in 1988. Havill, Sleigh, Kersel, and Marsh (1998b) reported that approximately 1400 people were admitted to the Waikato Hospital in Hamilton over a 41 month period with a TBI. The Waikato Hospital serves a population base of over 700,000 people. Twenty percent of those people admitted to hospital had injuries severe enough to require treatment in the Intensive Therapy Unit.

The incidence of TBI differs according to gender and age. Males are three times more likely to sustain a TBI than females (Jacobs, 1988; Vogenthaler, 1987) and the majority of those sustaining a TBI are between the ages of 15 to 24 years (Anderson & McLaurin, 1980; NHIF, 1984). Some research has commented on the "risk factors" associated with TBI. Those who have a history of a psychiatric disorder, substance abuse, or poor academic performance are highly represented amongst those presenting with TBI (Haas, Cope, & Hall, 1987; Vogenthaler, 1987). Lower socioeconomic groups and the unemployed are also more likely to sustain a TBI (Rimel & Jane, 1984).

Road traffic crashes account for the majority of TBI, followed by falls and then assaults. This can vary markedly between countries and the primary cause of TBI can differ as a function of the age group. Hospital admissions due to road traffic crashes ranged from 24% of all TBI in Scotland, to 90% of all TBI in Taiwan. For those under the age of 15 years and over the age of 70 years the most common cause of TBI is falls. In an American sample, road traffic crashes were the most common cause of TBI in males aged between 15 and 24 years. In contrast, a Scotland study showed that for the same age group, assault was twice as common as road traffic crashes as the primary cause of TBI (Jennett, 1990).

Research in New Zealand has found that road traffic crashes are the primary cause of TBI in 36% of those admitted to hospital (Caradoc-Davies & Dixon, 1995). This was the most common cause of TBI in both males and females between the ages of 15 and 35 years. Falls were the most common cause of TBI for those under the age of 5 years and over the age of 75 years. A TBI due to assault occurred in 11% of cases and this was most common in those aged between 15 and 34 years of age (Caradoc-Davies & Dixon, 1995).

Assessment of Severity of TBI

Teasdale (1995) describes the purpose of classification of severity of injury as threefold. Firstly, it is necessary in the management of the acute stage following TBI when information is needed regarding the patient's condition on arrival at hospital, how their condition is likely to progress, and what complications can be expected.

Secondly, accurate assessment of severity is required in the post-acute phase when an estimate of the potential for recovery is required. Thirdly, injury severity is used as a prognostic indictor of outcome.

Until the mid-1970s, research concerning the incidence and outcome following TBI lacked a standardised method for grading the severity of injury (Rimel et al., 1990). The development of the Glasgow Coma Scale (GCS) by Teasdale and Jennett (1974) provided the first such standardised measure and provides an assessment of the person's level of consciousness. Following a TBI there is usually a loss or alteration of consciousness. This can range from a clouding of consciousness where the person is confused or disorientated, to the person being fully unconscious. Severity of injury can be determined by the duration and degree of impaired consciousness.

The GCS allows for the assessment of eye opening, verbal responsiveness, and motor responsiveness to provide an overall score to indicate level of consciousness. The total score can range from 3 (no response of any kind) to 15 (no impairment). Patients with a GCS of 8 or less are considered to have sustained a severe TBI. Scores of 9 to 12 indicate a moderate TBI, and scores between 13 and 15 suggest a mild injury.

Criticism of the GCS has focused on two primary issues. Firstly, there is controversy over when is the ideal time postinjury for the scale to be administered. For example, use of the scale soon after injury may not take into account the development of secondary complications such as subarachnoid haemorrhages or infection. Secondly, there is no provision for occasions when one or more modality is untestable. For example, when a verbal response cannot be obtained because the patient is intubated or the presence of ocular swelling prevents an assessment of eye opening.

Another commonly used method of assessing level of severity is the measurement of post-traumatic amnesia. The measurement of post-traumatic amnesia focuses on the person's disorientation in time, place and person, and/or inability to recall new experiences on a day to day basis. Classification of post-traumatic amnesia was originally proposed by Russell and Smith (1961) and was expanded to the most commonly used form by Jennett and Teasdale (1981), who suggested the following criteria: post-traumatic amnesia of less than 5 minutes (very mild TBI), post-traumatic amnesia of 5-60 minutes (mild TBI), post-traumatic amnesia of 1-24 hours (moderate TBI), post-traumatic amnesia of 1-7 days (severe TBI), post-traumatic amnesia of 1-4 weeks (very severe TBI), and post-traumatic amnesia greater than 4 weeks (extremely severe TBI).

The manner in which post-traumatic amnesia is assessed varies between studies, making comparison of results across studies difficult. In an attempt to standardise the assessment of post-traumatic amnesia a number of standardised scales have been developed including the Galverston Orientation and Amnesia Test (Levin, O'Donnell, & Grossman, 1979) and the Westmead Post-Traumatic Amnesia Scale (Shores, Marosszeky, Scandanam, & Batchelor, 1986).

A major consideration when using changes in the level of consciousness as a measure of severity is the possibility that focal injury may be undetected. Cortical contusions, particularly in an area such as the frontal lobe, can occur in the absence of prolonged unconsciousness but can result in significant sequelae for the TBI patient.

A number of other clinical measures such as computerised tomography, intracranial pressure, and electroencephalography, have also been used to assess severity of injury following TBI, and their usefulness as prognostic indicators has been investigated (Espersen & Petersen, 1982; Gennarelli, 1982; Hutchinson, Frith, Shaw, Judson, & Cant, 1991; Miller & Dearden, 1992). Many of these measures however are affected by secondary variables such as drug intoxication and hypoxemia. The increasing use of barbiturates and neuromuscular blockers in the management of severe TBI can render the clinical examination, in particular, of little value (Frowein & Firsching, 1990).

The usefulness of evoked potential data collected within the first few days following injury has been investigated as a prognostic indicator of outcome (Greenberg, Mayer, Becker, & Miller, 1977; Narayan et al., 1981; Rappaport, Hall, Hopkins, & Belleza, 1981). Investigations continue into the relative value of visual, auditory and somatosensory evoked potentials (SEP). There appears to be overall agreement that the relationship between visual evoked potentials and outcome is poor. Similarly, there is agreement that although auditory evoked potentials have some value in predicting outcome, the strongest relationship is between SEPs and outcome (Greenberg, Becker, Miller, & Mayer,1977; Narayan et al., 1981; Rappaport, Hopkins, Hall, & Belleza, 1981). Research in New Zealand has confirmed these findings. Judson, Cant, and Shaw (1990) found SEPs to be reliable predictors of outcome following severe TBI when the Glasgow Outcome Scale was used to assess outcome. A significant advance in research into the use of SEPs was made by this group of New Zealand researchers who developed a more accurate method of interpretation of SEP data (Hume & Cant, 1978). Evoked potentials are reported to have the advantage of being easy to obtain and are not affected by drug intoxication or drugs used in the clinical management of the injury (Frowein & Firching, 1990). The use of SEPs as prognostic indictors therefore requires further investigation.

Accurate assessment of severity of TBI is therefore important for the acute management of TBI and later rehabilitation. It is well established that severity of injury is a useful prognostic indicator of outcome following TBI, although the degree to which severity can predict outcome remains contentious. Assessment of the severity of TBI and the determination of prognosis is essential for both the clinician and the family. It is required to ensure the appropriate allocation of treatment and rehabilitation resources and for designing family interventions. Therefore the effectiveness of measures of severity at predicting outcome following TBI requires further clarification.

Measurement of Outcome following TBI

The measurement of outcome following TBI can provide valuable information regarding the different kinds and varying degrees of disability that can result. There are three principle reasons for categorising outcome (Jennett, 1984). Firstly, such categorisation is necessary to allow for the systematic assessment of the results of different treatment. This provides the basis for comparing the efficacy of treatment methods, both in the acute stage and during rehabilitation. Secondly, the measurement of outcome allows recovery of different degrees to be related to specific aspects of the individual's acute medical status. This provides information which allows for predictive factors to be identified and for statistical rules concerning prognosis to be formulated. Finally, the accurate and precise assessment of outcome enables appropriate plans to be made for those with ongoing or permanent disability, who will require continuing care.

The outcome for people who experience a TBI can vary from death, to a good recovery, and from a total dependence on others for all activities, to a return to their previous occupation and a resumption of family and social activities. Prior to 1975 there was no uniform method available to assess outcome following TBI. Criteria such as survival or return to work were most commonly used. Often there was an overemphasis on physical handicap, thus neglecting to take into account both the neurobehavioural sequelae and neurological deficits following TBI.

In an attempt to assess not only survival but also the level of support needed in daily living and social reintegration, Jennett and Bond (1975) developed the Glasgow Outcome Scale (GOS). The GOS consists of five categories: death, persistent vegetative state, severe disability, moderate disability, and good recovery. Specific criteria are provided for inclusion in each category. This encourages consistency between raters and facilitates the comparison of outcome data between different patient samples, research centres, and even different countries. The GOS however remains a very global measure of outcome. Brooks (1987) suggested that the GOS is an appropriate measure for facilitating communication between research groups, but that it provides only a crude level of assessment when used as a measure of outcome. He notes that in fact this was all that the GOS was designed to provide and that it has often been misused in clinical settings. To provide a better understanding of outcome following TBI a more precise description of the nature of a person's disability is needed. This includes the neurophysical, cognitive, and psychosocial consequences of TBI.

Neurophysical changes commonly noted are related to impaired movement (ataxia, dysarthria, hemiparesis), vision (diplopia, blurred vision), hearing (conductive deafness, tinnitus), tactile sensation (pain, temperature), and altered taste and/or smell (Vogenthaler, 1987). Neurophysical changes tend to improve during the first few months although for a small group these changes result in permanent impairment (McClelland, 1988). Post-traumatic epilepsy is also one of the many neurophysical consequences following TBI. Post-traumatic epilepsy occurs in 4% to 7% of people following TBI and is more frequent following a severe TBI. Fifty percent of those who develop epilepsy will do so within the first year, and 80% will have a seizure by the end of the second year postinjury. After 5 years postinjury the risk of developing epilepsy for a person with a TBI is no greater than for the general population (Yablon, 1993).

Cognitive impairment following TBI is commonly reported (Brooks, 1984; Vogenthaler, 1987). This includes impairment of learning, memory, attention, concentration, perception, concept formation, problem solving, and language dysfunction. Ben-Yishay and Diller (1983) suggest that cognitive deficits have a greater impact on a person's psychosocial functional than physical impairments.

Despite the presence of ongoing physical and cognitive impairment, it is the psychosocial changes that are reported to cause the greatest degree of distress for the person with a TBI and their families (Brooks & Aughton, 1979b; Brooks & McKinlay, 1983; Florin, Katz, & Lahav, 1989; Lezak, 1988; Livingston & Brooks, 1988; Marsh, Knight, & Godfrey, 1990; Oddy, Humphrey, & Uttley, 1978a). Psychosocial functioning refers to the psychological/emotional, behavioural, and social aspects of a person's functioning. Emotional symptoms of anxiety and depression are commonly reported (Brooks & Aughton, 1979b; Tyerman & Humphrey, 1984) and changes in behaviour include verbally threatening or aggressive behaviour, disinhibited, inappropriate or irresponsible social behaviour, aspontaneity, restlessness, childishness, impulsivity, emotional lability, impatience, over-sensitivity, and egocentricity (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Oddy, Humphrey, & Uttley, 1978b). The presence of behavioural and emotional problems following TBI is thought to be associated with poor social adjustment, inability to return to work, decreased social contact, and decreased participation in leisure activities for patients (Livingston, Brooks, & Bond, 1985b; Stambrook, Moore, & Esses, 1990).

Another aspect of outcome following TBI is the effect of a TBI on the family of the TBI patient. Research to date indicates that relatives of severe TBI patients experience a significant degree of distress as a result of caring for the TBI patient. This can result in increased levels of stress, depression, and anxiety; a high incidence of psychosomatic disorders; increased consumption of prescription and non-prescription drugs; financial difficulties and role changes; poor social adjustment and increasing social isolation. Overall, caregiver burden appears to be most affected by changes in behaviour and emotion, commonly referred to as "personality changes", in the person who had sustained a TBI. It has been found to be comparatively less affected by changes in the cognitive ability, communication skills, and physical ability of the TBI patient (Brooks, 1992).

In summary, the literature on outcome following severe TBI suggests that severity is a reliable predictor of outcome and that both TBI patients and their families experience a number of ongoing difficulties as a result of the injury. Details on the prevalence and pattern of recovery of these difficulties differ between studies. The research to date in this area suffers from a number of methodological weaknesses and this may in part explain the different results that have been obtained. These weaknesses include poorly defined samples, heterogeneous groups in relation to severity and time postinjury, and bias in sampling techniques. Most studies have concentrated on a particular aspect of outcome, for example, cognitive functioning, rather than taking an holistic approach and investigating a broader range of the possible consequences. The few studies that have examined the relationship between the cognitive, emotional, and behavioural impairments displayed by the TBI patient and the impact of these impairments on the broader range of social functioning have used either simplistic measures of impairment, gross measures of social outcome, or have investigated only one or two discrete variables.

Purpose of the Current Study

A clearer description of the many consequences for the patient and their family following severe TBI is needed. Further information on the changes over time in these consequences, and the relationship between them is required. While some international research has attempted to address similar issues, there have been no such studies undertaken in New Zealand. The current research project provides a longitudinal study in the New Zealand context. A review of previous literature indicates that no such research has yet been carried out. New Zealand presents a unique geographical, political and social environment that requires indigenous research.

The current research project investigates three different aspects of outcome following severe TBI. The first study explores the use of measures of severity in the prediction of outcome following severe TBI. Research suggests that SEPs offer a rapid, comparatively simple and noninvasive method of reliably predicting outcome. Chapter 3 describes the analysis of SEPs obtained within 24 hours postinjury and the utility of these measures in predicting outcome for the TBI patient at 1 year postinjury.

The primary aim of the second study was to evaluate the consequences of TBI in a group of patients who has sustained a severe injury and who were consecutive admissions to a large base hospital in the mid- North Island of New Zealand. Chapter 4 describes the assessment of cognitive, emotional, behavioural, and social functioning undertaken at 6 months and 1 year postinjury. The study describes the degree and nature of the deficits observed and provides information regarding the pattern of recovery of these deficits over the first year following severe TBI. The relationship between the cognitive, emotional, and behavioural impairments of the person who had sustained a TBI and their social functioning was examined.

The third aspect of the research project was to evaluate the outcome for the primary caregiver of a TBI patient at 6 months and 1 year postinjury. Chapter 5 describes the comparative degree of distress caused to caregivers from both changes in the TBI patient and changes in their own lives. The impact of these changes on the caregiver's psychosocial functioning is also evaluated. Finally the relationship between caregiver reports of the TBI patient's physical, cognitive, emotional, behavioural, and social functioning, and the degree of caregiver objective burden, psychosocial impairment and subjective burden is examined. Chapter 6 discusses the implications of this research for neuropsychological assessment and rehabilitation for people with a severe TBI.

The overall aim of this study is to provide an understanding of the course of recovery following severe TBI, enable appropriate planning and allocation of treatment and rehabilitation resources, and facilitate the development of effective rehabilitation interventions for the patient and the family within a New Zealand context.

Chapter 2

Method

This chapter describes the methods of the current project. A detailed description of the subject groups, purpose and psychometric properties of the measures administered, and general procedures followed is provided. The rationale for the data analysis procedures employed is also described.

TBI Patients

This study involves a series of patients who were consecutive admissions to the Intensive Therapy Unit at Waikato Hospital from April 1993 to August 1996. Criteria for admission to the study were: (a) consent obtained from next of kin to participate in the study; (b) severe TBI as indicated by a Glasgow Coma Scale (Teasdale & Jennett, 1974) score of less than 9 obtained prior to intubation and within 24 hours of the injury; (c) the patient was required to be ventilated on clinical grounds for more than 24 hours, where the ventilation was, at least in part, required for the treatment of the TBI; (d) aged between 16 and 60 years; (e) English-speaking; (f) no previous psychiatric history; and (g) no prior significant TBI requiring hospitalisation.

Of the 99 patients who fulfilled these criteria, 15 (12%) were not available for follow-up at either 6 months or 1 year postinjury. The remaining 84 patients constitute the final sample for this study. Demographic information was obtained through the use of a questionnaire (Appendix A) and by checking hospital records. This demographic information is presented in Table 2.1. The TBI patients were predominantly male and over 50% of the patients were under 25 years of age with almost 70% being under the age of 30 years. The ethnic composition of the sample was: 58 (69%) New Zealand European, 21 (25%) New Zealand Maori, and the remaining 5 (6%) were from various other ethnic groups (Pacific Islander, Vietnamese, Chinese, Indian). Consistent with much of the research on TBI, road traffic crashes accidents were the primary cause of TBI, followed by falls and then assaults.

Table 2.1. Demographic Information for the Total Sample ($N = 84$)

Gender		
Female	19	(23%)
Male	65	(77%)
Age (years)		
Mean	29	
SD	12	
Range	16-59	
Ethnicity		
NZ European	58	(69%)
NZ Maori	21	(25%)
Other	5	(6%)
Cause of TBI		
Road traffic crash	66	(79%)
Fall	9	(11%)
Assault	5	(6%)
Other	4	(5%)
Type of road traffic crash*		
Driver	37	(44%)
Passenger	19	(23%)
Pedestrian	6	(7%)
Motorbike	4	(5%)

*$N = 66$

Primary Caregivers

The primary caregiver was identified by the next of kin as the person who had the most day-to-day contact with the TBI patient. Fifty-two caregivers were seen at both 6 months and 1 year postinjury. Demographic information on the primary caregiver sample is presented in Chapter 5.

Medical Assessment of the TBI Patients

All measures administered to the TBI patient can be found in Appendix B.

Glasgow Coma Scale (Teasdale & Jennett, 1974). This measure utilises three different types of responding: eye opening, verbal response, and motor response. Responses in each category are graded and assigned a numerical value. The total score can vary from 3 (no response of any kind) to 15 (no impairment). Severity of TBI is graded as severe (< 9), moderate (9 -12), or mild (13 -15). The GCS score was obtained either at the scene of the accident or on admission to hospital. In the majority of cases a score was obtained on both occasions. At the scene of the accident the GCS score was recorded by an ambulance officer and on admission to hospital this was done by a physician. The lowest GCS score obtained within 24 hours postinjury was used. The reliability and validity of the GCS are well-established (Wade, 1992).

***Somatosensory evoked potentials* (SEP).** These were obtained in response to the independent stimulation of the median nerve at the wrist. In patients who were sedated and curarized the stimulation was with subdermal electrodes. For patients not sedated or curarized an EMG stimulating pad electrode set was used. Stimulus intensity was sufficient to produce a visible thumb twitch. For patients who were paralysed stimulus intensity was at 100 volts. Frequency of stimulation was 5 pulses per second. Filter bandwidth was 20 to 2000Hz. One thousand responses were averaged per trial. A four channel system was used and the sweep time was 50 ms. The SEPs were performed by respiratory technicians who had been trained by a specialist electrophysiologist. For the majority of patients SEPs were performed while they were in the Intensive Therapy Unit. A small number of patients were tested while in the High Dependency Unit.

Cognitive Assessment of the TBI Patients

Psychometric tests were chosen bearing three major issues in mind: that the battery was brief enough that those who had sustained a severe TBI would be able to complete the items as early as 6 months postinjury; that the battery of tests was comprehensive enough to assess the relevant aspects of cognitive and psychological functioning; and that the tests used were established measures that are used in both clinical and research areas.

Premorbid intellectual functioning. The National Adult Reading Test - Revised (Nelson, 1982) was used to estimate the patient's premorbid level of intellectual functioning. Patients are required to read a list of 50 phonetically irregular words. A Wechsler Adult Intelligence Scale-Revised Full Scale IQ score is predicted from the number of errors made by the patient in reading the list of words. Normative data for the National Adult Reading Test - Revised is based on a sample of 120 patients aged 20-70 years.

For those patients who experienced language dysfunction (e.g., dysarthria), premorbid intellectual functioning was estimated using demographic information. A formula incorporating the person's age, gender, race, and educational and occupational background, as suggested by Barona, Reynolds, and Chastain (1984), was used. Recent evaluation of the Barona equations with TBI patients continues to support their use (Perez, Schlottmann, Holloway, & Ozolins (1996).

General intellectual functioning. A short form of the Wechsler Adult Intelligence Scale-Revised (WAIS-R; Brooker & Cyr, 1986) was used to assess level of general intellectual functioning. A short form of this test was chosen to allow for a brief but valid assessment of general intellectual functioning. Brooker and Cyr present three different short forms of the WAIS-R. These have been selected on the basis of a method which considers both reliability and validity. Brooker and Cyr claim that none of the Full Scale IQ equivalents derived from their short forms will be in error by more than 1 point. The short form of the WAIS-R used in this study contained the following subtests: Vocabulary, Block Design, Arithmetic, and Similarities. The sum of the age-scaled scores of these four subtests was converted to an equivalent Full Scale IQ score.

The Vocabulary subtest consists of 35 words that the patient is asked to define. The words are presented in order of difficulty until the patient fails five words consecutively. Correct responses are scored either one or two points according to the quality of the answer. Vocabulary is a measure of verbal and intellectual ability, although it is established that a person's performance is influenced by their socioeconomic and cultural background (Lezak, 1983). Reliability of the Vocabulary subtest has been demonstrated using split-half and test-retest procedures. Use of the split-half procedure resulted in a reliability coefficient of .96, and the test-retest of .93 for ages 25-34 and .91 for ages 45-54 (Wechsler, 1981).

The Block Design subtest is a construction test that requires the patient to assemble blocks according to diagrams presented. Each block has two white and two red sides and two half red half white sides. The first five presentations require four blocks and the last five presentations require nine blocks. The test is timed; the obtained score is determined by the time taken to correctly complete the task. Discontinuation of the test occurs after three consecutive failures. Reliability of the Block Design subtest has been demonstrated using split-half and test-retest procedures. Use of the split-half procedure resulted in a reliability coefficient of .87, and the test-retest of .91 for ages 25-34 and .80 for ages 45-54 (Wechsler, 1981). Block Design is a test of visual-spatial construction and organisation (Lezak, 1983).

The Arithmetic subtest consists of 14 arithmetic questions that require an oral answer and are arranged in order of difficulty. The test is timed and is discontinued after four consecutive failures. Arithmetic is a measure of concentration, immediate memory, and conceptual manipulation and tracking (Lezak, 1983). Reliability of the Arithmetic subtest has been demonstrated using split-half and test-retest procedures. Use of the split-half procedure resulted in a reliability coefficient of .84, and the test-retest of .80 for ages 25-34 and .90 for ages 45-54 (Wechsler, 1981).

In the Similarities subtest, patients are presented with paired items and asked to explain the similarity for each pair. The word pairs are arranged in order of difficulty. Correct responses are scored either two points for an answer that displays abstract generalisation, or one point for a specific concrete likeness. The test is discontinued after four consecutive failures. Reliability of the Similarities subtest has been demonstrated using split-half and test-retest procedures. Use of the split-half procedure resulted in a reliability coefficient of .84, and the test-retest of .82 for ages 25-34 and .86 for ages 45-54 (Wechsler, 1981). Similarities is a test of verbal concept formation and associative thinking (Lezak, 1983).

Attention. Simple attentional abilities were assessed by administration of the Digit Span subtest from the WAIS-R. Complex attentional abilities were assessed by administration of the Digit Symbol subtest of the WAIS-R.

The Digit Span subtest consists of two parts: Digits Forward and Digits Backward. Each test involves the presentation of random number sequences read aloud at a rate of one number per second. For Digits Forward, two trials of number sequences, beginning with three digits and progressing to nine digits are read to the patient. The patient is then required to repeat the number sequence. Administration is discontinued if the patient is unable to repeat the exact sequence for both trials. For Digits Backward the patient is required to repeat the sequence in reverse. The presentation begins with a span of two digits and progresses to eight digits. The test is discontinued after failure on both trials. Digits Forward is a measure of immediate memory span and attention. Digits Backward is a measure of working memory requiring storage and manipulation of information (Lezak, 1983). A total score is obtained by adding the total of number sequences correctly repeated for each test. Reliability of the Digit Span subtest has been demonstrated using test-retest procedures. This resulted in a reliability coefficient of .83 (Wechsler, 1981).

The Digit Symbol subtest is a symbol substitution task that consists of four rows of 100 divided boxes. Each box has a randomly assigned number from 1 to 9 with a blank space below. A printed key pairs each number with a simple geometric symbol. The patient is instructed to fill in the blank spaces with the symbol it is paired with in the key. There is a time limit of 90 seconds. The score is the number of squares completed correctly. Reliability of the Digit Span subtest has been demonstrated using test-retest procedures, yielding a reliability coefficient of .82 (Wechsler, 1981). The Digit Symbol subtest is a test of psychomotor performance which involves motor persistence, sustained attention, visuomotor coordination, and response speed (Lezak, 1983).

Verbal memory. The Auditory Verbal Learning Test (Rey, 1964) measures immediate memory span, new learning, and delayed memory retention. It involves the presentation of a list of 15 words (List A) read aloud for five consecutive trials. The patient is required to recall the list after each trial. The order of presentation of the words remains the same over successive trials. Following completion of the fifth trial an interference list of 15 words (List B) is presented and the patient is required to recall these. Delayed recall of List A is then tested. After 20 - 30 minutes a delayed recall trial of List A is administered. The recognition trial requires the patient to identify words from List A when given a list of 50 words containing all the words from Lists A and B, and 20 other words that are semantically and/or phonetically similar to words from Lists A and B.

Spreen and Strauss (1991) present normative data for men and women in each of seven age groups ranging from 16 to 70+ years of age. Over one-year intervals the Auditory Verbal Learning Test has modest test-retest reliability, with correlations of about .55. Research on the validity of the Auditory Verbal Learning Test demonstrates that it is sensitive to verbal memory deficits in a variety of patient groups. Factor-analytic studies have shown the Auditory Verbal Learning Test to have a single major factor of verbal learning and memory. It has also been shown to measure different functions than those assessed by tests of attention/concentration, perceptual organisation, and verbal intelligence (Spreen & Strauss, 1991).

Executive functions. Two measures of executive functions were also administered. These were the Similarities subtest from the WAIS-R described previously, and the Controlled Oral Word Association test.

The Controlled Oral Word Association test is a test of verbal fluency that consists of three word naming trials (Lezak, 1983; Spreen & Strauss, 1991). The person is required to orally produce as many words as possible beginning with a given letter of the alphabet excluding, proper nouns, numbers, and the same word with a different suffix. The letters F, A, and S were used and patients were given 60 seconds to complete each trial. The score is the total number of words produced over the three trials.

Normative data for the Controlled Oral Word Association test is available for males and females for the age range 15-40 years. Normative data for older age groups (i.e., 50+ years) is based on years of education, not gender. Given the absence of normative data for the 41-49 age group, in the current study the performance of those patients aged 41-44 years was interpreted with respect to the normative data for the 31-40 age group, and those aged 45-49 was interpreted with respect to the normative data for the 50-54 age group. The Controlled Oral Word Association test has demonstrated 19-42 days test-retest reliability of .88 with adults (Spreen & Strauss, 1991) and minimal practice effect with repeated use (Brasso, Borstein, & Lang, 1999). Studies of its validity has shown performance on the Controlled Oral Word Association test to have a weak relationship with age (-.14), WAIS VIQ (.14), and depression. Factor-analytic studies suggest that performance on the Controlled Oral Word Association test loads mainly on a "verbal knowledge" factor. The Controlled Oral Word Association test has also been demonstrated to be highly sensitive to frontal lobe damage, regardless of the side of lesion (Spreen & Strauss).

Visual-perceptual functions. Perception is a multi-faceted construct that includes visual, auditory, and tactile abilities. Visual-perceptual functioning involves visual-motor, visual-spatial, and visual-organisation skills. The Block Design subtest from the WAIS-R is a measure of visual-spatial, visual-motor, and visual-organisation skills. The TBI patients performance on the Block Design was used to assess visual-perceptual functions.

Psychosocial Assessment of the TBI Patients

Depression. The short form of the Beck Depression Inventory is a 13 item self-report measure of depression (Beck & Beck, 1972). Each item consists of a series of ordered statements relating to a particular symptom of depression. Responses are scaled from 0 (absence of the symptom) to 3 (most severe). The patient is asked to indicate which statement best described how they have felt over the past two weeks. The score is the sum of all statements chosen by the patient. The higher the score the more severe the depression. Knight (1984) has provided gender-specific, age-based, New Zealand normative data for the short form of the Beck Depression Inventory based on a sample of 1,091 people aged 16 - 89 years. Knight also provided evidence for the reliability of the short form reporting a coefficient alpha of .81, and Beck and

Beck provide evidence of its validity citing a correlation of .61 with clinicians' ratings of depression. The short form of this test was chosen to allow for a brief but valid assessment of depression.

Behavioural problems. The Head Injury Behaviour Rating Scale is a self-report questionnaire containing 20 items describing behavioural problems (e.g., anger, poor decision making, anxiety, lack of motivation) often associated with TBI (Smith & Godfrey, 1995). The person is asked to indicate whether the identified behaviour had become a problem for them since their TBI, and if so, how much distress this caused for them. The degree of distress is rated on a 4-point Likert scale from 1 (the behaviour is a problem for me but causes me no distress) to 4 (the behaviour is a problem for me and causes me severe distress). Two scores are derived from this questionnaire: a number of problems score, which is the total number of problem behaviours identified (range 0-20); and a distress score, which is calculated by summing the Likert scale rating for each of the items (range 0-80). Godfrey, Partridge, Knight, and Bishara (1993) provide reliability data for an earlier version of this scale, reporting high internal consistency with a Cronbach's alpha of .93

Social functioning. Changes in the TBI patients' employment, living arrangements, and relationship status were obtained by interview. Changes in the TBI patients' social contact and leisure activities were assessed using five items of the Socially Expected Activities scales from the relatives form of the Katz Adjustment Scale (Katz & Lyerly, 1963).

The Socially Expected Activities scales contain items relating to the patient's involvement in socially expected activities. For the purposes of the current study, the five items covering social contact and participation in leisure activities were used. On the first scale the caregiver is required to rate the patient's current level of involvement in these activities. The second scale contains identical items, but the caregiver is required to rate their expectations of the patient's level of performance in these activities. In the current study caregivers were instructed to base their expectations on the assumption that the patient had not received a TBI.

Glasgow Outcome Scale (GOS, Jennett & Bond, 1975). This clinician-administered scale is designed to measure outcome following brain injury. It has five levels: (1) death; (2) persistent vegetative state, no evidence of meaningful response; (3) severe disability, conscious but disabled; (4) moderate disability, independent but disabled; and (5) good recovery, resumes normal vocational and social activities. Inter-rater reliability for the GOS is reported to be as high as 95% (Jennett et al., 1981).

Caregiver Measures

All measures administered to the primary caregiver can be found in Appendix C.

Depression. Caregiver depression was assessed by administration of the short form of the Beck Depression Inventory (Beck & Beck, 1972), which is described above.

Anxiety. Caregiver anxiety was assessed by administration of the Trait Anxiety Inventory, from Form Y of the State-Trait Anxiety Inventory (Spielberger, 1983). The person is required to respond to 20 items by rating how they generally feel on a 4-point Likert scale from 1 (not at all) to 4 (very much so). The range of possible scores is 20 - 80.

Spielberger reports four normative samples for the Trait Anxiety Inventory. In the current study the primary caregivers responses were interpreted using the gender specific, normal adult sample. These normative data are also broken down into three age groups (i.e., 19 - 39, 40 - 49, 50 - 69 years). The Trait Anxiety Inventory has been reported as having high internal consistency (alpha coefficient = .90), and test-retest reliability over 1 hour to 104 days ranging from .65 to .86. Factor analytic studies have also confirmed the scales homogeneity. Spielberger (1983) also reports evidence demonstrating the discriminative and construct validity of the scale.

Social adjustment. The Social Adjustment Scale Self-Report was administered to assess the caregiver's level of social functioning (Weissman & Bothwell, 1976). This questionnaire contains 54 questions covering role performance in seven areas of functioning: work, social and leisure activities, relationships with extended family, marital, parental, family unit, and finances. Alternative questions on work are provided for students, housewives, and those employed. Therefore a total of 42 questions are answered by the caregiver. Questions relate to the person's functioning over the past two weeks. Responses are scored on a 5-point or 8-point scale, with higher scores reflecting greater impairment. A mean score is obtained for each area of functioning and an overall score can be derived from these.

Reliability data available on the Social Adjustment Scale Self-Report include a mean test-retest coefficient of .80 and an alpha internal consistency coefficient of .74. Validity studies have shown that Social Adjustment Scale-Self-Report scores are unaffected by socio-demographic status, are sensitive to improvement following treatment, and can discriminate between different diagnostic groups moderately well. The caregivers responses to the Social Adjustment Scale-Self-Report were interpreted with reference to the gender-specific norms of 482 community respondents provided by Weissman, Prusoff, Thompson, Harding, and Myers (1978).

Head Injury Behaviour Rating Scale (Smith & Godfrey, 1995). The relatives' version of this measure contains the same 20 items as those in the TBI patients version, described above. The primary difference is that the caregiver is asked to rate the presence/absence of the problem behaviours in the TBI patients, and then rate how much distress it causes for them (the caregiver). Godfrey, Partridge, et al. (1993) provide both reliability and validity data for an earlier version of this scale. They reported high internal consistency with a Cronbach's alpha of .87, and 1-year test-retest reliability of .68 for the number of problems score. Evidence for the validity of the number of problems score was provided by a correlation of .65 ($p <$ .01) with clinician ratings.

Caregiver's Questionnaire. This questionnaire was specifically developed for use in this study to allow for not only the identification of changes that had occurred in the caregiver's life and changes in the TBI patients functioning, but to also assess the degree of distress individual changes had caused them. Part A consists of 15 questions asking the caregiver to indicate whether identified lifestyle changes have occurred for them as a result of caring for the person who had sustained a TBI. If a change has occurred they are asked to estimate how much distress this caused for them. The degree of distress is rated on a 5-point Likert scale from 1 (no distress) to 5 (very great distress). Question 16 asks the caregiver to estimate the overall degree of distress that they experience as a result of the changes. The degree of distress is rated on a 7-point Likert scale from 1 (no distress) to 7 (very great distress). Part B contains four questions relating to the TBI patient's physical abilities, cognitive abilities, emotional functioning, and social contact. Each question asks the caregiver to indicate whether there has been a change in the TBI patient's level of functioning in each area since the injury. If a change has occurred they are asked to rate how much distress this change has caused them (the caregiver). The degree of distress is rated on a 5-point Likert scale from 1 (no distress) to 5 (very great distress). A fifth question asks the caregiver to estimate the overall degree of distress that they have experienced as a result of the changes that have occurred in the patient. The degree of distress is rated on a 7-point Likert scale from 1 (no distress) to 7 (very great distress).

Procedure

Ethical approval for this study was obtained from the Waikato Hospital Ethics Committee (Appendix D). The patient's next of kin was approached by the Director of the Intensive Therapy Unit who provided them with the description and rationale of the study.

At 6 months postinjury the next of kin was contacted and an appointment time was made to assess the person who had sustained a TBI and an appointed caregiver. Patients and caregivers were seen in an inpatient or outpatient hospital setting, or in their own home. Patients and caregivers were seen independently. For patients who continued to experience fatigue a break was taken during the assessment. The order in which tests and questionnaires were presented was the same for each TBI patient and for each caregiver. For the TBI patient the order was as follows: WAIS-R short-form, Auditory Verbal Learning Test (Trials 1-7), Controlled Oral Word Association test, Head Injury Behaviour Rating Scale-Patients version, short form of the Beck Depression Inventory, and Auditory Verbal Learning Test (Trial 7 and the Recognition trial). For the caregiver the order of presentation was as follows: Caregiver Questionnaire, short form of the Beck Depression Inventory, Trait Anxiety Scale, Head Injury Behaviour Rating Scale-Relatives version, Katz Adjustment Scales-Relatives form, and the Social Adjustment Scale. The Glasgow Outcome Scale was completed by the researcher.

At 1 year postinjury the TBI patient and their caregiver were again contacted and an appointment time arranged. The procedure was repeated in the same way as undertaken at 6 months. In addition to the above tasks the National Adult Reading Test-Revised was administered to the TBI patient. This test was administered at 1 year rather than 6 months postinjury to gain a more reliable estimate of the patient's premorbid level of intellectual functioning.

Research setting. Waikato Hospital is a 700 bed regional trauma hospital that serves a population base of over 700,000 people (Waikato Hospital, personal communication, June 1999). Waikato Hospital serves a predominantly rural area in the mid North Island. Early intervention following severe TBI is crucial for the prevention or early treatment of secondary complications that can occur following injury. The rural nature of the population base has serious implications for early intervention following severe TBI. In the current research project over 60% of TBI injuries occurred more than 30 kilometres from the first admitting hospital and 35%

were greater than 60 kilometres away. Fifty-six percent of those injured took more than 60 minutes to arrive at the first hospital, which for the majority of patients was Waikato Hospital. For some patients however their first admitting hospital was a rural hospital, but their condition was serious enough to necessitate transfer to Waikato Hospital. Helicopter transport was used to transport 34% of the patients from the scene of the accident to hospital (Havill, Sleigh, Kersel, & Marsh, 1998a). Patients often joked that this was the only time they had been in a helicopter and they could not remember it.

Follow-up occurred for the majority of patients in their home. Many of the people admitted to Waikato Hospital were not domiciled in the area. Almost 40% of the group lived more than 1 hour away from Waikato Hospital and many lived more than 3 hours away. Therefore considerable distances were travelled in collecting the follow-up data and precise timetabling of the follow-up assessments was not always possible. Despite this people were assessed as closely as possible to the 6 month and 1 year dates after their injury. While assessing people in their homes presented some difficulties, for example obtaining a quiet environment for formal assessment and ensuring privacy for both the patient and the caregiver, it also afforded a number of advantages. Many patients and families had limited transport or finances to travel. Some patients and caregivers were reluctant to attend a hospital setting either because it reminded them of the more acute phase of their injury and disabilities or because they were unhappy about services that they had received. That the majority of follow-up assessments took place in the person's home increased the degree of cooperation from patients and their families, resulting in an unusually high rate of completed follow-ups.

Data Analysis

The degree of impairment on each test, for each participant, was calculated. A score that was between one and two standard deviation from the mean was classified as mildly impaired and a score that was two standard deviations or more from the mean was classified as severely impaired. The proportion of TBI patients and caregivers obtaining scores indicative of mild and severe impairment was calculated.

One of the difficulties associated with assessing people following severe brain injury is whether or not to record a score for patients on those measures that they are unable to complete. Failing to record a score results in a patient being omitted from any subsequent statistical analyses, and thereby incorrectly underestimates the prevalence of impairment present in the population. Dacey et al. (1991) responded to this problem by assigning the worst observed score to those patients who were unable to perform psychometric tests. Therefore, in the current study, patients who, because of brain injury, were unable to complete a cognitive measure had the worst observed score entered for their performance on the respective test. Six patients were unable to complete any of the tests at the 6-month follow-up. Three of these patients continued to be too disabled to complete any of the tests at the 1-year follow-up, and a further patient was unable to complete the Auditory Verbal Learning Test. A further 5 patients were unable to complete the WAIS-R Digit Symbol subtest at 6 months, and three of these were also unable to complete this test at the 1-year follow-up.

Following the data screening considerations recommended by Tabachnick and Fidell (1989), data were checked to ensure accurate input, and missing data were identified. Cases with missing data were excluded from correlational and regression analyses. Tabachnick and Fidell also recommend checking data for normality of distribution and outliers. Previous research has indicated that the concept of normal distribution in clinical populations is unrealistic and that it is acceptable to use robust parametric tests to analyse data that are not normally distributed (Tiku, Tan, & Balakrishnan, 1986). Therefore the present study used parametric testing where necessary, regardless of the normality of the data under analysis.

All data analysis was completed using SPSS 8.0 (SPSS Inc., 1998). In general, an alpha level of .05 was used for statistical tests. However, to reduce the probability of Type I errors, when multiple tests of hypotheses were being undertaken with the same sample, an alpha level of .01 was used. The exact alpha level is reported where a statistically significant result was obtained. Where a statistically significant result was not obtained, alpha is reported as either $p > .05$ or $p > .01$.

Data were described using mean, standard deviation (*SD*), and range. Data were analysed using chi-square, two-tailed *t*-tests for dependent and independent samples, one way ANOVA, two-tailed Pearson product moment correlations, and standard multiple regression.

Prior to undertaking the regression analyses the independent variables were screened for multicollinearity. When *t*-tests for independent samples were completed an *F* test of sample variance was undertaken. If this was significant, *t* based on separate variance estimates was calculated.

Chapter 3

The Prediction of Outcome Following Severe TBI

Interest in the measurement of severity of injury is related to the need to be able to predict immediate and longer term outcome for the TBI patient. Various techniques have been used to assess severity of injury. However, these techniques vary in their reliability as they are often affected by secondary variables such as intoxication. Medical management of the TBI patient in the acute stages, particularly the need for sedation, also makes it impossible to administer some of these measures. Research suggests that SEPs offer a rapid, comparatively simple and noninvasive method of reliably predicting outcome at a global level. This chapter describes the analysis of SEPs obtained within 24 hours postinjury, and the utility of these measures in predicting outcome at 1 year postinjury. Their ability to predict outcome at a global level and in terms of more specific outcomes is examined.

Clinical Measures Used to Predict Outcome

The precise assessment of the severity and extent of brain damage, and the accurate determination of prognosis following severe TBI, are essential for both the clinician and the family. Reliable prognostic indicators provide objective data. These data can be used to form the basis for the appropriate allocation of treatment and rehabilitation resources, and for designing family intervention.

Various methods have been used to assess the severity of TBI, including standardised clinical examinations (Jennett & Teasdale, 1981), computerised tomography (Teasdale, Cardoso, Galbraith, & Teasdale, 1984), measurement of intracranial pressure (Miller et al., 1981; Miller & Dearden, 1992), and electroencephalography (Hutchinson et al., 1991). These measures vary in their reliability and they can be affected by secondary variables such as intoxication and hypoxemia. In addition, the increasing use of barbiturates and neuromuscular blockers in the management of severe TBI results in the clinical examination being of limited value. In such cases a method of assessing brain function that is not influenced by these drugs is required. It has been suggested that evoked potentials may not only be reliable prognostic indicators but that they are also unaffected by medications used in the acute management of TBI (De Weerd & Groeneveld, 1985).

Evoked Potentials in the Prediction of Outcome

An evoked potential is the electrical response obtained from the nervous system in response to a stimulus. The evoked potential describes the time course of electrical activity following a stimulus such as a strobe light flash (visual evoked potential), auditory click (auditory evoked potential), or sensory stimulation (somatosensory evoked potential). When an electroencephalogram is recorded from electrodes on the scalp the large changes in voltage of the electroencephalogram obscure the smaller evoked potentials. The evoked potential, although very small, is approximately the same after each stimulus. Recording the evoked potential involves stimulating the patient many times with the same stimulus. The method of averaging combines these many small signals which can then be extracted from the larger but more random electroencephalogram record.

Accurate and clinically useful interpretation of evoked potential data relies on standardised, precise methodology, and systematic meaningful data analysis that includes comparison with normal controls. Initially, the study of electrophysiological evaluation was difficult because of a lack of methodology to categorise the complex evoked responses produced by compromised neuronal functioning, and technical problems inherent in examining severely traumatised patients (Greenberg & Ducker, 1982).

In an early and classic study, Greenberg, Mayer, et al. (1977) developed a system for analysing and grading abnormal evoked potentials. The grading system was based on the wave latency, amplitude, duration, and morphology of evoked potentials. Following the collection of these data, Greenberg, Becker, et al. (1977) went on to examine the relationship between multimodal evoked potentials and post traumatic neurological conditions, duration of coma, focal neuroanatomic lesions, and patient outcome. Of the evoked potentials recorded soon after TBI (approximately the third day), SEPs were the evoked potential modality to be most significantly associated with 3 to 30 month outcome for the TBI patient.

Attempts to clarify the use of evoked potentials in the management of severe TBI patients were also made by Rappaport, Hall, et al. (1981) and Rappaport, Hopkins, et al. (1981). The primary purpose of the Rappaport, Hall, et al. paper was to collect normative latency and amplitude data for somatosensory, auditory, and visual evoked potential patterns. All evoked potentials were graded on a 9-point rating scale, according to the presence, latency and amplitude of specific peaks, and the morphology and replicability of evoked potential responses. Rappaport, Hopkins, et al. recorded multimodal evoked potentials from 88 patients who had sustained a severe TBI and who were comatose for a minimum of 6 hours. A significant relationship was found between evoked potential abnormality scores and the patient's level of disability at 6 to 56 months follow-up. A stronger correlation was found for combined multimodal evoked potentials than for any single evoked potential modality. Correlations were strongest for those evoked potentials recorded soon after injury. The authors suggested that the evoked potential patterns should not be relied upon to predict mortality except when the responses are extremely abnormal across at least two or more modalities.

The comparative value of multimodal evoked potentials as prognostic indicators was subsequently confirmed by a number of studies (Greenberg, Newlon, Hyatt, Narayan, & Becker, 1981; Lindsay et al., 1981; Narayan et al., 1981; Newlon, Greenberg, Hyatt, Enass, & Becker, 1982). These studies established normative data for multimodal evoked potentials. The authors proposed a number of grading systems with which to evaluate evoked potentials when they are used with patients with severe TBI. When multimodal evoked potentials were graded according to these systems, they were found to be accurate and reliable predictors of outcome for patients up to 30 months postinjury. In most studies outcome was assessed by administration of the Glasgow Outcome Scale. A significant relationship was found between multimodal evoked potentials and clinical indices of severity of injury such as, the clinical neurological examination, duration of coma, computerised tomography recordings, and intracranial pressure measurements (Greenberg, Becker, et al., 1977; Narayan et al., 1981). Some studies (e.g., Greenberg, Becker, et al., 1977; Lindsay et al., 1981) compared the effectiveness of individual evoked potential modalities. Overall, SEPs were found to be the single most reliable predictor of outcome.

The Use of Somatosensory Evoked Potentials in Predicting Outcome

The neural pathways involved in the transmission of SEPs extend through a significant amount of the central nervous system and provide information about the peripheral nerves, spinal cord, brain stem, diencephalon, and cortex. Although SEPs can be recorded by stimulation of the lower limb and other nerves, they are most commonly recorded from stimulation of the median nerve at the wrist. Evoked potentials are measured as changes in amplitude over time or by the latency in relation to stimulus onset or the sequential order of the response pattern (Greenberg & Ducker, 1982).

The clinical utility of SEPs has been established in a variety of disorders such as multiple sclerosis, central pontine myelinolysis, intracranial tumours, and spinal cord and brachial plexus diseases (Greenberg & Ducker, 1982). The usefulness of SEP recordings alone to predict outcome following severe TBI has been examined by a number of investigators (Ahmed, 1988; De La Torre, Trimble, Beard, Hanlon, & Surgeon, 1978; Hume, Cant, & Shaw, 1979). In an early study that evaluated SEPs according to the frequency of the waveforms, bilateral symmetry of peaks, and the amplitudes, De La Torre et al. recorded SEPs from 17 patients comatose due to a TBI. Recordings of SEPs were made between 3 days and 4 weeks following diagnosis of coma. Responses from the bilateral stimulation of the median and peroneal nerves were obtained. Outcome was assessed using the GOS. Despite the widely accepted understanding of the GOS as a global measure of outcome, the scale was further modified to provide only two categories of outcome; a "positive" outcome (good recovery to severe disability) and a "negative" outcome (death or persistent vegetative state). The authors reported that the prognostic outcome of all patients was accurately predicted following analysis of the SEPs. It was suggested that median nerve stimulation provided a more reliable measure than peroneal stimulation as the former provided SEPs that were freer of physiological "noise" artifacts.

Ahmed (1988) investigated the predictive value of SEPs in patients who were comatose due to TBI, cardiopulmonary arrest, or cerebrovascular disease. Depending on the latency and amplitude of the response, SEPs were graded as follows: Grade I, normal amplitude and latencies; Grade II, 50% drop in amplitude or prolongation of latencies beyond 3 *SD* of that obtained by their normal control group; Grade III, 75% drop in amplitude or prolongation of latencies beyond 3 *SD*; and Grade IV, no response. Recordings of SEPs were taken on admission and then repeated periodically. Outcome was assessed at 6 months postinjury using a modified 4-point GOS. A significant correlation was found between the SEPs and the GOS. The 7 patients with Grade I SEPs made a good recovery and all 8 patients who obtained a Grade II SEP made a moderate recovery. Those with Grade III responses remained severely disabled and the 3 patients with a Grade IV response died.

The Use of Somatosensory Evoked Potentials in Predicting Outcome: The Development of a Standard Method

The previously cited studies evaluated SEP recordings according to waveforms, wave latency, and amplitude. In a major series of studies conducted during the early 1980s Cant, Hume, and colleagues (Cant, Hume, Judson, & Shaw, 1986; Hume & Cant, 1978; Hume & Cant, 1981; Hume et al., 1979; Judson et al.,

1990) defined an alternate methodology for measuring and interpreting SEPs in people with severe TBI.

Hume and Cant (1978) suggested that the measurement of central brain conduction time in the somatosensory system would provide a more accurate interpretation of SEP data. They noted that the SEP component recorded from electrodes on the scalp may be affected by traumatic lesions not only to the brain stem, thalamus, or cortex, but also of the peripheral nerves and spinal chord. Simultaneous recordings of SEPs from electrodes on the scalp and the upper cervical spine provides a measure of conduction time in the central pathway only, which is independent of conduction time in the peripheral nerves and spinal chord. They suggested that conduction time within the somatosensory pathways of the brainstem and the cerebrum (central conduction time) therefore, should be used in the analysis of evoked potential data.

Using this new system of measurement, Hume et al. (1979) collected data from 21 normal volunteers, 13 comatose TBI patients, and 11 patients comatose due to nontraumatic cause (e.g., hypoxia, encephalitis). Serial recordings of SEPs were made at 3 to 5 day intervals until responsiveness was regained and then for longer intervals up to 12 months. The GOS was administered between 3 and 12 months to determine outcome. The GOS was modified with good recovery classified as a "good" outcome, and moderate disability, severe disability, persistent vegetative state, and death classified as "not good" outcome. For the 21 normal patients central conduction time was 5.6 +/- 0.5 msec. No central conduction time in a normal patient was more than 2 standard deviations from the mean. However, because of the small sample size, only values 3 standard deviations or more from the mean, or the absence of an evoked potential were defined as abnormal.

Patient outcomes were compared with the last SEP recording within 10 days and the last recording within 35 days of coma onset. Of the 10 patients who had a normal SEP within 10 days, 8 made a good recovery. Of those who obtained an abnormal SEP only 2 achieved a good recovery. When the last SEP within 35 days was compared to outcome, 11 of the 13 patients with normal SEP made a good recovery. The outcome for all 11 patients with an abnormal SEP was poor. When this group was separated into trauma and nontrauma patients the relationship between SEP and outcome remained significant for both groups.

In a larger study, Hume and Cant (1981) replicated their previous study design (Hume et al. 1979). In addition, they determined how soon after injury the SEPs could provide reliable prognostic information regarding outcome, and defined more precisely the nature and time course of changes that may occur in SEPs. Data were obtained from 55 normal volunteers and 94 patients who had sustained a severe TBI. SEPs were recorded as soon as possible after admission (5 hours to 33 days), and then every 3 to 5 days during hospitalisation and at longer intervals for up to 500 days. The amplitude ratio was calculated and SEP responses were classified as normal, abnormal, or absent rather than normal or abnormal as in their previous study. The GOS was used to assess outcome between 6 and 36 months using classifications of "good" outcome and "not good" outcome, although the definitions of these classifications were not reported. During each successive period after injury SEPs correlated with outcome in 75% to 84% of the patients. Within approximately 3 days the outcome was predicted in 78% of patients. The last recording during this period was normal in 70% of patients who made a good recovery and abnormal in 80% of patients who died or who were severely disabled. The bilateral absence of evoked potentials during any period was associated with death. Cant et al. (1986) compared the relative usefulness of SEPs and auditory brain-stem evoked potentials to predict the outcome in 40 patients with severe TBI. Recordings of SEPs were undertaken within the first four days post injury. The SEPs were considered to be abnormal if the evoked potential was absent or if the central conduction time was prolonged. SEPs taken over the 4 days were jointly graded as: Grade 1, normal bilaterally at least once and the evoked potential never absent over either hemisphere; Grade 2, central conduction time always prolonged on one or both hemispheres but the evoked potential never absent; and Grade 3, the evoked potential absent over one or both hemispheres at any time. The GCS was administered at 6 hours following admission or before the patient was sedated and curarised. The GOS was used to assess outcome, at least 1 year postinjury. While for most patients the SEPs varied over the 4 days that they were recorded, when these recordings were jointly graded a clear correlation was found between SEP grading and GOS scores. The results of auditory brain-stem evoked potentials obtained from the first recording showed no correlation with outcome. All Grade 1 SEPs were associated with a favourable outcome, and in all but one case, Grade 3 SEPs were associated with an unfavourable outcome. Of the 5 patients with a Grade 2 SEP, 2 had a favourable outcome and 3 had an unfavourable outcome.

The authors suggested that the first SEP recording gave a reliable indication of outcome. Ninety-four percent of those in whom the first recording was Grade 1 had a favourable outcome. Seventy-four percent of patients who had an abnormal SEP (Grade 2 or 3) had an unfavourable outcome. For 22 patients the first recording was carried out on the first day. For this group 91% patients with normal SEPs had a favourable outcome and 82% of patients with an abnormal SEP had an unfavourable outcome.

Cant, Hume, and colleagues made a significant contribution to the area by defining a reliable methodology for measuring and interpreting SEPs in people with severe TBI. This methodology provided reliable prognostic information regarding outcome for the TBI patient. However, in the majority of cases, outcome continued to be defined using a global measure of outcome such as the GOS. In many studies the GOS was further modified to provide an even more simplified scale. Outcome therefore continued to be defined in very global terms.

The Use of Somatosensory Evoked Potentials in Predicting Outcome: Results from Studies Using Central Conduction Time

Following the work of Cant, Hume, and colleagues research design incorporated the use of central conduction time to analyse evoked potential data. Rumpl, Prugger, Gerstenbrand, Hackl, and Pallua (1983) recorded the SEPs for a total of 63 patients with severe TBI. Thirty-four patients were studied within the first 2 days of injury, 23 patients were studied between 3 and 12 days postinjury and 6 patients were studied in brain death. Central conduction time and amplitude ratios were calculated. Outcome for the TBI patient was determined by the use of a modified version of the GOS. All patients who made a good recovery had a central conduction time and amplitude ratios similar to those recorded for normal patients. The most prolonged central conduction times were seen in 7 patients who all died within 14 days of their injury. Asymmetrical SEPs were noted in 11 patients. Of these, 4 made a good recovery, 2 made a moderate recovery, 3 remained severely disabled, and 2 died. In 2 patients unilateral absence of SEP was noted. Both of these patients remained moderately disabled. Three of the 4 patients with a bilateral absence of SEPs died. The fourth patient continued to be in a persistent vegetative state at 8-month follow-up. Overall, these results confirmed an association between prolonged central conduction time and low amplitude ratio in all outcome categories.

Anderson, Bundlie, and Rockswold (1984) obtained evoked potentials in one or more modalities from 39 severe TBI patients aged between 3 and 83 years. Brain-stem auditory evoked potentials were recorded for all 39 patients, SEPs were recorded for 23 patients, and visual evoked potentials for 12 patients. Evoked potentials were obtained on average 8.1 days (brain-stem auditory evoked potentials), 5.5 days (SEPs) and 11.8 days (visual evoked potentials). SEPs were graded according to the central conduction time: Grade 1, normal; Grade 2, presence of all waveforms, although a prolonged conduction time; Grade 3, unilateral absence of activity; and Grade 4, bilateral absence of activity. Information was also gathered on clinical predictors of outcome such as intracranial pressure, pupillary reflexes, and motor response. The GOS was used to assess outcome approximately 5 months postinjury. A significant correlation was found between all measures of severity and outcome. The strongest correlation was between SEPs and outcome. While all modalities of evoked potentials were reliable predictors of an unfavourable outcome, only SEPs predicted favourable outcome reliably. Of those who had Grade 1 or 2 SEPs, 9 made a good recovery and 2 obtained a poor recovery. Those who obtained Grade 3 or 4 SEPs all made a poor recovery. The authors noted that there were no examples of falsely pessimistic prognoses, an important issue in regard to a prognostic indicator in this group of patients.

Further follow-up at approximately 15 months was obtained for the 12 surviving patients who had obtained an unfavourable outcome at approximately 5 months postinjury. Three of these patients had died and 7 remained severely disabled or in a persistent vegetative state. One patient progressed from severely disabled to a good outcome and the other progressed from severely disabled to moderately disabled. Therefore outcome at 15 months resulted in two cases of false pessimism.

Houlden, Chen, Schwartz, and Katic (1990) evaluated the comparative value of SEPs obtained within one week postinjury and the GCS recorded on admission in predicting outcome 6 months following a severe TBI. SEPs and the GCS score were recorded for 51 patients. While Houlden et al. measured the SEPs using central conduction time as suggested by Hume and Cant (1978) the grading system they employed was different. The grading system employed by Houlden et al. was: Grade 1, bilaterally absent waves; Grade 2, unilaterally absent and one hemisphere delayed; Grade 3, unilaterally absent and one hemisphere normal; Grade 4, bilaterally delayed; Grade 5, one hemisphere delayed and one hemisphere normal; and Grade 6, normal. The GCS had to be modified as all patients were intubated when the scale was administered. Therefore the verbal component of the scale was eliminated and a maximum score of only 10 was possible. Outcome was determined by administration of the GOS and the Barthel Index at 6 months postinjury. The categories of each scale were collapsed to give only two outcome categories each. The GCS scores and SEPs were significantly related to outcome both the GOS and the Barthel Index scores. However, the relationship between SEPs and measures of outcome was found to be stronger. Combining the SEP grade and GCS score did not improve the predictive power of the model. All 13 patients with a Grade 1 SEP died or remained in a vegetative state and all 7 patients with a Grade 6 evoked potential had a moderate disability or good recovery. No patients with a Grade 2 evoked potential recovered beyond a severe disability and only patients with Grade 4 to Grade 6 made a good recovery or were left with a moderate disability. A stronger relationship was observed between the SEP grade and outcome measures for the extremes of the scale. The relationship with outcome for intermediate SEP grades was less obvious.

Analysis of SEP grades using an ANOVA suggested that Grades 1 and 2 were significantly different to Grades 4, 5, and 6 when compared with the measures of outcome. Therefore Grades 1, 2, and 3 were grouped together to indicate a "bad" SEP and Grades 4, 5, and 6 were grouped together to define a "good" SEP. The sensitivity and specificity of the good SEPs and the bad SEPs to predict a good GOS score and a good Barthel Index score was calculated. The proportion of patients with good SEPs and good outcome was 1.0 and 0.92 respectively (specificity). Positive predictive values of 1.0 and 0.91 respectively were obtained. The proportion of patients who obtained a bad SEP with a bad GOS score and a bad Barthel Index score was 0.74 and 0.86 respectively (sensitivity). Negative predictive values of 0.71 and 0.86 suggested that patients with good SEPs usually had good outcomes, but might also have a bad outcome.

In contrast to the above studies, Lindsay et al. (1990) argued that the addition of evoked potential data to the clinical examination did not improve the prediction of outcome. Brain-stem auditory evoked potentials and SEPs were recorded in a sample of 101 patients with severe TBI. SEPs were recorded between 1 and 13 days postinjury (median 2.5 days). The shorter latency obtained in either hemisphere was recorded as the best conduction time [CCT(B)] and the longer latency, or absent N20, was recorded as the worst conduction time [CCT(W)]. The three categories used to grade SEPs were: normal, abnormal (greater than 2 *SD* above the mean latencies for the control group), and absent. The difference in latency between the two hemispheres was also recorded [CCT(diff)]. The GCS and information regarding other clinical data such as, pupil response and eye movement was collected. At 6 months the GOS was used to assess patient outcome.

Ninety-eight patients were available for follow-up at 6 months postinjury. Of these 31% had made a good recovery or were moderately disabled, 23% were severely disabled, 3% were in a persistent vegetative state, and 43% had died. The SEP and brain-stem auditory evoked potentials correlated significantly with outcome although the correlation between SEPs and GOS scores was stronger. The correlation between outcome and the CCT(B) was marginally stronger than with the CCT(W). Of the 24 patients with an absent CCT(B), 22 died, 1 remained in a persistent vegetative state and 1 made a good recovery. The authors concluded that SEPs provide a reliable prognostic guide to outcome following severe TBI. However, they suggested that given the strong correlation between SEPs and clinical data, SEPs are only useful when the patient is sedated and paralysed. When a neurological examination is available the costs and effort required to record SEPs is not justified.

Further New Zealand research by Judson et al. (1990) was undertaken using 100 severe TBI patients. The primary focus of the study was to determine whether or not the predictive value of SEPs varied according to the time when they were recorded. Unless the patient died, SEPs were obtained on at least three of the first four days. Each SEP was grouped into one of 3 categories: Category 1, normal and symmetrical central conduction time; Category 2, an increase in central conduction time on one or both sides or asymmetrical; and Category 3, absence of the cortical potential on one or both sides. Mean normal central conduction time was defined as 5.6 msec. Therefore central conduction times greater than 7.0 msec for patients less than 50 years old and greater than 7.3 msec for patients 51 years of age and older were considered abnormal. Asymmetry of central conduction time between the two hemispheres was defined as a difference of more than 0.8 msec. SEPs taken over the 4 days were jointly graded according to the criteria used in the Hume and Cant (1981) study. Outcome was assessed at 6 months using the GOS that was also modified according to the Hume and Cant study. At 6 months, 36 patients had died. Of the remaining 64 patients, 33 had made a good recovery, 22 were moderately disabled, 7 were severely disabled and 2 were in a persistent vegetative state.

Results indicated a significant association between the first SEP category recorded and the outcome for each patient. A Category 1 SEP was related to a favourable outcome in 87% of patients, and a Category 2 SEP in 73%. A Category 3

SEP was related to unfavourable outcome in 92% of patients. Positive predictive values, sensitivity and specificity were calculated. A Category 1 SEP predicted a favourable outcome with a positive predictive value of 87%, a sensitivity of 60% and specificity of 89%. When Category 1 and Category 2 SEPs were combined they predicted a favourable outcome with a positive predictive value of 81%, a sensitivity of 95% and a specificity of 73%. A Category 3 SEP predicted an unfavourable outcome with a positive predictive value of 92%, a sensitivity of 73% and a specificity of 95%.

Further analysis of the data suggested that bilateral absence of SEP, or unilateral absence of SEP combined with a prolonged central conduction time, resulted in an unfavourable outcome in 100% of cases. Of the 3 patients who displayed a bilateral absence of response and survived, 2 were in a persistent vegetative state and 1 was severely disabled. The authors suggested that the cumulative analysis of multiple SEP recordings provided no clinically useful improvement in prediction. Similarly, the time of recording had no impact on the accuracy of prediction.

A comparison was made between the predictive power of the SEPs and that of the GCS scores. Results indicated greater positive predictive values, sensitivity and specificity of SEPs over GCS scores in predicting outcome at 6 months postinjury.

Summary

Severe TBI causes diffuse brain damage and dysfunction as a direct result of the energy dissipated in brain tissue, and secondly, because of lesions such as haematomas, elevated intracranial pressure, brain herniation, and ischemic insults.

Inability to communicate with comatose or sedated patients limits the amount of useful information that can be obtained from the clinical examination. During the early 1970s, in response to these problems, various investigators started to examine the usefulness of evoked potentials as a means of evaluating the location and extent of areas of brain dysfunction following TBI (Greenberg & Ducker, 1982).

Early studies focused on the use of multimodal evoked potentials to predict outcome following severe TBI, and the development of various grading systems (Greenberg, Mayer, et al., 1977; Lindsay et al., 1981; Rappaport, Hall, et al., 1981). These studies also demonstrated that of the three forms of evoked potentials, SEPs were the single most reliable predictor of outcome. The superior clinical utility of SEPs is considered to be due to their resistance to alteration by anything (e.g., barbiturates, general anaesthesia) other than structural pathology in the somatosensory pathways.

While other investigations (De La Torre et al., 1978) continued to confirm the utility of SEPs in predicting outcome following TBI, it was not until the seminal work of Hume and Cant (1981) that a standardised method for recording SEPs was established. The vast majority of subsequent researchers adopted the use of central conduction time as the primary method of measuring SEPs and confirmed the utility of SEPs in predicting outcome, and the clinical superiority of SEPs over other forms of evoked potentials (Anderson et al., 1984; Cant et al., 1986; Houlden et al., 1990; Rumpl et al., 1983).

An exception to these positive findings was that reported by Lindsay et al. (1990). These researchers concluded that SEP data was only useful in cases where a neurological examination cannot be undertaken because the patient is sedated and paralysed. With the exception of this situation, they recommended that the costs and effort required to record SEPs did not justify their use. Unfortunately Lindsay et al. used a grading system based on the separate SEP recording for each hemisphere of the brain. While all other researchers have also recorded SEPs separately for each hemisphere, they have used the information from both hemispheres when grading the SEP status of each patient.

The less positive results reported by Lindsay et al. (1990) may have been a consequence of their use of an atypical grading system for SEPs. These conflicting results also demonstrated the need to establish a uniform grading system for SEPs. In their second major contribution to methodological rigour in this area, the research group at Auckland Hospital proposed a uniform grading system which could be used to classify SEPs based on central conduction time (Judson et al., 1990). The results of the Judson et al. study not only supported the utility of their grading system, but also demonstrated that initial SEPs were as effective at predicting outcome as those taken up to 4 days postinjury.

Overall, the results from research conducted to date have demonstrated that evoked potentials are at least as effective as other clinical procedures in predicting outcome following severe TBI. In addition, evoked potentials can be obtained when the condition of the patient precludes the use of other assessment procedures. Of the three main forms of evoked potentials, SEPs are the best predictors of outcome. The results from the Judson et al. (1990) study not only demonstrate the use of a standardised procedure for measuring and grading SEPs, but also show that initial

SEPs are as clinically useful as SEPs obtained at later stages postinjury. A limitation of the Judson et al. study is that, like all previous studies, the research was not conducted in a 'blind' fashion. That is, those clinicians who recorded and graded the SEPs were also the same people who provided the ongoing clinical treatment and assessed the eventual outcome for the patients. Given the serious nature of the triage decisions that may be made on the basis of SEPs, it is only appropriate that the highest standard of scientific rigour is applied in determining their clinical utility.

In addition, no studies were found which examined the usefulness of SEPs in predicting outcome at anything other than a global level. The most commonly employed measure of outcome was the GOS. While the GOS provides a standardised scale that has specific inclusion criteria for each category, it lacks a more precise description of the physical, cognitive, and psychosocial consequences of the person's functioning. In many studies the GOS was further simplified to provide only two outcome categories, and the manner in which the scale was simplified varied between studies. The usefulness of SEPs would be enhanced if they were also found to be related to more specific aspects of outcome. Such findings could enable more precise planning to be made by rehabilitation services and families.

The purpose of the current study was to replicate the Judson et al. (1990) study in a fully blinded fashion. That is, the clinicians providing care to the patients would be unaware of their SEP status, the neurophysiologist grading the SEPs would be unaware of their clinical status, and the psychologists assessing patient outcome would also be unaware of the patient's clinical or SEP status. In addition, the usefulness of SEPs in predicting more specific outcome related to the cognitive and behavioural consequences of severe TBI was examined.

Method

Participants

Of the 84 people who sustained a severe TBI, that were described in Chapter 2, 76 constituted the sample used to predict outcome at 1 year postinjury. The eight TBI patients that were excluded from this part of the study were excluded because no SEP data were available, the initial SEP was not recorded within 48 hours of injury, or the SEP recording was judged not to be reliable by the neurophysiologist.

The average age of this sample was 29 years (*SD* = 11, range = 16 - 57 years). The sample consisted of 17 (22%) females and 59 (78%) males. Outcome for the sample was assessed on average, at 388 days (*SD* = 34, range = 345 - 497 days) postinjury.

Measures

Two measures of severity of injury were included in this analysis. These were the initial SEP recordings taken within 48 hours of injury and the GCS score assessed within 24 hours of the injury. Outcome was assessed by means of the GOS at approximately 1 year postinjury. Consistent with the Judson et al. (1990) study, the GOS categories dead, persistent vegetative state and severe disability were combined to indicate an "unfavourable" outcome and moderate disability and good recovery were combined to reflect a "favourable" outcome. Further details on these measures are presented in Chapter 2. As described in Chapter 2 the SEPs were obtained in response to the independent stimulation of the median nerve at the wrist. In patients who were sedated and curarized the stimulation was with subdermal electrodes. For patients not sedated or curarized an EMG stimulating pad electrode set was used. Stimulus intensity was sufficient to produce a visible thumb twitch. For patients who were paralysed stimulus intensity was at 100 volts. Frequency of stimulation was 5 pulses per second. Filter bandwidth was 20 to 2000Hz. One thousand responses were averaged per trial. A four channel system was used and the sweep time was 50 ms. The SEPs were performed by respiratory technicians who had been trained by a specialist electrophysiologist. For the majority of patients SEPs were performed while they were in the Intensive Therapy Unit. A small number of patients were tested while in the High Dependency Unit.

Data Analysis

Following Judson et al. (1990) the patient's GCS scores were categorised as follows: Category 1 was a GCS of 3 or 4, Category 2 a GCS of 5 or 6, and Category 3 a GCS of 7 or 8. For the SEPs a delayed central conduction time was calculated as 3 *SD* above the normal mean of 5.6 msec recorded by Judson et al. (1990). This resulted in 7.0 msec for patients less than 50 years old and 7.3 msec for those 50 years and older being defined as an abnormal SEP.

The initial SEP recordings were grouped into three categories by a Clinical Neurophysiologist who was blind to the clinical condition and outcome for each patient. The categories used were: Category 1, normal and symmetrical central conduction time; Category 2, an increase in central conduction time on one or both sides or asymmetrical central conduction time; and Category 3, absence of the cortical potential on one or both sides.

The sensitivity, specificity, and predictive values of the SEP grades were calculated. The Chi Square test was used to assess the relationship between severity and outcome.

Results

Severity and Outcome Measures

Inspection of the GCS scores demonstrated the extreme severity of the majority of the patient's injuries. Over 40% of the patients displayed no eye-opening, verbal or motor response to external stimuli (Figure 3.1).

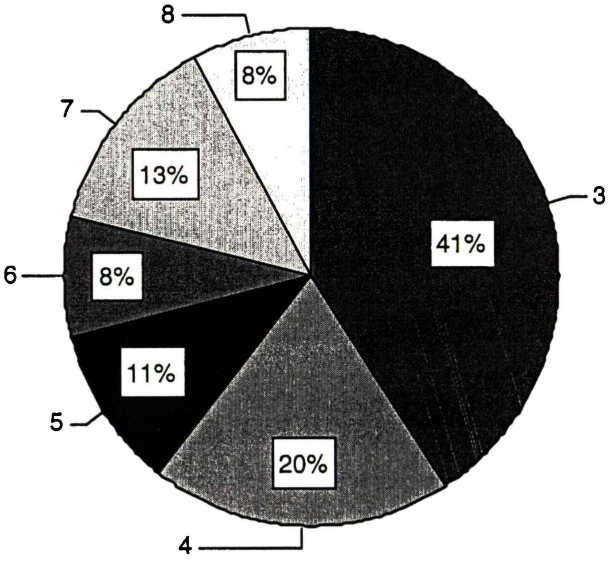

Figure 3.1. Glasgow Coma Scale scores (N = 76)

The majority (83%) of initial SEP recordings were made within the first 24 hours of injury. A Category 1 SEP was recorded for 39 (51%) patients, Category 2 SEP for 24 (32%) patients, and a Category SEP 3 for the remaining 13 (17%) patients (Figure 3.2).

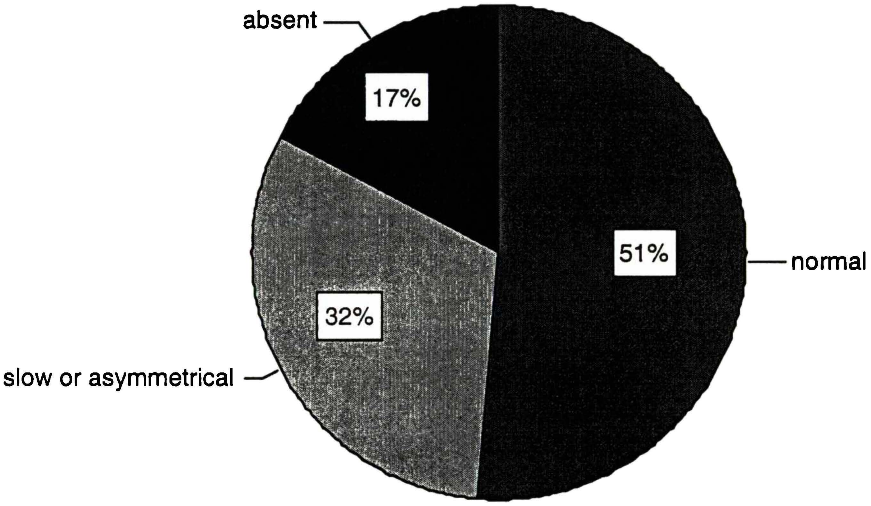

Figure 3.2. Somatosensory evoked potential categories (N = 76)

Outcome on the GOS at 1 year postinjury was: 18 (24%) deceased, 17 (22%) severe disability, 12 (16%) moderate disability, and 29 (38%) were considered to have made a good recovery following their TBI. No patients were in a persistent vegetative state. The 24% of the sample that were deceased all died from consequences of their TBI (Figure 3.3).

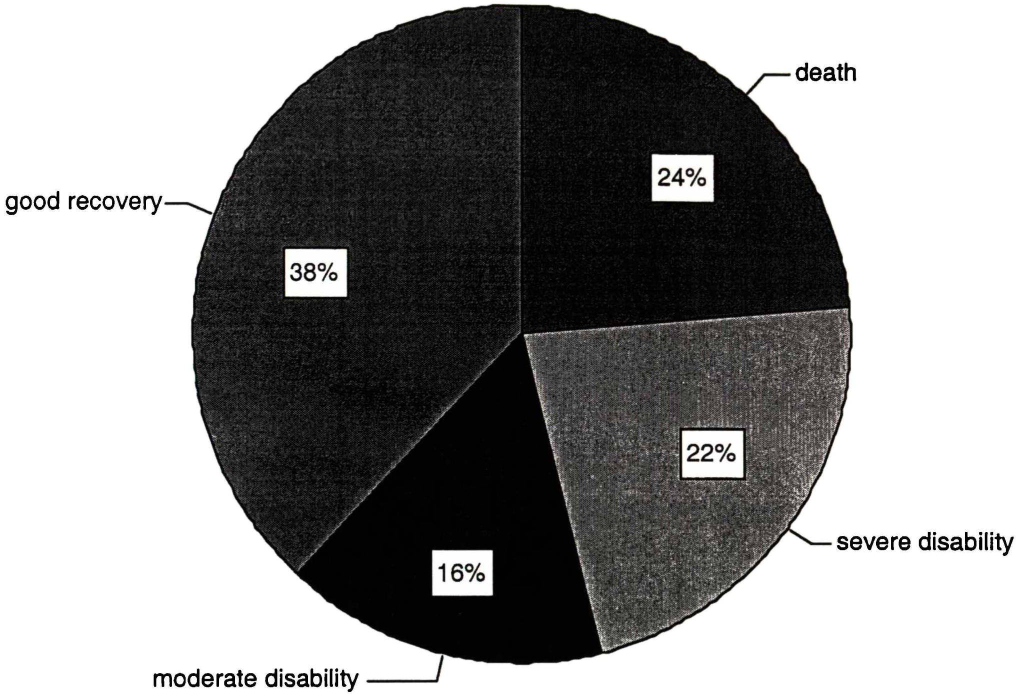

Figure 3.3. Glasgow Outcome Scale categories (N = 76)

SEP and Outcome

Initial SEP and mortality. A significant relationship, $\chi^2 = 27.84, p < .0005$, was found between the first SEP category recorded and mortality. A Category 1 SEP was associated with alive in 37 (95%) of cases and a Category 2 SEP in 18 (75%). A Category 3 SEP was associated with death in 10 (77%) of cases (Table 3.1).

When Category 1 and 2 SEPs were combined a positive predictive value of 87%, a sensitivity of 95%, and a specificity of 56% were obtained. A Category 3 SEP predicted death with a positive predictive value of 77%, a sensitivity of 56%, and a specificity of 95%.

Initial SEP and Glasgow Outcome Scale. The relationship between SEP category and unfavourable or favourable outcome on the GOS was statistically significant, $\chi^2 = 26.93$, $p < .0005$. A Category 1 SEP was associated with a favourable outcome for 31 (80%) patients, and a Category 2 SEP for 14 (58%). A Category 3 SEP was associated with unfavourable outcome for 13 (100%) patients. Category 1 and 2 SEPs combined predicted a favourable outcome with a positive predictive value of 65%, sensitivity of 100%, and specificity of 37%. A Category 3 SEP alone predicted an unfavourable outcome with a positive predictive value of 100%, sensitivity of 37%, and specificity of 100%.

When the full GOS was used there was a statistically significant relationship between the SEP category and outcome on the GOS, $\chi^2 = 38.38$, $p < .0005$. The patients who obtained a Category 3 or Category 2 SEP either died or were classified as having a severe disability. Of those who obtained a Category 1 SEP, 80% made a good recovery or had a moderate disability. Only 5% of those obtaining a Category 1 SEP died.

Absence of SEP. The bilateral absence of SEP was seen in 10 patients and unilateral absence of SEP was observed in 3 patients. Bilateral absence of SEP was associated with death in 90% of cases. For the three patients with unilateral absence of SEP the outcome was death for 1 patient, and severe disability for the remaining 2 (67%) patients.

Table 3.1. Relationship Between SEP and Outcome for 76 Severe TBI Patients

Outcome	SEP Category			χ^2
	1 (normal)	2 (slow)	3 (absent)	
Mortality				27.84*
dead	2 (5%)	6 (25%)	10 (77%)	
alive	37 (95%)	18 (75%)	3 (23%)	
Glasgow Outcome (abbreviated)				26.93*
unfavourable	8 (21%)	14 (58%)	13 (100%)	
favourable	31 (80%)	10 (42%)	0	
Glasgow Outcome Scale				38.38*
death	2 (5%)	6 (25%)	10 (77%)	
severe disability	6 (15%)	8 (33%)	3 (23%)	
moderate disability	7 (18%)	5 (21%)		
good recovery	24 (62%)	5 (21%)		

*$p < .05$

Initial SEP and Cognitive Outcome

Further analysis was undertaken to determine the extent to which SEP recordings predicted outcome at 1 year postinjury. Of the 65 patients who completed the 1 year outcome assessment, 7 did not have SEP recordings. Of the remaining 58 patients, 37 had an SEP category of 1, 18 of 2, and the remaining 3 had an SEP category of 3. Given the small number, these final 3 patients were excluded from further analysis. Therefore the analysis compared the predictive ability of 'normal' versus 'slow' SEP.

Five predictor variables of days since injury, age, gender, Glasgow Coma Scale score, and SEP were entered in the multiple regression analysis. Ten multiple regression analyses were completed. These were for the variables of WAIS-R Full Scale IQ, Auditory Verbal Learning Test - Sum, Auditory Verbal Learning Test - Trial 7, Controlled Oral Word Association test, Similarities, Block Design, Digit Span and Digit Symbol subtests of the WAIS-R, and number of problems reported on the Head Injury Behaviour Rating Scale by both the patient and their caregiver.

Nine of these regressions failed to reach significance. The regression for block design was significant $F(5,54) = 2.50$, $p = .043$. Together the five independent variables predicted 20% (12% adjusted) of the variance in raw block design scores. The only individual variable to attain significance was SEP ($p = .007$). Therefore, SEP made a significant unique contribution in predicting scores on the block design subtest at 1 year postinjury.

GCS and Outcome

GCS and mortality. There was a statistically significant relationship between GCS category and mortality, $\chi^2 = 7.95$, $p = .019$ (Table 3.3). A GCS of 3 to 4 predicted death with a positive predictive value of 35%, a sensitivity of 89%, and a specificity of 48%. A GCS of 5 to 8 predicted that the person would live with a positive predictive value of 93%, a sensitivity of 48%, and a specificity of 89%.

GCS and Glasgow Outcome Scale. The relationship between GCS category and unfavourable or favourable outcome on the GOS failed to reach significance, $\chi^2 = 2.16$, $p > .05$. As can be seen from Table 3.2, 24 (52%) of those who obtained a GCS of 3 to 4 had an unfavourable outcome and 22 (48%) had a favourable outcome. A GCS of 3 to 4 predicted an unfavourable outcome with a positive predictive value of 52%, a sensitivity of 69%, and a specificity of 46%. Similarly, a GCS of 5 to 8 predicted a favourable outcome with a positive predictive value of 63%, a sensitivity of 46%, and a specificity of 69%.

Use of the full GOS indicated that there was a statistically significant relationship between the GCS category and outcome on the GOS, $\chi^2 = 12.84$, $p = .046$. Despite this, Table 3.2 indicates that while 16 (35%) of those who obtained a GCS of 3 to 4 died, 13 (28%) of those in the same group achieved a good recovery. Ten (63%) patients who had a GCS of 5 to 8 made a good recovery, 1 (6%) was classified with moderate disability, while 4 (25%) continued to experience severe disability.

Table 3.2. Relationship Between GCS and Outcome for 76 Patients

Outcome	GCS Category			χ^2
	1 (low)	2 (medium)	3 (high)	
Mortality				7.95*
dead	16 (35%)	1 (7%)	1 (6%)	
alive	30 (65%)	13 (93%)	15 (94%)	
Glasgow Outcome (abbreviated)				2.16
unfavourable	24 (52%)	6 (43%)	5 (31%)	
favourable	22 (48%)	8 (57%)	11 (69%)	
Glasgow Outcome Scale				12.84*
death	16 (35%)	1 (7%)	1 (6%)	
severe disability	8 (17%)	5 (36%)	4 (25%)	
moderate disability	9 (20%)	2 (14%)	1 (6%)	
good recovery	13 (28%)	6 (43%)	10 (63%)	

* $p < .05$

Discussion

The interest in determining the value of SEPs as prognostic indicators following TBI is threefold and centers around medical, economic, and social issues. Firstly, the clinical evaluation of patients is hampered by the necessary use of sedative and paralysing drugs used in the early management of severe TBI. A reliable and effective method of assessing the degree of brain damage in such patients is required so that the best medical treatment can be determined. Secondly, severe TBI is associated with intensive, prolonged, and expensive treatment not only in the intensive care setting but also in the later rehabilitation phase. Often people who have sustained a severe TBI remain severely disabled and dependent. Decisions must be made regarding the allocation of resources such as continuation of life support and other treatments. Finally, families who experience the anguish of seeing a family member suffer horrific injury and who bear the burden of caring for their severely disabled family member require information about the likely outcome as soon as possible after the injury.

The purpose of the current study was to replicate and improve on the Judson et al. (1990) study, and to extend on previous research by examining the usefulness of SEPs in predicting more specific outcome related to the cognitive and behavioural consequences of severe TBI. The Judson et al. study incorporated the most effective way of measuring SEPs with an accepted and clinically useful grading system for SEPs. However, given that the results of Judson et al. and similar studies are used to make triage decisions in the emergency and critical care environment, it is important that the highest possible standards of scientific rigour be applied when undertaking such research. Therefore the current study incorporated an improved experimental design wherein all three aspects of the research were conducted blind to the results from each other.

While some previous research has not reported the period in which follow-up has been undertaken (Ahmed, 1988; De la Torre et al., 1978), others have assessed outcome as early as 6 months (Houlden et al., 1990), and as late as 5 years (Rappaport, Hopkins, et al., 1981) postinjury. For the purposes of this study outcome data was collected at 1 year postinjury. Given the severe degree of injury sustained by the patients in the current study it was more appropriate to use the 1 year rather than the 6 month outcome data. The longer follow-up time was considered to give a more accurate indication of the level of recovery achieved by the patients. To ensure consistency, outcome data were collected as close as possible to 1 year, the range being 345 - 497 days postinjury.

The Predictive Utility of SEPs

A statistically significant relationship was obtained between the three SEP categories and all three measures of outcome (mortality, the abbreviated GOS, and the full GOS). The greatest positive predictive value was found for Category 3 SEP and an unfavourable outcome (death, persistent vegetative state, severe disability) measured by the abbreviated version of the GOS. A Category 3 SEP alone predicted an unfavourable outcome with a positive predictive value of 100%. Therefore, all patients who obtained a Category 3 SEP either died or remained severely disabled. This finding is similar to that reported by Judson et al. (1990) who obtained a positive predictive value of 92% for the same relationship. Despite the strong relationship between a Category 3 SEP and an unfavourable outcome, a Category 3 SEP was associated with death in only 77% of cases. Therefore although an absent SEP was found to reliably predict an unfavourable outcome it was less reliable in predicting death. One of the conclusions drawn by Judson et al. (1990) was that the value of SEPs as a prognostic indicator lay in the unilateral or bilateral absence of SEP rather than the specific measurement of central conduction time. When Category 3 SEPs were categorised according to unilateral or bilateral absence, the predictive value of bilateral absence in predicting death improved to 90%.

The Predictive Utility of the GCS

The GCS, developed by Teasdale and Jennett (1974), is now a well accepted measure of severity of injury following TBI. Most of the studies investigating the usefulness of SEPs in the prediction of outcome following TBI have administered the GCS on admission to hospital or within a few days of injury to assess severity of injury. Few researchers have compared the predictive value of the GCS with SEPs. Many have suggested that the use of SEPs can only be justified if it can be shown that they offer more reliable information than other measures of severity such as, the clinical examination, or the GCS (Houlden et al., 1990; Lindsay et al., 1990). Lindsay et al. argued that SEPs were no more reliable that the clinical examination and GCS in predicting outcome following severe TBI. In contrast, Judson et al. (1990) found greater positive predictive values, and sensitivity and specificity for SEPs over GCS scores in predicting outcome at 1 year postinjury. The current results support the findings of Judson et al. and confirm that SEPs predict outcome following TBI with more accuracy than the GCS.

While a statistically significant relationship was found between the three GCS categories and the four categories of the GOS, the relationship between low GCS and outcome was not as consistent as that between high GCS and outcome. A high GCS score predicted a good recovery more accurately than a low GCS predicted a poor recovery. A similar relationship was found between GCS scores and the prediction of death following TBI. Although higher GCS scores were associated with increased chance of survival, low GCS scores were not strongly associated with death. Therefore, while there was a statistically significant relationship between GCS category and mortality, and GCS category and outcome on the GOS, GCS categories were found to be most useful at predicting those who would survive rather than those who would die.

A comparison of the relative usefulness of SEPs and the GCS in predicting outcome following severe TBI was undertaken. This showed that while SEPs and GCS scores were found to be equally reliable at predicting those who achieve a favourable outcome, SEPs were considerably more reliable at predicting an unfavourable outcome.

A review of the research on the use of SEPs following severe TBI found no studies that had examined the usefulness of SEPs in predicting outcome at anything other than a global level. The usefulness of SEPs would be enhanced if they were found to be related to more specific aspects of outcome, such as the cognitive, behavioural, or social functioning of the TBI patient. This would enable more precise planning to be made by rehabilitation services and families. In the current study this possibility was explored by examining the relationship between the five predictor variables of days since injury, age, gender, Glasgow Coma Scale score, and SEP with outcome at 1 year postinjury. Outcome consisted of eight measures of cognitive, and two measures of behavioural, functioning. Of the ten regressions, only the regression for the Block Design subtest reached significance. Together the five independent variables predicted 20% (12% adjusted) of the variance in raw block design scores. In addition, the individual variable of SEP made a significant unique contribution in predicting scores on the Block Design subtest at 1 year postinjury.

These results may indicate that successful performance on visual perceptual measures requires that basic physiological systems, such as those measured by SEP, are intact. In contrast, performance on other tests of cognitive function is more dependent on other factors such as the level of integration between various physiological systems. Alternatively, this result may be an example of a Type 1 statistical error that has occurred due to the multiple comparisons that were made. Irrespective of this possible difference between the requirements for performance on the Block Design subtest and the other measures of cognitive function, the amount of variance in Block Design performance explained by the predictor variables, while statistically significant, was small.

Summary

The current study sought to replicate and expand on the Judson et al. (1990) study. A more rigorous methodology was employed, and the research was expanded to explore the usefulness of SEPs in predicting more specific outcome related to the cognitive and behavioural consequences of severe TBI. SEPs obtained within 48 hours of injury predicted with 100% accuracy those who would make a favourable (moderate disability, good recovery) or an unfavourable recovery (death, persistent vegetative state, severe disability), according to the categories of the Glasgow Outcome Scale. The bilateral absence of SEP response predicted death with 90% accuracy. The one patient with bilateral absence of SEPs who did not die remained severely disabled. No significant relationship was found between the TBI patient's SEP response and their cognitive, emotional, behavioural, or social functioning at 1 year postinjury. SEPs were found to be more reliable predictors of outcome than the GCS score obtained within the 24 hours of injury. This finding is not surprising given the susceptibility of the GCS to factors such as alcohol and other recreational drugs. The majority of those who sustain a TBI do so as a result of road traffic crashes and alcohol and drugs are commonly involved. A GCS score obtained soon after injury can be adversely depressed due not to brain injury but to the effect of drug intoxication.

The relative usefulness of SEPs as prognostic indicators will vary according to the specific purpose for which the prediction is to be made. Prediction of outcome may be required to provide families with information regarding the eventual level of recovery of the patient, or it may be used to determine and plan for the rehabilitation resources that will be required. Today there is increasing pressure on health professionals and health managers to prioritise and allocate health services and the prediction of outcome may be used as a basis for triage decisions.

If the purpose of prediction is to provide families with information regarding outcome, SEPs appear to be a useful tool. Families can be advised with reasonable certainty whether or not their family member will survive. For most families arriving at the Intensive Therapy Unit, and in the following days, their initial concern is whether or not their family member will survive. The impact on families of being given information about the likely survival of their family member, and this information later proving to be incorrect, cannot be underestimated. A number of families in the current study expressed anger that they had been told that their family would probably die, when in fact they survived. Although they were obviously pleased that their family member had survived, they described the anguish and grief that they experienced in receiving this information and how difficult it was for them to remain hopeful of a better outcome. Some families had been asked to make a decision about resuscitation of their family member should they experience a cardiac arrest. For those families who made the decision to have "not for resuscitation" entered on the patient's medical file, but whose family member then survived, they expressed not only anger but guilt. Their perception was that they had made a decision that could have resulted in their family member's death.

Beyond those first few days families want to know how long will it take for their family member to get better and what will be their ongoing disabilities. Once again, using SEPs, families can be told, broadly, the likely outcome. That is, the TBI patient will be left with severe disability or they will make a moderate to good recovery. Therefore an approximate estimate of the TBI patient's eventual level of dependency and supervision needs can be made. Beyond this however, little can be said about the TBI patient's specific disabilities and therefore their specific needs. It will not be possible to describe the nature or extent of cognitive impairment, the presence of emotional or behavioural disturbance, or the TBI patient's ability to eventually reintegrate back into the community.

Similarly, in relation to rehabilitation resources, a broad estimate of the TBI patient's needs can be made from their SEP recordings. The length of inpatient rehabilitation could be estimated and the likely need for residential or long-term placement could be calculated. However, the more specific rehabilitation needs of the TBI patient are unlikely to be determined from their SEP recordings.

If decisions regarding triage are to be based on SEP recordings then the acceptable degree of accuracy and definition of outcome must be determined. The Judson et al. (1990) study suggests that the prediction of an unfavourable outcome may justify the withdrawal of therapy, "SEP offer a means of distinguishing between patients who are almost certain to do so badly that intensive therapy may not be justified and those patients with a high incidence of favorable outcome for whom resource allocation is warranted" (p. 367). The category of unfavourable outcome however includes those predicted not only to die or remain in a persistent vegetative state, but also those who will remain severely disabled. Whether severe disability is an acceptable outcome remains open to debate. Similarly, whether or not the prediction of death with 90% certainty is sufficient grounds to withdraw treatment requires further informed discussion.

Chapter 4

Recovery in the Year Following Severe TBI

This chapter describes the results from the assessment of the cognitive, emotional, behavioural, and social functioning, at 6 months and 1 year postinjury, for a group of severe TBI patients who were consecutive admissions to a large base hospital. The degree and nature of the deficits observed are described, and the pattern of recovery of these deficits over the first year following severe TBI is detailed. The relationship of the cognitive, emotional, and behavioural impairments of the TBI patient to their social outcome is examined. Social outcome includes the employment, living arrangements, relationship status, and social activities of the people with a severe TBI.

Recovery of Cognitive Functioning

The occurrence of cognitive deficits following TBI is well established. Early studies by Russell in the 1930s examined the presence of post traumatic amnesia following TBI. Later studies by Conkey (1938) and Ruesch (1944) focused more on recovery of function during the first year postinjury, differential rates of recovery of various cognitive functions and the use of neurological indices soon after injury to predict outcome. In 1943 Ruesch and Moore assessed people with mild TBI as soon as they were able to be assessed using simple measures such as serial subtraction of 7's and digit span. Both Reynell (1944) and Tooth (1947) used military personnel who had sustained a TBI to document the presence of deficits on a broad battery of tests. Overall, these studies suggested that more enduring cognitive impairment occurred on tests involving more complex functions or those that relied to a large degree on memory. Speed of information processing and judgment were also found to be significantly affected by TBI. Many of these early studies were unsophisticated in their research design with inadequately defined methodology and poorly defined samples. Despite this they raised many issues that continued to dominate later studies on cognitive outcome, although little interest was shown in this area again until the early 1970s.

During the 1970s many of the studies on cognitive recovery following TBI typically used the Wechsler Adult Intelligence Scale (WAIS) to assess intellectual functioning. Bond (1975) administered the WAIS to a group of 56 people with severe TBI. Assessment took place for different groups of patients at 3, 6, 9, 12, 18, and 24 months postinjury. Full Scale IQ, Performance IQ, and Verbal IQ were found to be related to length of post traumatic amnesia. Those patients who had a post traumatic amnesia longer than 12 weeks did not attain a Full Scale IQ greater than 80, even after 24 months. For those who had a post traumatic amnesia of 11 weeks or less the greatest gain in ability occurred within the first 6 months and by 13 months postinjury all patients had obtained a Full Scale IQ that was within one standard deviation of the mean. Verbal IQ scores were found to follow a similar pattern of recovery as Full Scale IQ scores, the greatest gain being made in the first 6 months with return to within the average range by 13 months postinjury. While Performance IQ scores followed the same pattern of recovery (the greatest gains being made in the first 6 months), improvement was slower and did not reach its maximum until 24 months postinjury.

The generalisability of the results reported by Bond (1975) is limited by a number of procedural factors and the failure to report methods in full. Specifically, the number of patients assessed at each time interval was not defined and the number of patients undergoing repeated assessment was not reported. In addition, because no measure of premorbid intelligence was obtained for patients in this study it was not clear to what extent people returned to their preinjury level of Full Scale IQ.

Despite this, similar findings were obtained by Mandleberg and Brooks (1975) who administered the WAIS to 40 people with severe TBI, who were admitted to a neurosurgical centre. Time intervals for assessment were classified into four blocks: 0 to 3 months, 4 to 6 months, 7 to 12 months and over 13 months. Only 10 of the 40 patients were consecutively tested in all four time blocks. The authors selected a comparison group based on the premise that those who sustain a TBI are not representative of the normal population, but that they are more likely to be socially maladjusted prior to their injury. Therefore a comparison group was selected from the patients who had referred to the Department of Psychological Medicine. Of the 40 patients selected 13 had been referred for vocational guidance and 27 were described as "neurotics". This consisted of people who had been diagnosed with a history of drug or alcohol abuse, reactive depression, suicide attempts, gambling problems and gender identification issues.

The results reported by Mandleberg and Brooks (1975) indicated that the change in obtained scores from one administration to another was small, but as a group, the Full Scale IQ of the severe TBI group eventually returned to the same level as the comparison group within 13 months. Similar to the findings of Bond (1975), a differential rate of recovery was observed between verbal and performance IQ scores. The authors reported that this may have been a reflection of the greater initial deficits observed on performance tasks. However, they also suggested that the slower recovery on performance tasks may have been due to the more complex nature of the performance items. They noted that successful completion of the performance items required the integration of a number of complex functions, such as, perception, learning, manual dexterity, speed, and attention. In comparison, verbal tasks appeared structurally simpler.

Although Mandleberg and Brooks (1975) provided a clearer description of their procedure than Bond (1975), the generalisability of their results is limited. Specifically, patients in their study were admissions to a neurosurgery unit. Such patients are likely to a have a high incidence of intracranial haematomas and post-traumatic surgery. Therefore, this sample was not necessarily representative of the broader range of people who receive severe TBI.

A more extensive battery of tests was used by Brooks and Aughton (1979a) to investigate cognitive impairment and recovery following TBI. The battery of tests included: Raven's Progressive Matrices, Mill Hill Vocabulary Scale, Logical Memory, Inglis Paired Associate Learning Test, Rey Figure, Block Design, Token Test, and word fluency tests. Twelve people with TBI were assessed at 1, 3, 6, and 12 months postinjury and 24 people with TBI were assessed at 3, 6, and 12 months postinjury. Severity of injury was defined by post traumatic amnesia and indicated that this sample included mild through to very severe injury. A control group comprising 30 orthopaedic patients was used.

At 12 months postinjury the TBI patients differed from controls on tasks involving learning, memory, and constructional skills. The authors suggested that these functions recover at a slower rate and to a lower level than other functions. On the two measures of intelligence the TBI patients performed more poorly than controls on the first administration. Subsequent assessment found a significant difference on only the measure of nonverbal intelligence. However, the authors warned that their findings were based on group data and that the pattern and extent of recovery between individuals showed wide variations.

In a second study, Brooks and Aughton (1979b) administered the Raven's Progressive Matrices, the Mill Hill Vocabulary Scale and the Inglis Paired Associate Learning test to a larger group of 89 people with TBI. As in the previous study, severity of injury ranged from mild through to very severe. The patient's performance on these tests was compared to the performance of 30 orthopaedic controls. The TBI patients scored significantly worse on all three tests when compared to controls. Patients were tested between 1 and 24 months postinjury, although the majority of people were seen within 6 months. These results therefore tend to be more reflective of early outcome following TBI.

In a further attempt to define cognitive recovery following TBI, Dye, Milby, and Saxon (1979) assessed 48 people who had sustained a severe TBI. The patients had been discharged from hospital within the preceding 3 years. Only patients who were able to complete the neuropsychological tests were admitted to the study thereby excluding those with more severe impairments. A group of 16 people who had been involved in accidents but who had not sustained a TBI acted as a control group. The WAIS and subtests from the Halstead-Reitan Battery were administered.

The patients in the Dye et al. (1979) study were found to perform more poorly on all 13 measures when compared with the control group. This difference was more evident on tests which involved a motor component. When the TBI patients were further divided according to severity of initial injury, the more severely injured group were found to perform more poorly on tests which required motor ability or manipulation skills. Despite the use of a small and ill-defined sample the results of this study were consistent with previous findings of more enduring impairment of performance abilities following severe TBI.

The WAIS and Halstead–Reitan Battery were also used by Drudge, Williams, Kessler, and Gomes (1984). Fifteen patients between the ages of 18 and 36 years were assessed soon after injury and again at 1 year postinjury. A control group of 15 people who had been referred for psychological evaluation of various psychological difficulties (low back pain, mild depression, headaches) was used for comparison purposes. At the initial testing TBI patients performed more poorly than controls on 28 of the 29 measures. At 1 year, while the performance of the TBI group had improved on all measures they continued to show more significant impairment on 18 of the 29 measures.

Consistent with other studies, Drudge et al. (1984) found a greater deficit on Performance IQ than Verbal IQ at the initial testing (Bond, 1975; Brooks & Aughton, 1979a; Dye et al., 1979; Mandleberg & Brooks, 1975). Similarly, at 1 year a greater improvement was found in Performance IQ scores so that the Performance IQ–Verbal IQ discrepancy apparent at the initial testing was eliminated.

Dikmen and colleagues have reported results from a number of studies investigating neuropsychological recovery following TBI. In the first study Dikmen, Reitan, and Temkin (1983) assessed a group of 27 people who had sustained a TBI. Severity of injury ranged from mild to severe and the patients were between 15 and 44 years old. Assessment took place as soon as the person was alert, orientated, and physically well. For the majority of the sample the first assessment was within 35 days of their injury. Follow-up assessment took place at 12 and 18 months postinjury. A control group matched on age and education was also assessed. Assessment involved the administration of the Halstead-Reitan Neuropsychological Test Battery and the Trail Making Test.

Overall the results indicated that those who suffer a TBI experience a broad range of neuropsychological deficit in the early stages of recovery. Most affected were tests of higher-level cognitive functions, specifically, reasoning and concept attainment, flexibility of thought, adaptation to tasks with unique requirements, psychomotor speed, and problem solving skills. The results were less consistent on measures of attention, concentration, and incidental memory. Improvement over time was found to occur in both complex as well as simple functions. The degree of impairment initially shown was found to be predictive of the later degree of recovery and the presence of residual deficits. Those with substantial losses showed a greater amount of improvement, but also a greater amount of residual impairment. In contrast, those with less initial impairment showed a smaller amount of improvement and a smaller remaining residual deficit.

This latter finding requires further investigation as the accuracy of the degree of reported deficits for individual patients is questionable. The degree of loss was calculated with reference to a control group rather than to the individuals premorbid level of ability. In those cases where the patients were not of average ability premorbidly the extent of their current deficits could have been either underestimated or overestimated. In addition, initial testing did not take place at a specific time postinjury. Therefore it is difficult to determine at what point following injury that degree of impairment is predictive of later deficits.

In a further study assessing late outcome following TBI Dikmen, Machamer, Temkin, and McLean (1990) assessed a group of 31 patients aged between 15 and 60 years. Severity of injury was defined as a GCS of 8 or less, and/or 2 weeks of post traumatic amnesia, and/or an inability to follow commands for more than 24 hours post injury. A comparison group selected from friends of the TBI patients and matched on variables of age and gender was used. The expanded Halstead-Reitan Neuropsychological Test Battery was administered at 1, 12, and 24 months postinjury. The TBI group performed significantly more poorly than the control group on almost all neuropsychological measures at each time period. While a significant improvement was noted in the performance of TBI patients between 1 month and 1 year postinjury, the improvement between 1 year and 2 years postinjury was small and not statistically significant. A clear relationship was found between length of coma and level of performance on neuropsychological measures.

Data from the Traumatic Coma Bank was analysed by Levin et al. (1990). One hundred and sixty-eight people with a severe TBI (GCS<9) were included in the study, although only 127 were able to complete all aspects of the assessment. In order to reduce the heterogeneity of the group those with a history of substance abuse, a history of psychiatric disorder, or previous TBI were excluded from the study. Patients were aged between 16 and 70 years old. The following measures were administered: Selective Reminding Test, Benton Visual Retention Test, Paced Auditory Serial Addition Test, Trial B of the Trail Making Test, Modified Card Sorting Test, Grooved Pegboard test, Block Design subtest of the WAIS-R, and Visual Naming subtest of the Multilingual Aphasia Examination.

At 1 year postinjury verbal learning and memory, visual memory and information processing speed were found to be impaired when compared with a control group matched for age, education, and occupation. In contrast, no difference was found between the two groups on measures of linguistic and visuospatial skills.

Early studies on the impairment and recovery of cognitive functioning following severe TBI tended to assess general intellectual functioning and primarily distinguished between verbal and nonverbal abilities. As the area of neuropsychology developed later studies began to focus on the assessment of more specific areas of cognitive functioning such as the domains of memory, learning, and attention. The change in research focus paralleled the development of more sophisticated assessment tools that assessed more accurately these different functions.

Attention. Attention deficits are common following TBI (Gronwall & Sampson, 1974; Miller, 1970; Stuss et al., 1985; Van Zomeren, 1981). Attention is described as a multi-dimensional concept and is often discussed in relation to selective attention, sustained attention, focused and divided attention, and speed of information processing (Ponsford & Kinsella, 1992; Van Zomeren & Saan, 1990). In reviewing the attention deficit literature, Van Zomeren, Brouwer, and Deelman (1984) confirmed that slowness of information processing is common after TBI particularly in the areas of conscious processing, such as, mental transformations, decision making, and response selection.

Shum, McFarland, and Bain (1990) administered eight tests of attention to 125 university controls, 45 normal controls from the community, and 37 people with a TBI. Those who had sustained a TBI were divided into three subgroups: severe-short-term (GCS of less than eight who were tested less than 1 year following injury), severe-long-term (GCS of less than eight who were tested more than 1 year following injury) and mild-short-term (GCS 14 to 15 who were tested less than 1 year following injury). The primary focus of the study was to examine the construct validity of eight tests of attention. Principal component factor analysis with varimax rotation indicated that each of the measures loaded on one of the following three components: visuomotor scanning (Digit Symbol, Symbol Digit Modality, Letter Cancellation, Trail Making), sustained selective processing (Serial Subtraction, Stroop Colour-Word) and visual/auditory span (Digit Span, Knox Cube).

The severe-short-term group performed significantly worse than the control group on both the visuomotor scanning and visual/auditory span components of attention. The severe-long-term group performed significantly worse than the control group only on tasks involving the visuomotor scanning component. The mild-short-term group's performance on all tasks was not significantly different from the controls. These results suggested that visual/auditory span functions (measured by the Digit Span and Knox Cube) improve with ongoing recovery, but that impairment of visuomotor scanning abilities (measured by the Digit Symbol, Symbol Digit Modality, Letter Cancellation, and Trail Making) are more enduring.

In an earlier study by Mandleberg and Brooks (1975) the performance of 40 severe TBI patients on the Digit Span and Digit Symbol subtests of the WAIS was reported. A statistically significant difference was found between the obtained scores, on both measures, of the TBI group and a comparison group when assessed at 0 to 3 months, 4 to 6 months, and 7 to 12 months postinjury. The TBI patients' performance on the Digit Symbol subtest was poorer than their performance on the Digit Span subtest.

In a similar study Drudge et al. (1984) administered the WAIS to 15 severe TBI patients and a control group of 15 neurologically normal patients referred for psychological evaluation. The severe TBI group was further divided into two groups. One group was assessed approximately 2 months postinjury and the other group was assessed approximately 1 year following injury. Consistent with the findings of Shum et al. (1990) and Mandleberg and Brooks (1975), the TBI group performed more poorly than the control group on the Digit Span and Digit Symbol subtests at 2 months postinjury. The findings of Drudge et al. differed from those reported by Shum et al. and Mandleberg and Brooks in regard to their 1-year follow-up. Drudge et al. reported that at 1 year the TBI group continued to differ from the control group on the Digit Span subtest but that their performance was not significantly different to that of the control group on the Digit Symbol subtest. The small sample size in the Drudge et al. study may have made comparison between the studies unreliable. In addition, the comparison group in the Drudge et al. study, although assessed as having no neurological disorders, consisted of people referred for psychological evaluation, including “concentration complaints secondary to mild depression”. The appropriateness of this comparison group is therefore questionable.

Overall, research that has investigated the impairment of attention following severe TBI has shown ongoing and pervasive deficits in this area. Assessment of attention using the Digit Span and Digit Symbol subtests of the WAIS-R indicates that impairment of such processes as auditory attention span (Digit Span) resolves more quickly than impairments of visuomotor scanning abilities (Digit Symbol). The differential recovery of these functions is thought to reflect the differing complexity of the tasks.

Verbal Memory. Memory impairments are one of the most commonly cited deficits associated with cognitive dysfunction following severe TBI (Conzen et al., 1992; Dikmen et al., 1983; Levin et al., 1990). Residual memory disturbance is often reported by people with TBI and their families (Brooks et al., 1986; McKinlay et al., 1981; Oddy, Coughlan, Tyerman, & Jenkins, 1985) and assessment of memory with neuropsychological tests has confirmed the presence of these difficulties (Brooker & George, 1984; Brooks & Aughton, 1979a; Crosson, Novak, Trenerry, & Craig, 1988; Dikmen, McLean, Temkin, & Wyler, 1986; Dikmen, Temkin, McLean, Wyler, & Machamer, 1987; Paniak, Shore, & Rourke, 1989; Parker & Serrats, 1976).

In an early study of verbal memory and learning, Lezak (1979) assessed 24 patients with TBI within 1 year of their injury and again at 2 years and 3 years postinjury. Digits Forward, Digits Backward and four trials of the Auditory Verbal Learning Test (Trial I, Trial B, Trial V, Trail VI) were used in data analysis. At 6 months postinjury, 61% of the group displayed impairment on Trail I of the Auditory Verbal Learning Test, 72% were impaired on Trail B, 94% were impaired on Trial V, and 94% were impaired on Trial VI. A large number of patients continued to display impairment at 1 year postinjury, with 52% being impaired on Trial I, 70% on Trail B, 78% on Trail V, and 87% on Trial VI. Although fewer patients displayed impairment at the 1-year follow-up, a statistically significant improvement was obtained only for Trial I. Lezak noted that immediate memory is the least affected memory function following TBI and that consistent improvement is shown on this test over time. She concluded that the prominence of effects of brain injury increases as the complexity of the task increases.

In a previously described study by Levin, Grossman, Rose, and Teasdale (1979) verbal memory functioning was assessed using the Selective Reminding Test. Twenty-seven people with a severe TBI were assessed at least 6 months postinjury and their performance was compared to their outcome as measured by the GOS. The results indicated the ability to learn across trial for patients with a good recovery or a moderate disability. However, this trend was not observed with the severely disabled group. Long term storage of words was defective in one patient with good recovery (10%), in three moderately disabled patients (33%), and in all severely disabled patients. Consistent retrieval from long term storage was evident in patients who had a good outcome or who were moderately disabled, but not for those who were severely disabled. Overall about one-third of patients displayed a deficit in memory storage and/or retrieval.

Outcome data from the Traumatic Coma Data Bank regarding the recovery of memory functioning following severe TBI has been reported by Levin et al. (1990). At 1 year postinjury verbal learning and memory was found to be significantly impaired in the severe TBI group. The median number of words consistently recalled by the TBI group was 46% of the median obtained in the normal population. Visual memory assessed by the Benton Visual Retention Test was also found to be significantly impaired.

Overall a significant proportion of people who have sustained a severe TBI will display impaired memory storage and retrieval problems on verbal learning tasks up to 1 year following their injury. The rate of recovery appears to differ according to the different aspects of memory being assessed.

Executive Functions. The term executive function is relatively new and was introduced by Lezak (1983). It is a multidimensional construct that refers to a number of related higher-order cognitive processes including initiation, planning, hypothesis generation, cognitive flexibility, decision making, self-regulation, judgment, and feedback utilisation (Spreen & Strauss, 1991). Lezak described executive functions as those that "enable a person to engage in independent, purposive, self-serving behaviour successfully" (p. 38). Disturbance of executive function tends to be associated with damage to the prefrontal regions although it may also occur when damage is sustained in other regions of the brain (Kolb & Wishaw, 1990). Executive dysfunction is commonly reported following TBI and is thought to be responsible for significant ongoing functional disability for the TBI patient. The assessment of executive functioning is in its infancy and presents a major challenge to neuropsychologists because of the multidimensional nature of the function. In addition, while numerous clinical and experimental tests have been developed, research into the reliability and validity of these measures to assess executive dysfunction is ongoing (Spreen & Strauss, 1991).

Two tests that have been used to assess concept formation and cognitive flexibility are the Similarities subtest of the WAIS-R and the Controlled Oral Word Association test (Lezak, 1983; Spreen & Strauss, 1991). Mandleberg and Brooks (1975) administered the Similarities subtest as part of the WAIS to 40 people who had sustained a severe TBI. Assessment took place at 0 to 3 months, 4 to 6 months, 7 to 12 months, and at more than 13 months postinjury. The performance of the TBI group on the Similarities subtest did not differ from that of the comparison group at any of the four assessment intervals. The Similarities subtest was the only WAIS subtest on which the TBI group did not score significantly lower than the comparison group.

In contrast, Drudge et al. (1984) found a statistically significant difference between the performance of a group of 15 severe TBI patients and a control group when they were administered the Similarities subtest approximately 2 months postinjury. The performance of the TBI group was significantly lower than that of the control group. However by 12 months the performance of the TBI group had improved and a statistically significant difference was no longer evident between the two groups.

Levin, Grossman, et al. (1979) administered the Controlled Oral Word Association test as part of the Multilingual Aphasia Examination to 27 severe TBI patients. Assessment took place between 5 months and 9 years postinjury. TBI patients were classified in relation to outcome according to the GOS. Ten patients had made a good recovery, 12 continued to experience moderate disability, and 5 remained severely disabled. Almost 50% of the TBI patients with a severe disability displayed impairment on the Controlled Oral Word Association test. Almost 20% of patients with moderate disabilities scored defectively, while approximately 1% of TBI patients classified as having achieved a good recovery displayed impairment. Overall therefore approximately 70% of the sample displayed impaired performance on the Controlled Oral Word Association test.

Verbal fluency was further investigated by Ruff, Evans, and Marshall (1986). A sample of 50 normal controls, 15 people with a moderate TBI, and 20 people with a severe TBI were assessed at least 6 months postinjury. The mean time period between injury and assessment was 1 year for the moderate TBI group and 2 years for the severe TBI group. The following tests were administered: Galveston Orientation and Amnesia Test, subtests from the WAIS-R, Finger Tapping test, Block Span, Letter Span, Delay for Block and Letter Span, Controlled Oral Word Association test, and Figural Fluency. The severe TBI group performed at a significantly lower level than the control group and the moderate TBI group on the Controlled Oral Word Association test. The authors suggested that the reduction in fluency observed on this measure was primarily due to an inflexibility in cognitive processing rather than impaired memory, impaired motor speed, or aphasia.

Despite the difficulties inherent in the assessment of executive functioning, research has shown that measures of verbal concept formation and verbal fluency assess specific aspects of executive abilities. The Similarities subtest of the WAIS-R has been found to be sensitive to the presence of damage to the frontal lobes (Lezak, 1983) and can be regarded as a measure of executive impairment. Results have shown that for those who initially display impairment on this test, their performance returns to within normal limits within 1 year postinjury. In contrast, those who sustain a severe TBI have been found to display ongoing and significant impairment on the Controlled Oral Word Association test. Once again the relative complexity of the tasks is the most likely explanation for the differential recovery observed on the two tests.

Visual-perception. The assessment of visual-perception has tended to be included in general measures of intelligence (Brooks, 1984). For example, most of the "performance" subtests of the WAIS-R are visual-perceptual in nature and measure different aspects of visual-perceptual functioning. As already noted in the previous literature that has been reviewed, the ability of severe TBI patients on "performance" subtests is slower to recover when compared to their ability on "verbal" subtests, and their ability on "performance" subtests tends to display marked and prolonged deficit (Bond, 1975; Brooks & Aughton, 1979a; Mandleberg & Brooks, 1975). The Block Design subtest of the WAIS-R has been used in a number of studies as a measure of visual-perception. This test requires visual-spatial, visual-motor, and visual-organisation abilities.

Mandleberg and Brooks (1975) administered the Block Design subtest as part of the WAIS to 40 people with a severe TBI. Serial assessments were undertaken at 0 to 3 months, 4 to 6 months, 7 to 12 months, and over 13 months postinjury. A comparison group matched on variables of age and education were recruited from referrals to the Department of Psychological Medicine. The authors found that performance of the TBI patients on the Block Design subtest improved at each successive testing. At initial testing the scores of the TBI group on Block Design were significantly lower than those obtained by the comparison group. By 12 months the scores for the TBI group were equal to those of the comparison group.

Similar to Mandleberg and Brooks (1975), Brooks and Aughton (1979a) undertook the serial assessment of 24 severe TBI patients with various measures of cognitive function. The Block Design subtest was administered at 3, 6, and 12 months postinjury to assess perceptual and constructional skills. The performance of the TBI group was significantly lower than the control group at 3 months postinjury. At 6 and 12 months the difference between groups did not reach statistical significance however the authors noted that the TBI group continued to obtain a lower mean score compared to the control group.

In a previously cited study that reported results from the Traumatic Coma Bank, Levin et al. (1990) administered the Block Design subtest of the WAIS-R to specifically assess visuospatial abilities, while also measuring a broader range of cognitive functions. The Block Design subtest was administered to 127 people who had sustained a severe TBI. When the TBI patients performance was compared to that of the control group no statistically significant difference was found. The authors concluded therefore that visuospatial ability in this group of severe TBI patients approximated a normal level by 1 year following their injury.

Conzen et al. (1992) included the Block Design subtest to assess spatial ability in a battery of tests designed to assess cognitive functioning in a group of 37 severe TBI patients. Assessment took place at least 15 months postinjury. Despite all of the patients being classified as having made a good recovery on the GOS, Conzen et al. reported the ongoing presence of significant cognitive impairment when they were compared with a control group matched on gender, age, education and social class. A significant difference was found between the performance of the control group and the severe TBI patients on the Block Design subtest suggesting ongoing impairment of visuospatial abilities.

The assessment of visual-perception has often been subsumed under the assessment of nonverbal or “performance” skills. However, the majority of studies that have attempted to assess visual-perceptual functioning per se, have found the performance of severe TBI patient’s on the Block Design subtest of the WAIS-R to steadily improve over time and to be within normal limits by 1 year postinjury.

Summary of findings on recovery of cognitive functioning. In summary, a wide range of cognitive impairments are apparent following severe TBI. Early studies on cognitive outcome following TBI concentrated on the pattern of deficits, and rate of recovery of intellectual functioning. Different functions were found to recover at different rates, the rate of recovery appearing to correspond to the severity of the initial injury. Overall, verbal abilities were found to recover more quickly. Performance skills took longer to recover and did not recover to the same extent, suggesting that these involve more complex cognitive functions.

Consistent with the development of neuropsychology as a specialist area within psychology and the evolution of more sophisticated assessment tools, later research began to focus on the assessment of more specific areas of cognitive functioning. Therefore, the focus of study became assessment of abilities such as, attention, memory, perception, and executive functioning. Initial impairment and recovery on tests of specific cognitive functions has generally reflected the findings of earlier studies that investigated broader intellectual functioning. The literature indicates that different aspects of cognitive functioning are more susceptible to injury and that recovery takes place at a differential rate across functions. However, there is no clear consensus regarding which functions are the most susceptible or the precise nature of the recovery for different functions.

The methodologies used across studies often differ and makes comparability between studies difficult. This may explain, in part, the equivocal findings. In addition, many studies employed poor methodologies, with ill-defined samples, poor sampling techniques, and inadequate measures. These problems are outlined in more detail on page 129.

Recovery of Emotional and Behavioural Functioning

Despite the presence of ongoing physical and cognitive impairment, the families of individuals with severe TBI report that it is the emotional and behavioural disabilities that cause the most concern (Brooks & McKinlay, 1983; Florin et al., 1989; Lezak, 1988; Livingston & Brooks, 1988). Emotional symptoms of anxiety and depression are commonly reported (Brooks & Aughton, 1979b; Fordyce, Roueche, & Prigatano, 1983; Levin, Benton, & Grossman, 1982; Tyerman & Humphrey, 1984). Changes in behaviour have been reported following TBI and these include verbally threatening or aggressive behaviour, disinhibited, inappropriate or irresponsible social behaviour, aspontaneity, restlessness, childishness, impulsivity, emotional lability, impatience, over-sensitivity, and egocentricity (Brooks et al., 1986; McClelland, 1988; McKinlay et al., 1981; Oddy, Humphrey, & Uttley, 1978b; Van Zomeran & Van den Berg, 1985).

The presence of emotional and behavioural problems following TBI has been associated with poor social adjustment, such as inability to return to work, decreased social contact and decreased participation in leisure activities for patients, and increased distress and burden for families (Brooks et al., 1986; Livingston et al., 1985b; McLean, Dikmen, Temkin, Wyler, & Gale, 1984; Oddy et al, 1978a; Peters, Stambrook, Moore, & Esses, 1990). These problems have also been identified as the most challenging for rehabilitation staff (Brooks, 1992; Elsass & Kinsella, 1987; Kinsella, Moran, Ford, & Ponsford, 1988). Research to date has focused on providing information regarding the presence and frequency of psychosocial problems. However, a better understanding of the impact that these problems have on the TBI patient, their family, and their potential for rehabilitation is required.

Studies using the reports of a relative or significant other. Many early studies consulted with a relative or significant other to determine changes in the TBI patient. Brooks and Aughton (1979b) administered a questionnaire to the relatives of

35 people with a severe TBI. The questionnaire, which was administered 3 months following the person's injury, consisted of 94 possible objective burden items. The items most frequently reported by relatives were: irritability (78%), slowness (77%), tiredness (76%), tension/anxiety (74%), impatience (74%), depression (73%), anger (72%), personality change (71%), and complaining (69%). The least frequently reported changes (scored by less than 6% of relatives) were: paralysis, trouble with the law, seizures, decreased mobility, blackouts, voices in head, attempted suicide, dressing problems, and tinnitus. The authors suggested that changes involving affective and emotional functioning and general behaviour were perceived to be the most common by relatives. Unfortunately the specific relationship of the relative (i.e., mother, father, daughter) was not defined in the study.

In a larger study McKinlay et al. (1981) administered a structured interview schedule to a close relative of 55 people with a severe TBI. Severity of injury was defined as at least 2 days post traumatic amnesia and patients were aged between 16 and 60 years. An interview schedule containing 90 items relating to the patient's physical and mental state, behaviour, and self-care ability was administered to a relative at 3, 6, and 12 months. The relative was asked to indicate those changes which had occurred in the patient since their injury. The most frequently reported changes in the patients' functioning, on all occasions, were slowness, tiredness, irritability, and poor memory. The 90 items were then divided into seven categories: physical (vision, balance, paralysis), language (fluency, dysarthria, receptive), emotional (irritability, anxiety, depression), dependence (personal care, activities of daily living), subjective (slowness, tiredness, headaches), memory (disorientation, memory lapses) and disturbed behaviour (violent and inappropriate behaviour). A higher number of emotional and subjective items were reported at all follow-up time periods than any other category and there was a tendency for these types of problems to be reported more frequently at each subsequent follow-up. For example, bad temper was reported in 48% of cases at 3 months and 67% of cases at 12 months; mood swings were reported in 33% of cases at 3 months and 62% of cases at 12 months; impatience was reported in 60% of cases at 3 months and 71% of cases at 12 months. The authors suggested that the increased frequency of these problems at 12 months may be due to the patient's reaction to their disability. Alternatively, it may be a primary result of the injury and although present since the time of the injury was not observed or not admitted by the relatives at first.

Brooks and McKinlay (1983) reported the results from a study that attempted to define more clearly the term "personality change". As part of the procedures followed by McKinlay et al. (1981) an adjective checklist was administered to the 55 relatives in this study. The relative was asked to fill in the checklist describing the patient before the injury and at the time of the interview. The checklist contained 18 dichotomous items such as: talkative-quiet, affectionate-cold, energetic-lifeless, cruel-kind, and irritable-easy going.

The number of relatives reporting a personality change increased over the 3 to 12 month period. The number of changes noted by the relative also increased. These changes were towards more negative or unpleasant features of personality.

Studies using patient self-report. The lack of attention to TBI patients' own perspective regarding changes in their psychosocial functioning was raised by

Tyerman and Humphrey (1984). In their study of 25 people with a severe TBI they attempted to describe the individual's own perception of the changes that had occurred as a result of their injury. Patients aged between 18 and 25 years were admitted to the study from two specialist rehabilitation units and assessed between 2 and 15 months postinjury. They were evaluated neuropsychologically on intellectual and memory tests, and during a structured interview they completed four self-report scales. The scales were the Leeds Scales of Anxiety and Depression, the Litman Physical Disability Self-Conception Scale, a 20-item semantic differential scale, and a 30-item neuropsychological problem schedule. On the Leeds Scales of Anxiety and Depression, 64% of patients indicated that they were experiencing significant psychological distress with 60% of patients attaining scores indicative of clinical depression and 44% of clinical anxiety. Many patients described a reduced sense of personal worth and were self-conscious about their disabilities. On the semantic differential scale patients were required to make judgments regarding their present, past and future selves. Overall patients described their present self as substantially changed when compared to their past self, but confidently expected a return to their premorbid self within a year. Fourteen patients made additional ratings of a typical person and a typical TBI person. These patients rated a person with TBI more negatively than a typical person and themselves as more like a typical person.

In an earlier study of emotional disturbance following TBI, Dikmen and Reitan (1977) administered the Minnesota Multiphasic Personality Inventory to 27 people admitted to a neurosurgical ward. Severity of injury ranged from mild to severe. Assessment was carried out soon after injury and again 12 and 18 months later. The results indicated that those with TBI report symptoms of depression, anxiety, somatic problems, and strange experiences soon after injury. Fewer symptoms were reported at both 12 and 18 months postinjury. Those patients who displayed significant initial and residual cognitive deficits also displayed greater emotional distress.

McLean et al. (1984) examined the behavioural and psychological functioning at 1 month postinjury for 102 patients who had sustained a TBI. The patients were consecutive admissions to a local hospital and the level of severity of injury ranged from mild to very severe. The five measures used to assess functioning were the Sickness Impact Profile, a measure of sickness-related changes in behaviour with 12 subscales; a Head Injury Symptom Checklist, of 12 symptoms frequently reported in the TBI literature; an analogue rating scale of overall level of functioning; and a structured interview. A control group of 102 patients selected from friends of the TBI patients were matched for age, education, gender, ethnicity, and relationship status.

On the symptom checklist the TBI patients reported experiencing headaches, fatigue, dizziness, blurred vision, decreased concentration, sensitivity to noise, impaired memory, and insomnia more frequently than controls. On the Sickness Impact Profile the TBI patients reported higher levels of dysfunction in the areas of sleep and rest, body care and movement, home management, mobility, social interaction, ambulation, alertness behaviour, pastimes and recreation, and work. There was no significant difference between the TBI and the control group on scales assessing emotional behaviour, communication, and eating. When the TBI patients were divided into groups according to injury severity, as measured by length of post traumatic amnesia, there was no significant difference between their responses on the measures administered.

In a follow-up study by McLean, Dikmen, and Temkin (1993), 92 of the original 102 people with TBI were reassessed using the same measures. At 12 months the people with TBI continued to differ from the control group on all subscales of the Sickness Impact Profile, except for the Eating subscale. However, there was a noticeable reduction in the frequency of dysfunction reported by people with TBI on each scale. Similarly, on the Head Injury Symptom Checklist, those with a TBI reported significantly fewer symptoms at 12 months when compared with 1 month.

Studies using reports from both the TBI patient and relative or significant other. In a further group of studies, both the person with a TBI and a close relative were interviewed. Oddy et al. (1978a) studied psychosocial outcome in a group of 49 people with a severe TBI. A 37-item symptom checklist relating to personality and somatic changes, cognitive, sensory, and psychiatric symptoms was administered to both the patient and a close relative. A control group of 35 patients with traumatic limb fractures was used as a comparison group. At 6 months postinjury 23% of patients were reported to be symptom free, while 35% of patients indicated that they experienced six or more symptoms resulting from their TBI. For the TBI patients, cognitive and personality changes were the most frequently identified type of changes, with impaired memory (38%), loss of temper (35%), fatigue (33%), difficulty concentrating (29%), and irritability (29%) being the most common. They also noted impatience (27%), restlessness (27%), and difficulty becoming interested in things (21%). There was a significant correlation between the symptoms noted by the relatives and the patients although the authors cautioned that there were marked discrepancies in individual cases. The relatives noted difficulties with impatience (35%), loss of temper (33%), irritability (31%), and restlessness (21%). The comparison group reported experiencing a fewer number of symptoms than the TBI group, and those symptoms that were reported were more reflective of anxiety and depression than cognitive or personality changes. The TBI patients in the Oddy et al. (1978a) study were aged between 16 and 39 years with 80% of patients being under 25 years of age. The sample is therefore a "young" sample and not representative of the broader age range that is affected by severe TBI.

The retrospective review of the files of 52 severe TBI patients who had been referred for neuropsychological assessment was undertaken by Fordyce et al. (1983). Patients were divided into acute and chronic groups. The 17 TBI patients in the acute group had been assessed within 6 months (mean = 3.7 months) of their injury and the 35 TBI patients in the chronic group had been assessed more than 6 months (mean = 25.3 months) postinjury. The patients had been administered the Minnesota Multiphasic Personality Inventory and a close relative had completed the Katz Adjustment Scale. Patients in the chronic group reported significantly higher levels of affective distress on the Minnesota Multiphasic Personality Inventory than those in the acute group. This was confirmed by the close relatives' responses on the Katz Adjustment Scale. No relationship was found between the TBI patients' emotional functioning and their level of cognitive impairment.

The authors noted that the study was cross-sectional and therefore did not allow for any definitive statements regarding recovery process. However they did suggest that emotional disturbance may increase with time as the patient becomes more aware of their residual deficits and problems in social adjustment. Accurate data on injury severity was not available for all patients and therefore the range of severity of the sample could not be defined.

Levin, Grossman, et al. (1979) compared psychological outcome with outcome on the GOS. A structured interview with the patient, and where possible a family member, provided information for completion of the Brief Psychiatric Rating Scale. This instrument is used to assess neuropsychiatric and behavioural disturbance. Behavioural disturbance characterised by tangential and fragmented speech, impaired ability to cognitively filter irrelevant material, failure to appreciate the severity of their cognitive deficits (and thereby focusing on relatively minor symptoms or denying any sequelae), and slowing and lack of spontaneity of gross movement were common to both moderately and severely disabled groups. Anxiety and depression were common, with four patients (15%) displaying severe psychiatric disturbance. Increased aggression was reported in 30% of patients. Other commonly reported symptoms were family and/or relationship problems, social isolation, fatigue, weakness, and incoordination.

Kinsella et al. (1988) administered the General Health Questionnaire, the Leeds Scales for Depression and Anxiety, and Visual Analogue Scales for Depression and Anxiety to a group of 39 severe TBI patients. The average age of the TBI patients was 27.8 years with 67% of patients less than 30 years old. Assessment took place up to 2 years postinjury with almost 60% of TBI patients being less than 1 year postinjury. In 35 cases the same measures were administered to a close other and they were asked to respond to questions as if they were the TBI patient. The TBI patients' responses on the General Health Questionnaire indicated that 59% of the group were experiencing minor emotional difficulties, while on the Leeds Scales 33% were classified as depressed and 26% were classified as experiencing anxiety. The authors reported that the most significant predictor of depression, as measured by the Leeds Scale of Depression, was the non-availability of a confidant. The authors suggested therefore that those TBI patients who experience deficiencies in social relationships may also experience a greater degree of emotional disorder.

In addition to providing information regarding the prevalence of emotional disorders among TBI patients, Kinsella et al. (1988) also sought to determine whether or not the TBI patient is able to reliably complete the selected measures and the validity of the use of these measures in this population. High short-term test-retest reliability was obtained for all measures used suggesting that TBI patients, as a group, do not respond randomly or impulsively to items on these three measures. Good agreement was found between the close others' perception and the TBI patients' self-report of emotional issues when the General Health Questionnaire and the Leeds Scale of Depression were used.

Longer term studies on emotional and behavioural functioning. Longer term outcome in relation to emotional and behavioural functioning has been studied by a number of authors (Brooks et al., 1986; Klonoff, Snow, & Costa, 1986; Oddy et al., 1985; Van Zomeran & Van den Burg, 1985; Weddell, Oddy, & Jenkins, 1980).

In the study by Van Zomeran and Van den Burg (1985) 57 people were assessed two years following a severe TBI. Patients underwent an interview and were required to answer a 17-item questionnaire comparing their present state to their functioning before their injury. Eighty-four percent of patients reported some type of residual psychosocial complaint. The most frequent complaint was irritability (39%), followed by slowness (33%), poor concentration (33%), and fatigue (30%).

In the first of two studies Thomsen (1974) interviewed 50 TBI patients and a relative, at an average of 30 months after injury. All TBI patients were reported to have sustained a severe injury. The main problem reported by the TBI patients was lack of social contact and consequent loneliness. Few patients reported changes in their personality or level of cognitive functioning. In contrast, 84% of the relatives complained of changes in personality such as irritability, poor temper control, aspontaneity, restlessness, emotional regression, emotional lability, and stubbornness. Pathological laughter was commonly reported and this caused concern and embarrassment for family. The author noted that overall mothers appeared to accept changes in the TBI patient more easily than partners.

A further follow-up of 40 severe TBI patients was undertaken 10-15 years after injury and reported by Thomsen (1984). At this second follow-up relatives and patients were given an expanded questionnaire. Although relatives and TBI patients reported a gradual improvement in behaviour over the interceding years, two-thirds reported permanent changes in personality and emotion.

In a study designed to evaluate quality of life following TBI, Klonoff et al. (1986) administered the Sickness Impact Profile to 78 patients who had experienced a TBI. Patients were seen between 2 and 4 years postinjury. Severity of injury ranged from mild to severe and patients were aged between 17 and 40 years at the time of their injury. In addition, the Katz Adjustment Scale-Relatives Form was administered to 63 relatives or close friends of the patient. The most common symptoms reported by the TBI patient were poor memory (60%), irritability (53%), and decreased concentration (24%). Depression was reported by 15% of the TBI patients. On the Katz Adjustment Scale-Relatives Form, the TBI group were reported to score higher on items of belligerence, verbal expansiveness, negativism, suspiciousness, withdrawal and retardation, general psychopathology, and confusion. Scores within the normal range were obtained for helplessness, anxiety, nervousness, bizarreness, hyperactivity, and stability.

As part of a study examining social adjustment following severe TBI, Newton and Johnson (1985) administered the Questionnaire of Social and Evaluative Anxiety, comprising the Social Anxiety and Distress and Fear of Negative Evaluation sub-scales, and the Rosenberg Self-Esteem Scale to 11 patients who had sustained a severe TBI. A behavioural rating of a five-minute video-taped social interaction was completed and a relative was asked to complete the Katz Adjustment Scale-Relatives Form. The age of the TBI patients ranged from 20 to 56 years (mean age = 34.8 years) and assessment took place between 2 and 13 years postinjury (mean time since injury was 5.4 years). Two control groups were used: a group of 20 outpatient referrals to the clinical psychology department with social interaction difficulties; and a non-clinical group of 32 volunteers recruited from a university subject panel. Results obtained on the Social Anxiety and Distress scale indicated that the TBI patients reported high levels of social anxiety relative to the non-clinical group and while they scored lower, on average, than the outpatient group the range of scores was greater.

On the Self-Esteem scale the TBI patients displayed lower self-esteem compared to the non-clinical group, but higher self-esteem than the outpatient group. The authors concluded that the TBI patients high social anxiety and low self-esteem were related to the social interaction difficulties that they were observed to display. The mean scores for the TBI group on the Katz Adjustment Scale-Relatives form were found to be similar to those obtained for a psychiatric population although the TBI patients were reported to be significantly more confused, less anxious, less nervous, and less hyperactive than the psychiatric sample. When compared to the general population the TBI group were reported to display more belligerence, negativism, helplessness, suspiciousness, withdrawal, confusion, and less stability. Relatives also reported that their TBI family member engaged in fewer socially expected activities.

The psychosocial changes in a group of 17 severe TBI patients were compared to changes reported in a group of 31 people with moderate TBI and a group of 24 spinal cord patients by Stambrook et al. (1991). The patients completed the Sickness Impact Profile and Profile of Mood State, and the spouses completed the Katz Adjustment Scale-Relatives form. Assessment was carried out at a mean of approximately 4 years postinjury. Severe TBI patients experienced significantly more depression, dejection, and bewilderment in comparison to the moderate TBI and spinal cord patients. The spouses of severe TBI patients described their husbands as more belligerent, negativistic, helpless, suspicious, and withdrawn. They suggested that their husbands engaged in less social activity and that when in a social situation they displayed more behaviours of an inappropriate social nature.

Weddell et al. (1980) selected 44 patients who had sustained a very severe TBI and who were aged between 16 and 39 years for inclusion in their study. The TBI patient and a relative were seen approximately 2 years postinjury. Relatives underwent the same semi-structured interview used by Oddy et al. (1978b), and were asked about the presence of memory impairment and personality change in the patient. A comparison group of 43 people who had recently sustained a TBI were matched for age, sex, and social class. Relatives of the comparison group were interviewed within 4 weeks of the accident in order to assess the social adjustment of the patient during the 2 months prior to the injury. A comparison was made between the social adjustment of the chronic TBI patients and the preinjury social adjustment of the acute patients. The most common change identified by relatives was increased irritability. Other changes included a tendency to behave in a more affectionate manner, increased talkativeness, increased disinhibition, and childishness.

Oddy et al. (1985) have reported data from a 7-year follow-up of 33 patients from the Weddell et al. (1980) study. The relatives of 28 patients completed the same assessment procedure as in the Weddell et al. study. In addition, the patient and relative were asked to complete a checklist about recent physical, cognitive, and behavioural symptoms. Impatience (43%), difficulty in becoming interested in things (43%), childish behaviour (40%), and a need to keep things tidy (40%) were most frequently identified by relatives. Similar symptoms were reported by the patients themselves. Approximately 25% of relatives reported that the TBI patient experienced anxiety or tension, although only 10% displayed a clinical level of disturbance (anxiety or depression) on the Wimbledon Self Report Scale.

Five year follow-up data from the previously cited study by McKinlay et al. (1981) was reported by Brooks et al. (1986). The relative of 42 of the original 55 patients was interviewed and asked to report any changes in the patient that had occurred after the injury and that were still present. The same procedure as that used in the one year study was used. At 5 years, as at 1 year, the most frequently reported items were in the broadly "mental" or "behavioural" areas. The single most frequently reported item was personality change, which had increased from 60% to 74%. The next most frequently reported symptoms were slowness, poor memory, irritability, and bad temper, all of which were reported by more than 63% of relatives. The other item to be reported more frequently at 5 years was threats of violence, which increased from 15% to 54%.

Brooks et al. (1986) discussed possible reasons for the reported increase in the frequency of behaviour problems over time. They suggested that attribution, where the behaviour is seen as a direct result of the injury when in fact this causal link is questionable, may occur. Alternatively, it is possible that the difficult behaviours were actually present soon after the accident but that the relative had not noticed the behaviour or had denied the presence of the behaviour. The relatives tolerance for negative behaviours may lessen with time and they are therefore more likely to report occurrence of the behaviour at the later date. Also to be considered is that the reported increase in frequency of difficult behaviour is due to genuine changes in the patient, who finds it increasingly difficult to deal with the distressing changes in their life.

In a comprehensive study by Elsass and Kinsella (1987), 15 patients with a severe TBI were administered the General Health Questionnaire to assess for the presence of nonpsychiatric disorders in the TBI population. The average age of the TBI patients was 25 years and they were assessed between 3 and 5 years postinjury. A control group matched for age, gender, relationship status, and to some extent educational and occupational levels was used. Results indicated that 53% of the TBI group were identified as "psychiatric cases" compared to 27% of the matched control patients. Although there was no statistically significant difference between the two groups the authors noted that the high prevalence of symptoms reported by TBI patients was never-the-less of clinical concern. In the same study TBI patients, a close other, and the control group were administered a behaviour checklist to measure behaviour change. The TBI patients and their close other were asked to compare the patients' current behaviour with their preinjury behaviour using a 24-item behaviour checklist. Control patients and their close other were administered the same measure. The TBI patients obtained significantly higher scores than the control patients and differed significantly from the control patients on 13 of the 24 items. The TBI patients reported that they were more impulsive, more likely to tire easily, more likely to have sudden mood changes, less able to approach people, more likely to become upset by criticism, more likely to experience memory difficulties, and less able to concentrate. The TBI patients also differed from the control patients in that they reported more attention seeking behaviour, becoming more easily upset when their needs were not immediately met, slowness in performing tasks, greater difficulty becoming interested in things, and increased stereotyped responses even when the response was clearly inappropriate. Interestingly, the TBI patients' report of changes in their behaviour was consistent with the changes in their behaviour reported by the close other.

Jacobs (1988) contacted 1700 patients who had sustained a severe TBI one to six years earlier, and their families, by mail. A total of 310 families replied by completing a six page questionnaire that covered basic information about the TBI person's injury, subsequent rehabilitation, and current as opposed to premorbid activities such as work, leisure, social, mobility, and family responsibilities. Of these 310 families, 150 were randomly selected for a more intensive assessment, and 142 participated in an interview. Behavioural and emotional problems varied among individuals, with depression, fatigue, anxiety, and general tension being noted in approximately 50% of the sample. Loss of motivation, lability, mood changes, restlessness, and temper tantrums were identified in approximately one third of all cases. Other behaviours ranging from demanding constant attention to specific tension related behaviours were identified in 5 - 25% of the group. Of the 51 questions regarding behaviour and emotional problems, patients were reported as experiencing at least one behavioural or emotional difficulty that could be attributed to the TBI, with approximately 25% displaying severe or multiple difficulties.

Although this study involved a large sample it was a very heterogeneous group. The age of patients ranged from 10 years to over 60 years. While 10% of the sample was seen more than 6 years following their injury 20% were seen within the first year postinjury. The author described the sample as having experienced a severe TBI although the criteria determining severity of injury were not made explicit. It was reported however that length of coma and duration of post traumatic amnesia were not used.

In the only New Zealand study to outline the ongoing emotional and psychological affects following severe TBI, Crawford (1983) assessed a group of 51 people who had sustained a severe TBI. The TBI patient and, where possible, a close relative were interviewed between 12 and 36 months postinjury. The GOS was used to assess outcome. Crawford reported that after a severe TBI 75% of TBI patients were so badly disabled as to need daily assistance from other people, or were so emotionally and socially impaired that relationships with family and friends were strained. Less than 10% of patients were found to return fully to their previous lifestyles. Crawford noted that the emotional and intellectual consequences of the injury were the most disabling and distressing symptoms for those in the moderately disabled and good recovery groups. Twenty-five percent of the good recovery group and 75% of the moderately disabled group complained of poor memory, and almost 50% of the moderately disabled were reported to be irritable and aggressive.

Summary of findings on recovery of emotional and behavioural functioning. In summary, there tends to be general agreement in the TBI literature regarding the nature of emotional and behavioural difficulties that are present following a severe TBI. These difficulties are associated with emotional and personality changes such as depression, anxiety, irritability, anger, complaining, impatience, and fatigue. However, there is little agreement on the prevalence and pattern of recovery of these problems. Some studies have suggested that symptoms resolve over time (Dikmen & Reitan, 1977; McLean et al., 1993), while others report a worsening of symptoms (McKinlay et al. 1981).

Tyerman and Humphrey (1984) reported that 60% of their sample displayed symptoms of clinical depression, while Kinsella et al. (1988) and Levin, Grossman, et al. (1979) reported the prevalence of clinical depression to be as low as 33% and 37%, respectively. Similar differences are found in relation to the prevalence of clinical anxiety (Klonoff et al.,1986; Tyerman & Humphrey, 1984).

Studies have varied with regard to the source from which information is gathered. Some studies have assessed changes in functioning according to the relatives perspective (Brooks & Aughton, 1979b; Brooks & McKinlay, 1983; McKinlay et al., 1981), others have been based on the TBI patients' view (Dikmen & Reitan, 1977; McLean et al., 1993; Tyerman & Humphrey, 1984), and a number have interviewed both the TBI patient and a relative (Fordyce et al., 1983; Oddy et al., 1978b; Thomsen, 1984). While some literature has suggested that there is a marked discrepancy in the reports provided by the TBI patient and the close relative (Oddy et al., 1978b; Thomsen, 1974), other studies have noted a significant degree of agreement (Elsass & Kinsella, 1987; Fordyce et al., 1983; Oddy et al., 1985). The major difficulty of obtaining information from only one source is the inability to collaborate the information given by the respondents.

As with the literature on cognitive impairment following TBI, the literature on the emotional and behavioural sequelae of TBI suffers similar methodological problems, and this may explain the equivocal findings. Given the enduring and pervasive nature of these impairments further research is required into the early pattern of their presentation so that appropriate rehabilitation interventions can be designed.

Recovery of Social Functioning

Previous research has shown that people who experience a severe TBI are at high risk for a significant decrease in social contact, friendship, and leisure activities (Jacobs, 1988; Tyerman & Humphrey, 1984; Weddell et al., 1980). High unemployment caused by an inability to return to work compounds these difficulties by decreasing the opportunity to develop social contacts and leisure activities. Many return to live at home and become more dependent on family (Jacobs, 1988; Oddy et al., 1978b; Thomsen, 1984).

One of the first studies to investigate psychosocial functioning following severe TBI was conducted by Hpay (1971). In this study 58 patients with severe TBI and their relatives were seen between 2 and 5 years postinjury. At 6 months 29% had returned to their original employment and 5% had returned to work with altered duties. By 12 months a further 9% had returned to their original work and a further 7% had returned to altered duties. Approximately 55% of patients had returned to their original employment by 5 years postinjury although many of these patients had achieved this outcome by 6 months. Sixty-five percent reported a return to their previous social life and 14% were described as being "complete social outcasts". Although this sample is described by the authors as having sustained a severe TBI, in 14 cases the duration of post traumatic amnesia could not be established and in another 14 cases post traumatic amnesia was reported to be less than 24 hours suggesting only a moderate TBI. While approximately 59% of the sample were reported to be under the age of 20 years the lower age limit was not reported. This group therefore represents a relatively young group of TBI patients.

Thomsen (1974) reported interview data from 50 people with a severe TBI and a relative when they were seen between 1 and 5 years (mean = 2.5 years) following injury. The main difficulty noted by TBI patients was lack of social contact and associated loneliness. Most patients had lost their preinjury friends and many had little opportunity to make new friends because they spent most of their time at home. Only 28% of this group of TBI patients had some sort of job outside of their homes.

In a later study Thomsen (1984) reported follow-up results at 10 to 15 years postinjury, from 40 of the TBI patients assessed in her earlier study (Thomsen, 1974). A loss of social contact remained the most significant concern for patients and more than 68% of relatives reported this to be a problem. Two-thirds of the group reported no contact outside the close family, and only three patients had returned to full-time employment. While at 1 to 5 years 24 patients lived with parents, only 9 continued to live with their parents at 10 to 15 years postinjury. Of the 9 patients who were married at the first follow up, 7 were divorced by 10 to 15 years postinjury.

In a comprehensive group of studies Michael Oddy and colleagues have documented the disruption of social functioning that occurs following severe TBI. Their first follow-up occurred at 6 months with 49 individuals aged between 16 and 39 years (Oddy et al. 1978b). A close relative of each patient was seen within the first four weeks after the injury and again six months later. Twenty-four patients were classified as having sustained a severe TBI (post traumatic amnesia of 1-7 days) and 26 sustaining a very severe TBI (post traumatic amnesia greater than 7 days). A control group of 35 patients who had sustained a traumatic limb fracture was used for comparison. Social recovery was assessed in terms of return to work, contact with friends, leisure activities, family life, marital relationships, parenting behaviour, and financial situation. Of the 45 patients who were working full-time prior to their injury, 49% had returned to work full-time and 16% had returned to work in a part-time capacity. Only those people with a very severe TBI were reported to have a marked reduction in the amount of leisure activities and show an increase in boredom compared with the control group. Social isolation was confined to patients with a very severe TBI, and the authors suggested that this was due to them being less likely to be back at work. Of the 12 TBI patients who were married, in only one case was the relationship reported to be significantly worse.

In an earlier described study by Tyerman and Humphrey (1984) none of the 25 severe TBI patients had returned to work approximately 7 months following their injury. Seventy-six percent reported disruptions in their social life, 68% reported restricted leisure activities and 40% reported negative changes in their family relationships.

The group of patients seen by Oddy et al. (1978b) were seen again at 12 months and contacted by mail at 2 years postinjury (Oddy & Humphrey, 1980). Of those working at the time of their accident, a total of 64% had returned to either full-time or part-time work within 6 months. A further 16% had returned to work during the next 6 months and one person resumed work between 12 months and 2 years postinjury. The authors reported that none of those back at work had been downgraded or had been required to take on less demanding work. However this conclusion was contradictory to other information presented in the paper where they described the cases of a policeman and a marine engineer who had returned to work only to carry out office duties. The authors suggested that speed of return to work was influenced more by physical disability rather than cognitive deficits. They also noted that premorbid personality traits such as nervousness and suspiciousness tended to delay return to work, whilst verbal expansiveness (brashness) indicated a more rapid return.

When return to leisure activities was examined, 50% of patients were still engaged in fewer leisure activities at 12 months postinjury. Involvement in fewer activities appeared to be related to complaints of "difficulty in becoming interested in anything", and to those experiencing impaired motivation. Fewer social encounters were common for those with a very severe TBI. At 6 months postinjury this reflected less contact with close friends and a less frequent exchange of visits. However at 12 months this group no longer paid fewer social visits than prior to their injury but they continued to receive fewer visits.

Some deterioration in family relationships, particularly between the patients and their siblings was noted at 12 months postinjury. Those patients who were reported to have sustained personality changes had significantly poorer family relationships, but only when the patient had at least one sibling living at home. Of the 12 married patients seen at 6 and 12 months the only change was noted by spouses who reported a decrease in the amount of affection felt towards the patient. No significant change was reported in sexual behaviour and only one couple had divorced between the 6 and 12-month follow-ups.

The 2-year follow-up consisted of a postal questionnaire to which 35 patients and relatives responded. Little change was reported in the areas of return to work and participation in leisure activities. The tendency for the TBI group to report fewer social outings observed at 6 and 12 months reached statistical significance by 2 years. Neither the person with the TBI nor the relative reported poorer family relationships and only one spouse and two patients suggested their marital relationship to be less satisfactory.

A further 2-year study was reported by Weddell et al. (1980). Information regarding the social recovery of 44 people with a severe TBI was obtained from a close relative using the structured interview described by Oddy et al. (1978b). Of the 44 patients, 11% had returned to their former employment and were reported to be fully competent in their work. Another 3 (7%) people had competently resumed the role of homemaker. Twenty-five percent of the group were in full-time employment but at a reduced capacity. These people had generally had to find different employment and relied on the goodwill of their employer as they continued to require assistance in their work. Three people had had short periods of employment in a number of jobs and 2 were in part-time employment. The remaining 20 (46%) patients were unable to work. Of these 10 attended a day centre but the other 10 remained at home and responsibility for their daily activities fell to the family. TBI patients were reported to have fewer interest or hobbies, fewer friends, make and receive fewer visits, and to date less frequently. Despite this, in only six cases did relatives see loneliness as a major problem.

Thirty-four patients from the study described by Weddell et al. (1980) were followed up at 7 years postinjury by Oddy et al. (1985). The authors noted that little change had occurred in relation to return to work. Those who were employed at 2 years postinjury were still employed although many had changed jobs. Those who were unemployed at 2 years remained so at 7 years. A decrease in social and leisure activities was noted particularly for those who were not employed. While boredom was not reported to be a problem, loneliness was commonly reported. Fifty percent of patients had only limited contact with friends. Sixty percent had no partner, and this was often reported to be a major problem by both patients and relatives. At 7 years those who had been in a relationship at 2 years were no longer in this relationship and a new relationship had not been formed. Of those married at the time of the injury, 2 had separated from their partners, but 3 had continued in the relationship. Five patients had married since their injury, all of whom were in employment.

The authors concluded that improvement in social adjustment following severe TBI is significantly influenced by an ability to return to work. Returning to work results in job satisfaction, better self-esteem, and structure in their home life. The maintenance of established friendships is made difficult not only because of enforced withdrawal from their social network, but also because of negative personality changes. Many of the patients in this study lived at home with parents and the ability to develop new leisure activities was restricted by loss of previous skills, lack of initiative and interest, and problems with mobility

McLean et al. (1984) examined the psychosocial functioning at 1 month postinjury of 102 patients who had sustained a TBI. Injury severity ranged from mild to very severe. The Modified Function Status Index was used to assess the patient's level of ability in five areas of functioning. These were related to the resumption of major activities, such as work, school, homemaking, and leisure. When compared to an appropriate group of control patients, the TBI patients were severely limited in all areas of daily living. The authors noted the difficulty in determining the relative impact of physical injuries and brain-related injuries on the person's ability to resume many of these activities.

In a previously described study Jacobs (1988) attempted to identify the long term needs of people with severe TBI. One hundred and forty two patients were interviewed between 1 and 6 years postinjury. For 78% of the group studied wages was their primary source of income preinjury as compared to 27% at follow-up. Seventy percent of all previously employed had left their jobs due to their injury and an additional 10% of people were dismissed from their positions. Only 2% continued to work in their positions relatively undisrupted. The consequent change in the functional and financial situation of these people required many of them to return to live with their parents rather than continue to live independently. Prior to their injury 35% lived with parents, 31% lived with spouses, 2% lived in a professionally supervised facility, 10% lived alone, and 22% lived with friends. Following their injury 48% lived with parents, 22% lived with spouses, 12% lived in a professionally supervised facility, 10% lived alone, and 9% lived with friends.

Rather than focus on individual components of psychosocial functioning such as employment and interpersonal relationships, Tate, Lulham, Broe, Strettles, and Pfaff (1989) attempted to assess psychosocial outcome in overall terms using a structured interview and the Lidcombe Psychosocial Disability Scale. Overall level of social reintegration as well as specific aspects of psychosocial functioning were compared with the patients classification according to the GOS. Eighty-seven people with a severe TBI and aged between 19 and 53 years were interviewed an average of 6 years postinjury. A close relative was also interviewed. Approximately half of the sample was classified as having made a good recovery, 26 were classified as having a moderate disability, and 16 as severely disabled. The overall level of social reintegration was "good" for 24% of the sample, "substantially limited" for 43% and "poor" for 33%. Within the good recovery group less than half of the patients attained an overall good reintegration, and for the majority of patients within that group the level of psychosocial reintegration was substantially limited. While most patients in the good recovery group were able to live independently they often required emotional support, had difficulty maintaining relationships, were socially isolated, had poorly defined leisure activities, and one-third were not involved in work or an avocational programme. Half of those patients in the moderate disability group were classified as having substantially limited reintegration. Eighty percent of the group required supported and supervised living arrangements, despite them being independent in self care tasks. Most were unable to form significant interpersonal relationships and 7 of the 11 patients who were married prior to their injury were now separated. Only one patient had returned to paid employment. In the severe disability group overall psychosocial outcome was poor for all patients. All but 1 person was fully dependent on others for daily living tasks and 4 were dependent in basic self care activities. None of the patients were in employment and most were described as socially isolated, unable to form or maintain significant relationships, and had few leisure activities. While 8 of the 16 patients were married or in a de facto relationship prior to their injury, only 3 remained married at follow-up. The authors concluded that even those who were classified as having made a good recovery on the GOS continued to experience significant impairment of psychosocial functioning a number of years postinjury.

In an earlier cited study Elsass and Kinsella (1987) attempted to define the quantity and quality of the social interactions of a group of 15 severe TBI patients assessed between 3 and 5 years postinjury. Control patients were matched with the TBI patients on demographic variables. The TBI patient, control patients, and a close other completed the Interview Schedule for Social Interaction to assess the patients' perception of their immediate social environment and the relationships within it. This is a semi-structured interview that generates six indices: availability of attachment, adequacy of attachment, availability of social integration, adequacy of social integration, tolerance to not having attachment, and the number of attachment persons with whom the respondent has recently been having arguments or unpleasant interactions. Results indicated that when compared with control patients, TBI patients obtained significantly lower scores on the availability of attachment (the perceived frequency or quantity of contact with the individual's primary or central attachment figures) and availability of social integration (perceived frequency or quantity of contact with friends and the wider social network) indices. There were no differences between the groups on either of the adequacy indices, the tolerance index, or the argument index. The authors concluded that while TBI patients experienced a decrease in the availability of attachment figures when compared to the control group, they were as satisfied with their level of social interaction as the control group. Results also indicated that TBI patients relied significantly more heavily on family members as their primary attachment, while control patients relied more on friends, boy or girlfriends, and fiance(e)s.

Zencius & Wesolowski (1999) found that the social networks of TBI patients contained fewer members than the social networks of physically injured patients. In addition the make-up of the TBI patients social network differred in that it contained primarily family members and staff members from the rehabilitation facility where they resided.

A search of the literature indicated only two New Zealand studies that reported the incidence of return to work following severe TBI (Crawford, 1983; Godfrey, Bishara, Partridge, & Knight, 1993). Crawford interviewed 44 people with severe TBI who had been in full-time employment prior to their injury. Follow-up occurred between 12 months and 36 months postinjury. Of this group 26% had returned to full-time employment, 23% had returned to work at a reduced capacity, and 51% remained unemployed. No attempt was made to examine the relationship between the impairments experienced by the TBI patients and their ability to return to work. However, the relationship between return to work and outcome for the TBI patient defined by the GOS was explored. Of those patients who remained severely disabled, none were able to return to work. Fifteen percent of the moderately disabled group returned to work in some capacity and less than 20% of those classified as having made a good recovery returned to employment.

In a second New Zealand study Godfrey, Bishara, et al. (1993) investigated the return to work of 59 people who had sustained a severe TBI. Follow-up occurred between 6 months and 3 years postinjury, at which time 58% of the sample had returned to full-time work or study, 17% had returned to work under altered conditions, and 25% had failed to return to work. Godfrey, Bishara, et al. went on to examine the factors associated with return to work. Their results will be described in more detail in the following section.

Summary of findings on recovery of social functioning. Those experiencing a severe TBI continue to experience difficulties in areas of social adjustment involving return to work, social contact, friendships, and leisure activities. However, the current literature pertaining to social outcome following TBI has produced diverse results. Most of the literature in this area has assessed the effects of severe TBI on return to work. While there is no doubt that the consequences of a severe TBI compromise the person's return to work, the extent of this problem is difficult to determine as reports of return to work vary considerably in the literature. Oddy and Humphrey (1980) reported that 80% of their sample of severe TBI patients had returned to work in the same or similar capacity by 1 year postinjury. In contrast, other studies have reported the rate of return to work to be as low as 28% (Thomsen, 1974).

For many TBI patients their injury requires them to return to live with family, usually their parents (Jacobs, 1988) and a decrease in social contact and leisure activities has been generally noted. Thomsen (1984) reported that 68% of the 40 patients in her sample experienced a decrease in social contact with two-thirds of the group having no contact with people outside of the immediate family. While these results are generally supported, Oddy et al. (1978b) suggested that only those with a very severe TBI experience a significant decrease in social contact. Elsass and

Kinsella (1987) confirmed that the TBI patient experiences a decrease in social contact following their injury but also noted that they do not report being distressed by this. This finding is in contrast to that of Thomsen (1974) who noted that TBI patients reported a significant degree of loneliness associated with decreased social contact. Some authors have argued that those who return to work or continue to live independently are less likely to experience a decrease in social contact. They suggest that being employed and living independent of family facilitates independent social interaction (Jacobs, 1988; Oddy et al., 1985).

The documented impact of TBI on relationships varies between studies. Positive findings were reported by Oddy and Humphrey (1980) who found that at 1 year postinjury only one couple in their group of 12 couples had divorced. Less positive findings have been reported by other authors (Tate et al, 1989; Thomsen, 1984).

The lack of consistency in findings is likely to be due to differing methodologies used in different studies and this is discussed more fully on page 129.

The Relationship between Cognitive Functioning and Emotional and Behavioural Functioning, and Social Outcome

While a number of studies have investigated the cognitive, emotional, and behavioural consequences of severe TBI few studies have explored the relationship of these variables to social outcome. That TBI patients experience impaired social functioning following their injury, and that this causes distress not only to the patient, but also to the family is recognised in the literature. Assisting the TBI patient to return to their previous level of social functioning is therefore a primary goal of rehabilitation. However, there is a dearth of literature investigating the factors that affect a return to premorbid social roles and activities.

Some studies have related cognitive, emotional and/or behavioural impairments to global outcome following TBI. Levin, Grossman, et al., (1979) investigated the specific neuropsychological deficits produced by severe TBI that lead to chronically impaired functioning as measured by the GOS. Twenty-seven patients with a severe TBI were assessed between 5 months and 9½ years postinjury. Severity of injury was established by a GCS of 8 or less, or duration of coma. In some cases GCS score was rated retrospectively from hospital admission examination notes. The follow-up assessment included a structured interview and the following neuropsychological tests: the WAIS, the selective reminding technique, and selected subtests of the Multilingual Aphasia Examination.

Using the GOS, 10 patients were classified as having made a good recovery, 12 had a moderate disability, and 5 were severely disabled. All patients who made a good recovery were functioning within the normal range on the verbal and performance scales (i.e., within one standard deviation of the population mean). The good recovery group and the moderately disabled group differed on only the Performance IQ, confirming previous findings of a slower rate of recovery on Performance IQ compared to Verbal IQ (Bond, 1975; Brooks & Aughton, 1979a; Mandleberg & Brooks, 1975). Severely disabled patients displayed profound intellectual impairment, with none recovering to within two standard deviations of the population mean, and with Performance IQ scores being markedly lower than Verbal IQ scores.

The authors suggested that a characteristic pattern of neuropsychological deficits could be identified as primarily responsible for chronic disability after severe TBI. This included impairment on tests of Performance IQ, memory, and retrieval of names. These deficits were more likely to be observed in those who were classified as having a "moderate disability" when compared with those who made a "good recovery". Those still experiencing "severe disability" displayed a broad and pervasive impairment of most functions.

Conzen et al. (1992) also investigated the relationship between performance on neuropsychological tests to functional outcome using the GOS. Thirty-seven patients with a severe TBI who had attained a "good recovery" on the GOS when discharged from hospital were seen at least 15 months postinjury. A control group of 15 people who were hospitalised for minor, usually orthopaedic injuries was used. All patients completed a neuropsychological assessment involving verbal ability, visuomotor speed, memory and learning, attention, spatial ability, and abstract thinking. The TBI group performed significantly worse on measures of verbal memory, spatial ability, and attention. The authors concluded that subtle neuropsychological deficits can be found in people after severe TBI even when they obtain a "good recovery" on the GOS.

The GOS is a measure of gross outcome. Therefore while these studies suggested a relationship between cognitive impairment and later outcome, they fail to provide information on more specific aspects of outcome for the TBI patient.

Some studies investigating the relationship between cognitive, emotional, behavioural functioning, and social functioning have used a telephone interview with the TBI patient to gather follow-up information (Dombovy & Olek, 1996; Greenspan, Wrigley, Kresnow, Branche-Dorsey, & Fine, 1996; Ip, Dornan, & Schentag, 1995). The difficulties with these studies is that the investigator does not have the opportunity to have a "face-to-face" interview with the patient and clinical observation cannot even be used to evaluate the reliability of the information. In neither of the mentioned studies was information gathered from another source to corroborate the information obtained.

Acker and Davis (1989) used the neuropsychological tests scores of 148 TBI patients obtained approximately 2½ years postinjury, to predict outcome at approximately 6 years postinjury. The TBI patients had been assessed using the WAIS, Wechsler Memory Scale, Wisconsin Card Sorting Test, Trail Making Test, Stroop Test, Quick Test, Raven's Progressive Matrices, Motor Free Visual Perception Test, Bender Gestalt Test, and the Draw A Person test. Outcome was assessed using the Social Status Outcome survey. Information for the Social Status Outcome survey was obtained from either the patient, a caretaker, or a family member by telephone. A significant relationship was found between all test scores, except the Wisconsin Card Sorting Test and the Stroop interference score, and ratings on the Social Status Outcome survey. A larger correlation was found with measures of specific functions than with tests of broader-based general intelligence.

Despite these positive findings the Social Status Outcome survey, like the GOS, is a global measure of outcome and revealed little about the TBI patients' ability to take part in specific activities. The study also had serious methodological flaws in that severity of initial injury was unavailable and information for follow-up was obtained from a variety of people by telephone interview.

An important aspect of the Bond (1975) study described earlier, was the attempt to investigate the relationship between the TBI patient's intellectual abilities, physical functioning, mental abilities, and social functioning. Three simple indices of outcome were used to assess the person's neurophysical, mental, and social functioning, and the WAIS was administered to assess intellectual abilities. Significant correlations were obtained between all scales and the TBI patient's Full Scale IQ. Social functioning was most closely associated with impaired memory, personality, and physical disability. Return to work was significantly affected by mental and physical disability. Although the scales used in the study were simplistic and heterogeneous in content, the study was one of the first to examine the relationship between different aspects of the TBI patient's functioning.

In a later study by Weddell et al. (1980) the relatives of 44 severe TBI patients were interviewed about the TBI patient's level of social functioning and the presence of cognitive and personality changes. The Neurophysical Scale developed by Bond (1975) and the Standard Progressive Matrices was administered to the TBI patient. Weddell et al. found that those TBI patients who were reported to have experienced personality changes were less likely to have returned to work, had fewer interests, were more frequently bored, and were more dependent on their families. They were also found to have lower scores on the Standard Progressive Matrices and more memory impairments. TBI patients with personality changes maintained less contact with preinjury friends. Relatives reported that although the TBI patient has lost this contact with preinjury friends they had made new friends. However, these new friendships appeared to be qualitatively different. They described situations in which the TBI patient would go to the pub, either alone or with a family member, and form casual relationships with other patrons, presumably because this is a "captive audience". Often patients would form friendships with older people, presumably because older people are more tolerant and will listen. Alternatively patients would develop friendships with friends of their parents. Those patients who displayed gross intellectual loss had significantly fewer social contacts than those patients with personality changes.

In 1985 Van Zomeren and Van den Burg published the results from their study that investigated the relationship between cognitive and psychological impairment, and return to work. Fifty-seven TBI patients were administered a 17-item questionnaire and asked to identify which of the items were a problem for them since their injury. The questionnaire contained items relating to cognitive, emotional, behavioural, and somatic changes that commonly occur following a severe TBI. Return to work was graded on a 5-point scale from 'not working at all' to 'resumption of previous work or study without any changes'. Follow-up took place two years postinjury. A significant relationship was found between the number of complaints reported by the TBI patient and successful return to work. Those patient's reporting more complaints were less likely to have returned to work. A significant relationship was also evident between reports of slowness and an inability to do two things simultaneously, and a failure to return to work.

The work of both Wedell et al. (1980) and Van Zomeren and Van den Berg (1985) established a relationship between cognitive impairment, the presence of personality changes, and the resumption of activities such as return to work and social contact following severe TBI. Notably these studies used practical, everyday activities as their measures of outcome which provide more specific and relevant information than global measures of outcome such as the GOS. However, the measures of impairment used in these studies were simplistic and provided only limited information regarding the degree and nature of impairments experienced by the TBI patient.

In the most comprehensive study to date Godfrey et al. (1993) compared the cognitive and personality functioning of 66 severe TBI patients with their employment status between 6 months and 3 years postinjury. Cognitive ability was assessed using the Raven's Progressive Matrices, the Paced Serial Addition Test, and the Auditory Verbal Learning Test. In addition, an informant, usually a parent or partner, completed the Neuropsychological Impairment Scale and the Memory Impairment Scale. TBI patients undertook a social skills assessment and an informant completed the Head Injury Behaviour Rating Scale to determine personality change in the TBI patient. Sixty-three of the TBI patients were in paid employment prior to their injury and a further 24% were involved in either secondary or tertiary study. A significant relationship was reported between the measure of general intelligence, the Neuropsychological Impairment Scale, and return to work. Both measures of personality change were significantly correlated to return to work. A regression analysis indicated that the informant's report of the neuropsychological symptoms displayed by the TBI patient was the only significant predictor of return to work. The authors concluded that neuropsychological impairment is the primary factor influencing the TBI patient's ability to return to employment.

Summary of findings on the relationship between cognitive functioning and emotional and behavioural functioning, and social outcome. Few researchers have investigated the interaction between cognitive, emotional and behavioural impairment, and social functioning following severe TBI. Where this relationship has been investigated the results indicate that the presence of cognitive, emotional, and behavioural problems significantly affect the TBI patient's ability to return to work and participate in other social and leisure activities. The impact of these variables on the TBI patient's ability to live independently and to maintain close relationships has not been explored. The ultimate goals of rehabilitation are to assist the TBI patient to return to their preinjury lifestyle. Rehabilitation however often focuses on the remediation of specific impairments, such as impaired memory, without an understanding of the way in which memory impairment will affect the person's ability to function in the workplace, or if in fact it will affect the person's real world functioning at all. Further research is required to explore the relationship between cognitive, emotional, and behavioural impairments and social outcome to ensure the development of appropriate rehabilitation programmes.

Overall Findings on Recovery in the First Year Following Severe TBI

In summary, a wide range of cognitive, emotional, behavioural, and social deficits are apparent following severe TBI. Early studies on cognitive outcome following TBI concentrated on the pattern of deficits, and rate of recovery of intellectual functioning. With the development of more sophisticated assessment tools research began to focus on the presence and recovery of more specific areas of cognitive function. Similar to the findings in the area of general intellectual functioning, different functions were found to be more susceptible to injury and to recover at different rates.

Ongoing difficulties with emotional disorders, personality and behaviour change, and poor social adjustment are reported following severe TBI. These changes are noted by family members and are reported to be the greatest cause of burden for family members. Most frequently reported changes are depression, anxiety, irritability and aggression, complaining, fatigue, and impatience. Changes in the patient's functioning are reported as early as one month following the injury and continue to be reported up to 10 years later.

Those who have sustained a severe TBI continue to experience difficulties in areas of social adjustment involving return to work, social contact, friendships, and leisure activities. Many TBI patients do not return to work, or return to work in a reduced capacity. Many return to live with family, and both the TBI patient and the family report a reduction in social contact and involvement in leisure activities for the TBI patient. A severe TBI is also thought to have a negative impact on relationships, with many relationships ending in divorce. The precise impact of cognitive, emotional, and behavioural impairment on social functioning has been relatively ignored in the literature.

Although there is general agreement in the literature that an individual's cognitive, emotional, behavioural, and social functioning is changed following a severe TBI injury, there is little agreement about the prevalence of such changes, pattern of recovery, and the relationship between them.

Methodological issues. Research in the area of outcome following TBI suffers from a number of methodological and practical problems that make comparability between studies difficult (Brooks et al., 1984; McKinlay & Brooks, 1984; Parsons & Prigatano, 1978). Many studies provide inadequate descriptions of the population being investigated (Leahy & Lam, 1998). Where samples are described patients within a sample may vary in terms of severity of injury (Finch, Sandel, Spettell, Mack, & Spivack, 1997). Some studies have included patients with mild through to severe TBI (Brooks & Aughton, 1979; Dikmen et al., 1983; Dikmen, Machamer, Winn, & Temkin, 1995; Dikmen, Ross, Machamer, & Temkin, (1995); Klonoff et al., 1984; McLean et al., 1993; McLean et al., 1984), while others have included only those who have had a severe TBI in their studies (Brooks & Aughton, 1979; Drudge et al., 1984; Dye et al., 1979; Levin, Grossman, et al., 1979; Levin et al., 1990; Tyerman & Humphrey, 1984). Different indices of severity of injury have been used and include the GCS (Levin, Grossman, et al., 1979), post traumatic amnesia (Brooks & Aughton, 1979a; Mandleberg & Brooks, 1975; McKinlay et al., 1981), and length of coma and time to follow commands (Dikmen et al., 1990; Dye et al., 1979). The age distribution of the samples can vary widely. The inclusion criteria for the sample used by Dikmen et al. (1983) included those between 15 and 44 years of age and the sample used by Tyerman and Humphrey (1984) included those aged between 18 and 25 years. In contrast other studies have involved a much wider range of ages (Dikmen et al., 1990; Levin et al., 1990). In the study reported by Jacobs (1988) 27% of the patients were aged between 10 and 19 years of age and 2% were over 60 years old.

The selection of patients is also liable to bias. Selection often occurs on the basis of admission to a specific facility. When this is a specialist centre such as a neurosurgery facility the sample is likely to represent those with a very severe injury and is therefore not representative of the larger group of severe TBI (Brooks & Aughton, 1979b; Mandleberg & Brooks, 1975).

The question of when it is most appropriate to undertake assessment of the TBI patient is a difficult one. Different studies adopt different criteria in regard to when the first assessment is undertaken. In some studies where follow-up occurs soon after injury those patients who are unable to complete the chosen tests are excluded (Dye et al., 1979). This results in a biased sample of those who are less severely disabled. The most frequent follow-up duration used is approximately 1 year. This is based on the assumption that the majority of recovery occurs soon after injury and is maximised by about 1 year. However a wide variety of follow-up intervals has been used and this has varied from days to years. Levin, Grossman, et al. (1979) reported the findings from a group of severe TBI patients seen between 132 and 3452 days postinjury, Hillier & Metzer (1997) assessed patients 5 years following their injury and Ponsford, Olver, & Curran (1995) interviewed patients 2 years postinjury. Such a wide range of time since injury does not contribute to our understanding of the recovery pattern following TBI. This is particularly so in the case of severe TBI when the period during which significant recovery occurs appears to be longer than in mild or moderate injuries.

A large number of different tests are used by various researchers also making comparability between studies difficult. In addition, inadequate measures of either impairment or outcome have been selected by some researchers (Acker & Davis, 1989; Conzen et al., 1992; Levin, Grossman, et al., 1979; McCleary, Satz, Forney, Light, Zaucha, Asarnow, & Namerow, 1998; Van Zomeren & Van den Burg, 1985)

Previous research has used both cross sectional and longitudinal designs to assess recovery following TBI. Provided that patient dropout rates are keep to a minimum, longitudinal studies provide the most effective means to answer questions concerning recovery following severe TBI.

The Present Study

The present study used a longitudinal design and also addressed other methodological issues. The time period for the first assessment was chosen so as to ensure that as many patients as possible would be able to complete the assessment measures, the second assessment occurred at 1 year postinjury to allow for comparison with a greater proportion of previous research, individual patients were assessed at similar time periods postinjury, a variety of tests with established validity and sampling key domains of functioning were used, and tests with acceptable test-retest reliability were chosen to reduce practice effects.

The first aim of the present study was to determine the nature and severity of the patient's deficits in cognitive, emotional, behavioural, and social functioning in the first year following severe TBI. The second aim was to determine the pattern of recovery of these deficits in the first year following severe TBI. Thirdly, the relationship between cognitive, emotional, and behavioural impairment, with social outcome was examined.

Method

TBI Patients

Of the 84 TBI patients described in Chapter 2, 19 died as a result of their TBI. The remaining 65 patients completed both the 6-month and 1-year follow-up, and constitute the sample reported on here. The TBI patients were assessed, on average, at 201 days (*SD* = 23, range = 153 - 277 days) and 387 days (*SD* = 33, range = 345 - 497 days) postinjury. These assessments are referred to as the 6-month and 1-year follow-up, respectively.

The average age of the patients was 28 years (*SD* = 11, range = 16 - 57 years). Forty-nine (75%) were male. The average premorbid Full Scale IQ of the TBI patient sample was 98.18 (*SD* = 13.26, range = 71 - 123). Results from the Glasgow Outcome Scale indicated that at 6 months postinjury, 20 (31%) patients were severely disabled, 19 (29%) were moderately disabled and 26 (40%) had made a good recovery. At 1 year 19 (29%) patients remained severely disabled, 13 (20%) continued to be moderately disabled and 33 (51%) had made a good recovery. Overall only one patient improved from the severely disabled category to the moderately disabled category, and seven improved from a moderate disability to make a good recovery between 6 months and 1 year.

Measures

As described in Chapter 2, assessment of the TBI patient's cognitive functioning included measures of general intellectual ability, attention, verbal memory, executive functioning, and perceptual functioning. Assessment of psychosocial functioning included measures of depression, behavioural problems, and various aspects of social functioning.

Results

Cognitive Functioning

Table 4.1 presents the number of TBI patients displaying a mild or severe degree of impairment at 6 months and 1 year postinjury. The mean scores on each of the test measures at 6 months and 1 year and the results of *t*-tests undertaken to determine the significance of change is presented in Table 4.2. An improvement was observed for the mean scores on all measures. This reached statistical significant for 9 of the 11 measures. These included the WAIS-R ($p < .0005$), Digit Span ($p = .002$), Digit Symbol ($p < .0005$), Similarities ($p = .001$), Controlled Oral Word Association test ($p < .0005$), Block Design ($p < .0005$), and the immediate ($p = .002$), total learning ($p = .002$), and recognition trials ($p = .048$) of the Auditory Verbal Learning Test (Table 4.2). Although the number of patients who obtained scores within the impaired range decreased on all measures between 6 months and 1 year, the relative proportion of impairment across tests remained the same. At 6 months and at 1 year impairment was most common on the measure of verbal memory. Similarly, the fewest number of patients were impaired on the measure of visual-perception (Block Design) at both assessment periods.

Of note was the differential impact on the two measures of attention and the two measures of executive functioning. On the two measures of attention, fewer patients were impaired on the simpler measure of Digit Span. Similarly, for the two measures of executive functioning more patients were found to be impaired on the more complex measure, the Controlled Oral Word Association test.

A one way ANOVA was undertaken to compare the changes in the patient's performance on the estimate of premorbid Full Scale IQ (mean = 98.18, *SD* = 13.26) and Full Scale IQ scores at 6 months and 1 year postinjury. A statistically significant difference was found between these three Full Scale IQ scores $F(2,128) = 13.44$, $p < .001$. Post-hoc *t*-tests showed that there was a statistically significant difference between the estimated premorbid and 6 month Full Scale IQ scores $t(64) = -4.36$, $p < .0005$, 6 month and 1 year Full Scale IQ scores $t(64) = -4.26$, $p < .0005$, and estimated premorbid and 1 year Full Scale IQ scores $t(64) = -2.55$, $p = .013$. Therefore, on average, Full Scale IQ scores were significantly decreased at 6 months postinjury, recovered between 6 months and 1 year postinjury, but still failed to return to estimated premorbid levels by 1 year postinjury.

Table 4.1. Degree of Cognitive Impairment at 6 Months and 1 Year Postinjury

Variable	Level of impairment Mild	 Severe	 Total
Intelligence-WAIS-R			
6 months	18 (28%)	13 (20%)	31 (48%)
1 year	15 (23%)	9 (14%)	24 (37%)
Attention-Digit Span			
6 months	17 (26%)	12 (19%)	29 (45%)
1 year	18 (28%)	5 (8%)	23 (35%)
Attention-Digit Symbol			
6 months	24 (37%)	21 (32%)	45 (69%)
1 year	21 (32%)	18 (28%)	39 (60%)
Verbal Memory-Auditory Verbal Learning Test			
6 months			
Immediate	13 (20%)	35 (54%)	48 (74%)
Total learning	14 (22%)	29 (45%)	43 (66%)
Retention	9 (14%)	35 (54%)	44 (68%)
Delayed Recall	9 (14%)	32 (49%)	41 (63%)
Recognition	13 (20%)	33 (51%)	46 (71%)
1 year			
Immediate	13 (20%)	28 (43%)	41 (63%)
Total learning	11 (17%)	30 (46%)	41 (63%)
Retention	7 (11%)	29 (45%)	36 (55%)
Delayed Recall	7 (11%)	29 (45%)	36 (55%)
Recognition	7 (12%)	27 (42%)	34 (52%)
Executive-Similarities			
6 months	18 (28%)	11 (17%)	29 (45%)
1 year	19 (29%)	6 (9%)	25 (38%)
Executive-Controlled Oral Word Association test			
6 months	9 (14%)	36 (55%)	45 (69%)
1 year	9 (14%)	27 (42%)	36 (55%)
Visual-Perception-Block Design			
6 months	10 (15%)	16 (25%)	26 (40%)
1 year	12 (18%)	8 (12%)	20 (31%)

Table 4.2 Mean Scores on Measures of Cognitive Outcome at 6 Months and 1 Year Postinjury

Variable	6 months Mean	*SD*	1 year Mean	*SD*	*t*
Intelligence					
WAIS-R	89.68	18.76	93.37	18.60	-4.26*
Attention					
Digit Span	12.17	4.91	13.49	4.43	-3.16*
Digit Symbol	33.94	19.74	39.08	20.99	-5.73*
Verbal Memory					
Auditory Verbal Learning Test					
immediate	5.06	1.95	5.71	2.62	-3.21*
total learning	36.86	15.45	40.00	16.77	-3.30*
retention	6.58	4.62	7.18	4.85	-1.99
delayed recall	6.51	4.76	6.97	5.05	-1.47
recognition	9.51	5.28	10.35	5.59	-2.02*
Executive Functioning					
Similarities	15.25	6.78	16.94	6.18	-3.37*
Controlled Oral Word Association test	27.17	15.19	30.91	15.93	-4.03*
Perception					
Block Design	24.40	16.19	28.06	14.90	-4.03*

*$p < .05$

Emotional and Behavioural Functioning

Depression. The short form of the Beck Depression Inventory was used to determine the presence of depressive symptomatology. At 6 months postinjury, 6 patients were unable to complete the depression rating scale due to the severity of their impairment, and 1 other patient refused. Of the remaining 58 patients, 14 (24%) patients were rated as clinically depressed. Five (9%) reported symptoms consistent with a mild degree of depression and 9 (16%) reported symptoms suggestive of severe depression.

At 1 year postinjury 4 patients continued to display such a severe level of impairment that they were unable to complete the questionnaire while 3 patients refused. Of the 58 remaining patients, 8 (14%) displayed a mild level of depression and 6 (10%) were found to be severely depressed.

There was no statistically significant difference ($t(55) = -.10$, $p > .05$) between the average depression score at 6 months (mean = 3.54, *SD* = 4.39) and 1 year postinjury (mean = 3.61, *SD* = 4.64). Inspection of individual patient's data indicated that 7 patients experienced the same level of depression at both 6 months and 1 year postinjury, 3 experiencing mild depression and 4 experiencing severe depression. Six patients reported an increase in the symptoms of depression between 6 months and 1 year, and 6 patients reported a decrease in the symptoms of depression. One patient who reported a severe level of depression at 6 months refused to fill out the questionnaire at 1 year postinjury.

Behavioural problems. The frequency and distress ratings of self-reported behaviours at 6 months and 1 year postinjury are presented in Table 4.3. The only behaviour to be reported by 50% or more patients at 6 months was impatience (51%). The other most commonly reported behaviours were irritability (49%), argumentative (44%), anger (42%), depression (42%), and difficulty becoming interested (41%). Those behaviours reported by less than 20% of patients were lack of initiative (9%), irresponsibility (12%), aggression (14%), lack of control (15%), complaining (17%), and poor decision making (17%).

Table 4.3. Frequency and Mean Distress Level of Self-Reported Behaviours at 6 Months and 1 Year Postinjury

	6 months		*1 year*	
Item	Frequency	Mean Distress*	Frequency	Mean Distress
Impatience	30 (51%)	2.07	38 (63%)	2.21
Irritability	29 (49%)	2.00	26 (43%)	2.19
Argumentative	26 (44%)	1.69	21 (35%)	2.14
Anger	25 (42%)	2.24	26 (43%)	2.16
Depression	25 (42%)	2.00	28 (47%)	2.18
Difficulty Becoming Interested	24 (41%)	2.13	19 (32%)	2.21
Anxiety	23 (39%)	2.04	26 (43%)	2.31
Lack Motivation	21 (36%)	2.05	16 (27%)	2.19
Overly Sensitive	19 (32%)	2.05	20 (33%)	2.30
Impulsive	17 (29%)	1.94	23 (38%)	2.04
Mood Change	15 (25%)	1.93	15 (25%)	2.40
Dependent	15 (25%)	1.53	13 (22%)	1.85
Poor Insight	13 (22%)	2.00	13 (22%)	1.85
Childishness	13 (22%)	1.85	13 (22%)	2.00
Poor Decision Making	10 (17%)	2.20	14 (23%)	2.00
Complaining	10 (17%)	2.50	13 (22%)	2.39
Lack of Control	9 (15%)	2.44	9 (15%)	1.79
Aggression	8 (14%)	2.13	9 (15%)	1.89
Irresponsible	7 (12%)	2.14	2 (3%)	2.00
Lack of Initiative	5 (9%)	1.80	7 (12%)	2.00

* Note. Distress ratings obtained on a 4-point scale from 1 = no distress to 4 = severe distress

The ranking of the frequency of which problems were reported did not change a great deal between 6 months and 1 year, although there was a tendency for a greater number of patients to report experiencing individual behaviours. TBI patients tended to report an increase in the presence of half of the behaviours identified, and a decrease in the presence of six of the behaviours. Impatience continued to be the most frequently reported item and at 1 year postinjury a further 12% of TBI patients reported this to be present. Impulsiveness and lack of initiative were reported by a further 9% of the group at 1 year. A decrease of the same magnitude was noted for argumentativeness, difficulty becoming interested, and irresponsibility.

There was considerable change in those behaviours that were reported to cause the greatest degree of distress. At 6 months postinjury three of the four (complaining, lack of control, poor decision making) less frequently identified behaviours caused the greatest degree of distress. The exception to this was the higher degree of distress associated with anger. At 1 year postinjury, while impatience continued to be ranked as causing a high degree of distress, the other behaviours causing a higher degree of distress were difficulty becoming interested, anxiety, overly sensitive, and mood changes.

A comparison of the mean number of behavioural problems and mean distress scores at 6 months and 1 year postinjury was undertaken. Although there was an increase in the average number of behavioural problems reported by the TBI patient between 6 months (mean = 5.81, *SD* = 4.30) and 1 year postinjury (mean = 5.95, *SD* = 4.43) this was not statistically significant ($p > .05$). Similarly, the increase in patient distress level between 6 months (mean = 13.10, *SD* = 11.30) and 1 year postinjury (mean = 14.68, *SD* = 11.76) was not statistically significant ($p > .05$).

The Relationship between TBI Patient and Caregiver Reports of the Frequency of Problem Behaviours

An examination of the degree of correspondence between patient and caregiver reports of the frequency of behaviour problems displayed by the patient was undertaken. There was a statistically significant difference between the total number of behaviour problems reported on the Head Injury Behaviour Rating Scale by the patients (mean = 5.91, *SD* = 4.45) and their caregivers (mean = 9.72, *SD* = 5.56) at 1 year postinjury $t(56) = 5.57$, $p < .001$.

The extent to which the two groups differed in their reports of the frequencies of individual items was examined. A chi-square analysis was completed for each item in the Head Injury Behaviour Rating Scale at 1 year postinjury. Given the increased probability of Type I errors occurring because of multiple hypothesis testing, an alpha level of .01 was used to define the critical range of the test statistic.

In all cases the caregivers reported a higher frequency of problem behaviours on the Head Injury Behaviour Rating Scale than the patients. This difference reached statistical significance on 9 of the 20 behaviours (Table 4.4). These included impulsiveness, lack of control, poor decision making, childishness, poor insight, lack of initiative, irresponsibility, overly sensitive, and lack of motivation.

Table 4.4. Comparison Between TBI Patient and Caregiver Reports of Behavioural Problems at 1 Year Postinjury

	TBI Patient		Caregiver		
Item	Yes	No	Yes	No	χ^2
Anger	25 (43%)	33 (57%)	31 (53%)	27 (47%)	1.24
Impatience	37 (64%)	21 (36%)	42 (72%)	16 (28%)	0.99
Complaining	13 (22%)	45 (78%)	22 (38%)	36 (62%)	3.31
Aggression	9 (16%)	49 (85%)	18 (31%)	40 (69%)	3.91
Impulsive	22 (38%)	36 (62%)	37 (64%)	21 (36%)	7.76*
Argumentative	21 (36%)	37 (64%)	32 (55%)	26 (45%)	4.20
Lack of Control	9 (16%)	49 (85%)	22 (38%)	36 (62%)	7.44*
Dependent	13 (22%)	45 (78%)	20 (35%)	38 (66%)	2.08
Poor Decision Making	14 (24%)	44 (76%)	29 (50%)	29 (50%)	8.32*
Childishness	13 (22%)	45 (78%)	34 (59%)	24 (41%)	15.77*
Poor Insight	13 (22%)	45 (78%)	29 (50%)	29 (50%)	9.56*
Difficulty Becoming Interested	19 (33%)	39 (67%)	32 (55%)	26 (45%)	5.91
Lack of Initiative	7 (12%)	51 (88%)	23 (40%)	35 (60%)	11.51*
Irritability	25 (43%)	33 (57%)	28 (48%)	30 (52%)	0.31
Mood Change	15 (26%)	43 (74%)	25 (43%)	33 (57%)	3.82
Anxiety	25 (43%)	33 (57%)	29 (50%)	29 (50%)	0.55
Depression	28 (48%)	30 (52%)	30 (52%)	28 (48%)	0.14
Irresponsible	2 (3%)	56 (97%)	17 (29%)	41 (71%)	14.16*
Overly Sensitive	19 (33%)	39 (67%)	34 (59%)	24 (41%)	7.82*
Lacks Motivation	16 (28%)	42 (72%)	32 (55%)	26 (45%)	9.10*

*$p < .01$

Social Functioning

Employment. The occupational status of the TBI patients prior to their injury, at 6 months, and at 1 year postinjury is presented in Figure 4.1. The most noticeable change was the number of patients who failed to return to work following their injury and consequently became reliant on a government funded benefit as their primary income source.

At 6 months postinjury 13% of those who had been employed prior to their injury had returned to work and at 1 year a further 20% had returned to work. Of the 12 TBI patients who were in paid employment at 1 year, 7 were employed in a full-time capacity, although 2 of these had returned to altered duties. Of those employed at 1 year only 4 (33%) had returned to work by 6 months. Therefore in the current sample the majority of those who returned to work achieved this between 6 months and 1 year postinjury. Despite this, only 30% of those previously employed were in paid employment by 1 year postinjury.

Of the 13 TBI patients who were students prior to their injury, 8 were enrolled in a tertiary institution and the other 5 were attending high school. At 6 months postinjury, 5 (39%) had returned to study and by 1 year 7 (54%) had returned to study. Of the 7 who had returned to study by 1 year postinjury, 2 had returned to high school and 5 had returned to tertiary study. Of the 2 patients who had returned to high school only 1 was enrolled in mainstream classes. The other person was attending high school with maximum support from a teacher aide, and the purpose of his return to school was to provide him with meaningful activities and social contact rather than continuing academic learning. All 5 patients who had returned to tertiary study by 1 year were enrolled in a full-time capacity. Therefore, 54% of those who were previously students had returned to study in some capacity by 1 year postinjury.

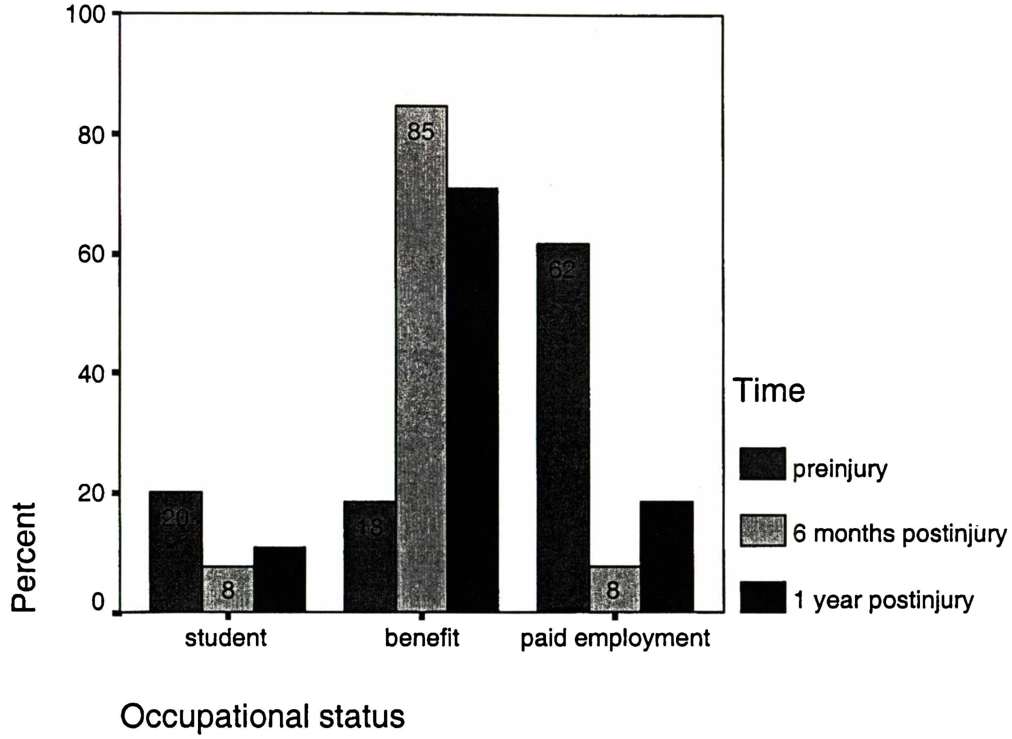

Figure 4.1. Changes in occupational status

Living arrangements. The living arrangements of the TBI patient prior to their injury, at 6 months postinjury, and at 1 year postinjury is presented in Table 4.5. The most noticeable change was the number of patients who were either living alone or in a flatting situation prior to their accident and who had not returned to their previous accommodation by 1 year postinjury. Examination of individual cases indicated that 18 patients who had been flatting prior to their accident had not returned to live alone or in a flat. Fourteen had moved to live with parents, 3 lived with other family members or friends of the family, and 1 person was living in supported accommodation monitored by Mental Health Services. At 6 months postinjury 15 of the 21 patients who had lived with their partner prior to their injury had returned to live with their partner. Of the remaining 6 patients, 4 continued to require institutional care and 2 moved to live with their parents. At 1 year postinjury 4 of those who had initially returned to live with their partner were now living with parents (2) or were living alone or in a boarding situation (2). Of the 4 TBI patients who were in residential care at 6 months, by 1 year postinjury 2 continued to require residential care, 1 returned to live with her parents and 1 returned to live with her husband.

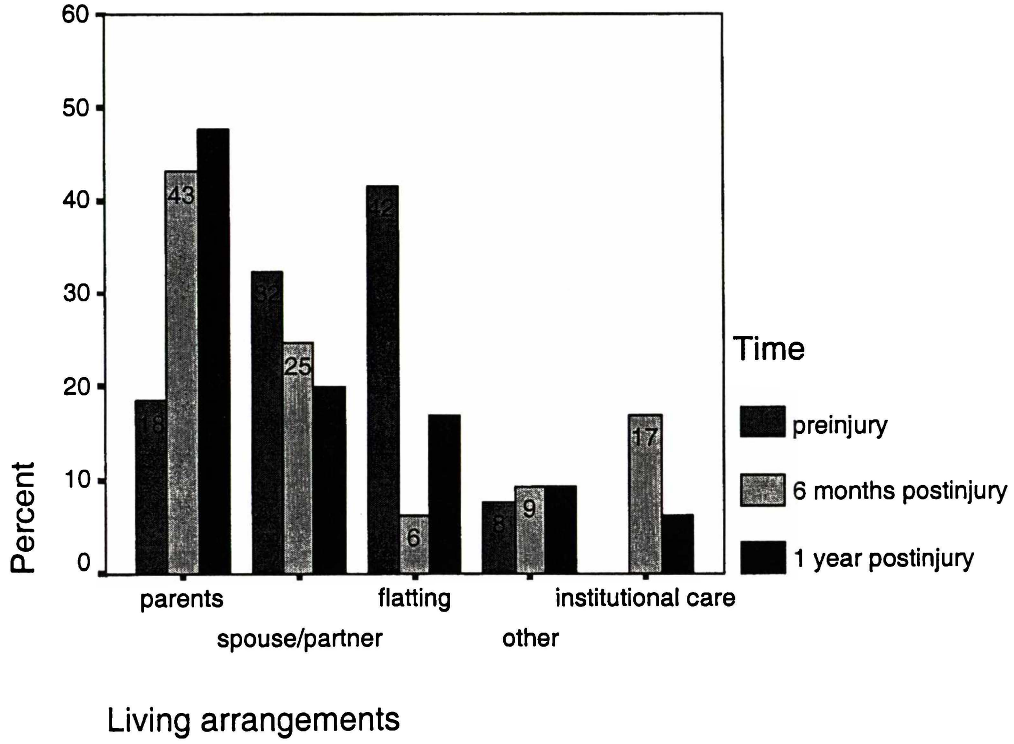

Figure 4.2. Changes in living arrangements

Relationship status. The relationship status of the TBI patient prior to their injury, at 6 months postinjury, and at 1 year postinjury is presented in Figure 4.3. Of note was the number of TBI patients whose relationships dissolved following their injury. For most couples the separation occurred between 6 months and 1 year postinjury.

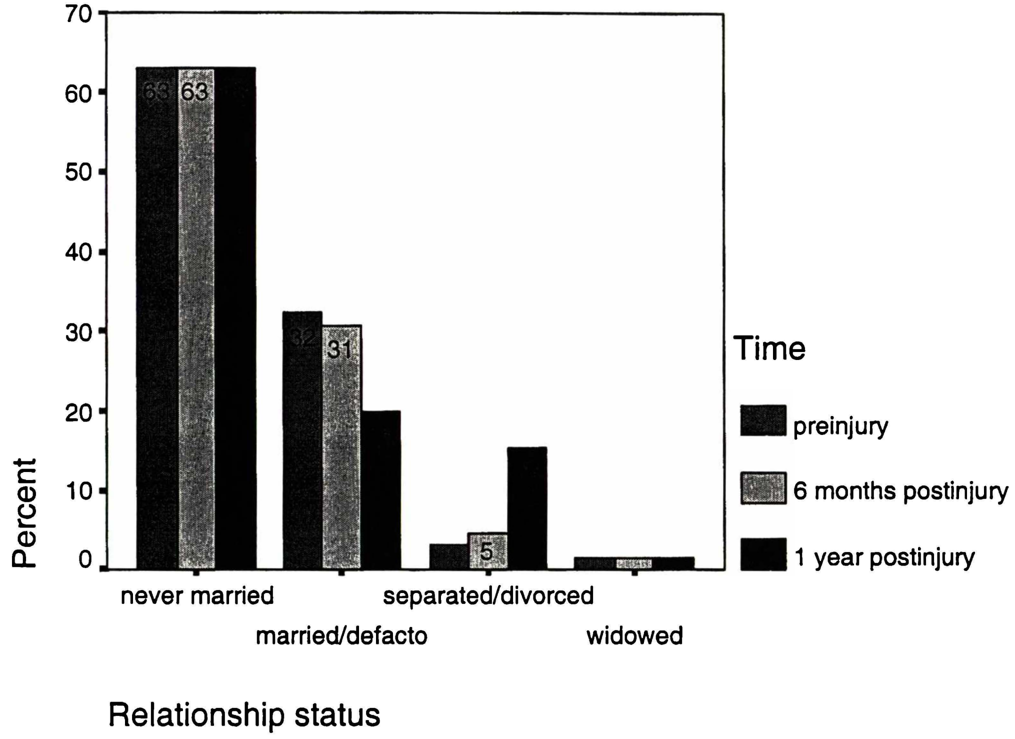

Figure 4.3. Changes in relationship status

Social contact. The number of TBI patients who had social contact with friends and family, and the changes in this area of functioning over the first year following injury, is presented in Table 4.5. At 6 months postinjury fewer TBI patients were reported to entertain friends at home, make visits to see friends, get along with family members, and make visits to see family compared to prior to their injury. The amount of social contact had decreased further by 1 year postinjury. Of the four aspects of social contact considered, the greatest impact was seen in the decrease in the number of visits received from friends.

Table 4.5. Social Functioning Preinjury and at 6 Months and 1 Year Postinjury (*N* = 65)

Characteristic	Preinjury	6 months	1 year
Social Contact			
Receives visits from friends	60 (95%)	39 (62%)	37 (59%)
Makes visits to see friends	63 (100%)	48 (76%)	47 (75%)
Gets along with family	62 (98%)	59 (94%)	57 (91%)
Makes visits to see family	59 (94%)	44 (70%)	43 (68%)
Leisure Activities			
Engages in social activities	60 (95%)	39 (62%)	44 (70%)

Leisure activities. The number of TBI patients who were reported to engage in leisure activities prior to their injury, at 6 months postinjury and at 1 year postinjury is reported in Table 4.5. While TBI patients were reported to participate in fewer leisure activities at 6 months postinjury compared to prior to their injury, an increase in participation was reported between 6 months and 1 year. At 1 year postinjury the number of patients engaging in leisure activities had not returned to premorbid levels.

The Relationship between Cognitive, Emotional and Behavioural Functioning and Social Outcome

The extent to which impairments impact on social outcome has rarely been detailed in previous studies. From a rehabilitation perspective this is one of the most important aspects of planning for patients with severe TBI. The outcome variables used in this study are generally dichotomous in nature. That is, the patient's social outcome postinjury is reported simply as a 'change' or 'no change' compared to their premorbid status. Therefore, following the methodology employed by Godfrey, Bishara, et al. (1993), the patient sample was divided into two groups for each of the social variables at 1 year postinjury. Group membership for each variable was based on whether or not the postinjury status for a particular social variable represented no change from premorbid status or negative change compared to premorbid status.

For each social variable the resulting two groups were then compared for the three matching variables of age, days since injury, and estimated premorbid Full Scale IQ. There were no significant differences between groups on the three matching variables for any of the five social outcome variables (Tables 4.6 - 4.10). The differences between the two groups were examined in terms of five cognitive variables, one emotional variable, and two behavioural variables. The five cognitive variables were intelligence (based on WAIS-R Full Scale IQ), attention (based on the combined raw scores for the Digit Span and Digit Symbol subtests), verbal memory (based on the combined sum, Trail 6, Trail 7, and Recognition scores from the Auditory Verbal Learning Test), executive functioning (based on the combined raw score from the Similarities subtest and the score from the Controlled Oral Word

Association test) and visual-perception (the raw score from the Block Design subtest). The emotional variable was the patient's score on the short-form of the Beck Depression Inventory. The behavioural variables were the frequency of behavioural problems reported by both the patient and the caregiver on the Head Injury Behaviour Rating Scale.

Occupational status. Prior to their injury 40 patients were in paid employment. At 1 year postinjury 12 of these had returned to paid employment and the remaining 28 were unemployed (Table 4.6).

Table 4.6. Differences Between Those Who Remained Employed (*N* =12) and Those Who had Become Unemployed (*N* = 28) at 1 Year Postinjury.

Variable	Employed		Unemployed		
	Mean	*SD*	Mean	*SD*	*t*
Matching variables					
Age	33.58	12.95	31.61	12.54	0.45
Days postinjury	386.67	30.28	386.18	34.59	0.04
NART IQ	106.25	7.25	98.04	14.40	1.87
Cognitive variables					
Intelligence	106.83	15.13	90.89	17.07	2.79*
Attention	66.50	12.13	48.82	27.36	2.83*
Verbal memory	79.75	16.92	57.39	32.46	2.85*
Executive functioning	60.33	9.57	44.21	21.45	3.29*
Visual perception	36.42	7.94	26.43	15.73	2.66*
Emotional/Behavioural variables					
Beck Depression Inventory	2.67	2.50	3.39	3.83	-0.59
Behavioural problems (frequency)					
self-report	3.92	3.60	6.58	4.22	-1.87
caregiver report	6.00	4.05	10.85	5.38	-2.79*

The average scores for the unemployed group were significantly lower on all five cognitive variables. The two groups were not significantly different on the measure of depression. Although there was no difference on the average number of behavioural problems reported by the patients in the two groups, the difference between caregiver reports of number of behavioural problems was significantly different. Caregivers of the employed group reported significantly fewer behavioural problems than caregivers of the unemployed group.

Living arrangements. Changes in the living arrangements of the patients was assessed in terms of whether any change that occurred could be considered to indicate a loss of independence. For example, those who had been living independently in a flat or with a partner premorbidly, but who had returned to live with their parents by 1 year postinjury were considered to have experienced a negative change in their living arrangements.

At 1 year postinjury 35 of the patients had not experienced a change in their living arrangements, whereas the remaining 30 had experienced a change that reflected a loss of independence from premorbid status (Table 4.7). The average scores for those who had experienced a change in living arrangements were significantly lower on four of the five cognitive variables. There was no statistically significant difference on the fifth cognitive variable of visual-perception. The two groups were not significantly different on the measure of depression, or the two measures of behavioural problems.

Table 4.7. Differences Between Those Whose Living Arrangements Remained the same ($N = 35$) and Those Who Required a Change in Their Living Arrangements ($N = 30$) at 1 Year Postinjury.

Variable	No Change Mean	No Change *SD*	Change Mean	Change *SD*	*t*
Matching variables					
Age	28.74	13.11	28.10	8.58	0.24
Days postinjury	388.11	31.01	386.63	35.73	0.18
NART IQ	97.63	14.66	98.83	11.62	-0.36
Cognitive variables					
Intelligence	98.91	17.20	86.90	18.35	2.72*
Attention	59.91	18.73	44.00	26.12	2.78*
Verbal memory	72.66	27.22	55.00	32.24	2.40*
Executive functioning	54.57	17.52	40.00	21.64	2.60*
Visual perception	31.37	12.89	24.20	16.33	1.94
Emotional/Behavioural variables					
Beck Depression Inventory	2.97	3.30	4.38	5.93	-1.15
Behavioural problems (frequency)					
self-report	5.46	4.50	6.33	4.35	-0.74
caregiver report	8.79	5.59	10.83	5.02	-1.51

Visits to friends. For 19 patients there had been a decrease in the frequency with which they visited friends, and for 39 patients there had been no change in this behaviour (Table 4.8). The average scores for the group whose visits to friends had decreased were significantly lower on all five cognitive variables. There were no statistically significant differences between the two groups on the emotional/behavioural variables.

Table 4.8. Differences Between Those Who Continued to Make the Same Number of Visits to Friends ($N = 19$) and Those Who had a Decrease in the Number of Visits They Made to Friends ($N = 39$) at 1 Year Postinjury.

Variable	No Change Mean	No Change *SD*	Change Mean	Change *SD*	*t*
Matching variables					
Age	31.21	11.40	27.95	11.74	1.00
Days postinjury	394.58	33.98	382.72	33.91	1.25
NART IQ	101.89	13.00	96.03	13.95	1.54
Cognitive variables					
Intelligence	102.95	16.85	88.26	17.33	3.06*
Attention	61.11	15.00	48.69	24.74	2.34*
Verbal memory	77.89	20.47	56.21	32.64	3.09*
Executive functioning	57.68	16.78	42.97	21.07	2.66*
Visual perception	33.26	11.98	25.82	15.39	2.02*
Emotional/Behavioural variables					
Beck Depression Inventory	2.26	2.88	4.58	5.43	-1.72
Behavioural problems (frequency)					
self-report	4.68	4.06	6.56	4.76	-1.45
caregiver report	8.32	5.87	10.62	5.20	-1.52

Visits from friends. For 36 patients there had been a decrease in the frequency of visits from friends, while for 22 there had been no change (Table 4.9). There was no statistically significant difference between the two groups on the five cognitive variables, but the two groups did differ on the three emotional/behavioural variables. Those who received less visits from friends reported higher depression and more behavioural problems, and were considered by their caregivers to have a higher frequency of behavioural problems.

Table 4.9. Differences Between Those who Continued to Receive the Same Number of Visits From Friends (*N* = 22) and Those who had a Decrease in the Number of Visits They Received From Friends (*N* = 36) at 1 Year Postinjury.

Variable	No Change Mean	No Change *SD*	Change Mean	Change *SD*	*t*
Matching variables					
Age	30.45	12.40	28.28	11.15	0.70
Days postinjury	389.45	34.70	384.64	34.19	0.52
NART IQ	102.36	10.67	95.58	15.26	1.83
Cognitive variables					
Intelligence	98.91	20.73	90.42	17.71	1.66
Attention	55.45	19.90	50.72	25.03	0.75
Verbal memory	67.59	29.96	60.17	31.24	0.89
Executive functioning	53.64	20.19	45.08	21.41	1.51
Visual perception	31.05	14.25	26.44	15.28	1.14
Emotional/Behavioural variables					
Beck Depression Inventory	1.71	1.93	5.06	5.63	-3.06*
Behavioural problems (frequency)					
self-report	4.19	3.86	6.97	4.71	-2.30*
caregiver report	7.05	4.78	11.56	5.20	-3.30*

Social activity. For 26 patients there had been a decrease in their level of social activity, whereas for 31 patients their level of social activity at 1 year postinjury remained the same as prior to their injury (Table 4.10). The two groups were significantly different on the cognitive variable of verbal memory and number of behavioural problems reported by the caregiver. Therefore those whose level of social activity had decreased had poorer verbal memory and were considered by their caregivers to have more behavioural problems.

Table 4.10. Differences Between Those Whose Level of Social Activity Remained the Same (*N* = 26) and Those Who had a Decrease in Their Level of Social Activity (*N* = 31) at 1 Year Postinjury

Variable	No Change		Change		
	Mean	*SD*	Mean	*SD*	*t*
Matching variables					
Age	28.04	11.04	30.03	12.30	-0.64
Days postinjury	384.04	29.27	385.06	33.90	-0.12
NART IQ	100.62	12.93	96.00	13.76	1.30
Cognitive variables					
Intelligence	97.00	18.50	88.58	17.14	1.78
Attention	56.38	21.31	46.84	25.15	1.53
Verbal memory	71.27	28.45	53.58	31.91	2.19*
Executive functioning	52.00	21.81	42.45	20.41	1.71
Visual perception	30.92	14.75	24.97	15.09	1.50
Emotional/Behavioural variables					
Beck Depression Inventory	4.04	5.68	3.59	3.92	0.33
Behavioural problems (frequency)					
self-report	5.70	4.33	6.43	4.73	-0.57
caregiver report	8.00	5.06	11.81	5.15	-2.80*

Discussion

Cognitive Functioning

Results from the current study reflect the pervasive impact of severe TBI across many different areas of cognitive functioning. At least 40%, and up to 74%, of TBI patients displayed some degree of impairment on tests administered at 6 months postinjury. Different areas of cognitive functioning were affected to a different degree. At 6 months postinjury the greatest prevalence of impairment was on measures of verbal memory, complex attention (Digit Symbol), and some aspects of executive functioning (Controlled Oral Word Association test).

Improvement was found to occur in all areas of cognitive functioning over the first year following injury. Despite this recovery the differential impact on various aspects of cognitive functioning remained apparent over time. Therefore at 1 year as at 6 months, impairment was most frequently observed in the areas of verbal memory, complex attention (Digit Symbol), and executive functioning (Controlled Oral Word Association test). The areas of general intelligence, perception, and aspects of attention (Digit Span) and executive functioning (Similarities) were least affected at both 6 months and 1 year postinjury.

General intelligence. A number of studies have used the Wechsler Adult Intelligence Scales (WAIS, WAIS-R) to assess recovery of general intellectual function following severe TBI. A consistent pattern of recovery has been reported in which scores on verbal subtests recover to normal within a year of injury, with scores on performance subtests showing a similar but slower recovery over a longer period (Bond, 1975; Drudge et al., 1984; Dye et al., 1979; Mandleberg & Brooks, 1975). The most common explanation for the differential recovery of these abilities is that performance items require the integration of more complex cognitive functions than verbal tasks that are structurally simpler. Therefore recovery of performance abilities occur at a slower rate.

A direct comparison of recovery between verbal and performance skills was not made in the present study as the short form of the WAIS-R was used. Despite this, the overall pattern of recovery observed in the current study was consistent with that reported in previous literature in that a significant improvement was found in the mean Full Scale IQ scores between 6 months and 1 year postinjury. However, when the Full Scale IQ scores obtained at 1 year were compared with the estimated premorbid Full Scale IQ scores a significant difference remained between the scores, suggesting that as a group the mean Full Scale IQ of the TBI patients had not recovered to premorbid levels. The current findings support those obtained by Hellawell, Taylor, & Pentland, (1999), however the current study obtained much higher follow-up rates and these results can be therefore be seen as more reliable.

This incomplete recovery is reflected in the number of TBI patients who continued to display a significant degree of impairment at 1 year postinjury. Thirty-seven percent of the TBI group continued to obtain scores suggestive of impairment, with 14% of these in the severely impaired range. Of those patients who continued to score in the severely impaired range, the majority had estimated premorbid Full Scale IQ scores in the average range of ability. Therefore this represents a significant decline from premorbid functioning for these individual patients.

Many studies have defined recovery to premorbid levels of general intellectual functioning as a return to a Full Scale IQ score that is within one standard deviation of the mean (Bond, 1975). Alternatively, they have compared the obtained scores of the TBI group with those of a comparison group (Drudge et al., 1984; Mandleberg & Brooks, 1975). A more precise picture of the recovery of general intellectual ability following severe TBI is afforded by the current study that compared obtained Full Scale IQ with a valid estimate of premorbid Full Scale IQ. Therefore while some previous studies have documented a full recovery of Full Scale IQ, these studies have used less precise measures to determine the level at which Full Scale IQ could be considered to have returned to 'normal'.

Attention. In the current study attention was assessed by administration of the Digit Span and Digit Symbol subtests of the WAIS-R. On the Digit Span subtest almost half of the TBI patients had scores indicating impairment at 6 months. A statistically significant improvement in the mean score obtained by the group occurred between 6 months and 1 year although one-third of TBI patients continued to obtain scores in the impaired range on the Digit Span subtest at 1 year postinjury. An even greater proportion of TBI patients were found to be impaired on the Digit Symbol subtest. Overall, a greater proportion of TBI patients obtained scores in the severely impaired range on the Digit Symbol subtest at both assessment periods, compared to scores obtained on the Digit Span subtest.

These findings are consistent with those reported by Mandleberg and Brooks (1975) and Shum et al. (1990) who both reported significant impairment among TBI patients on the Digit Span and Digit Symbol subtests. Shum et al. reported a significant difference between the severe TBI patients and a control group on the Digit Span and Digit Symbol subtests at approximately 2 months postinjury, although this difference was no longer apparent on the Digit Span subtest at approximately 2 years postinjury. In contrast, the performance of the TBI group on the Digit Symbol subtest was significantly different from that of the control group at both assessment periods. Similarly, Mandleberg and Brooks also found a significantly lower performance by TBI patients on both the Digit Span and Digit Symbol subtests at 0 to 3 months, 4 to 6 months and 7 months to 1 year postinjury. These authors suggested that the Digit Symbol subtest was more sensitive to the effects of TBI than the Digit Span subtest.

The findings of the current study are consistent with this previous research and suggest that severe TBI patients display impairment on both the Digit Span and Digit Symbol subtests, with a more gradual recovery occurring on the Digit Symbol subtest. The most obvious conclusion that can be drawn from this is that the Digit Symbol subtest is a more complex task than the Digit Span subtest and hence the greater prevalence of impairment and slower rate of recovery. The specific aspects of the task that make it more complex remain undefined. It may simply be that successful performance on the Digit Symbol subtest requires the integration of a greater number of cognitive processes and the diffuse organic damage which results from TBI means that there is a higher probability that a cognitive process related to performance on the Digit Symbol subtest will be disrupted. Analysis of the processes involved in completing these two tasks have indicated that performance on the Digit Span requires intact auditory attention and short-term memory capacity. In contrast, performance on the Digit Symbol involves motor speed and dexterity, visual search and scanning, sustained attention, visual memory rather than verbal memory, and an ability to alternate between different tasks. In addition, the Digit Symbol subtest, unlike the Digit Span subtest, has a time requirement for completion. This adds the further dimension of speed of processing to this test.

Verbal memory. One of the most commonly cited consequences of severe TBI reported by both the TBI patient and their family is memory impairment. Objective assessment of memory functioning with standardised tests has confirmed this complaint.

In the present study the Auditory Verbal Learning Test was used to assess verbal learning and memory. This test is sensitive to different aspects of memory including immediate memory (Trial I), simple learning (total words recalled over five trials), retention following an interference trial (Trial VI), delayed recall (Trial VII) and a recognition trial. In the current study more than 50% of TBI patients displayed some level of impairment on all trials of the Auditory Verbal Learning Test at both 6 months and 1 year postinjury. For the majority of these patients the level of impairment was classified as severe. Significant improvement was noted on all trials, except the retention and delayed recall trials, between 6 months and 1 year postinjury. Therefore, while on average, the TBI patients ability to learn verbal material improved, their ability to retain the information they had learnt did not. It is the ability to retain new information over time that has the greater functional importance. From a practical perspective, therefore, the TBI patient's verbal memory abilities could not be considered to have improved in the first year postinjury.

The current findings are similar to those reported by other researchers. Lezak (1979) administered the Auditory Verbal Learning Test to a group of 24 TBI patients and found that at 6 months postinjury 61% of patients were impaired on Trial I, and 94% were impaired on Trial V and Trial VI. At 1 year there had been little change with 52% displaying impairment on Trail I, 78% on Trail V and 87% on Trial VI. Similar to the findings of the current study, Lezak reported no statistically significant improvement on the retention trial between 6 months and 1 year postinjury.

For the majority of severe TBI patients the impairment in recall of new information that is evident at 6 months postinjury will continue to be evident to a relatively similar degree at 1 year. Analysis of performance on the recognition trial of the Auditory Verbal Learning Test allows the clinician to determine whether an individual's memory impairment results from deficits in recall (i.e., the material has been learnt but there are problems in accessing it) or retention (i.e., the material has not been adequately stored in memory and therefore is not available to be accessed). This distinction has important implications for rehabilitation. People who have memory difficulties due to impaired recall can be assisted by programmes which involve the use of cues and similar behavioural procedures. Those whose difficulties result from impaired retention are less likely to benefit from the use of such procedures, and in fact, being expected to use such strategies can result in increased frustration for them.

For the patients in the current study, analysis of their performance on the recognition trial of the Auditory Verbal Learning Test showed that for those who were impaired on the recognition trial, 61% had difficulties with recall and the remaining 39% with retention. However, this was not consistent across the impairment categories, and difficulties with retention were more prevalent in the severely impaired group than in the mildly impaired group (42% and 29% respectively). Unfortunately the implications of this are that those with more severe memory impairments are less likely to benefit from the strategies commonly offered in memory rehabilitation programmes

Executive functioning. Executive functioning refers to a multidimensional construct that describes a number of loosely related higher-order cognitive processes (Spreen & Strauss, 1991). It encompasses such abilities as decision making, judgment and reasoning, cognitive flexibility, self-regulation, self-awareness, planning and problem solving. Impairment across the different cognitive processes involved in executive functioning is variable, but is understood to have a significant impact on the day-to-day functional abilities of the TBI patient. The description and measurement of executive functioning continues to be a major challenge for neuropsychologists, particularly given the impact it has on the person's ability to function in an independent manner (Lezak, 1993).

In the current study the Similarities subtest and the Controlled Oral Word Association test were used to assess executive functioning. Improvement was noted on both measures between 6 months and 1 year postinjury. Despite this, a significant number of patients continued to display impairment at 1 year postinjury.

The Similarities subtest is understood to be primarily a measure of verbal concept formation. The person is required to make verbal abstractions and generalisations in relation to apparently dissimilar objects or concepts. Research has found poor performance on the Similarities subtest to be associated with bilateral frontal lesions. Positron emission tomography studies investigating glucose metabolism in the brains of normal subjects while completing the Similarities subtest have found increased activity in the left temporal and frontal areas (Lezak, 1983).

The results obtained from administration of the Similarities subtest in the current study are inconsistent with previous research. Previous research has suggested that few TBI patients display impairment on this measure, and if impairment is evident it is resolved by 1 year postinjury. Mandleberg and Brooks (1975) found no difference between the scores of the TBI group and the comparison group on the

Similarities subtest at any time up to 1 year postinjury. While Drudge et al. (1984) found that their group of TBI patients obtained lower scores than the control group on the Similarities subtest at approximately 2 months postinjury, this difference had resolved by 1 year. A possible explanation for the different findings may be found in the comparison groups used in the Mandleberg and Brooks and Drudge et al. studies. In both studies the comparison groups included people who had relatively serious psychiatric diagnoses. It is possible that their performance on cognitive tests was detrimentally affected by their psychological state and therefore no significant difference may have been found between the groups.

The number of TBI patients displaying impairment on the Controlled Oral Word Association test and the degree of that impairment was of particular concern. Of those displaying impairment at 6 months, 55% obtained scores in the severe range and at 1 year postinjury 42% continued to obtain scores in the severe range.

The results obtained for the TBI patients' performance on the Controlled Oral Word Association test are consistent with those reported in previous literature. Impairment of verbal fluency appears to be a common and pervasive sequelae of severe TBI. Levin, Grossman, et al. (1979) reported that approximately 70% of their sample of severe TBI patients obtained defective scores on this test, and Ruff et al. (1986) reported that their group of severe TBI patients obtained significantly lower scores than the control group on the same measure.

In their 1986 paper Ruff et al. discussed the possible cognitive mechanisms by which TBI patients displayed impaired functioning on the Controlled Oral Word Association test. They suggested that there are three commonly used strategies employed in word fluency tasks to facilitate the recall of words (a) choosing words that begin with various combinations of letters, such as, FA, FU, FE; (b) defining a higher order classification starting with a certain letter, such as items of clothing, food, animals (c) making associations between words, for example, sun-shine, shoe-sole. Ruff et al. reported that impairment on this test results primarily from an inflexibility in processing. That is, the TBI patient is unable to take advantage of using more than one strategy because the lack of cognitive flexibility renders them unable to switch between or within the different strategies. Ruff et al. discounted the presence of aphasia in their sample and found no relationship between scores obtained on tests of memory, and verbal fluency.

Inspection of the test profiles of the TBI patients in the current study supported the hypothesis put forward by Ruff et al. (1986). Few of the patients in the current study used more than one of the strategies described by Ruff et al., and even when a particular strategy was used it was not used in a consistent manner. Interestingly, the majority of patients in the current study rarely used any of the strategies. This was more evident in those whose performance was extremely poor. This may suggest that for many patients, not only are they unable to maintain or switch between strategies, but they are unable to even develop a strategy or planned approach to a task.

Overall, the results from the current and previous studies demonstrate that the Controlled Oral Word Association test is sensitive to the effects of brain injury. Use of the framework proposed by Ruff et al. (1986) allows for further qualitative as well as quantitative analysis of individual performances. The development and use of such theoretically-derived frameworks will allow the nature of the impairment that is reflected in the test performance and its functional implications for the person to be determined.

Visual-perception. Ongoing impairment of visual-perception was evident in almost half of the severe TBI patients assessed in the current study, with the majority of patients displaying severe impairment. While a statistically significant improvement in scores was found between 6 months and 1 year postinjury, one-third of the total sample continued to display impaired performance in this area of cognitive functioning.

Previous studies investigating the prevalence and recovery of visual-perceptual impairment following severe TBI have tended to suggest that these abilities return to normal levels by 1 year following injury. Brooks and Aughton (1979a), and Mandleberg and Brooks (1975), found that the visual-perceptual functioning in their severe TBI group was impaired when assessed soon after injury, but that this had improved to similar levels as the comparison group by 1 year. However, as already noted the comparison group used in the Mandleberg and Brooks study included people who had relatively serious psychiatric diagnoses and therefore this may not have been the most appropriate comparison group. Levin et al. (1990) also found the performance of TBI patients as a group, returned to within normal limits by 1 year postinjury. Unfortunately, the study reported by Levin et al. included TBI patients with varying degrees of severity from mild through to severe, making direct comparison of results difficult.

In a more recent study by Conzen et al. (1992) evidence of continuing impairment of visuospatial abilities was found in a group of 37 severe TBI patients at 15 months postinjury. The purpose of the Conzen et al. study was to assess for the presence of cognitive impairment in a group of severe TBI patients who had in fact made a good recovery. Therefore, given that this group of TBI patients who had made a good recovery were experiencing ongoing impairment, it is likely that other TBI patients whose outcome was not so positive would also be displaying these difficulties.

Summary of cognitive outcome. Overall severe TBI results in pervasive deficits across a wide range of cognitive functions, and this perhaps underlines the diffuse nature of the damage that results from a TBI. More recent research by Dikmen et al. (1995) also provides evidence that those who had sustained more severe injuries experienced more severe and pervasive impairment on a range of neuropsychological tests 1 year postinjury. While improvement was noted on all measures between 6 months and 1 year postinjury a high prevalence of cognitive deficits continued to be observed at 1 year postinjury. Furthermore, the frequency of impairment and degree of recovery across the various cognitive domains differs. On average, at 1 year postinjury, a greater number of TBI patients displayed impairment on measures of verbal learning, complex attention, and verbal fluency than on measures of general intelligence, simple attention, and perceptual abilities.

An understanding of the type of impairments displayed by TBI patients and the natural recovery of these impairments enables the development of a more precise rehabilitation plan. Given the findings of the current study it is likely that many TBI patients presenting for rehabilitation, even 1 year following their injury, will display impairment of verbal learning, complex attention, and verbal fluency. In addition, it is likely that the natural recovery of these functions is beginning to slow and is becoming closer to the eventual optimum level of recovery. Fewer patients will present with difficulties of general intelligence, simple attention, and perceptual abilities. A comprehensive assessment of cognitive functioning will determine the extent of impairment and provide information that forms the basis of the rehabilitation plan.

While the frequency and pattern of recovery of cognitive impairment following severe TBI is important, the specific cognitive processes involved in these tasks remains unclear. Most tests can be conceptually defined in terms of the broad cognitive function that they measure. However, it is generally accepted that most tests measure more than one specific cognitive function. Further research is required to identify the discrete functions required to successfully complete a task. To provide even more concise and relevant information for rehabilitation we must be able to isolate these discrete functions. This will enable a better understanding of cognitive processes and allow more accurate investigation of the relationship between performance on cognitive tests and ability to perform everyday tasks.

Emotional and Behavioural Functioning

The development of depression following acquired disability, particularly in neurologically impaired populations, is well established. While depression has been investigated in many neurological disorders, for example, stroke, dementia, and multiple sclerosis, comparatively little research has been undertaken on the prevalence of depression in TBI populations.

Many studies assessing for the presence of depression following severe TBI have relied on the reports of a significant other, usually a relative, who it is assumed, will provide a more reliable assessment of the situation. This relies on the relatives understanding and knowledge of depression, their knowledge of the TBI patient, and assumes that their opinion is not biased by their own subjective well-being. The final point is of particular concern given the current understanding that relatives tend to experience increased levels of depression themselves as a function of caring for the TBI patient. In addition, Tyerman and Humphrey (1984) noted that "Whilst accurate self-appraisal of the severely head injured will be limited by cognitive impairment (especially lack of insight), it is the subjective impairment which represents distressing reality for these patients and dictates their psychological adjustment." (p. 14).

Of those studies that have included an interview with the TBI patient, only a few have used standardised scales to assess for the presence of depression. In the current study the short form of the Beck Depression Inventory was administered to the TBI patients, and their responses were interpreted using normative data from a New Zealand sample. The prevalence of depression in the current study is lower than has been reported in previous literature. Tyerman and Humphrey (1984) reported the prevalence of depression to be 60% in their sample and Kinsella et al. (1988) reported a prevalence of 33%. Both studies used the Leeds Scale of Depression. Levin, Grossman, et al. (1979), using the Brief Psychiatric Rating Scale found that 37% of their sample were rated as depressed. Possible explanations for the discrepancies can be found in the description of the relative samples. The TBI patients in the Tyerman and Humphrey study were selected from a group of patients who were attending a rehabilitation centre. This may represent a biased group in that their need for rehabilitation may suggest that they are having greater difficulties, including depression. In addition, the severity of injury in the Tyerman and Humphrey group was less homogeneous, and ranged from mild to severe, with 28% of the patients having experienced a mild TBI. The follow-up period in the Levin et al. study ranged from 5 months to 9 ½ years which does not allow for an accurate estimation to be made of the prevalence of depression at specific times postinjury.

There has been some suggestion in previous literature that the presence of depression among TBI patients increases with time (Brooks et al., 1987; Fordyce et al., 1983). The findings of the current study do not support this suggestion as a general rule. Indeed, the current results indicate a large amount of individual variation in the occurrence and recovery of depressive symptomatology. Half of the TBI patients who were depressed at 6 months reported a lessening of symptoms or full recovery by 1 year postinjury. No patients reported a worsening of symptoms between 6 months and 1 year postinjury. Only 6 (10%) new cases of clinical depression were reported at 1 year postinjury. Some authors have argued that depression following TBI is a logical reaction to the losses and frustration that occur as a consequence of their injury (Brooks et al, 1987; Van Zomeren & Van den Burg, 1985). The comments of some the TBI patients in the current study lend support to this suggestion. Some TBI patients were able to identify significant events or consequences of their injury that had resulted in them feeling despondent and hopeless about their future. For example, one patient who was successfully involved in a return to work programme as a truck driver had developed epilepsy and had been told that he would be unlikely to return to that occupation again. Another had attempted to return to study, but after 3 months they found they were not able to cope and had resigned themselves to not being able to complete their degree. Still another patient had experienced a psychotic episode that required emergency admission to the psychiatric unit. This had been an unexpected and frightening situation for the patient. Each person said that these events had left them feeling less hopeful and uncertain about the future.

In contrast, similar events had also occurred for other people in the study, but a clinical depression had not similarly developed for them. The presence of depression therefore cannot be associated simply with losses or negative events relating to the injury, but is likely to be affected by among other things, the patients expectations, their level of support, and their premorbid coping strategies.

It is interesting to note that at 1 year postinjury while only 24% of TBI patients reported symptoms consistent with clinical depression on the short form of the Beck Depression Inventory, 47% of patients reported experiencing the presence of depression on the Head Injury Behaviour Rating Scale. A similar trend was evident at 6 months postinjury also. This highlights the difference between the presence of a clinical depression and the general "feeling" of being depressed or sad that was expressed by the TBI patients. While it can be assumed that the symptoms associated with a clinical depression will be significant enough to affect the person's ability to participate in everyday activities, including rehabilitation, the relationship between the TBI patient's reports of "feeling" depressed and their ability to be involved in such tasks is unclear. Further research is required to delineate this relationship. Neuropsychologists working with patients with TBI should be aware that the absence of a clinical depression does not preclude the patient from "feeling" depressed, and careful assessment must be undertaken to define in what way this may be influencing the patient's behaviour.

The Head Injury Behaviour Rating Scale is a 20-item self-report measure that allows for the description of various problem behaviours that have been previously identified as sequelae of severe TBI. In addition, it allows for a comparative analysis of the level of distress caused by the presence of such problems. In a longitudinal study such as this it also provides a means by which to assess changes in the prevalence of behavioural problems and their associated distress over time.

At 6 months postinjury at least one-third of the TBI patients reported experiencing almost half of the items on the scale. Impatience was the most frequently reported followed by irritability, argumentativeness, anger, depression, and difficulty becoming interested in things. The least frequently identified items were lack of initiative, irresponsibility, aggression, lack of control, complaining, and poor decision making. Little change occurred in the reported frequency of problem behaviours between 6 months and 1 year postinjury. In addition, those behaviours reported most frequently and those behaviours reported least frequently remained relatively similar.

While the behaviours reported by the TBI group in the current study have frequently been reported in the TBI literature there is little agreement on the prevalence of such behaviours, and the manner in which the pattern of behaviours change over time. Many studies poorly define the particular behaviours being studied, and there does not appear to have been any attempt to assess the degree of distress associated with the presence of these behaviours for the TBI patient.

Because the behaviours under scrutiny are often poorly defined, comparison between studies is difficult. Both Dikmen and Reitan (1977) and Fordyce et al. (1983) reported the presence of ongoing behavioural and emotional difficulties in their respective samples at 1 year postinjury. However, their use of the Minnesota Multiphasic Personality Inventory results in them reporting a group of behaviours clustered under one heading rather than specific behaviours. Of the previous research that has defined behaviours more precisely most have examined only a small number of behaviours. McLean et al. (1984) administered a symptom checklist that included only three items relating to behaviour. The symptom checklist was administered at 1 month postinjury and they reported a higher prevalence of irritability and anxiety in their sample than that found in the present study. A direct comparison between the results reported by McLean et al. and the current results is not possible because of the different follow-up periods employed.

Studies carried out by Oddy et al. (1978b) at 6 months postinjury and Tyerman and Humphrey (1984) at approximately 7 months postinjury also precisely defined the behaviours to be studied, but again only included a small number of behaviours for analysis. When compared to findings obtained in the current study, Oddy et al. reported a lower prevalence of irritability (29%), impatience (27%), and difficulty becoming interested in things (21%). In contrast, Tyerman and Humphrey reported a much higher prevalence of aggression (36%) and depression (60%) among their sample compared to the current study where only 14% reported aggressive behaviour and 42% reported the presence of depression at 6 months postinjury.

Many studies that have investigated the prevalence of behavioural problems following severe TBI have recorded the frequency with which TBI patients report these difficulties. Implicit in many of these studies is the assumption that the self-report of a particular behaviour indicates an associated degree of distress. In the current study the degree of distress associated with the presence of a particular behaviour was assessed. The behaviours that caused the most distress were not necessarily the most frequently reported behaviours. For example, a higher degree of distress was reported for less frequently identified items such as complaining, lack of control, and poor decision making when compared to the more frequently reported items of argumentativeness, irritability, and impatience.

While there was no statistically significant difference between the mean distress score for the group between 6 months and 1 year, those behaviours reported to cause the most distress for the TBI patient changed over time. Those behaviours reported to cause the greatest degree of distress at 6 months could be categorised as externalising behaviours while at 1 year postinjury the TBI patients reported problem behaviours that could be categorised as internalising behaviours. This may represent a change in the TBI patient's perception of their difficulties (possibly representing an increase in insight) and their response to these problems. This has important implications for rehabilitation in that it emphasises the importance of investigating which problem behaviours cause the greatest degree of distress for the TBI patient.

The extent to which TBI patients can accurately report on their postinjury behaviour and compare this to their preinjury behaviour has been the subject of much debate. McKinlay and Brooks (1984) suggested that the agreement between patients and caregivers is generally high in relation to physical and cognitive deficits, but that less agreement is found on emotional and behavioural problems. This has lead to a reliance on reports from caregivers to determine behavioural change in the patient. While some research has supported the findings of McKinlay and Brooks (Thomsen, 1974), others have reported closer agreement between the TBI patient and their caregiver (Elsass & Kinsella, 1987; Fordyce et al., 1983; Oddy et al., 1978b).

In the current study the caregivers reported a higher frequency of problem behaviours on all items of the Head Injury Behaviour Rating Scale than the patients, although this difference reached statistical significance on only 9 of the 20 items. A difference was apparent in the type of items on which the patient and caregivers most frequently differed. For example, the patient and caregiver agreed on the frequency of behaviours related to mood change. Therefore, there was agreement on items related to anxiety, depression, and degrees of anger from irritability through to aggression. Disagreement occurred more frequently on items that can be more directly related to the TBI patient's degree of insight. These included items such as irresponsible behaviour, impulsiveness, lack of control, and poor decision making. It may be that the TBI patient and caregiver differ in their reports of behavioural problems according to the type of behaviour that is being enquired about. While the TBI patient may be able to self-monitor and accurately report on their emotional state, they are less able to accurately report other behaviours. In particular, these appear to be behaviours that are associated with self-monitoring and self-regulation.

Therefore the disagreement between researchers concerning the ability of TBI patients to accurately report on their own behaviour may be a consequence of the type of behaviour that is being asked about. In the current study there was a high level of agreement for behaviours associated with emotional functioning, and a low level of agreement on behaviours associated with executive functioning.

Social Functioning

TBI can also impact on an individual's wider social functioning. Issues of relevance here are employment, income, living arrangements, relationship status, and social activities. Although there has been criticism in the literature regarding the emphasis placed on return to work as a measure of outcome, the return to employment is central to social reintegration for the TBI patient. Figures reflecting the proportion of TBI patients that return to work vary widely in the literature. Even when consideration of studies is confined to those that have investigated TBI patients who have experienced a severe TBI and that assess the patient within 1 year of injury the return to work figures still vary from 50% to 80%. The studies by Oddy and colleagues (Oddy & Humphrey, 1980; Oddy et al., 1978b) reported that 64% of their sample of 45 severe TBI patients had returned to work by 6 months and this increased to 80% by 1 year postinjury. This contrasts significantly with the findings of the current study where 13% of the sample had returned to work at 6 months and only 30% had returned to work by 1 year. The sample described by Oddy et al. was much younger, with ages ranging from 16 to 39 years, while those in the current sample were from 16 to 57 years of age. However, even when those 40 years of age and older were taken out of the current study the percentage of patients returning to work did not increase. Other studies, for example Hpay (1971) who interviewed 58 TBI patients at 6 months and again at 1 year postinjury reported the rate of return to work to be 34% at 6 months and 50% at 1 year. Although Hpay reported the severity of TBI to be severe for the group, it was noted that in 14 cases the severity of injury could not be established, and in a further 14 cases the duration of post-traumatic amnesia was less than 24 hours, indicating an injury of moderate severity. In a small sample of 15 patients with a severe TBI, Drudge et al. (1984) reported that by 1 year postinjury 20% had returned to work in a full-time capacity, 33% had returned to work either with altered duties or in a part-time capacity. Both Oddy et al. and Hpay suggested that the majority of patients who had returned to work by 1 year had done so by 6 months postinjury. Once again these results differ from those of the current study where less than half of those at work by 1 year had achieved this by 6 months.

In one of the few New Zealand studies to investigate return to work following severe TBI, Crawford (1983) reported 26% of a group of 43 TBI patient had returned to full-time employment and 27% had returned to work in a reduced capacity. Fifty-one percent were unable to return to work in any capacity. Follow-up occurred between 12 and 36 months postinjury.

The variables that may account for the difference in findings are the economic and employment conditions that vary as a function of time and country. This highlights the difficulties of comparing international studies, particularly in relation to employment, where the politically determined economic and social conditions differ.

It also highlights the difficulties of comparing research conducted in the same country but at different periods of time. For example, the Crawford (1983) study was conducted at a time when unemployment in New Zealand was approximately 75,000. In the early 1990s when the current study was undertaken unemployment had risen to over 200,000 (Scollay & St John, 1996).

Although the New Zealand research reported by Godfrey, Bishara, et al. (1993) was undertaken over a similar period to the current study Godfrey, Bishara, et al. reported a higher frequency of return to some form of employment. Their results indicated a significant difference in return to work according to severity of injury, with those having received more severe injuries being less likely to return to work. Their use of post-traumatic amnesia to assess severity of injury makes comparison to the current study, in which GCS was used to assess severity difficult. However, more than 50% of the TBI patients in the current study had a GCS of 3 or 4, indicating the extremely severe nature of their injury. This difference in sample groups may explain, in some part, the different results obtained. The specific factors that were found to be associated with successful return to work are discussed later in this chapter.

When return to study was examined a similarly concerning picture emerged. Only 54% of the group who had been students at the time of their accident had been able to return to study. Of note was the relatively fewer students who had returned to secondary school compared with those who returned to tertiary education. It can be generally expected that the secondary school system is better able to accommodate a person with ongoing impairment and therefore the return to study would be easier for a secondary school student than for a student returning to more independent tertiary education. In the current study this finding appeared to reflect the more severe nature of the impairments sustained by the younger students. Implications for these younger students in terms of the long-term consequences for their ongoing education, employment opportunities, and consequent independent living are great.

Few studies have documented the change in living accommodation that occurs for a person with a severe TBI following their injury. Thomsen (1974) in her 1 to 5-year follow-up of 50 severe TBI patients reported that 74% of the group lived at home with parents, 14% lived on their own and 12% lived in nursing homes or hospitals at the time of follow-up. Unfortunately Thomsen did not report the premorbid living arrangements of this group. Jacobs (1988) noted the significant number of TBI patients who had returned to live with their parents due to functional and financial limitations consequent to their injury. At the time of Jacobs' follow-up 48% lived with parents compared to 35% premorbidly. In addition, 9% lived with flatmates compared to 22% premorbidly. The proportion of TBI patients returning to live with flatmates in the current study is similar to that reported by Jacobs although comparatively more patients continued to live with parents. Because the follow-up in the Jacobs study was up to 6 years postinjury it may be that more TBI patients leave their parents home between 1 and 6 years postinjury.

In the current study a number of significant changes were seen in the TBI patients' living arrangements following their injury. The most noticeable change was the number of patients who were either living alone or in a flatting situation prior to their accident and who had not returned to their previous accommodation by 1 year. The majority of these TBI patients had returned to live with their parents. In most cases the reason for returning to live with their parents was the need for assistance or supervision. This is reflected in the GOS scores of those who returned to live at home. The majority of these TBI patients obtained a GOS score of 3 or 4, indicating severe or moderate disability. For some TBI patients in this study their accident had resulted in them losing their employment, which had in turn resulted in financial hardship that made returning to a flatting situation difficult. Noticeable changes in living arrangements at 1 year postinjury were evident amongst those who were living with a spouse or partner at the time of their accident. Once again the majority of these patients returned to live with their parents. The degree of stress that this places on parents is further explored in Chapter 5.

While it is generally accepted that a severe TBI will have an effect on relationships for the TBI patient, the magnitude of this effect remains unclear. Oddy and Humphrey (1980) reported that there was little change in the marital relationships of their sample. Twelve TBI patients in their group were in a relationship at the time of their injury and only one couple had divorced within 1 year. Studies that have looked at longer term follow-up have reported a higher incidence of separation or divorce following severe TBI. Thomsen (1984) reported a divorce rate of 78% at 10 to 15 years postinjury, and Tate et al. (1989) reported a divorce rate of 55% in their sample of 31 severe TBI patients seen approximately 6 years postinjury.

In the current study 38% of those who were in relationships at the time of their injury were separated by 1 year postinjury. This is much higher than that reported by Oddy and Humphrey (1980) but lower than that reported by Thomsen (1984) and Tate et al. (1989). The follow-up period cited by the latter studies was between 6 and 15 years and it is possible that the incidence of separation following TBI continues to increase for a number of years following injury.

Similar to the findings of Tate et al. (1989) the current study found that separation was more frequent for those TBI patients who were more severely disabled. Comments made by the TBI patient's partner commonly referred to the changed nature of their relationship. Many partners explained that they now viewed themselves as the TBI patient's "mother" rather than their partner, and that they now had another "child" in the family. Many commented that their partner was a different person to the one that they had entered a relationship with.

Five items of the Katz Adjustment Scale-Relatives Form were administered to a family member to assess for changes in the amount of social contact and the amount of social activities that the TBI patient participated in. Overall the results indicated a decrease in both areas of social functioning for the TBI patient. In a study reported by Hpay (1971) 34% of the TBI patients interviewed had either experienced an obvious change in their social contact or had become "complete social outcasts". Thomsen (1974) also noted a lack of social contact to be one of the main difficulties faced by TBI patients. Thomsen suggested that the poor rate of return to employment and the lack of alternative 'work' opportunities in the community exacerbated the social isolation that the TBI patient experienced. Oddy et al. (1978b) reported 38% of their sample to have experienced a decrease in leisure activities at 6 months, and in a 1 year follow-up, this had increased to 50% (Oddy & Humphrey, 1980). These authors suggested that the decreased involvement in leisure activities was related not to the degree of physical disability experienced by the TBI patient, but to a decrease in motivation.

Predictors of social functioning. An examination of the relationship of cognitive, emotional, and behavioural impairment to social outcome has been relatively ignored in the previous literature. Difficulties with the research that has been conducted to date includes the use of global measures of impairment and/or outcome. These studies therefore lack the more specific detail on the TBI patient's functioning that is required. Other studies have attempted to explore only the relationship between some variables, for example the impact of cognitive functioning on return to work, and therefore lack a more holistic view of the TBI patient's world. In the current study the relationship of cognitive, emotional, and behavioural impairment to a number of variables associated with social functioning was examined.

Those TBI patients who did not return to work were found to experience a greater degree of impairment on all measures of cognitive functioning, and to display more behavioural problems as reported by their caregiver. These findings are generally consistent with those of Godfrey, Bishara, et al. (1993) who found the TBI patient's ability to return to work to be affected by negative changes in their cognitive functioning and personality.

As a group, those who did not return to work were impaired on measures of general intelligence, verbal memory, attention, visual-perception, and executive functioning. The impact of cognitive impairment on return to work was evident irrespective of the age and premorbid general intelligence of the TBI patient. While return to work is affected by a range of cognitive impairments, it is likely that impairment of specific functions will differentially affect a person according to their type of employment. For example, an architect or carpenter will be more affected by impairment of visual-perception than someone who relies more on verbal ability, such as a lawyer. Similarly, someone who routinely uses machinery tools may require more intact attention skills than someone in a clerical position.

> *Kevin was a 40 year old man who had been employed as a car salesperson prior to his accident. Following his accident he attempted to return to his previous employment. His mechanical knowledge of cars and his knowledge of sales techniques remained intact. However, he experienced expressive language difficulties such as word finding problems and decreased verbal fluency. Despite his technical knowledge remaining intact he was unable to converse with customers in a fluent, relaxed manner. He was unable to provide important information to customers and did not portray an impression of competency. For Kevin therefore his language impairments prevented him from successfully returning to his chosen employment.*

For those TBI patients who did not return to work, not only do they experience a greater degree of cognitive impairment but they were reported by a caregiver to display more behavioural problems. Their ability to perform at work therefore is not only affected by the presence of cognitive impairments but also the occurrence of behavioural problems. The specific impact on employability of the presence of behavioural problems is unknown. Employment of most types will require the employee to interact with other people, whether a fellow worker or a consumer of the service or business, and the behavioural difficulties displayed by the TBI patient will undoubtedly impact on their ability to appropriately interact with others. Behavioural problems may in fact be less tolerated in the workplace than cognitive difficulties. This is particularly so when the most frequent behaviours noted by caregivers are impatience, impulsiveness, childishness, overly sensitive, decreased motivation, and argumentativeness.

The ability of the TBI patient to return to work may be further complicated by a lack of insight regarding their behavioural difficulties. Prigatano, Altman, and O'Brien (1990) have described how TBI patients typically underestimate their behavioural problems. No relationship was found between the patient's self-report of behavioural problems and return to work, despite reports by the caregiver of numerous behavioural problems. Therefore, it is probable that those TBI patients who did not return to work not only displayed significant behavioural problems, but also lacked some degree of insight regarding their social behaviour. In the workplace this will make the resolution of conflict even more difficult. This problem was evident in the comments made by some patients in the study who had been unsuccessful in returning to work. This group of TBI patients often attributed their failure in the workplace to the behaviours of others and did not recognise that their own behaviour was at fault.

> *Michael was a 29 year old man who sustained a severe TBI after being assaulted. Prior to his injury he was employed as a chef in a large international hotel. Michael made a gradual return to work and was found to be able to carry out his duties to an acceptable level. However,*

> *Michael displayed significantly impaired anger control. This resulted in him becoming verbally abusive towards the other staff. When this was discussed with Michael he agreed that he got angry but suggested that the problem lay with the other staff. He said he only got angry because the staff were lazy, did not know what they were doing, or they had a "bad attitude" towards him. This perception was not supported by his supervisor.*

While the TBI patient's perception of their cognitive impairments was not assessed in the current study, if they lacked insight regarding their behavioural problems then it is likely that they also lacked insight regarding their cognitive impairments. This may explain the common situation where TBI patients' complained that they were being required to do "menial" tasks rather than the work that they did prior to their injury. In the majority of cases the TBI patient was no longer able to safely or effectively perform the same work that they had preinjury, but they were unable to reconcile themselves to this. Many TBI patients also complained that while they had been offered employment, they were being offered a much lower hourly rate and they refused to take up such employment. Once again the TBI patient, in most cases, failed to recognise their reduced ability and therefore their reduced earning capability.

> *Bruce was a 31 year old man who was a professional photographer prior to his accident. Assessment of Bruce's cognitive functioning at 1 year postinjury indicated that he continued to function in the above average range for general intellectual functioning. Despite this he displayed*

> *severe impairment of memory, attention, and executive functioning. The technical quality of his work was poor. He had difficulties interacting with clients. He confused or simply forgot client's appointments and then suggested that the client had made the mistake. He became very rigid when working with clients about how photographs should be taken. As a result Bruce was unable to function as a professional photographer. Consequently, a work placement was arranged where Bruce was to work with a photographer, mounting photographs and maintaining equipment. This was unsuccessful as Bruce constantly criticised the work of the other photographer (especially to other staff and clients) and tried to tell the photographer how he should do his work. In addition, Bruce quickly became dissatisfied with the work as he thought that his work was so much better that he should be doing the photography himself. This was despite him having recently failed to achieve a successful return to his own business.*

Overall therefore, the presence of cognitive impairment, behavioural problems, and in particular the patient's degree of insight, following severe TBI appear to significantly impact on the patient's ability to return to work. These results indicate that the usefulness of neuropsychological assessment prior to commencing a return to work rehabilitation programme cannot be over emphasised. Such an assessment, that combines both cognitive and behavioural aspects of the TBI patient's functioning will highlight areas of strengths and weaknesses. An accurate assessment of the TBI patient's actual cognitive abilities is necessary. This once again the highlights the importance of being able to relate performance on neuropsychological tests to everyday functions, such as those required in a particular work setting. A neuropsychological assessment also provides an understanding of the patient's behaviour and their insight about their behaviour. While rehabilitation must focus first on increasing the patient's insight, this may have only limited success. If this is the case then the focus must shift to adapting the environment to accommodate these behaviours and/or alter others' expectations of the TBI patient's abilities.

The results of the current study found that for many TBI patients, a consequence of their injury is a change in their living arrangements. At the time of their accident the majority of patients had left the home of their parents and were living alone, sharing a flat, or were living with a partner. Following their accident many returned home to live with parents. Those who continued to live at home with their parents at 1 year were found to display a greater degree of cognitive impairment. Greater impairment was noted on measures of general intelligence, attention, verbal memory, and executive abilities. The presence of behavioural problems and the patient's affective state were not related to a change in living arrangements.

The need to return home to live is therefore most closely related to the level of cognitive impairment experienced by the person. It is possible that those who experience a more significant level of cognitive impairment require a greater level of assistance and support, and this necessitates them moving to live with their parents. Given the impact of cognitive impairment on the TBI patient's ability to successfully return to work, those who return to live at home may be less likely to be able to return to work. The consequent financial loss for these people may further necessitate a return to live with parents where their costs are presumably lower. The impact of having to move home to live with parents was evident by comments they often made. All of these patients expressed gratitude towards their parents and many suggested that they would not have recovered so well if it had not been for the support of their families. Despite this, they described how living at home made them feel like they were children again. They felt that their parents were often overprotective. They said that they had had to adjust to being dependent on their parents again and having less privacy for themselves.

> *Joanne was a 23 year old woman who sustained a severe TBI when she was involved in a road traffic accident. She had recently returned to New Zealand after living and working in the United Kingdom for 2 years and had enrolled in her Master of Arts Degree. She was flatting with a friend when the accident occurred. Joanne remained in hospital for 6 months before being discharged home to the care of her mother. At 1 year following her accident she continued to live with her mother. She was unable to return to her studies due to ongoing cognitive impairment and was unable to find employment. Because she had been a student at the time of her accident she was financially dependent on the Sickness Benefit. Joanne reported that she had a good relationship with her mother and was grateful for the constant support that her mother had provided. Despite this she said she "hated" having to live at home. She said that she was now staying in the bedroom she had had as a child and while this provided some level of comfort it reminded her that she was*

> *like a child again. Because she was unable to drive she had to ask her mother to take her out. She said that constant contact with her mother was leading to friction between them. She said that although she knew she needed the assistance from her mother she resented her level of dependency.*

TBI patients, as a group, were found to experience less social contact following their injury. They made fewer visits to see friends, and friends initiated contact with them less often. Those TBI patients who were reported to visit friends less often were found to be more impaired on all five measures of cognitive function. A number of mechanisms may account for this situation. Cognitive impairment manifests in a number of behavioural responses. The patient may lack motivation and display impaired planning, decision making, and memory, all of which may impact on their ability to plan and initiate contact with others. For those who are more cognitively impaired, the degree of pleasure that they gain from social contact outside of the home may vary. Many TBI patients in the study commented on the amount of effort that was required for them to socialise with others. Many discussed the difficulties that they experienced following conversations when they were with a group of friends. They noted their own difficulties with word finding and being able to express themselves adequately. Others commented on their tendency to "say the wrong thing" when with others, and the embarrassment that this caused them. For some TBI patients it may be that they choose to make less contact with friends because the effort required to do so is so great, and the pleasure they gain is so little.

The TBI patient's loss of contact with their friends was most evident in the fewer visits that they received from friends. Those TBI patients who were reported to receive fewer visits from friends were found to be significantly more depressed, to self-report more behavioural changes, and their caregivers reported observing more behavioural problems. They were not found to be more impaired on measures of cognitive ability. Therefore the decrease in contact initiated by friends, and so often reported by the TBI patient and their family, is related to the affective and behavioural state of the TBI patient. While friends may accept and tolerate the cognitive changes that occur in the TBI patient they may find it more difficult to cope with behavioural and affective changes.

At 1 year postinjury a greater number of TBI patients reported a decrease in their overall contact with friends than at 6 months, suggesting that this problem may worsen as time postinjury becomes greater. The degree to which this loss of interest by friends is distressing for the TBI patient is unclear. While many TBI patients reported that they did not see friends as often, this change was more commonly reported by the caregiver and appeared to cause the caregiver a greater degree of distress.

Less involvement in social activities was noted for many TBI patients 1 year following their injury. A decrease in social activity was associated with impaired verbal memory and the number of behavioural problems reported by the caregiver. Those TBI patients who experience more severe memory impairments may gain less enjoyment from social activities as a result of this impairment, and therefore are not as interested in being involved in social activities. Those who were reported to be less involved in social activities were also reported by caregivers to display a greater number of behaviour problems. It may be that these TBI patients are invited to social events less often because of their behaviour. Alternatively, caregivers may be less likely to encourage the patient to be involved in social activities because of fear or embarrassment that the patient will behave inappropriately. This may be particularly so if the TBI patient is reliant on the caregiver to provide transport or supervision to enable them to attend social events.

Both Elsass and Kinsella (1987) and Marsh, et al. (1990) found that while the TBI patients in their samples reported a decrease in the quantity of contact that they had with close friends, they did not report a decrease in the quality of the relationships that they had with others. Elsass and Kinsella suggested that the cognitive impairment that the TBI patient may experience, for example loss of insight and egocentricity, may affect the TBI patient's perception of a relationship and therefore they do not miss the loss of such relationships. Secondly, they hypothesised that the TBI patient may be satisfied with fewer social relationships. This may be due to their decreased ability to cope psychologically with the demands of close relationships, which is brought about by the cognitive, emotional, and personality changes that have occurred for them. Alternatively, the TBI patient may experience lowered self-esteem or self-worth as a result of their impairments and as such have lowered expectations regarding the nature and quality of their social contacts. Elsass and Kinsella noted that most of the TBI patients in their sample relied more heavily on close family members for emotional support and attachment. This finding was also noted by Zencius and Wesolowski (1999).

The procedures employed in this study did not allow for an assessment of the degree of distress caused to the TBI patient by their loss of social contact. However, the results indicate that the loss of social relationships and activities following severe TBI is related to various cognitive, affective, and behavioural difficulties. Of significant importance is the concern that these losses continue to increase beyond the first year following severe TBI.

Overview of Patient Functioning following Severe TBI

Overall, severe TBI results in the presence of a wide range of deficits across a broad range of cognitive functions. While improvement is noted in the majority of these functions between 6 months and 1 year postinjury, there is still a high prevalence of cognitive deficits at 1 year postinjury. The pattern of recovery appears to differ across various cognitive domains, with more complex functions displaying a slower recovery. It is also likely that these functions ultimately recover to a lesser extent than more basic functions, although it was not possible to determine this in the current study.

That different functions are differentially affected, highlights the need for tests that assess more specific and discrete areas of cognitive functioning. While most tests can be conceptually defined in terms of the broad cognitive function that they measure, for example, verbal memory, successful completion of the majority of tests requires more than one cognitive function. In order to further increase our understanding of the brain-behaviour relationship additional research is required to define more clearly the discrete cognitive processes required to complete a particular test. A better understanding of the relationship between performance on cognitive tests and the ability to perform everyday tasks is also required.

Research into the prevalence of depression following TBI has suffered from a number of methodological limitations. These have mainly been associated with the procedures used to assess for the presence of depression. This has included the use of inappropriate depression scales and the use of a family member as the primary informant rather than the TBI patient themselves. The current study used the short form of the Beck Depression Inventory. The prevalence of depression within the group was found to remain relatively low and constant throughout the first year following severe TBI. Analysis of individual data indicated a notable degree of individual variation.

TBI patients reported the presence of a number of behavioural changes following their injury, with no significant change in the frequency of behaviours experienced between 6 months and 1 year. Previous research has often assumed that the self-report of a problem behaviour by a TBI patient indicates an associated degree of distress for that patient. Results of the current study found that the behaviours reported to cause the greatest degree of distress were not necessarily those behaviours that were most frequently reported. In addition, the behaviours causing the most distress changed between 6 months and 1 year postinjury. This appears to represent a change in the TBI patient's perception of their difficulties (possibly representing an increase in insight) and their response to these problems. This highlights the need for neuropsychologists to assess the degree of distress associated with the problem behaviours reported by TBI patients themselves and the patient's perception of these difficulties.

The extent to which TBI patients can accurately report on their current and preinjury behaviour has been the subject of some debate. The results of the current study confirmed that the TBI patient and caregiver differ in their reports of behavioural problems. However the disagreement between the TBI patient and the caregiver appears to be a function of the type of behaviour that is being inquired about. For example, the patient and caregiver agreed on the frequency of behaviours related to mood change, such as, anxiety, depression, and anger. Disagreement occurred most frequently on items that are often related to poor insight. These included items such as irresponsible behaviour, impulsiveness, lack of control, and poor decision making. Therefore, while the TBI patient may be able to self-monitor and accurately report on their emotional state, they are less able to accurately report other behaviours. In particular, these appear to be behaviours associated with self-monitoring and self-regulation.

Perhaps the most obvious impact of the injury on the TBI patient was evident in the high prevalence of poor social adjustment. In the current study the areas of employment, changes in relationships, living arrangements, social contact, and participation in leisure activities were examined. Changes from premorbid status were apparent in all areas of social functioning. While in some areas improvement was noted between 6 months and 1 year postinjury (e.g., return to work), in other areas a trend towards further dysfunction was noted (living arrangements, changes in relationships, and social contact).

Overall therefore a severe TBI results in ongoing impairment of cognitive, emotional, and behavioural functioning for the patient at 1 year following their injury. Consequent to this the TBI patient also experiences significant losses in a number of areas of their social functioning. In the current study cognitive impairment experienced by the TBI patient was found to significantly impact on a number areas of social functioning. Those TBI patients who did not return to employment were not able to return to their premorbid living situation, and those who initiated less contact with friends were found to experience a greater degree of cognitive impairment. Those who did not return to work were also reported by caregivers to display a greater number of behavioural problems. Return to work therefore appears to be affected not only by impaired cognition but also by the presence of behavioural difficulties. While some TBI patients lost contact with friends because they stopped making visits to see friends, the majority experienced a decrease in the number of visits that they received from friends. The group of TBI patients who reportedly received fewer visits from friends were found to self-report more behavioural problems, were more likely to be clinically depressed, and their caregivers reported a greater number of problem behaviours. The implications of these findings for the rehabilitation of the TBI patient will be described in Chapter 6.

Chapter 5

The Impact on the Primary Caregiver

This chapter describes the outcome for the primary caregiver of a TBI patient at 6 months and 1 year postinjury. The impact of caregiving on the caregiver's psychosocial functioning, and the factors underlying their experience of objective and subjective burden are detailed. Changes in these variables over the first year postinjury are also examined. Finally the relationships between caregiver reports of the TBI patient's physical, cognitive, emotional, behavioural, and social functioning, and the degree of caregiver objective burden, psychosocial impairment and subjective burden are outlined.

In a classic study of families caring for a psychiatrically ill relative, Grad and Sainsbury (1963) systematically investigated the proposal that caring for an ill relative can result in burden for family members. Many studies have been conducted on the impact of caring for relatives with different types of disabilities, including those with neurological disorders (Knight, 1992). One of the most consistent findings is that the level of burden experienced by family caregivers is not necessarily directly related to the severity of impairment. The relationship between severity of impairment in the person with the neurological disorder and burden in their caregiver appears to be mediated by a variety of factors. In his model of caregiver burden for those caring for people with degenerative neurological disorders, Knight identified three factors that may mediate the relationship between stressors and burden. These were social support, coping strategies, and the caregiver's appraisal of the stressors. However, to date, much of the research into caregiver burden following TBI has failed to take into account the possible role of mediating factors, including caregiver appraisal, in determining the level of caregiver burden.

Panting and Merry (1972) completed one of the first studies that focused on family outcome following TBI. A family member of 30 male TBI patients who had reportedly sustained a severe TBI was interviewed and administered questionnaires. Evaluation took place on discharge from an inpatient rehabilitation facility where the average length of stay for the TBI patient had been 4 to 5 months. Panting and Merry commented on the significant degree of stress placed on the family as a result of the TBI patients' injury. Families were most disturbed by outbursts of anger expressed by the TBI patient. Sixty-one percent of family members interviewed required sleep medication or tranquilisers in order to cope.

In a further study reported by Romano (1974) the most consistent feature of coping displayed in families was denial of changes that had occurred in the patient as a result of their injury. Thirteen severe TBI patients and their families were interviewed between 7 months and over 4 years postinjury. Romano noted how this denial lead to the family having to make significant compromises in their daily living. Family life came to centre around the TBI patient. Family members experienced a decrease in contact with non-family members and some family members developed emotional disturbance.

In the same year Thomsen (1974) interviewed a family member of 50 severe TBI patients approximately 30 months postinjury. Family members reported that personality changes were more difficult to deal with on a day-to-day basis than physical or cognitive deficits. In a follow-up study 10 to 15 years later Thomsen

(1984) found that personality and emotional changes in the TBI patient contributed most to family burden. As already noted by Romano (1974), Thomsen found the family of a severe TBI patient to experience a high degree of social isolation.

While the early studies undertaken by Panting and Merry (1972), Romano (1974), and Thomsen (1974) resulted in an increased awareness of the difficulties faced by the families of TBI patients, they suffered from a number of methodological problems that made comparison with further studies difficult. The specific relationship of the family member interviewed was rarely defined. Information relating to the TBI patient such as age and time postinjury were not always reported. The criteria used to determine severity of TBI were not made explicit and informal methods of assessment were often used.

The results from one of the first longitudinal studies of a large group of TBI caregivers were reported by Oddy et al. (1978a). Fifty-four relatives of severe TBI patients were interviewed at 1, 6, and 12 months postinjury. Relatives were administered the Wakefield Scale to assess depression and the Katz Adjustment Scale to measure the social adjustment of the TBI patient. Both the relative and TBI patient completed a symptom checklist that identified possible somatic, sensory, cognitive, personality, and psychiatric problems that the patient may experience. For the 14 married or cohabitating patients the spouse was interviewed. Of those patients who were single the mother was seen in 30 cases and father in the remaining 10 cases. Within one month of the injury 39% of relatives obtained scores indicating clinical levels of depression. While fewer relatives obtained such high scores at the 6-month follow-up there was no difference in obtained scores between 6-months and 12-

months postinjury. A significant relationship was found between the level of depression experienced by the relative and the number of items identified by both the patient and relative on the symptom checklist. More than 50% of relatives reported that they were experiencing stress at both 6 and 12 months. Relatives attributed their stress to some aspect of the patient's functioning (behaviour change, fear of epilepsy, physical demands of caring for a disabled person) and concern for the patient's future (eventual degree of recovery, fear of another accident). Information regarding the stress that relatives experienced was gathered during an interview with the relatives. During the 6 months preceding the assessment approximately 25% of relatives reported an illness. The majority of these illnesses were regarded as emotional or psychosomatic in nature with 8% of relatives reporting the use of tranquilisers or antidepressants. At each follow-up interval approximately 10% of relatives reported psychosomatic disorders such as asthma, migraine, and ulcer.

Oddy et al. (1978a) provided one of the first longitudinal studies in the area of caregiver burden. They confirmed the ongoing presence of stress up to 12 months following the TBI patient's injury, and explored the relationship between depression experienced by the relative and the number of changes that had occurred in the TBI patient's behaviour. Although information about the presence of stress and general health of the relatives was collected they used informal methods to collect this information. No attempt was made to investigate the possible causes of stress and ill-heath for the relative. Oddy et al. failed to report the number of TBI patients and relatives involved at each follow-up period, but acknowledged that this differed according to their availability.

Brooks and Aughton (1979a) reported the results from one of the first studies to specifically utilize the concept of burden in TBI caregiver research. Brooks and Aughton distinguished between objective burden, observable changes in the caregiver's lifestyle (Type 1) or the TBI patient's behaviour (Type 2), and subjective burden, perceived stress in the caregiver. Thirty-five relatives of TBI patients were interviewed at 3, 6, and 12 months postinjury. These relatives were a subsample of a larger group of mild to severe TBI patients who participated in other aspects of the study. Although the severity of injury of TBI patients that made up this subsample was described as severe, the method of assessing severity was not reported.

Subjective burden was assessed by administration of a 7-point Likert scale. The changes in the TBI patients' behaviours most frequently related to subjective burden in the relative at 6 months were childish behaviour, loss of interest, change in sex life, depression, and tension/anxiety. With the exception of incontinence, physical disabilities appeared to be completely unrelated to the degree of subjective burden. Unfortunately, although Brooks and Aughton (1979a) made a distinction between Type 1 objective burden (changes in the caregiver's lifestyle) and Type 2 objective burden (changes in the TBI patient's behaviour) they reported results for only Type 2 objective burden. Therefore, the way in which the caregiver's lifestyle had changed as a result of caring for the TBI patient, and the impact that this had on the degree of stress that they experienced was not explored.

In a further series of studies by Brooks and colleagues (Brooks et al., 1986; Brooks & McKinlay, 1983; McKinlay et al., 1981) attempts were made to define the particular changes in the TBI patient that were associated with stress in the caregiver.

In their first paper McKinlay et al. (1981) reported the results from a study that involved 55 relatives of severe TBI patients. Relatives were interviewed at 3, 6, and 12 months postinjury. The authors developed a seven-point rating scale from 1 (no stress) to 7 (severe stress) that was used to assess the degree of subjective burden experienced by the relative. In addition, a structured interview was used to rate various neurobehavioral problems experienced by the TBI patient. The mean level of stress reported by relatives was 3.5 (moderate stress) and this did not change over the three follow-up periods. While a significant relationship was found between the degree of stress experienced by the relatives and the severity of injury sustained by the TBI patient, this relationship weakened over time. The authors therefore argued that stress in relatives is not a simple reflection of severity of injury. A significant relationship was also observed between stress experienced by the relative and specific types of problems reported in the TBI patient. In general, changes related to subjective (slowness, headaches, tiredness), emotional (irritability, impatience, anxiety, depression), and disturbed behaviour (violent and inappropriate social behaviour), rather than physical or language difficulties were related to the degree of stress experienced by the relative.

McKinlay et al. (1981) cautioned that it must not be assumed that the relationship between the identified changes in the TBI patient and stress in the relatives was causal. Both objective and subjective burden was assessed on the basis of the relatives' report and there may be an association between the stress in relatives and the relatives' perception of changes in the TBI patient. Specifically, the relatives' perception of changes in the TBI patient may be influenced by the degree of stress that they are experiencing themselves. McKinlay et al. suggested that in order to overcome this difficulty information regarding the functioning of the TBI patient must be collected from other sources as well as from the relatives.

Brooks and McKinlay (1983) noted that many relatives of TBI patients reported that "personality changes" had occurred in the TBI patient since their injury. Using the same sample as in the McKinlay et al. (1981) study Brooks and McKinlay attempted to define more clearly the behaviours associated with the term "personality change" and the relationship between these behaviours and relative's distress. The particular aspects of personality change that were found to be more frequently identified by those relatives reporting higher degrees of burden were lack of control of temper, social withdrawal, decreased affection, lack of energy, cruelty, meanness and unreasonableness. At 12 months other changes including immaturity, insensitivity, and changeability were noted.

Brooks et al. (1986) reported the results of a 5-year follow-up from the McKinlay et al. (1981) study. At 5 years postinjury, relatives reported a similar pattern of major personality changes in the TBI patient. The degree of subjective burden reported by the relatives also increased from 1 year postinjury to 5 years postinjury. Of the 39 relatives who had been interviewed at both 1 year and 5 years, 20% of relatives with "high" burden at 1 year showed a reduction at 5 years. In contrast, 62% of relatives with "low" or "medium" burden at 1 year reported "high" burden at 5 years. As at 1 year postinjury, the greater the degree of personality, behavioural and affective changes in the TBI patient, the greater the degree of subjective burden experienced by the relative.

The studies by Brooks and colleagues (Brooks et al., 1986; Brooks & McKinlay, 1983; McKinlay et al., 1981) expanded on the work of Oddy et al, (1978a) by defining more clearly the particular changes in the TBI patient's behaviours that were associated with stress in the relative. Overall, the changes in the TBI patient most frequently related to a high level of stress in the caregiver were those associated with subjective, emotional, and disturbed behaviour.

Livingston and colleagues (Livingston, 1987; Livingston et al., 1985b; Livingston et al., 1985a) have also reported the results from a serial assessment of a group of severe TBI patients and their relatives. Livingston and colleagues, unlike previous studies, undertook a more systematic assessment of the psychological and social functioning of the relative, using standardised assessment tools. In their first paper Livingston et al. (1985b) administered the General Health Questionnaire-60 to assess psychiatric function, the Leeds General Scales for anxiety and depression, and Weissman's social adjustment scale to 42 female relatives of severe TBI patients, 3 months postinjury. Outcome for the patient was assessed using two clinician rating scales; the Glasgow Outcome Scale and the Glasgow Assessment Schedule. In addition the relatives' perception of the burden of living with the patient was assessed by means of a semi-structured interview. The perceived burden rating scale consisted of 25 items taken from the 90-item checklist used by McKinlay et al. (1981). The interviewing clinician rated each item on a presence/absence basis. The same measures were administered to a group of 41 relatives of mild TBI patients who acted as a control group. Amongst the relatives of the severe TBI group 22 were spouses, 16 were mothers and 3 were daughters. Their ages ranged from 25 to 65 years and assessment took place at 3 months postinjury

A greater number of relatives of the severe TBI patients displayed psychiatric disturbance and anxiety when compared with the control group. Fifty-seven percent of the relatives obtained significant scores on the General Health Questionnaire indicating high levels of psychiatric morbidity and 45% of relatives were classified as clinically anxious. Twenty-one percent of relatives were found to be depressed, although the difference between the frequency of depression in the relatives of the severe TBI patients and the relatives of the mild TBI patients did not reach significance. Relatives of the severe TBI patients reported greater dysfunction on the marital functioning and family unit functioning variables of the social adjustment scale. The perceived burden rating for the relatives of the mild TBI patients was 1.83 and for the relatives of the severe TBI patients it was 7.24. Therefore there was a significant difference between the two groups in terms of their subjective rating of the TBI patients' difficulties. Unfortunately, the actual items reported by relatives were not described by the authors.

In a second paper Livingston et al. (1985a) reported the results of a 3, 6, and 12-month follow-up of relatives of a group of severe TBI patients. The procedure and measures used in their previous study (Livingston et al., 1985b) were once again employed. Thirty-seven relatives were assessed on all three occasions, 42 were seen at only 3 months, 47 at 6 months and 50 at 1 year postinjury. High levels of psychiatric disturbance and anxiety were reported by the relatives at 3 months postinjury and this persisted throughout the year. On the Leeds Anxiety scale 34%, 41%, and 38% of relatives obtained scores indicative of clinical anxiety at 3, 6, and 12 months, respectively. Although lower rates of depression were evident, 20%, 23%, and 26% of relatives were clinically depressed at 3, 6, and 12 months, respectively. Evidence of increased social dysfunction was observed between 3 and 6 months postinjury, and continued to be high at 12 months. The mean role scores for work, social and leisure, extended family, marital, and parental and nuclear family functioning indicated dysfunction. Marital functioning in particular displayed the most significant deterioration. Despite this, no statistically significant difference was found between the levels of psychiatric morbidity, anxiety, depression, or social adjustment of wives and mothers.

Measures of severity of injury were not found to be associated with relative outcome variables, although patient outcome variables were frequently significantly associated with the relative's outcome. A regression analysis was conducted to identify the patient variables that were related to the relative's psychosocial functioning. The major predictor of the relative's psychosocial functioning (usually accounting for more than 50% of the variance) was the subjective complaints subscale of the Glasgow Assessment Schedule. The items of this subscale include primarily physical symptoms such as loss of balance, impaired hearing, vision or smell, headaches, impaired sexual functioning, incontinence, and disturbed sleep.

The results obtained by Livingston et al. (1985a) differed from the results of previous studies that found changes in the TBI patient's emotional and behavioural functioning, rather than their physical functioning, to be most consistently related to the relative's level of stress. The difference in findings is likely to be due to the different methodologies employed in the studies, particularly the respective measures of relative and patient outcome that were used. Livingston et al. undertook a more precise assessment of the relative's psychosocial functioning, using standardised assessment techniques to separately measure psychiatric morbidity, depression, anxiety, and social functioning. Other studies have assessed only one aspect of functioning, for example, depression (Oddy et al, 1978a), or have used a single global measure, such as a Likert scale to assess stress (Brooks & Aughton, 1979a; Brook et al., 1986; McKinlay et al., 1981). In the Livingston et al. study, patient outcome was assessed using clinician rating scales, whereas other studies have gathered information from the relative regarding the behavioural changes that they have observed in the TBI patient.

Early research by Panting and Merry (1972) and Thomsen (1974) has suggested that spouses may be more vulnerable to the stress of caring for a severe TBI patient than parents. While later research has supported this hypothesis (Leathem, Heath, & Woolley, 1996) this finding has not been consistent in the literature. For example, Oddy et al. (1978a) found no difference between the level of depression when measured by the Wakefield Depression Scale of parents and spouses. In addition, Livingston et al. (1985b, 1985a) found no evidence of a difference in the psychological reactions of mothers and wives to caring for the TBI patient when the areas of psychiatric morbidity, depression, and anxiety were assessed at 3, 6, and 12 months postinjury.

The specific effect of caring for a severe TBI patient on a spouse and on a parent has been investigated in two separate studies (Peters et al., 1990; Tarter, 1990).

Peters et al. compared the marital adjustment of the female spouses of a group of severe TBI patients and the spouses of moderate and mild TBI patients. The Dyadic Adjustment Scale and the Personal Assessment of Intimacy in Relationships were administered to assess marital adjustment and intimacy. The spouses of severe TBI patients reported a greater degree of marital dysfunction when compared to the spouses of mild and moderate TBI patients. They reported more disagreement and difficulty in reaching decisions and fewer overt acts of physical or verbal affection between them and their partners. The most significant variables in predicting marital dysfunction were related to severity of injury, high psychosocial maladjustment of the patient, and restrictiveness in the day-to-day physical functioning of the patient.

In an attempt to delineate the factors associated with parental adjustment following TBI Tarter (1990) assessed the parents of 48 TBI patients. Eighty-five percent of the parents were female. Parents completed the Sickness Impact Profile, to quantify the parent's perception of the TBI patient's severity of impairment, the Symptom Checklist-90, in which the parent rated their own level of distress, the Hassles Scale, to assess the parent's perceived level of stress, and the Ways of Coping Questionnaire (Revised) to determine the parent's style of coping. Overall, psychosocial dysfunction, impaired social interaction and emotional disturbance of the TBI patient, but not their physical dysfunction, were found to be associated with the degree of stress experienced by the parent.

Summary

The general picture gained from past research indicates that relatives of severe TBI patients experience a significant degree of subjective burden (distress) as a result of caring for the TBI patient. Specifically, caring for a person who has sustained a TBI can result in increased levels of stress, depression, and anxiety; a high incidence of psychosomatic disorders; increased consumption of prescription and non-prescription drugs; financial difficulties and role changes; poor social adjustment; and increasing social isolation. There is some suggestion that spouses are at greater risk than parents are, although this has not been a consistent finding.

Research into the prediction of caregiver burden has generally found caregiver burden to be most affected by changes in behaviour and emotion, commonly referred to as "personality changes", in the TBI patient. It is comparatively less affected by changes in the cognitive ability, communication skills, and physical ability of the TBI patient. However these findings have not been conclusive. Despite recent improvements in the assessment methods used, much of the research into caregiver burden following severe TBI continues to utilise samples that are too heterogeneous with regard to both severity and time since injury (Brooks & Aughton, 1979b; Gillen, Tennen, Affleck, & Steinpresis, 1998; Kosciulek & Lustig, 1999; Moules & Chandler, 1999; Peters et al., 1990; Tarter, 1990). Some studies have used postal questionnaires to assess caregivers functioning (Frosch, Gruber, Jones, Myers, Noel, Westerlund, & Zavisin, 1997; Wallace, Bogner, Corrigan, Mysiw, & Fugate, 1998; Zinner, Ball, Stutts, & Philput, 1997). The major limitation with this methodology is the difficulty associated with gaining corroborative information.

Research involving samples of varying levels of severity may contribute to our understanding of the relationship between injury severity and caregiver burden. However, to develop a better understanding of the process of family adaptation following TBI we require a longitudinal series of studies within which caregivers are assessed at approximately the same time postinjury. In addition, previous research has tended to rely on a limited use of standardised, psychometrically sound questionnaires or the use of semistructured interviews and checklists (McKinlay et al., 1981), to assess both patient and caregiver outcome, making comparison across studies difficult.

The Livingston (1987) study presents the most comprehensive assessment of caregiver functioning to date. However, while the Livingston study utilised psychometrically sound measures and a homogeneous patient sample, the assessment of patient functioning was based on a clinician rating scale. As Knight (1992) has pointed out, for caregivers of those with degenerative neurological disorders, the impact of stressors on caregiver burden is mediated by the caregivers' perception of those stressors. Therefore it is the caregivers' appraisal of the stressors, rather than the objective (i.e., clinically determined) nature of the stressors, that has the greatest impact on caregiver functioning. In keeping with this perspective, in the current study the relationship between the caregiver's perception of changes in the TBI patient and caregiver functioning is examined.

The current study sought to describe the outcome for the primary caregiver of a TBI patient at 6 months and 1 year postinjury. The comparative degree of distress caused to caregivers from both changes in the TBI patient, and changes in their own life, are outlined. The impact of these changes on the caregiver's psychosocial functioning is evaluated. Finally, the relationship between caregiver reports of the TBI patient's physical, cognitive, emotional, behavioural, and social functioning, and the degree of caregiver objective burden, psychosocial impairment and subjective burden is examined.

Method

Primary Caregiver Sample

Forty-six (89%) of the 52 caregivers seen at the first and second follow-up were female. The average age of the total sample was 43 years (*SD* = 9 years, range = 18 - 65 years). Thirty-six (69%) of the caregivers were a parent, 15 (29%) were a partner or spouse, and 1 (2%) sibling was involved. Demographic information on the caregivers is presented in Table 5.1.

Table 5.1. Demographic Information for the Primary Caregivers (*N* = 52)

	6-months	*1-year*
Age (years)		
Mean	43	
SD	9	
Range	18 - 65	
Gender		
Female	46 (89%)	
Male	6 (12%)	
Relationship to TBI patient		
Parent	36 (69%)	
Spouse/Partner	15 (29%)	
Sibling	1 (2%)	
Living with TBI patient		
Yes	37 (71%)	35 (67%)
No	15 (29%)	17 (33%)

Measures

As described in Chapter 2, caregiver affect was assessed by administration of the short-form of the Beck Depression Inventory and the Trait Anxiety Inventory, and social adjustment by the self-report version of the Social Adjustment Scale. The caregiver's perspective on the functioning of the TBI patient was assessed by the relative/friend version of the Head Injury Behaviour Rating Scale and Part B of the Caregiver Questionnaire. An objective burden score was obtained from Part A of the Caregiver Questionnaire. This score represented the total number of areas in their life that caregivers reported had changed as a result of caring for the TBI patient. A subjective burden score was obtained by summing the scores on the two global items in the Caregiver Questionnaire which required caregivers to indicate how much the changes in their life, and the changes in the TBI patient's functioning, distressed them. For the purposes of undertaking the correlational and standard multiple regression analyses, five scores each for both the TBI patient and their caregiver were used. The five TBI patient scores were for changes in physical, cognitive, emotional, and social functioning (all derived from the Caregiver Questionnaire) and number of behavioural problems (derived from the Head Injury Behaviour Rating Scale). The five caregiver scores were depression, anxiety, overall social adjustment, objective burden, and subjective burden.

Results

TBI Patient Functioning

Caregiver reports of changes in the patient's level of functioning and the degree of distress that it caused to them as caregivers are presented in Table 5.2. In terms of overall functioning, the most frequently reported changes occurred in the TBI patients' cognitive ability, followed by their physical abilities, then emotional functioning. The least frequent changes were reported in their level of social functioning. This remained true at both 6 months and 1 year postinjury. Although the frequency of changes in each category remained relatively the same between 6 months and 1 year postinjury, the changes that caused the most distress altered. At 6 months the most distressing changes were related to changes in the TBI patient's physical and social functioning. By 1 year physical changes were reported to cause the least amount of distress, while emotional and social functioning were the most relevant for caregivers..

At 6 months postinjury, 5 of the 20 behavioural problems listed in the Head Injury Behaviour Rating Scale were reported by 50% or more of the caregivers. Impatience (60%), poor decision making (56%), poor insight (54%), depression (54%), and difficulty becoming interested (50%) were the most frequently reported problems. The least frequently reported problems, those reported by less than 30% of caregivers, were dependency (21%), irresponsibility (23%), aggression (23%), and complaining (29%). Although these were the least frequently reported problems, dependency, irresponsibility, and aggression caused the greatest degree of distress for the caregiver. At 1 year postinjury, 12 of the 20 behaviours were identified as occurring by 50% or more of the caregivers. Impatience (69%) continued to be identified as the most frequent behaviour problem. The other most frequently identified behaviours were impulsivity (64%), overly sensitive (58%), childishness

Table 5.2. Caregivers Frequency and Mean Distress Ratings for Changes in the TBI Patient at 6 Months and 1 Year Postinjury

	6 months		*1 year*	
Problem area	Frequency	Distress	Frequency	Distress
Physical	42 (81%)	3.50	44 (85%)	3.16
Cognitive	45 (87%)	3.24	45 (87%)	3.24
Emotional	40 (77%)	3.30	43 (83%)	3.33
Social	37 (71%)	3.41	40 (77%)	3.28
Behavioural*				
Impatient	31 (60%)	2.58	36 (69%)	2.67
Poor decision making	29 (56%)	2.55	26 (50%)	2.39
Poor insight	28 (54%)	2.46	26 (50%)	2.62
Depressed	28 (54%)	2.32	27 (52%)	2.44
Difficulty becoming interested	26 (50%)	2.54	28 (54%)	2.75
Overly sensitive	25 (48%)	2.52	30 (58%)	2.33
Impulsive	25 (48%)	2.36	33 (64%)	2.21
Mood changes	24 (46%)	2.63	24 (46%)	2.79
Anger	24 (46%)	2.50	27 (52%)	2.85
Childishness	24 (46%)	2.42	30 (58%)	2.17
Loss of Motivation	24 (46%)	2.42	29 (56%)	2.72
Anxious	24 (46%)	2.33	24 (46%)	2.50
Irritable	23 (44%)	2.52	26 (50%)	2.42
Argumentative	23 (44%)	2.48	29 (56%)	2.35
Lack of initiative	21 (40%)	2.24	19 (37%)	2.37
Social behaviour	18 (35%)	2.56	20 (39%)	2.65
Complaining	15 (29%)	2.47	20 (39%)	2.35
Aggression	12 (23%)	2.83	17 (33%)	2.53
Irresponsible	12 (23%)	2.83	14 (27%)	2.57
Dependent	11 (21%)	2.91	17 (33%)	2.59

* Note. Distress ratings obtained on a 4-point scale from 1 = no distress to 4 = severe distress

(58%), loss of motivation (56%), argumentativeness (56%), difficulty becoming interested (54%), depression (52%), anger (52%), poor decision making (50%), poor insight (50%), and irritability (50%). Despite the high frequency of these behaviours most were reported to cause comparatively little distress. Those behaviours causing the greatest degree of distress were anger, mood changes, and a lack of interest in things. Only one behaviour, irresponsibility (27%) was reported by fewer than 30% of caregivers at 1 year postinjury.

The mean number of problems identified in the TBI patients' behaviour by the caregivers is presented in Table 5.2, as well as the mean distress scores derived from this measure. The increase in the mean number of behavioural problems between 6 months and 1 year postinjury was not statistically significant, $t(51) = -1.93, p > .05$. Similarly, despite an increase in the mean distress score between 6 months and 1 year postinjury this increase was not statistically significant, $t(49) = -1.65, p > .05$.

Caregiver Psychosocial Functioning

Anxiety. At 6 months postinjury, 16 (31%) caregivers reported clinically significant levels of anxiety on the Trait Anxiety Inventory, with the majority of these caregivers experiencing a mild degree of anxiety. Little change was noted in the prevalence of anxiety between 6 months and 1 year postinjury (Table 5.3) with no significant difference, $t(50) = 0.63, p > .05$, observed between the mean obtained scores (Table 5.4).

Depression. On the short form of the Beck Depression Inventory a total of 17 (33%) caregivers reported clinically significant levels of depression at 6 months. For approximately half of these caregivers their scores indicated a severe level of depression (Table 5.3). As can be seen in Table 5.4, the mean scores on the depression measure obtained at 6 months and 1 year postinjury were not significantly different, $t(50) = 1.36, p > .05$.

Table 5.3. Degree of Impairment in Caregiver Psychosocial Functioning

	Mild	Severe	Total
Anxiety			
6 months	11 (21%)	5 (10%)	16 (31%)
1 year	15 (29%)	3 (6%)	18 (35%)
Depression			
6 months	8 (15%)	9 (17%)	17 (33%)
1 year	7 (13%)	9 (17%)	16 (31%)
*Social Adjustment**			
Work			
6 months	8 (16%)	5 (10%)	13 (25%)
1 year	5 (10%)	2 (4%)	7 (14%)
Social & Leisure			
6 months	13 (25%)	5 (10%)	18 (35%)
1 year	7 (14%)	4 (8%)	11 (22%)
Extended Family			
6 months	6 (12%)	9 (18%)	15 (29%)
1 year	5 (10%)	6 (12%)	11 (22%)
Marital			
6 months	4 (10%)	5 (13%)	9 (23%)
1 year	6 (15%)	1 (3%)	7 (18%)
Parental			
6 months	6 (17%)	6 (17%)	12 (33%)
1 year	3 (9%)	2 (6%)	5 (14%)
Family Unit			
6 months	11 (22%)	8 (16%)	19 (39%)
1 year	9 (18%)	3 (6%)	12 (24%)
Overall			
6 months	11 (22%)	7 (14%)	18 (35%)
1 year	6 (12%)	5 (10%)	11 (22%)

*Note: N differs due to fact that not all role areas were applicable.

Social adjustment. Caregiver reports of their overall social adjustment at 6 months indicated that 18 (35%) caregivers had impaired levels of social adjustment. For most of these caregivers their level of impairment was mild in degree (Table 5.3). A statistically significant difference, $t(49)= 3.13$, $p = .003$, was found when the level of overall impairment was compared at 6 months and 1 year postinjury (Table 5.4). Therefore the caregivers, on average, reported an improvement in their overall levels of social adjustment between 6 months and 1 year postinjury.

Table 5.4. Means and Standard Deviations for Changes in the TBI Patient's Behaviour and Caregiver Burden and Psychosocial Adjustment between 6 Months and 1 Year Postinjury

	6 months		*1 year*		
	Mean	SD	Mean	SD	*t*
TBI Patient's Behaviour					
Number of problems	8.60	5.69	9.65	5.67	-1.93
Total distress	22.69	18.54	25.69	17.12	-1.65
Objective Burden					
Number of changes	6.23	3.84	5.52	4.04	1.86
Total distress	20.09	14.92	16.83	14.15	2.42*
Anxiety	39.31	12.70	38.61	11.49	0.63
Depression	5.08	5.90	4.24	4.78	1.36
*Social Adjustment**					
Work	1.64	.59	1.47	.44	2.38*
Social & Leisure	2.10	.57	2.02	.56	1.44
Extended Family	1.57	.50	1.49	.47	1.36
Marital	1.78	.59	1.72	.47	0.80
Parental	1.72	.74	1.45	.46	2.39*
Family Unit	2.01	.81	1.76	.63	3.07*
Overall	1.81	.47	1.69	.39	3.13*
Subjective Burden	7.42	3.69	6.62	3.19	1.85

* $p < .05$

Inspection of the scores obtained for particular role areas indicated that at 6 months postinjury the most commonly affected roles were those within the family unit (39%), and social and leisure (35%). At 1 year fewer caregivers reported poor social adjustment, and the most commonly affected roles continued to be in the areas of the family unit and social and leisure. At both 6 months and 1 year postinjury, the highest frequency of severe impairment was reported for the role within the extended family (Table 5.3). At 1 year the mean score for impairment in each of the six role areas was lower than that obtained at 6 months (Table 5.4). This difference was statistically significant for the following three role areas: work, $t(47) = 2.38$, $p = .021$, parental, t(28) = 2.39, $p = .024$, and family unit, $t(47) = 3.07$, $p = .004$.

Caregiver Objective Burden

Caregiver reports of the nature and comparative level of distress caused by the changes in their life that had resulted from caring for the patient are reported in Table 5.5. At 6 months, 6 of the 15 possible changes were reported as occurring by more than 50% of the caregivers. The most frequently reported changes were having less time for themselves (71%), increased anxiety (67%), changes in sleep pattern (60%), less privacy (60%), changes in their financial situation (54%), and changes in their relationships (52%). Increased physical illness (6%), increased use of medication (8%), and increased use of alcohol or other non prescription drugs (17%) were the least frequently reported changes.

Increased physical illness, time for themselves, and change in employment were reported as causing the most distress for the caregiver. Those changes that caused the greatest distress were amongst those least frequently reported. An exception to this was found for the most frequently occurring problem of having less time to themselves; this factor was also ranked as the second most distressing change.

Table 5.5. Caregivers Frequency and Mean Distress Ratings for Changes in Their Life at 6 Months and 1 Year Postinjury

	6 months		*1 year*	
Problem area	Frequency	Distress*	Frequency	Distress
Time for myself	37 (71%)	3.19	31 (60%)	3.07
Anxiety	35 (67%)	3.00	30 (58%)	2.73
Sleep	31 (60%)	3.00	27 (52%)	2.67
Privacy	31 (60%)	2.68	25 (48%)	2.92
Financial	28 (54%)	2.93	24 (46%)	2.75
Relationships	27 (52%)	2.56	29 (56%)	2.45
Depression	23 (44%)	3.09	21 (40%)	2.95
Anger	23 (44%)	3.00	23 (44%)	2.74
Employment	22 (42%)	3.14	21 (40%)	3.10
Energy	21 (40%)	3.05	14 (27%)	2.86
Appetite	16 (31%)	2.75	11 (21%)	2.46
Housing	14 (27%)	2.50	15 (29%)	2.20
Substance (Alcohol etc.) use	9 (17%)	3.00	7 (14%)	3.00
Medication use	4 (8%)	3.00	3 (6%)	3.33
Illness	3 (6%)	4.67	6 (12%)	3.17

* Note. Distress ratings obtained on a 4-point scale from 1 = no distress to 4 = severe distress

At 1 year postinjury, little change was noted in the rank order of the changes that had occurred for the caregiver. Similarly, the least frequently reported changes occurring at 1 year tended to cause the most distress for caregivers. Increase in the use of medication, and an increase in the presence of physical illness were reported to be the most distressing. Having decreased time for themselves was also reported to cause a higher level of distress. There was no statistically significant difference between the number of changes identified at 6 months postinjury compared to 1 year, $t(51) = 1.86$, $p > .05$. However there was a statistically significant decrease in the total degree of stress caused by these changes, $t(46) = 2.42$, $p = .02$. Despite this, the overall level of subjective burden was not significantly different between 6 months and 1 year postinjury, $t(51) = 1.85$, $p > .05$. Further information on these variables is presented in Table 5.5.

Correlational Analysis

The relationships between reported changes in the TBI patient and caregiver psychosocial functioning and degrees of objective and subjective burden were initially examined by two-tailed correlational procedures. Caregiver reports of changes in the five areas of physical, cognitive, behavioural, emotional, and social TBI patient functioning were correlated with the caregiver self-reports of anxiety, depression, social adjustment, objective burden, and subjective burden (Tables 5.6 & 5.7).

At 6 months postinjury those caregivers who reported that the patient's physical abilities had changed as a result of the accident also reported higher levels of both objective ($p = .019$) and subjective ($p = .008$) burden. At 1 year postinjury the significant relationship with caregiver levels of objective ($p = .003$) and subjective ($p = .007$) burden remained. In addition the relationship between caregiver reports of a change in the patient's physical abilities and the caregiver's level of depression ($p = .044$) was significant.

At 6 months postinjury there were no significant relationships between caregiver reports of a change in the patient's cognitive abilities and caregiver functioning. At 1 year postinjury a significant relationship was found for caregiver levels of objective burden (*p* = .009), and subjective burden (*p* = .001).

Table 5.6. Correlations between the TBI Patient's Functioning and Caregiver Burden and Psychosocial Adjustment at 6 Months Postinjury

Variable	1	2	3	4	5	6	7	8	9	10
1. Physical	--	.24	.08	-.17	.34*	-.33*	.05	-.02	-.10	-.36*
2. Cognitive		--	.19	-.002	.37*	-.23	.02	-.07	-.05	-.23
3. Emotional			--	-.36*	.36*	-.30*	-.04	-.16	-.16	-.29*
4. Behavioural				--	-.23	.35*	.28*	.15	.31*	.27
5. Social					--	-.49*	-.09	-.14	-.23	-.53*
6.Objective Burden						--	.60*	.59*	.61*	.78*
7. Anxiety							--	.84*	.81*	.56*
8. Depression								--	.77*	.58*
9. Social Adjustment									--	.56*
10. Subjective Burden										--

*$p < .05$.

A significant relationship between caregiver's reports of the presence of emotional difficulties in the patient and caregiver levels of both objective (*p* = .032) and subjective (*p* = .038) burden was found at 6 months postinjury. At 1 year those caregivers who reported a negative change in the emotional functioning of the patient continued to have higher levels of both objective (p = .008), and subjective (p = .012) burden. In addition, by 1 year postinjury, there was a significant relationship with caregiver social adjustment (p = .015).

Table 5.7. Correlations between the TBI Patient's Functioning and Caregiver Burden and Psychosocial Adjustment at 1 Year Postinjury

Variable	1	2	3	4	5	6	7	8	9	10
1. Physical	--	.46*	.37*	-.03	.40*	-.40*	-.21	-.28*	-.21	-.37*
2. Cognitive	--	--	.56*	-.17	.32*	-.36*	-.05	-.14	-.13	.43*
3. Emotional			--	-.47*	.35*	-.36*	-.26	-.27	-.43*	-.35*
4. Behavioural					-.19	.34*	.27	.17	.28*	.41*
5. Social						-.38*	-.15	-.27	-.23	-.47*
6.Objective Burden							.65*	.68*	.58*	.82*
7. Anxiety								.84*	.68*	.53*
8. Depression									.78*	.57*
9. Social Adjustment										.45*
10. Subjective Burden										

*$p < .05$.

At 6 months postinjury the number of patient behavioural problems reported by the caregiver was related to caregiver levels of objective burden (p = .011), anxiety

(p = .042), and social adjustment (p = .03). At 1 year a significant relationship was found for objective burden (p = .015), subjective burden (p = .002), and social adjustment (p = .046).

At 6 months postinjury there was a significant relationship between caregiver reports of a change in the patient's amount of social contact and caregiver levels of objective burden ($p < .001$) and subjective burden ($p < .001$). At 1 year this relationship remained significant for both objective (p = .006) and subjective ($p < .001$) burden.

Multiple Regression Analysis

To further investigate these relationships standard multiple regression analyses were conducted. The caregiver's perception of changes in the TBI patient's physical, cognitive, emotional, behavioural, and social functioning were entered simultaneously as independent variables. Caregiver depression, anxiety, social adjustment, objective burden, and subjective burden were the dependent variables. Prior to conducting the multiple regressions, the dependent variables were screened for multicollinearity (Tabachnick & Fidell, 1989). The results from this screening procedure supported the use of the five patient variables as independent variables in the multiple regressions. Results from the 6 month regression analysis are presented in Table 5.8 and results from the 1 year regression analysis are presented in Table 5.9.

Table 5.8. Summary of Simultaneous Regression Analysis for TBI Patient Variables Predicting Caregiver Burden at 6 Months Postinjury

Caregiver	TBI Patient	β	*t*	
Objective burden	Physical	.27	2.04*	
	Cognitive	.05	0.41	
	Emotional	.05	0.40	
	Behavioural	.31	2.35*	
	Social	.28	2.00	
	$R^2 = .36$	Adjusted $R^2 = .29$		$R = .60$*
Anxiety	Physical	.005	0.34	
	Cognitive	.03	0.17	
	Emotional	.08	0.52	
	Behavioural	-.30	-1.87	
	Social	-.06	-0.37	
	$R^2 = .09$	Adjusted $R^2 = -.01$		$R = .30$
Depression	Physical	-.002	-0.02	
	Cognitive	-.03	-0.18	
	Emotional	-.09	-0.53	
	Behavioural	-.11	-0.66	
	Social	-.07	-0.41	
	$R^2 = .04$	Adjusted $R^2 = -.06$		$R = .20$
Social Adjustment	Physical	-.11	-0.70	
	Cognitive	.03	0.20	
	Emotional	-.004	-0.03	
	Behavioural	-.29	-1.85	
	Social	-.14	-0.83	
	$R^2 = .13$	Adjusted $R^2 = .03$		$R = .36$
Subjective burden	Physical	-.27	-2.07*	
	Cognitive	-.02	-0.18	
	Emotional	-.06	-0.46	
	Behavioural	-.21	-1.57	
	Social	-.36	-2.52*	
	$R^2 = .37$	Adjusted $R^2 = .30$		$R = .60$*

*$p < .05$.

At 6 months postinjury the total variance explained by the regression equation for objective burden was significant, $F(5,46) = 5.23$, $p = .0007$. In total the five independent variables explained 36% (29% adjusted) of the variance in objective burden. The two individual variables of physical changes ($p = .0471$), and number of behavioural problems ($p = .0229$) both made significant unique contributions to the prediction of objective burden.

The regression equation for anxiety, $F(5,46) = 0.88, p > .05$, was not significant. In total the five independent variables explained 8% (1% adjusted) of the variance in the anxiety scores. The regression equation for depression, $F(5,46) = 0.40$, $p > .05$ was also not significant. In total the five independent variables explained 4% (6% adjusted) of the variance in caregiver depression. Finally, the regression equation for caregiver social adjustment, $F(5,45) = 1.35, p > .05$ failed to reach significance. On this occasion the five independent variables explained 13% (3% adjusted) of the variance in social adjustment.

The regression equation for subjective burden was significant, $F(5,46) = 5.30$, $p = .0006$. The five independent variables explained 37% (30% adjusted) of the variance in subjective burden. On this occasion the two individual variables of physical changes ($p = .0444$), and social contact ($p = .0154$) both made significant unique contributions to the prediction of subjective burden.

At 1 year postinjury the total variance explained by the regression equation for objective burden was significant, $F(5,46) = 4.20, p = .0032$. The five independent variables explained 31% (24% adjusted) of the variance in objective burden. No individual variable reached significance, indicating that none of the independent variables made a significant unique contribution to the variability in objective burden.

Table 5.9. Summary of Simultaneous Regression Analysis for TBI Patient Variables Predicting Caregiver Burden at 1 Year Postinjury

Caregiver	TBI Patient	β	*t*	
Objective burden	Physical	.26	1.76	
	Cognitive	.14	0.90	
	Emotional	-.001	-0.008	
	Behavioural	.27	1.93	
	Social	.18	1.29	
	$R^2 = .31$	Adjusted $R^2 = .24$		$R = .56^*$
Anxiety	Physical	-.21	-1.27	
	Cognitive	.19	1.09	
	Emotional	-.20	-1.03	
	Behavioural	-.20	-1.22	
	Social	-.02	-0.12	
	$R^2 = .14$	Adjusted $R^2 = .05$		$R = .38$
Depression	Physical	-.21	-1.27	
	Cognitive	.11	0.63	
	Emotional	-.17	-0.90	
	Behavioural	-.07	-0.44	
	Social	-.15	-0.96	
	$R^2 = .14$	Adjusted $R^2 = .05$		$R = .38$
Social Adjustment	Physical	-.13	-0.81	
	Cognitive	.13	0.75	
	Emotional	-.26	-1.34	
	Behavioural	-.16	-1.01	
	Social	-.10	-0.67	
	$R^2 = .17$	Adjusted $R^2 = .07$		$R = .41$
Subjective burden	Physical	-.17	-1.25	
	Cognitive	-.29	-2.02*	
	Emotional	.16	1.01	
	Behavioural	-.38	-2.90*	
	Social	-.29	-2.30*	
	$R^2 = .42$	Adjusted $R^2 = .36$		$R = .65^*$

$^*p < .05$.

The regression equation for anxiety, $F(5,45) = 1.48, p > .05$, was not significant. In total the five independent variables explained 14% (5% adjusted) of the variance in the anxiety scores. The regression equation for caregiver depression, $F(5,45) = 1.51$, $p > .05$, was not significant. In total the five independent variables explained 14% (5% adjusted) of the variance in caregiver depression. The regression equation for social adjustment, $F(5,45) = 1.80$, $p > .05$, also failed to reach significance. On this occasion the five independent variables explained 17% (7% adjusted) of the variance in caregiver social adjustment.

Finally, the regression equation for subjective burden was significant, $F(5,46) = 6.79$, $p = .0001$. In total the five independent variables explained 42% (36% adjusted) of the variance in subjective burden. For subjective burden at 1 year postinjury, the three individual variables of cognitive changes ($p = .049$), number of behavioural problems ($p = .0058$), and social contact ($p = .0259$) all made significant unique contributions to the prediction of subjective burden.

Discussion

This study of the primary caregivers of people with severe TBI had three main objectives. The first objective was to describe from the caregivers' perspective, how being the primary caregiver for someone with a severe TBI had affected their lives and how the injury had impacted on the TBI patient. The second objective was to examine the changes that occurred in these areas over the first year following TBI. The final objective was to obtain an understanding of the relative contribution of various factors in determining the degree and type of burden experienced by the caregivers. This was achieved by describing the extent to which the caregivers' perspective of various changes in the TBI patient's functioning impacted on the lifestyle and psychosocial functioning of the primary caregivers.

As can be expected, given the previously reported high prevalence of various deficits following severe TBI, caregivers reported significant changes in the functioning of the TBI patients. At a global level there was a high incidence of cognitive impairment, emotional difficulties, physical impairment, and social dysfunction reported for the TBI patient. At 6 months postinjury physical difficulties were reported to cause the greatest degree of distress, and while cognitive difficulties were the most frequently reported problem they were reported to cause the least distress. At 1 year postinjury the frequency of problems identified in each of the areas remained relatively the same. However, at 1 year physical problems were reported to cause the least degree of distress for the caregiver, and social and emotional difficulties were now of prime importance. The emphasis on physical recovery expressed by caregivers (and usually the patients themselves) soon after injury is well recognised in the clinical setting. By 1 year postinjury however this emphasis has changed and caregivers expressed more concern about the social and emotional changes that have become apparent in the TBI patient. Previous research that has undertaken longer term follow-up of TBI patients has shown that social and emotional problems do not decrease with time and often increase in frequency and intensity. It is possible therefore that caregivers may experience further increases in distress as time goes on.

Responses by the caregivers on the Head Injury Behaviour Rating Scale allowed a more detailed description of the specific behaviours exhibited by the TBI patient and the degree of distress that each behaviour caused for the caregiver. At 6 months postinjury, 5 of the 20 different behavioural problems listed were reported as occurring by at least half of the caregivers. At 1 year there was an overall increase in the prevalence of problem behaviours with 12 of the 20 behavioural problems being reported by more than half of the caregivers, although the increase in the mean number of problem behaviours reported by caregivers at 6 months and 1 year postinjury did not reach statistical significance. At 6 months those behaviours reported most frequently were a combination of cognitive (poor decision making, poor insight) and emotional (impatience, depressed, lack of interest) difficulties. By 1 year postinjury the pattern of difficulties most frequently reported had changed. At this time the most frequently reported behaviours were all of an emotional nature (impatience, impulsiveness, childishness, overly sensitive, decreased motivation, and argumentativeness). The items reported least frequently remained the same at both 6 months and 1 year postinjury, although overall, there was an increase in the number of caregivers reporting the presence of these difficulties. Therefore at 1 year the behaviours most frequently noted by caregivers were those associated with the TBI patients' emotional functioning. This was in contrast to the most frequently reported behaviours at 6 months that were a reflection of the TBI patients' emotional and cognitive functioning. This pattern did not appear to reflect a resolution of cognitive problems, as behaviours associated with cognitive functioning continued to be reported at a similar frequency. It is possible that by 1 year postinjury caregivers have adapted to the cognitive changes in the TBI patient and therefore these behaviours, although still present, are not of primary importance to the caregiver. Instead the emotional difficulties experienced by the TBI patient may be more relevant and are therefore more likely to be reported by the caregiver.

Overall, there was no significant difference in the mean level of distress caused by the behaviour problems at 6 months and 1 year postinjury. Behaviours that involved emotional control were reported to cause the greatest degree of distress for caregivers at both 6 months and 1 year postinjury. At 6 months postinjury the three most distressing behaviours of dependency, irresponsibility, and aggression, were also the least frequently reported behaviours. However there were no other obvious relationships between the prevalence of, and distress caused by, the problem behaviours.

The current findings concerning the prevalence of problem behaviours provide a clearer description than that present in previous literature. The prevalence of the behaviours reported by relatives in the McKinlay et al. (1981) study were similar to those obtained in the current study. Relatives in the McKinlay et al. study reported an increase in the number of emotional and subjective problems in the TBI patient at all follow-up periods when interviewed at 3, 6, and 12 months postinjury. Brooks and McKinlay (1983) also reported similar prevalence figures and noted an increase in the number of behavioural problems reported by relatives between 3 months and 12 months. While the prevalence data found in the current study is similar to that reported by previous researchers, the current findings differ in regard to which behaviours are most distressing for caregivers. Brooks and Aughton (1979b) found that the behaviours of childishness, loss of interest, depression, and anxiety were the most distressing for caregivers. Although, the current study used a similar list of behaviours to that used by Brooks and Aughton, the behaviours identified as causing the most distress for caregivers differed to those in the current study.

Psychosocial functioning was significantly impaired for a substantial proportion of this group of caregivers at both 6 months and 1 year postinjury. Over one-third of the caregivers were found to be clinically anxious at 6 months with the prevalence of anxiety remaining relatively stable throughout the year. A similar level of clinically significant depression was also reported by the caregivers at 6 months and 1 year postinjury. Analysis of individual caregiver data revealed that in the majority of cases those who were either anxious or depressed at 6 months postinjury continued to report symptoms at 1 year. These figures are similar to those reported by previous researchers (Oddy et al., 1978a; Livingston, 1987; Livingston et al., 1985b, 1985a). Livingston et al. (1985a) reported the prevalence of depression and anxiety in a group of relatives of severe TBI patients at 6 months to be 23% and 41% respectively. These figures again remained relatively stable at 1 year. The small differences observed in the prevalence figures obtained by Livingston et al. (1985a) and the current study may be due to the use of different scales to assess anxiety and depression.

Social adjustment was impaired for over one-third of the caregivers at 6 months postinjury. On average, a statistically significant improvement in the caregivers' overall level of social adjustment between 6 months and 1 year postinjury was observed. However, inspection of individual role areas found no improvement between 6 months and 1 year for the role areas of extended family, marital, and social and leisure. At both 6 months and 1 year postinjury the role area most frequently disrupted was that of the family unit. The other commonly reported area of dysfunction was the extended family and the highest proportion of cases reporting a severe degree of impairment occurred for this role area. This suggests that the impact of caring for a person with a severe TBI extends beyond the immediate caregiving relationship and affects the caregivers' relationships with their own extended family

The current results are consistent with those obtained by Livingston et al. (1985a) who also administered the Weissman social adjustment scale. However, unlike Livingston et al. who found the greatest degree of dysfunction to be in the marital role area, in the current study the greatest dysfunction was found to occur in the family and the extended family unit. This difference in results may be due to the greater number of spouses in the Livingston et al. study.

An obvious gap in the previous literature on caregiver burden following TBI is the absence of reports on the objective impact of caring for a TBI patient on the caregiver. Much of the previous literature concentrates on the objective impact of TBI on the patient, and the subjective or emotional impact on the caregiver. However passing reference has been made to these issues in some of the literature. For example, Panting and Merry (1972) reported that 61% of the relatives in their sample required the use of medication in order to cope with changes that had resulted from the TBI patient's injury. Both Romano (1974) and Thomsen (1974) commented on the social isolation of the families of people with severe TBI. Various other references have been made to the changes in the financial situation (Jacobs, 1988) and changes in the role within the family (Thomsen, 1974) for the caregiver of a TBI patient.

However systematic investigation of the effect of these changes on the caregiver has not been undertaken.

In the current study various forms of objective burden were reported as being experienced by a large number of caregivers on the Caregiver Questionnaire. At 6 months postinjury over half of the caregivers confirmed that at least 6 of the 15 changes had occurred in their life as a result of caring for the TBI patient. The most commonly reported items were less time for myself, anxiety, change in sleep pattern, less privacy, changes in finances, and changes in their relationships with families and friends. At 1 year the same items were reported most frequently although only 4 of these were now reported by over half of the caregivers. The least frequently reported items at both 6 months and 1 year postinjury were increased illness, medication use, and substance abuse. While having less time for themselves was reported as one of the changes that caused the most distress at both 6 months and 1 year, less frequently occurring changes such as illness, medication use, and changes in employment were also reported to cause high degrees of distress. In the current study, approximately 50% of caregivers noted a negative financial impact.

> *Lynn was the mother of a 17 year old man, Ben, who displayed significant cognitive impairment and behavioural difficulties such as lack of insight and impulsive behaviour. At the time of her son's accident Lynn was employed in a full-time capacity in an accountant's office and was about to begin the final year of her accountancy degree. Following Ben's accident Lynn gave up work and deferred her degree. Lynn described how Ben, although independent in many tasks, he required constant*

> *supervision due to his behavioural problems. She said that she really missed her work and study but felt that she was the best person to be with Ben. Giving up work had placed significant burden on the family financially and this had lead to some friction between her and her husband. She said that as time went on many of her friends and the extended family showed less understanding and tolerance of Ben and showed little understanding of her situation. As such she has maintained less contact with them.*

The third objective of this caregiver study was to examine the relationship between the effect of changes in the TBI patient and the impact of these changes on the primary caregiver. Previous studies (e.g., Livingston, 1987) have examined the role of clinically determined impairment in predicting levels of caregiver burden. However, in order to take into account the caregiver's appraisal of the stressors (Knight, 1992), in the current study, the caregivers' perceptions of changes in the TBI patient were used as the independent variables. Following the preliminary correlational analysis, the relationships between the five aspects of TBI patient functioning and five aspects of caregiver functioning were further examined by multiple regression. The current study found statistically significant correlations between some aspects of TBI patient functioning and caregiver anxiety, depression, and social adjustment. Despite this, at both 6 months and 1 year postinjury, the five patient variables were, on their own, insufficient to explain these three aspects of caregiver psychosocial functioning. Therefore, despite the significant correlations, other variables not assessed in the present study must have a more direct role in affecting caregiver levels of anxiety, depression, and social adjustment. Knight's (1992) model of caregiver burden allows for consideration of the role of social support and caregiver coping strategies in determining level of caregiver burden. It is likely that these two variables, which were not assessed in the current study, play a major role over and above that of caregiver appraisal, in determining caregiver levels of anxiety, depression, and social adjustment.

The caregivers' level of objective and subjective burden was significantly predicted by the five TBI patient variables at both 6 months and 1 year postinjury. The significant and unique contribution made by individual variables, over and above their contribution as part of the group of variables, provides a possible understanding of the changing difficulties that face primary caregivers in the first year following severe TBI. The individual variables of physical changes and number of behavioural problems each played a unique role in determining objective burden at 6 months but not at 1 year postinjury. This is despite the fact that caregiver reports did not indicate an improvement in the TBI patients' physical functioning or a decrease in the number of behavioural problems over this time. Therefore it may be that caregivers adapt in a practical way to managing the physical and behavioural changes that occur in the TBI patient.

Examination of the changes most frequently noted by caregivers provides an indication of the way in which caregivers may adapt to the physical and behavioural difficulties that the TBI patient displays. Caregivers as a group reported the most frequent changes for them to be less time for themselves, decreased privacy, changed financial situation, and changes in their relationships with family and friends.

Therefore the caregivers manner of coping or adapting to the changes in the TBI patient may relate to them making changes in their lives so that they can be with the TBI patient and provide direct assistance. This is consistent with the trend for many TBI patients to return to live with their parents, who also become their primary caregivers. For many caregivers in this study, they had given up their employment, or had at least taken a years leave of absence, in order to provide the physical support that was required by the TBI patient. In addition, they were the most likely person to be involved in managing the TBI patients difficult behaviours, either when the TBI patient was in the home or when they were in the community.

Despite the lessening impact of the TBI patients' behavioural problems on the objective burden of the caregiver, by 1 year postinjury these problems have begun to play a significant role in the level of subjective distress experienced by the caregivers. Similarly, although caregivers did not report a change in the TBI patients' cognitive problems over time, these problems were also making a unique contribution to the level of subjective distress being experienced by the caregivers at 1 year postinjury.

The mechanism by which this change occurs is unknown. It may be that the functional impact of cognitive and behavioural difficulties becomes more apparent to the caregiver between 6 months and 1 year postinjury and consequently plays a greater role in the subjective distress that they experience. Between 6 months and 1 year rehabilitation is more likely to focus on the TBI patient returning to such premorbid activities as employment. As noted earlier in this study, those who were unable to return to work were found to be more cognitively impaired and display a greater number of behaviour problems. Similarly, changes in living arrangements and involvement in social activities were found to be most affected by cognitive and behavioural changes. The focus on returning to these activities may highlight the functional impact of cognitive and behavioural difficulties on these important areas of functioning and they may therefore become obvious to the caregiver.

While physical impairment in the TBI patient made a significant contribution to the subjective distress experienced by the caregiver at 6 months postinjury it no longer made a unique contribution to distress at 1 year. Physical changes are often the most obvious impairments at 6 months postinjury and cause the most obvious handicap for the TBI patient. At 6 months physical impairments often remain the primary focus for many TBI patients. The perception of the TBI patient that once their physical functioning returns to normal they will be "better" is commonly incurred. This is further supported by rehabilitation services that continue to focus on physical recovery after TBI. In many senses physical impairment is the easiest area of disability to apply rehabilitation strategies to, and physical disability can be seen as more socially acceptable than other types of disability. For these reasons it is possible that caregivers in the early stages of recovery focus more on physical impairments and as such this causes them a greater degree of distress. By 1 year postinjury however, most physical recovery has occurred and both the caregiver and the TBI patient are reaching a realisation that further recovery is unlikely. As already discussed, impairments in cognition and behaviour are becoming more apparent and this may mean that the focus of the caregivers attention shifts away from physical impairments.

Overall however, it is the loss of social contact for the TBI patient that consistently caused the caregivers distress in the year following severe TBI. The level of this distress was best exemplified by Jim, the father a 19 year old man who had lost all of his friends since his injury. While talking about the lack of social contact that his son now had Jim became quite upset. He said, “It’s bloody wrong you know! A young guy like that. It would be alright if it was an old guy like me, but he’s got his whole life ahead of him. It’s bloody wrong!”. That a loss of social contact is distressing for the caregiver is of concern given the indications in the present study regarding the TBI patients’ social functioning. While there was a decrease in the amount of social contact that the TBI patient was involved in following their injury, there was a tendency for them to have even less social contact at 1 year postinjury. Previous research has indicated that lack of social contact is a permanent feature of the long term outcome of severe TBI (e.g., Marsh et al. 1990).

The impact of decreased social contact for the TBI patient and for the caregiver requires further investigation. The reasons why caregivers become distressed about the patient’s reduced social contact are unclear. It may be that caregivers become distressed because they perceive that decreased social contact causes distress for the TBI patient. Alternatively, or additionally, the caregiver may be distressed because they feel that the lack of social contact has important and negative implications for the TBI patient’s future.

The overall picture that emerges from the regression analysis of objective and subjective burden is that many aspects of the TBI patient’s functioning results in practical difficulties and subjective distress for the primary caregivers. At a more specific level it appears that the impact of physical impairment is comparatively short-lived. Similarly, the caregivers learn some practical ways to manage the behavioural problems of the TBI patients. Despite this, over time the TBI patients behavioural and cognitive problems begin to play a larger role in the level of distress experienced by the caregiver. However, it is the TBI patients' social isolation that has a stable and consistent role in the experience of subjective burden for primary caregivers in the first year postinjury.

Despite the significant correlations that were found between aspects of TBI patient functioning and caregiver anxiety, depression, and social adjustment, at both 6 months and 1 year postinjury, the five patient variables were, on their own, insufficient to explain these three aspects of caregiver psychosocial functioning. Therefore despite the significant correlations, other variables not assessed in the present study must have a more direct role in affecting caregiver levels of anxiety, depression, and social adjustment.

Knight's (1992) model of caregiver burden allows for consideration of the role of social support and caregiver coping strategies in determining level of caregiver burden. It is likely that these two variables, which were not assessed in the current study, play a major role over and above that of caregiver appraisal, in determining caregiver levels of anxiety, depression, and social adjustment. Support for this hypothesis has been provided by recent research by Douglas and Spellacy (2000) who investigated the prevalence of depression among a group of caregivers of severe TBI patients. The results indicated that 60% of caregivers were classified as depressed using the Self-Rating Depression Scale. This represents a greater prevalence of depression among caregivers compared to the findings of the present study and may be due to the use of different measures. The caregivers in the Douglas and Spellacy study were assessed between 3.5 and 10 years following the patient's injury and their results may suggest an increase in the prevalence of depression as time since injury becomes greater. Interestingly, the authors found that social support contributed significantly to the prediction of depression for the caregivers.

Similarly, Sander, High, Hannay, and Sherer (1997) found that use of an emotion focused coping style rather than a problem focused coping style was related to a greater level of distress among caregivers. Caregiver psychological distress was more strongly related to coping style than patient level of functioning. Increased satisfaction with social support was also associated with less emotional distress for the caregiver. The implications of these findings for rehabilitation will be discussed in Chapter 6.

Chapter 6

General Discussion and Future Directions

This chapter summarises the results of the three studies that make up the current research project. The practical implications of the findings for rehabilitation practise in New Zealand are discussed. Directions for future research are outlined.

Despite advances in medical care and road safety, TBI continues to be a leading cause of death and disability in New Zealand. The costs, both economic and social, are great. A review of the literature finds research that has described the consequences of severe TBI in terms of the cognitive, emotional, behavioural, and social outcome for the TBI patient. However, previous research has tended to concentrate on only one or two of these aspects of outcome, rather than investigating the multiple consequences and the relationship between these different aspects of functioning. Previous research has suffered from methodological problems including poorly defined samples, heterogeneous groups in relation to severity and time postinjury, bias in sampling techniques, and measures of impairment and outcome that lack reliability and validity. Previous studies examining the relationship between severity of injury and outcome, and the effect of a severe TBI on the family of the TBI patient, has similarly suffered from methodological weaknesses.

The current research project sought to provide the first comprehensive, longitudinal study of outcome following severe TBI in a New Zealand sample. The purpose of the project was to provide a more precise description of the many consequences of severe TBI for the patient and their family in the first year postinjury.

Changes over time in these consequences and the relationship between them was examined. The prediction of outcome using a relatively new measure of severity was also explored.

Early Prediction of Outcome

Research into the prediction of outcome following severe TBI has been driven on medical, economic, and social grounds. The degree of accuracy of prediction that is required varies according to the use that will be made of the information, and the type of decisions that are to be made based on that information. In the current study some SEP patterns were found to predict a favourable, as opposed to unfavourable outcome with absolute certainty. While SEP recordings predicted death with a high degree of accuracy, false positives did occur. No relationship was found between SEP recordings and more specific areas of patient outcome, such as cognitive and behavioural functioning.

The use of SEPs to allocate, or withdraw, treatment in the acute stage following injury is complex. The selective allocation of health resources is an economic reality in the modern health care system. This already occurs in the treatment of both acute and chronic illness. The most recent estimate of annual costs for hospital treatment in New Zealand, for severe TBI patients are 10.9 million dollars for Intensive Care treatment alone, and 19 million dollars for total hospital inpatient treatment (Havill et al., 1998b). The costs of outpatient or community rehabilitation, and then ongoing support have not been estimated.

If decisions regarding triage are to be based on SEP recordings then the acceptable degree of accuracy and definition of outcome must be determined. SEPs can be used to predict those who will die with 90% accuracy and those who will either die, be in a persistent vegetative state, or remain severely disabled with 100% accuracy. Whether or not this represents an acceptable degree of accuracy to justify the withdrawal of treatment is an issue which is beyond the scope of this thesis; but which needs serious consideration.

Despite the uncertainty regarding the usefulness of SEPs in triage situations, they can be used effectively to provide families with information about the probability that a patient will survive his/her injury. In addition, the families can be reliably informed as to the likely, broad level of disability that will result from the injury. This information will enable the family to prepare themselves, at least to some degree, for the longer term outcome. Similarly, rehabilitation professionals can be provided with a broad understanding of the degree and length of rehabilitation that will be required.

More precise information relating to the specific impairments and disabilities that will result from the injury remain unknown in the acute stages postinjury. Despite this, results from the current study indicate that many severe TBI patients continue to experience cognitive, emotional, and behavioural impairment 1 year following injury. These impairments impact significantly on the TBI patient's social adjustment and on their primary caregiver. Our current inability to make early predictions of outcome at a more specific level highlights the need for ongoing assessment throughout the recovery process. This will be needed to ensure that the TBI patient's individual needs can be ascertained and an appropriate rehabilitation plan can be developed.

Severe TBI, in the current study, was found to result in pervasive deficits across a wide range of cognitive functions. While improvement was noted on all measures over time, a high prevalence of cognitive deficits continued to be observed at 1 year postinjury. Similarly, TBI patients reported a high prevalence of behavioural problems, particularly those associated with emotional control. These reports were consistent at both 6 months and 1 year postinjury. There was no consistent relationship between the frequency of behaviour problems and the distress that they were reported to cause for the patient. Perhaps the most obvious and dramatic impact on the TBI patient's life is evident in the changes in their social status. Few TBI patients return to work, the majority experience a loss of independence in their living arrangements, and there is a deterioration in their personal relationships and associated social activities. An examination of the relationship between the patient's deficits and their social status allows for the development of an understanding of the real world consequences of these deficits.

Ecological Validity of Neuropsychological Testing

A recent development in neuropsychology has been the consideration of what is termed the ecological validity of psychometric tests. Ecological validity is defined by Tupper and Cicerone (1990) as "the relationship between test performances and the ability to function in the real world" (pg. 6). The results from the current study demonstrate that the TBI patients' performance on cognitive tests has ecological validity for predicting their ability to return to work, independence in living arrangements, and changes in social relationships.

The broader implications for neuropsychology can be best understood by examining the historical development of neuropsychology as a discipline. The early development of neuropsychology through to the 1960s is referred to as 'static' neuropsychology and concerned attempts by neuropsychologists to relate an individual's performance on tests to a static neurological condition or specific brain lesions. The focus during this period was on differential diagnosis. In the 1960s and 1970s the focus in neuropsychological models shifted to encompass a better understanding of brain-behaviour relationships. This cognitive neuropsychology phase was characterised by attempts to analyse and understand the nature of the tests being used, so as to clarify the correlation with brain functioning. More recently in the 1980s a change in the conceptualisation of the brain-behaviour relationship occurred and is referred to as 'dynamic' neuropsychology. In this model both the brain and behaviour were viewed as capable as undergoing change, and the relationship between the two is seen in terms of their dynamic interplay (Tupper & Cicerone, 1990).

Consideration of the ecological validity of neuropsychological measures represents the fourth and current stage of neuropsychology. This fourth stage incorporates consideration of the environment or stimulus variables in the dynamic interplay between the brain and behaviour. Increasingly, neuropsychologists are being asked to be more precise about the functional deficits of the patient. The change in demands on neuropsychologists has been brought about to a large extent by rising heath care costs and the consequent changes in the funding and provision of health services. There is a growing emphasis on the need to justify the practical utility and efficacy of assessment procedures, and for assessments to be of direct relevance to rehabilitation treatment and planning. While the results from the current study demonstrate that the performance by TBI patients on cognitive tests has ecological validity for various aspects of their social functioning, further research needs to define this relationship more clearly. This will involve research that further defines the relationship between damage to brain tissue, disturbed cognitive function, performance on cognitive tests, and ability to function in the real world.

Impact of Caring for a Person with TBI

Severe TBI affects not only the person who receives the injury but also their family. For most families, their lives are changed forever in an instant. The impact on the primary caregiver is of particular interest. This person will often be the key support person for the TBI patient. In the majority of cases the primary caregiver is female and will usually be the TBI patient's mother. The results of the current study indicated that overall, a significant number of caregivers experience symptoms of clinical depression, clinical anxiety, and disrupted social functioning. While, on average, no significant changes in the levels of depression or anxiety were apparent between 6 months and 1 year postinjury, a small but significant improvement in overall social adjustment was noted.

Caregivers reported a number of changes occurring in their life as a direct result of caring for the TBI patient. While the number of these changes did not decrease over the first year postinjury, the degree of distress associated with these changes did decrease. This suggests some adaptation on the part of the caregivers to the changes that have occurred for them. The TBI patient variables, which represented the caregiver's appraisal of the patients functioning, explained a significant amount of subjective and objective burden at both time periods. At 6 months postinjury the TBI patient variables of physical impairment and number of behavioural problems also made unique contributions in explaining caregiver objective burden. Similarly, the TBI patient variables of physical impairment and the patient's social isolation made unique contributions in explaining subjective burden. At 1 year postinjury the three variables of cognitive impairment, number of behavioural problems and social isolation made unique contributions in explaining caregiver subjective burden.

The TBI patient variables were not sufficient on their own to explain caregiver levels of anxiety, depression, or social adjustment at either 6 months or 1 year postinjury. It is possible that variables not assessed in the current study, such as social support and caregiver coping strategies have a significant impact on the psychosocial functioning of caregivers.

The Stress-Appraisal-Coping Model

More recently, researchers have postulated the application of the stress-appraisal-coping model, developed by Lazarus and Folkman (1984), to explain the psychosocial adjustment of the patient and the caregiver following TBI (Douglas & Spellacy, 1996; Kendall & Terry, 1996; Knight, Devereux, & Godfrey, 1998; Godfrey, Knight, & Partridge, 1996; Sander et al, 1997). This model suggests that the person's level of adjustment is mediated by their cognitive appraisal of the stressor, their level of social support, and their use of coping skills. When a stressor is identified by the person and they do not perceive that they have the social support or the coping strategies to deal with the stressor, then distress or subjective burden develops.

New Zealand research by Knight et al. (1998) and Godfrey et al. (1996) has begun to explore the usefulness of this model to explain adjustment in the TBI patient and the caregiver. Godfrey et al. (1996) describes the application of this model to explain adjustment in the TBI patient. They suggested that the TBI patient's appraisal of the stressor, their coping skills, and the degree of social support they receive are affected by a range of neurological and non-neurological factors. Amongst these are cognitive impairment, premorbid coping abilities and styles of coping, and the level of social skill displayed by the TBI patient.

Preliminary research undertaken by Knight et al. (1998) found that the degree of distress caused to the caregiver by the TBI patients' symptoms, and the caregivers' ratings of their ability to cope, were predictive of caregiver burden. The variable most predictive of burden in the caregivers was their perception of their ability to cope. However social support was not found to be a significant predictor of caregiver burden.

As noted by Godfrey et al. (1996) the conceptualisation of adjustment within the framework of this model allows for the identification of the mediating factors that contribute to the development and maintenance of stress, and thereby provides a focus for rehabilitation intervention. Further research is needed to investigate the usefulness of this model in explaining adjustment in both the TBI patient following their injury, and their primary caregiver and family.

Implications for Assessment and Intervention in Rehabilitation

The purpose of rehabilitation is to return the patient to their previous level of ability so that they can participate in the psychosocial roles they were engaged in prior to their injury. For many people with severe TBI their level of disability will preclude a return to all previous activities. In these cases the purpose of rehabilitation is to assist the patient to develop a different, but still rewarding, lifestyle. This study emphasises a number of issues relevant to the provision of assessment and rehabilitation services for people who have sustained a severe TBI.

The results from the current research project show that the assessment of severity of injury provides only very gross indications of the TBI patients rehabilitation needs. An accurate determination of an individual patient's rehabilitation needs requires individualised and ongoing assessment. The rapid changes that occur in patient functioning in the early stages postinjury necessitate frequent assessment. In addition, the life-long disabilities that can result from severe TBI indicate the need for ongoing but less frequent reassessment over a much longer period.

The high prevalence of deficits in cognitive, emotional, and behavioural functioning following severe TBI demonstrates the need for assessments to be broad-based and comprehensive in nature. The role of the neuropsychologist is to provide a holistic picture of the person detailing their physical, cognitive, emotional, behavioural, and social functioning. The results of the current project have demonstrated the relationship between the patient's cognitive, emotional, and behavioural presentation with their ability to return to premorbid psychosocial activities. While ongoing research is still required to further clarify these relationships, the neuropsychologist currently working in a rehabilitation setting is able to use the results of their assessment to develop individualised rehabilitation plans.

The relationship between cognitive impairment and failure to return to work suggests the necessity for neuropsychological assessment prior to commencing vocational rehabilitation. The TBI patient's ability to meet the cognitive demands of their work duties must be assessed. In addition, the impact of behavioural problems and the patient's insight regarding any difficulties must be assessed in the context of the work environment. The presence of behavioural difficulties does not preclude the person from returning to employment but their employer and other staff may require training to deal with these problems. Alternatively the TBI patient's responsibilities may need to be altered. Although some patients may accept the need to alter their duties at work, those who lack insight regarding their abilities are likely to see that they are being given tasks that are below their capabilities. In these latter cases, assisting the patient to become more aware of their impairments will be necessary.

Those TBI patient's who were unable to return to independent living displayed more severe cognitive impairment. The precise way in which specific cognitive impairments impact on the ability to live independently is unclear. It may simply be that those with more severe cognitive impairment require more assistance with day-to-day activities and/or a higher level of supervision. Alternatively, it could be that the decrease in income that results from unemployment leads to a decrease in the financial ability to live independently.

Many of those who were unable to return to independent living were young people between 16 and 25 years of age who had been living in a flatting situation and had now returned to live with their parents. These patients generally reported feeling frustrated at having to be dependent on parents again and there is some suggestion in previous literature that living with parents further affects the patients ability to develop age-appropriate social contact. However many of these people require a constant level of support and supervision, and will require this for the rest of their lives. Unfortunately this is only available if they return to live with their parents. This finding highlights the lack of appropriate facilities for young adult TBI patients who are relatively independent but who need some support and ongoing supervision. Ideally these people could live in a "flat" with other TBI patients who have a similar level of disability and require a similar level of supervision. Even today no such facilities exist in New Zealand.

The TBI patient experiences significant changes in their social functioning following their injury. The mechanisms by which the TBI patient experiences a decrease in contact with friends differs according to whether it is them who fail to maintain contact or whether it is their friends who do not maintain contact. Therefore the neuropsychologist assessing the patient's decrease in social contact must determine whether this is a consequence of social withdrawal by the patient or avoidance of them by their friends.

Those patients who initiate less contact display more severe impairment of cognitive functioning. It may be that as a result of this impairment they are less motivated, or are less able, to initiate contact and therefore require prompting and encouragement to do this. For others their level of impairment may affect their ability to enjoy contact with friends. They may find the demands of maintaining such interaction to be beyond their capabilities or they may be embarrassed by their impairments. Rehabilitation should aim to first define the specific difficulties for each TBI patient and then implement appropriate strategies.

Those TBI patients who displayed a decrease in visits from friends had higher levels of depression, self-reported more behavioural problems, and were reported by their caregiver to display more behavioural problems. While rehabilitation will need to address these issues it may be important to include friends in the TBI patient's rehabilitation. The more direct involvement of friends in this process will allow them to gain a better understanding of the fact that the changes in their friends behaviour are a consequence of their injury. They may then be more accepting of these behaviours and learn adaptive ways of responding.

Ultimately, it is the family who provide the necessary and long-term support for the TBI patient. The health and general wellbeing of the family therefore, is an important factor in the process and maintenance of the TBI patient's rehabilitation. The current project focused on the functioning of one family member; the family member who was considered to have the most day to day contact with the patient. Many of these primary caregivers experienced significant distress as a consequence of the changes in their life and the changes in the TBI patient.

One of the more obvious findings from the current study is that the needs of caregivers change over time. While the physical, cognitive, emotional, behavioural, and social functioning of the TBI patient all contributed to the objective and subjective burden experienced by the caregiver, different areas caused a greater degree of concern at different follow-up periods. At 6 months postinjury physical changes in the TBI patient caused the caregivers a greater degree of objective and subjective burden, although this was not the case at 1 year postinjury. In the early stages following injury strategies that will reduce the difficulties associated with physical impairment, such as house modifications and adaptive devices, should occur as soon as possible, preferably before the person is discharged home from hospital.

Behavioural problems also caused a greater degree of objective burden at 6 months postinjury. This suggests that early intervention to provide the caregiver with information and strategies to deal with behavioural problems is needed. The negative changes most commonly reported by caregivers were less time for themselves, a disturbed sleep pattern, less privacy, and financial hardship. Therefore rehabilitation must ensure that caregivers are provided with adequate attendant care and/or respite care. Many TBI patients and families are unaware of the services (both treatment and financial support) that they may be entitled to and it is the role of the rehabilitation professional to ensure that appropriate recommendations are made.

Caregivers reported changes in their relationships with other family members and friends to cause additional burden. Ideally caregivers should have access to counselling to address this issue and to ensure that caregivers do not become socially isolated through the loss of these relationships. Unfortunately, current rehabilitation funding within New Zealand does not allow for the assessment and maintenance of caregiver well-being to be incorporated into the overall rehabilitation plan. Because funding is not available, health professionals, despite their knowledge of the true needs of the caregivers, may fail to make comprehensive recommendations concerning the caregiver's health needs. Caregivers can of course seek assistance from health professionals but in most cases they will be required to personally fund this service. For many families caring for the TBI patient results in increased financial pressure that may preclude the extra burden of funding private health care for themselves.

The TBI patient's behavioural problems and social isolation consistently have a negative impact on caregiver wellbeing. Therefore training caregivers in ways of responding to the behavioural problems will not only reduce distress for the caregiver but also reduce the prevalence of these behavioural problems. Given the relationship between the presence of behavioural problems and social isolation a reduction in the patient's behavioural problems will also result in an increase in their social networks. Reducing the TBI patient's social isolation will assist to improve the caregivers wellbeing. The pivotal role of the primary caregiver, and the fact that they can experience significant levels of distress, highlights the importance of specifically assessing the caregiver's level of functioning when devising any rehabilitation plan.

Summary

The results of this project have highlighted the difficulties faced by health professionals in the acute stage following trauma who, while they understand the importance of providing families with accurate information regarding the prognosis for their family member, can provide only a broad guideline to eventual outcome. It has documented the numerous impairments that many people with severe TBI experience and the widespread consequences this has on many aspects of their day to day functioning. It has also reported the widespread impact that this has on the TBI patient's family, in particular their primary caregiver.

As technological advances in acute medical care reduce the mortality associated with severe TBI, there is an obligation to ensure that the morbidity that results from such injuries is minimised. The provision of rehabilitation in New Zealand requires not only an examination of rehabilitation practises but also an examination of political and social policies that dictate the funding and provision of services.

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Appendix A

WAIKATO TRAUMATIC BRAIN INJURY RESEARCH GROUP
(University of Waikato & Waikato Hospital)

Head Injury Study - Intensive Therapy Unit Patients

Subject ID: [

Name: ____

Address: ____

Date: ____ [

Date (2nd assessment): ______________________________ [

Age: __________ [

Date of Birth: ______________________________

Gender: [

1. Female 2. Male

Dominant Hand: [

1. Right 2. Left

Ethnicity: [

1. NZ European/Pakeha 2. NZ Maori
3. Pacific Islander 4. Other (Specify: __________________)

Relationship Status: **pre [**

1. Never married 2. Married/De facto **T1 [**
3. Separated/Divorced 4. Widowed
5. Other (Specify: ______________________) **T2 [**

Years of Education:

[

Age when left school: (- 5)
Currently attending school

Occupational Status **pre [**

1. Student 2. Unemployed **T1 [**
3. Homemaker 4. ACC/Invalid/Sickness Beneficiary
5. Retired 6. Paid employment (Specify type) **T2 [**

Occupational Training Qualifications [

1. Nil
2. School Certificate
3. U.E./Sixth Form Certificate
4. HSC/Bursary
5. Trade (Specify: ______________________________)
6. Professional (Specify:______________________________)
7. Tertiary (Specify: ______________________________)
8. Other (Specify: ______________________________)

Living Arrangements
(Include number of people living with) **pre** [

1. Alone
2. Parents **T1** [
3. Relations (including siblings)
4. Partner
5. Partner plus children
6. Flatmate/s **T2** [
7. Other (Specify: ____________)
8. Hospital

Number of Dependent Children: ____________ [

Current Medication: [

1. No
2. Yes (Type: ________________)

Current Medical Conditions [
(Do you currently have any condition affecting your eyesight, hearing, smell, or touch, or conditions of epilepsy, diabetes, etc?)

1. No
2. Yes (Diagnosis: ________________)

Previous Medical Conditions [
(Have you ever had any condition affecting your eyesight, hearing, smell, or touch, or conditions of epilepsy, diabetes, etc?)

1. No
2. Yes (Diagnosis: ________________)

Previous Hospitalizations [

1. No
2. Yes (Diagnosis: ________________)

Previous Neurological Complaints [
(Prior to your head injury, have you frequently suffered from headaches, dizziness, fainting spells, or insomnia?)

1. No
2. Yes (If so, how often? __________)

Previous Psychiatric History [
(Prior to your head injury, have you ever been treated by a Psychiatrist or Psychologist?)

1. No
2. Yes (Diagnosis: ________________)

Current Psychiatric Treatment
(Are you currently being treated by a Psychiatrist or Psychologist?) **T1** [

1. No
2. Yes (Diagnosis: ________________) **T2** [

History of Head Injury

Previous head injury: [

1. No 2. Yes (Date: ____________)

Current head injury:

Date: Time elapsed since injury:

Glasgow Coma Score: Length of Hospitalization:

How injury occurred: Other Details:

Caregiver Data

Time 1

Age: [

Gender [

1. Female 2. Male

Living with patient [

1. Yes 2. No

Relationship with patient [

1. Parent 2. Spouse/Partner
3. Sibling 4. Relative (________________)
5. Other (________________)

Time 2

Age: [

Gender [

1. Female 2. Male

Living with patient [

1. Yes 2. No

Relationship with patient [

1. Parent 2. Spouse/Partner
3. Sibling 4. Relative (________________)
5. Other (________________)

Same caregiver at T1 & T2 [

1. Yes 2. No

Appendix B

The following measures of the TBI patient's functioning are not included in this appendix due to copyright regulations:

1. National Adult Reading Test (NART; Nelson, 1982)
2. Vocabulary, Similarities, Block Design, Digit Span, Digit Symbol subtests of the Wechsler Adult Intelligence Scale-Revised (Wechsler, 1981)

Therefore, this appendix includes the following measures:

1. Glasgow Coma Scale
2. Auditory Verbal Learning Test
3. Controlled Oral Word Association test
4. Beck Depression Inventory (BDI-SF)
5. Head Injury Behaviour Rating Scale
6. Glasgow Outcome Scale

WAIKATO TRAUMATIC BRAIN INJURY RESEARCH GROUP
(University of Waikato & Waikato Hospital)

Head Injury Study – Intensive Therapy Unit Patients

Subject ID:

Glasgow Coma Scale

Eye Opening	
Spontaneous	4
To speech	3
To pain	2
Nil	1
Best Motor Response	
Obeys	6
Localises	5
Withdraws	4
Abnormal flexion	3
Extensor response	2
Nil	1
Verbal Response	
Oriented	5
Confused conversation	4
Inappropriate words	3
Incomprehensible sounds	2
Nil	1

Total Score ____

AUDITORY-VERBAL LEARNING TEST

Subject ID:
Date:

TRIALS

A1	A2	A3	A4	A5	B	A6	A7

LIST A	LIST B
Drum	Desk
Curtain	Ranger
Bell	Bird
Coffee	Shoe
School	Stove
Parent	Mountain
Moon	Glasses
Garden	Towel
Hat	Cloud
Farmer	Boat
Nose	Lamb
Turkey	Gun
Color	Pencil
House	Church
River	Fish

RECOGNITION LIST

- Bell
- Window
- Hat
- Barn
- Ranger
- Nose
- Weather
- School
- Hand
- Pencil
- Home
- Fish
- Moon
- Tree
- Balloon
- Bird
- Mountain
- Coffee
- Mouse
- River
- Towel
- Curtain
- Flower
- Color
- Desk
- Gun
- Crayon
- Church
- Turkey
- Fountain
- Boat
- Hot
- Parent
- Water
- Farmer
- Rose
- Cloud
- House
- Stranger
- Garden
- Glasses
- Stocking
- Shoe
- Teacher
- Stove
- Nest
- Children
- Drum
- Toffee
- Lamb

WAIKATO TRAUMATIC BRAIN INJURY RESEARCH GROUP
(University of Waikato & Waikato Hospital)

Head Injury Study - Intensive Therapy Unit Patients

Controlled Oral Word Association test

Subject ID:
Date:

Instructions: *I will say a letter of the alphabet. Then I want you to give me as many words that you can think of that begin with that letter, as quickly as you can. You may say any words at all, except proper names such as the names of people or places (rotorua, robert). Also do not use the same word again with a different ending (eat, eating).*

For example, if I say "B", you could say "bad" "battle", or "bed". Can you think of other words that begin with the letter "B"?

That is fine, now I am going to give you another letter and again you say all the words beginning with that letter that you can think of. Remember, no names of people or places, just ordinary words. Also, if you should draw a blank, I want you to keep on trying until the time limit is up. You will have a minute for each one.

The first letter is "F".

F	**A**	**S**

WAIKATO TRAUMATIC BRAIN INJURY RESEARCH GROUP
(University of Waikato & Waikato Hospital)

Head Injury Study - Intensive Therapy Unit Patients

BDI-SF

Subject ID:
Date:

Instructions: *This is a questionnaire. On the questionnaire are groups of statements. Please read the entire group of statements in each category. Then pick out the one statement in that group which best describes the way you feel today, that is, RIGHT NOW! Circle the number beside the statement you have chosen. If several statements in the group seem to apply equally well, circle each one.*

BE SURE TO READ ALL THE STATEMENTS IN EACH GROUP BEFORE MAKING YOUR CHOICE

A.

3 I am so sad or unhappy that I can't stand it.

2 I am blue or sad all the time and I can't snap out of it.

1 I feel sad or blue.

0 I do not feel sad.

B.

3 I feel that the future is hopeless and that things cannot improve.

2 I feel I have nothing to look forward to.

1 I feel discouraged about the future.

0 I am not particularly pessimistic or discouraged about the future.

C.

3 I feel I am a complete failure as a person (parent, husband, wife.)

2 As I look back on my life, all I can see is a lot of failures.

1 I feel I have failed more than the average person.

0 I do not feel like a failure.

D.

3 I am dissatisfied with everything.

2 I don't get satisfaction out of anything any more.

1 I don't enjoy things the way I used to.

0 I am not particularly dissatisfied.

E.

3 I feel as though I am very bad or worthless.

2 I feel quite guilty.

1 I feel bad or unworthy a good part of the time.

0 I don't feel particularly guilty.

F.

3 I hate myself.

2 I am disgusted with myself.

1 I am disappointed in myself.

0 I don't feel disappointed in myself.

G.

3 I would kill myself if I had the chance.

2 I have definite plans about committing suicide.

1 I feel I would be better off dead.

0 I don't have any thoughts of harming myself.

H.

3 I have lost all of my interest in other people.

2 I have lost most of my interest in other people and have little feeling for them.

1 I am less interested in other people than I used to be.

0 I have not lost interest in other people.

I.

3 I can't make any decisions at all any more.

2 I have great difficulty in making decisions.

1 I try to put off making decisions.

0 I make decisions about as well as ever.

J.

3 I feel that I am ugly or repulsive-looking.

2 I feel that there are permanent changes in my appearance and they make me look unattractive.

1 I am worried that I am looking old or unattractive.

0 I don't feel that I look any worse than I used to.

K.

3 I can't do any work at all.

2 I have to push myself very hard to do anything.

1 It takes extra effort to get started in doing something.

0 I can work about as well as before.

L.

3 I get too tired to do anything.

2 I get tired from doing anything.

1 I get tired more easily than I used to.

0 I don't get any more tired than usual.

M.

3 I have no appetite at all any more.

2 My appetite is much worse now.

1 My appetite is not as good as it used to be.

0 My appetite is no worse than usual.

SCORE =

HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for sufferer but causes me NO distress.
2. The behaviour is a problem for sufferer and causes me MILD distress.
3. The behaviour is a problem for sufferer and causes me MODERATE distress.
4. The behaviour is a problem for sufferer and causes me SEVERE distress.

BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?
1. Anger; difficulty controlling temper.	Y : N	1 2 3 4
2. Impatience, upset when needs not easily met.	Y : N	1 2 3 4
3. Frequent complaining.	Y : N	1 2 3 4
4. Aggression; violent behaviour.	Y : N	1 2 3 4
5. Impulsivity; does things without thinking.	Y : N	1 2 3 4
6. Argumentative; often disputes topics.	Y : N	1 2 3 4
7. Lacks control over behaviour behaviour is inappropriate for social situations.	Y : N	1 2 3 4
8. Overly dependent; relies on others unnecessarily; does not do things for him/herself.	Y : N	1 2 3 4
9. Poor decision making; does not think of consequences.	Y : N	1 2 3 4
10. Childish; at times behaviour is immature.	Y : N	1 2 3 4

HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for sufferer but causes me NO distress.
2. The behaviour is a problem for sufferer and causes me MILD distress.
3. The behaviour is a problem for sufferer and causes me MODERATE distress.
4. The behaviour is a problem for sufferer and causes me SEVERE distress.

	BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?
11.	Poor insight; refuses to admit difficulties.	Y : N	1 2 3 4
12.	Difficulty in becoming interested in things.	Y : N	1 2 3 4
13.	Lack of initiative; does not think for him/herself.	Y : N	1 2 3 4
14.	Irritable; snappy; grumpy.	Y : N	1 2 3 4
15.	Sudden/rapid mood change.	Y : N	1 2 3 4
16.	Anxious; tense; uptight.	Y : N	1 2 3 4
17.	Depressed; low mood.	Y : N	1 2 3 4
18.	Irresponsible; can't always be trusted.	Y : N	1 2 3 4
19.	Overly sensitive; easily upset.	Y : N	1 2 3 4
20.	Lacks motivation; lack of interest in doing things.	Y N	1 2 3 4

WAIKATO TRAUMATIC BRAIN INJURY RESEARCH GROUP
(University of Waikato & Waikato Hospital)

Head Injury Study - Intensive Therapy Unit Patients

Glasgow Outcome Scale

Subject ID:
Date:

1

Death

State date of death.

2

Persistent Vegetative State

No evidence of meaningful responsiveness. May breathe spontaneously, have periods of spontaneous eye-opening when they may follow moving objects with their eyes, show reflex responses in their limbs (to postural or painful stimuli), and they may swallow food placed in their mouths.

3

Severe Disability

Conscious but disabled. Dependent for assistance with activities of daily living ranging from total dependency (for washing and feeding, etc.) to the need for help with only one activity such as dressing, or mobility.

4

Moderate Disability

Independent but disabled. Can look after themselves and are independently mobile, but some previous activities (either vocational or social) are no longer possible due to either mental or physical disabilities or both.

5

Good Recovery

Resume normal vocational and social activities. May have persisting minor physical and mental deficits that preclude all previous social activities and may not be working.

Appendix C

The following measure of the caregiver's functioning are not included in this appendix due to copyright regulations:

1. State-Trait Anxiety Inventory

Therefore, this appendix includes the following measures:

1. Beck Depression Inventory (BDI-SF)
2. Social Adjustment Scale
3. Head Injury Behaviour Rating Scale
4. Caregiver Questionnaire

WAIKATO TRAUMATIC BRAIN INJURY RESEARCH GROUP
(University of Waikato & Waikato Hospital)

Head Injury Study - Intensive Therapy Unit Patients

BDI-SF

Subject ID:
Date:

Instructions: *This is a questionnaire. On the questionnaire are groups of statements. Please read the entire group of statements in each category. Then pick out the one statement in that group which best describes the way you feel today, that is, RIGHT NOW! Circle the number beside the statement you have chosen. If several statements in the group seem to apply equally well, circle each one.*

BE SURE TO READ ALL THE STATEMENTS IN EACH GROUP BEFORE MAKING YOUR CHOICE

A.

3 I am so sad or unhappy that I can't stand it.

2 I am blue or sad all the time and I can't snap out of it.

1 I feel sad or blue.

0 I do not feel sad.

B.

3 I feel that the future is hopeless and that things cannot improve.

2 I feel I have nothing to look forward to.

1 I feel discouraged about the future.

0 I am not particularly pessimistic or discouraged about the future.

C.

3 I feel I am a complete failure as a person (parent, husband, wife.)

2 As I look back on my life, all I can see is a lot of failures.

1 I feel I have failed more than the average person.

0 I do not feel like a failure.

D.

3 I am dissatisfied with everything.

2 I don't get satisfaction out of anything any more.

1 I don't enjoy things the way I used to.

0 I am not particularly dissatisfied.

E.

3 I feel as though I am very bad or worthless.

2 I feel quite guilty.

1 I feel bad or unworthy a good part of the time.

0 I don't feel particularly guilty.

F.

3 I hate myself.

2 I am disgusted with myself.

1 I am disappointed in myself.

0 I don't feel disappointed in myself.

G.

3 I would kill myself if I had the chance.

2 I have definite plans about committing suicide.

1 I feel I would be better off dead.

0 I don't have any thoughts of harming myself.

H.

3 I have lost all of my interest in other people.

2 I have lost most of my interest in other people and have little feeling for them.

1 I am less interested in other people than I used to be.

0 I have not lost interest in other people.

I.

3 I can't make any decisions at all any more.

2 I have great difficulty in making decisions.

1 I try to put off making decisions.

0 I make decisions about as well as ever.

J.

3 I feel that I am ugly or repulsive-looking.

2 I feel that there are permanent changes in my appearance and they make me look unattractive.

1 I am worried that I am looking old or unattractive.

0 I don't feel that I look any worse than I used to.

K.

3 I can't do any work at all.

2 I have to push myself very hard to do anything.

1 It takes extra effort to get started in doing something.

0 I can work about as well as before.

L.

3 I get too tired to do anything.

2 I get tired from doing anything.

1 I get tired more easily than I used to.

0 I don't get any more tired than usual.

M.

3 I have no appetite at all any more.

2 My appetite is much worse now.

1 My appetite is not as good as it used to be.

0 My appetite is no worse than usual.

SCORE =

Subject ID:
Date:

SOCIAL ADJUSTMENT SELF REPORT QUESTIONNAIRE

We are interested in finding out how you have been doing in the last *two weeks*. We would like you to answer some questions about your work, spare time, and your family life. There are no right or wrong answers to these questions. Check the answers that best describe how you have been in the last *two weeks*.

WORK OUTSIDE THE HOME

Please check the situation that best describes you.

I am
1 ☐ a worker for pay
2 ☐ a housewife
3 ☐ a student
4 ☐ retired
5 ☐ unemployed

Do you usually work for pay more than 15 hours per week?
1 ☐ YES 2 ☐ NO

Did you work any hours for pay in the last two weeks?
1 ☐ YES 2 ☐ NO

Check the answer that best describes how you have been in the last two weeks.

1. How many days did you miss from work in the last 2 weeks?
1 ☐ No days missed
2 ☐ One day missed
3 ☐ I missed about half the time
4 ☐ Missed more than half the time but did make at least one day
5 ☐ I did not work any days
8 ☐ On vacation all of the last two weeks

If you have not worked any days in the last two weeks, go on to Question 7.

2. Have you been able to do your work in the last 2 weeks?
1 ☐ I did my work very well
2 ☐ I did my work well but had some minor problems
3 ☐ I needed help with work and did not do well about half the time
4 ☐ I did my work poorly most of the time
5 ☐ I did my work poorly all the time

3. Have you been ashamed of how you do your work in the last 2 weeks?
1 ☐ I never felt ashamed
2 ☐ Once or twice I felt a little ashamed
3 ☐ About half the time I felt ashamed
4 ☐ I felt ashamed most of the time
5 ☐ I felt ashamed all the time

4. Have you had any arguments with people at work in the last 2 weeks?
1 ☐ I had no arguments and got along very well
2 ☐ I usually got along well but had minor arguments
3 ☐ I had more than one argument
4 ☐ I had many arguments
5 ☐ I was constantly in arguments

5. Have you felt upset, worried, or uncomfortable while doing your work during the last 2 weeks?
1 ☐ I never felt upset
2 ☐ Once or twice I felt upset
3 ☐ Half the time I felt upset
4 ☐ I felt upset most of the time
5 ☐ I felt upset all the time

6. Have you found your work interesting in the last 2 weeks?
1 ☐ My work was almost always interesting
2 ☐ Once or twice my work was not interesting
3 ☐ Half the time my work was uninteresting
4 ☐ Most of the time my work was uninteresting
5 ☐ My work was always uninteresting

WORK AT HOME – HOUSEWIVES ANSWER QUESTIONS 7 - 12. OTHERWISE, GO ON TO QUESTION 13.

7. How many days did you do some housework during the last 2 weeks?
1 ☐ Every day
2 ☐ I did the housework almost every day
3 ☐ I did the housework about half the time
4 ☐ I usually did not do the housework
5 ☐ I was completely unable to do housework
8 ☐ I was away from home all of the last 2 weeks

8. During the last 2 weeks, have you kept up with your housework? This includes cooking, cleaning, laundry, grocery shopping and errands.
1 ☐ I did my work very well
2 ☐ I did my work well but had some minor problems
3 ☐ I needed help with my work and did not do it well about half the time
4 ☐ I did my work poorly most of the time
5 ☐ I did my work poorly all of the time

9. Have you been ashamed of how you did your housework during the last 2 weeks?
1 ☐ I never felt ashamed
2 ☐ Once or twice I felt ashamed
3 ☐ About half the time I felt ashamed
4 ☐ I felt ashamed most of the time
5 ☐ I felt ashamed all the time

10. Have you had any arguments with salespeople, tradesmen or neighbours in the last 2 weeks?
1 ☐ I had no arguments and got along very well
2 ☐ I usually got along well, but had minor arguments
3 ☐ I had more than one argument
4 ☐ I had many arguments
5 ☐ I was constantly in arguments

11. Have you felt upset while doing your housework during the last 2 weeks?
1 ☐ I never felt upset
2 ☐ Once or twice I felt upset
3 ☐ Half the time I felt upset
4 ☐ I felt upset most of the time
5 ☐ I felt upset all of the time

12. Have you found your housework interesting these last 2 weeks?
1 ☐ My work was almost always interesting
2 ☐ Once or twice my work was not interesting
3 ☐ Half the time my work was uninteresting
4 ☐ Most of the time my work was uninteresting
5 ☐ My work was always uninteresting

FOR STUDENTS

Answer Questions 13-18 if you go to school half time or more. Otherwise, go on to Question 19.

What best describes your school program? (Choose one)
1 ☐ Full time
2 ☐ ¾ Time
3 ☐ Half time

Check the answer that best describes how you have been the last 2 weeks.

13. How many days of classes did you miss in the last 2 weeks?
1 ☐ No days missed
2 ☐ A few days missed
3 ☐ I missed about half the time
4 ☐ Missed more than half time but did make at least one day
5 ☐ I did not go to classes at all
8 ☐ I was on vacation all of the last 2 weeks

14. Have you been able to keep up with your class work in the last 2 weeks?
1 ☐ I did my work very well
2 ☐ I did my work well but had minor problems
3 ☐ I needed help with my work and did not do well about half the time
4 ☐ I did my work poorly most of the time
5 ☐ I did my work poorly all the time

15. During the last 2 weeks, have you been ashamed of how you do your school work?
1 ☐ I never felt ashamed
2 ☐ Once or twice I felt ashamed
3 ☐ About half the time I felt ashamed
4 ☐ I felt ashamed most of the time
5 ☐ I felt ashamed all of the time

16. Have you had any arguments with people at school in the last 2 weeks?
1 ☐ I had no arguments and got along very well
2 ☐ I usually got along well, but had minor arguments
3 ☐ I had more than one argument
4 ☐ I had many arguments
5 ☐ I was constantly in arguments
8 ☐ Not applicable; I did not attend school

17. Have you felt upset at school during the last 2 weeks?
1 ☐ I never felt upset
2 ☐ Once or twice I felt upset
3 ☐ Half the time I felt upset
4 ☐ I felt upset most of the time
5 ☐ I felt upset all of the time
8 ☐ Not applicable; I did not attend school

18. Have you found your school work interesting these last 2 weeks?
1 ☐ My work was almost always interesting
2 ☐ Once or twice my work was not interesting
3 ☐ Half the time my work was uninteresting
4 ☐ Most of the time my work was uninteresting
5 ☐ My work was always uninteresting

SPARE TIME – EVERYONE ANSWER QUESTIONS 19 – 27

Check the answer that best describes how you have been in the last 2 weeks.

19. How many friends have you seen or spoken to on the telephone in the last 2 weeks?
    1 ☐ Nine or more friends
    2 ☐ Five to eight friends
    3 ☐ Two to four friends
    4 ☐ One friend
    5 ☐ No friends

20. Have you been able to talk about your feelings and problems with at least one friend during the last 2 weeks?
    1 ☐ I can always talk about my innermost feelings
    2 ☐ I usually can talk about my feelings
    3 ☐ About half the time I felt able to talk about my feelings
    4 ☐ I usually was not able to talk about my feelings
    5 ☐ I was never able to talk about my feelings
    8 ☐ Not applicable; I have no friends

21. How many times in the last 2 weeks have you gone out socially with other people? For example, visited friends, gone to movies, bowling, church, restaurants, invited friends to your home?
    1 ☐ More than 3 times
    2 ☐ Three times
    3 ☐ Twice
    4 ☐ Once
    5 ☐ None

22. How much time have you spent on hobbies or spare time interests during the last 2 weeks? For example, bowling, sewing, gardening, sports, reading?
    1 ☐ I spent most of my spare time on hobbies almost every day
    2 ☐ I spent some spare time on hobbies some of the days
    3 ☐ I spent a little spare time on hobbies
    4 ☐ I usually did not spend any time on hobbies but did watch TV
    5 ☐ I did not spend any spare time on hobbies or watching TV

23. Have you had open arguments with your friends in the last 2 weeks?
    1 ☐ I had no arguments and got along very well
    2 ☐ I usually got along well but had minor arguments
    3 ☐ I had more than one argument
    4 ☐ I had many arguments
    5 ☐ I was constantly in arguments
    8 ☐ Not applicable; I have no friends

24. If your feelings were hurt or offended by a friend during the last 2 weeks, how badly did you take it?
    1 ☐ It did not affect me or it did not happen
    2 ☐ I got over it in a few hours
    3 ☐ I got over it in a few days
    4 ☐ I got over it in a week
    5 ☐ It will take me months to recover
    8 ☐ Not applicable; I have no friends

25. Have you felt shy or uncomfortable with people in the last 2 weeks?
    1 ☐ I always felt comfortable
    2 ☐ Sometimes I felt uncomfortable but could relax after a while
    3 ☐ About half the time I felt uncomfortable
    4 ☐ I usually felt uncomfortable
    5 ☐ I always felt uncomfortable
    8 ☐ Not applicable; I was never with people

26. Have you felt lonely and wished for more friends during the last 2 weeks?
    1 ☐ I have not felt lonely
    2 ☐ I have felt lonely a few times
    3 ☐ About half the time I felt lonely
    4 ☐ I usually felt lonely
    5 ☐ I always felt lonely and wished for more friends

27. Have you felt bored in your spare time during the last 2 weeks?
    1 ☐ I never felt bored
    2 ☐ I usually did not feel bored
    3 ☐ About half the time I felt bored
    4 ☐ Most of the time I felt bored
    5 ☐ I was constantly bored

Are you a Single, Separated, or Divorced Person not living with a person of the opposite sex; please answer below:

1 ☐ YES, Answer questions 28 & 29
2 ☐ NO, go to question 30

28. How many times have you been with a date these last 2 weeks?
    1 ☐ More than 3 times
    2 ☐ Three times
    3 ☐ Twice
    4 ☐ Once
    5 ☐ Never

29. Have you been interested in dating during the last 2 weeks? If you have not dated, would you have liked to?
    1 ☐ I was always interested in dating
    2 ☐ Most of the time I was interested
    3 ☐ About half the time I was interested
    4 ☐ Most of the time I was not interested
    5 ☐ I was completely uninterested

FAMILY

Answer Questions 30 – 37 about your parents, brothers, sisters, in laws, and children not living at home. Have you been in contact with any of them in the last 2 weeks?
    1 ☐ YES, Answer questions 30 – 37
    2 ☐ NO, go to question 36

30. Have you had open arguments with your relatives in the last 2 weeks?
    1 ☐ We always got along very well
    2 ☐ We usually got along very well but had some minor arguments
    3 ☐ I had more than one argument with at least one relative
    4 ☐ I had many arguments
    5 ☐ I was constantly in arguments

31. Have you been able to talk about your feelings and problems with at least one of your relatives in the last 2 weeks?
    1 ☐ I can always talk about my feelings with at least one relative
    2 ☐ I usually can talk about my feelings
    3 ☐ About half the time I felt able to talk about my feelings
    4 ☐ I usually was not able to talk about my feelings
    5 ☐ I was never able to talk about my feelings

32. Have you avoided contacts with your relatives these last 2 weeks?
    1 ☐ I have contacted relatives regularly
    2 ☐ I have contacted a relative at least once
    3 ☐ I have waited for my relatives to contact me
    4 ☐ I avoided my relatives, but they contacted me
    5 ☐ I have no contacts with any relatives

33. Did you depend on your relatives for help, advice, money or friendship during the last 2 weeks?
    1 ☐ I never need to depend on them
    2 ☐ I usually did not need to depend on them
    3 ☐ About half the time I needed to depend on them
    4 ☐ Most of the time I depend on them
    5 ☐ I depend completely on them

34. Have you wanted to do the opposite of what your relatives wanted in order to make them angry during the last 2 weeks?
    1 ☐ I never wanted to oppose them
    2 ☐ Once or twice I wanted to oppose them
    3 ☐ About half the time I wanted to oppose them
    4 ☐ Most of the time I wanted to oppose them
    5 ☐ I always opposed them

35. Have you been worried about things happening to your relatives without good reason in the last 2 weeks?
    1 ☐ I have not worried without reason
    2 ☐ Once or twice I worried
    3 ☐ About half the time I worried
    4 ☐ Most of the time I worried
    5 ☐ I have worried the entire time
    8 ☐ Not applicable; my relatives are no longer living

EVERYONE answer Questions 36 and 37, even if your relatives are not living.

36. During the last 2 weeks, have you been thinking that you have let any of your relatives down or have been unfair to them at any time?
    1 ☐ I did not feel that I let them down at all
    2 ☐ I usually did not feel that I let them down
    3 ☐ About half the time I felt that I let them down
    4 ☐ Most of the time I have felt that I let them down
    5 ☐ I always felt that I let them down

37. During the last 2 weeks, have you been thinking that any of your relatives have let you down or have been unfair to you at any time?
    1 ☐ I never felt that they let me down
    2 ☐ I felt that they usually did not let me down
    3 ☐ About half the time I felt they let me down
    4 ☐ I usually have felt that they let me down
    5 ☐ I am very bitter that they let me down

Are you living with your spouse or have been living with a person of the opposite sex in a permanent relationship?
    1 ☐ YES, please answer questions 38 – 46
    2 ☐ NO, go to question 47

38. Have you had open arguments with your partner in the last 2 weeks?
    1 ☐ We had no arguments and we got along well
    2 ☐ We usually got along well but had minor arguments
    3 ☐ We had more than one argument
    4 ☐ We had many arguments
    5 ☐ We were constantly in arguments

39. Have you been able to talk about your feelings and problems with your partner during the last 2 weeks?
    1 ☐ I could always talk freely about my feelings
    2 ☐ I usually could talk about my feelings
    3 ☐ About half the time I felt able to talk about my feelings
    4 ☐ I usually was not able to talk about my feelings
    5 ☐ I was never able to talk about my feelings

40. Have you been demanding to have your own way at home during the last 2 weeks?
    1 ☐ I have not insisted on always having my own way
    2 ☐ I usually have not insisted on having my own way
    3 ☐ About half the time I insisted on having my own way
    4 ☐ I usually insisted on having my own way
    5 ☐ I always insisted on having my own way

41. Have you been bossed around by your partner these last 2 weeks?
    1 ☐ Almost never
    2 ☐ Once in a while
    3 ☐ About half the time
    4 ☐ Most of the time
    5 ☐ Always

42. How much have you felt dependent on your partner these last 2 weeks?
    1 ☐ I was independent
    2 ☐ I was usually independent
    3 ☐ I was somewhat dependent
    4 ☐ I was usually dependent
    5 ☐ I depended on my partner for everything

43. How have you felt about your partner during the last 2 weeks?
    1 ☐ I always felt affection
    2 ☐ I usually felt affection
    3 ☐ About half the time I felt dislike and half the time affection
    4 ☐ I usually felt dislike
    5 ☐ I always felt dislike

44. How many times have you and your partner had intercourse?
    1 ☐ More than twice a week
    2 ☐ Once or twice a week
    3 ☐ Once every two weeks
    4 ☐ Less than once every two weeks but at least once in the last month
    5 ☐ Not at all in a month or longer

45. Have you had any problems during intercourse, such as pain these last 2 weeks?
    1 ☐ None
    2 ☐ Once or twice
    3 ☐ About half the time
    4 ☐ Most of the time
    5 ☐ Always
    8 ☐ Not applicable; no intercourse in the last 2 weeks

46. How have you felt about intercourse during the last 2 weeks?
    1 ☐ I always enjoyed it
    2 ☐ I usually enjoyed it
    3 ☐ About half the time I did and half the time I did not enjoy it
    4 ☐ I usually did not enjoy it
    5 ☐ I never enjoyed it

QUESTIONS 47 – 54 On Next Page.

CHILDREN

Have you had unmarried children, stepchildren, or foster children living at home during the last 2 weeks?

1 ☐ YES, answer questions 47 – 50.
2 ☐ NO, go to question 51.

47. Have you been interested in what your children are doing – school, play or hobbies during the last 2 weeks?
    1 ☐ I was always interested and actively involved.
    2 ☐ I usually was interested and involved.
    3 ☐ About half the time interested and half the time not interested.
    4 ☐ I usually was disinterested.
    5 ☐ I was always disinterested.

48. Have you been able to talk and listen to your children during the last 2 weeks? (Include only children over the age of 2).
    1 ☐ I always was able to communicate with them.
    2 ☐ I usually was able to communicate with them.
    3 ☐ About half the time I could communicate.
    4 ☐ I usually was not able to communicate.
    5 ☐ I was completely unable to communicate.
    8 ☐ Not applicable; no children over the age of 2.

49. How have you been getting along with the children during the last 2 weeks?
    1 ☐ I had no arguments and got along very well.
    2 ☐ I usually got along well but had minor arguments.
    3 ☐ I had more than one argument.
    4 ☐ I had many arguments.
    5 ☐ I was constantly in arguments.

50. How have you felt toward your children these last 2 weeks?
    1 ☐ I always felt affection.
    2 ☐ I mostly felt affection.
    3 ☐ About half the time I felt affection.
    4 ☐ Most of the time I did not feel affection.
    5 ☐ I never felt affection toward them.

FAMILY UNIT

Have you ever been married, ever lived with a person of the opposite sex, or ever had children? Please check

1 ☐ YES, Please answer questions 51 – 53.
2 ☐ NO, go to question 54.

51. Have you worried about your partner or any of your children without any reason during the last 2 weeks, even if you are not living together now?
    1 ☐ I never worried.
    2 ☐ Once or twice I worried.
    3 ☐ About half the time I worried.
    4 ☐ Most of the time I worried.
    5 ☐ I always worried.
    8 ☐ Not applicable; partner and children not living.

52. During the last 2 weeks have you been thinking that you have let down your partner or any of your children at any time?
    1 ☐ I did not feel I let them down at all.
    2 ☐ I usually did not feel that I let them down.
    3 ☐ About half the time I felt I let them down.
    4 ☐ Most of the time I have felt that I let them down.
    5 ☐ I let them down completely.

53. During the last 2 weeks, have you been thinking that your partner or any of your children have let you down at any time:
    1 ☐ I never felt that they let me down.
    2 ☐ I felt they usually did not let me down.
    3 ☐ About half the time I felt they let me down.
    4 ☐ I usually felt they let me down.
    5 ☐ I feel bitter that they have let me down.

FINANCIAL – *EVERYONE PLEASE ANSWER QUESTION 54.*

54. Have you had enough money to take care of your own and your family's financial needs during the last 2 weeks?
    1 ☐ I had enough money for needs.
    2 ☐ I usually had enough money with minor problems.
    3 ☐ About half the time I did not have enough money but did not have to borrow money.
    4 ☐ I usually did not have enough money and had to borrow from others.
    5 ☐ I had great financial difficulty.

HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for sufferer but causes me NO distress.
2. The behaviour is a problem for sufferer and causes me MILD distress.
3. The behaviour is a problem for sufferer and causes me MODERATE distress.
4. The behaviour is a problem for sufferer and causes me SEVERE distress.

	BEHAVIOUR	Is the behaviour a PROBLEM?			How much DISTRESS does problem cause?			
1.	Anger; difficulty controlling temper.	Y	:	N	1	2	3	4
2.	Impatience, upset when needs not easily met.	Y	:	N	1	2	3	4
3.	Frequent complaining.	Y	:	N	1	2	3	4
4.	Aggression; violent behaviour.	Y	:	N	1	2	3	4
5.	Impulsivity; does things without thinking.	Y	:	N	1	2	3	4
6.	Argumentative; often disputes topics.	Y	:	N	1	2	3	4
7.	Lacks control over behaviour behaviour is inappropriate for social situations.	Y	:	N	1	2	3	4
8.	Overly dependent; relies on others unnecessarily; does not do things for him/herself.	Y	:	N	1	2	3	4
9.	Poor decision making; does not think of consequences.	Y	:	N	1	2	3	4
10.	Childish; at times behaviour is immature.	Y		N	1	2	3	4

HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for sufferer but causes me NO distress.
2. The behaviour is a problem for sufferer and causes me MILD distress.
3. The behaviour is a problem for sufferer and causes me MODERATE distress.
4. The behaviour is a problem for sufferer and causes me SEVERE distress.

BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?
11. Poor insight; refuses to admit difficulties.	Y : N	1 2 3 4
12. Difficulty in becoming interested in things.	Y : N	1 2 3 4
13. Lack of initiative; does not think for him/herself.	Y : N	1 2 3 4
14. Irritable; snappy; grumpy.	Y : N	1 2 3 4
15. Sudden/rapid mood change.	Y : N	1 2 3 4
16. Anxious; tense; uptight.	Y : N	1 2 3 4
17. Depressed; low mood.	Y : N	1 2 3 4
18. Irresponsible; can't always be trusted.	Y : N	1 2 3 4
19. Overly sensitive; easily upset.	Y : N	1 2 3 4
20. Lacks motivation; lack of interest in doing things.	Y N	1 2 3 4

WAIKATO TRAUMATIC BRAIN INJURY RESEARCH GROUP
(University of Waikato & Waikato Hospital)

Head Injury Study - Intensive Therapy Unit Patients

Caregiver's Questionnaire

Subject ID:
Date:

Name: DoB:

Relationship to injured person __________________

Living with injured person: Yes No

Part A (Please tick or circle the appropriate answer).

What changes have occurred in your life as a result of caring for _________?

1. There have been changes in my sleep pattern.

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

2. There have been changes in my appetite

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

3. I get depressed more often

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

4. I get anxious more often

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

5. I get angry more often

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

6. I get sick more often

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

7. I am on more medication

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

8. My use of alcohol/cigarettes/drugs has increased

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

9. I have less energy

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

10. I have less time to myself

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

11. I have less privacy

Yes ___
No ___

If yes, how much distress does this cause you?

1 none	2	3	4	5 very great

12. I have had to make changes in my job

Yes ___
No ___

If yes, how much distress does this cause you?

1 none	2	3	4	5 very great

13. There are changes in my relationships with family and/or friends

Yes ___
No ___

If yes, how much distress does this cause you?

1 none	2	3	4	5 very great

14. My financial position has changed

Yes ___
No ___

If yes, how much distress does this cause you?

1 none	2	3	4	5 very great

15. There have been changes to my housing (moved house, altered existing house)

Yes ___
No ___

If yes, how much distress does this cause you?

1 none	2	3	4	5 very great

16. Overall, how much do the changes that have occurred in your life distress you?

1 none	2	3	4	5	6	7 very great

<u>Part B</u> (Please tick or circle the appropriate answer).

What changes have occurred in _________ as a result of the accident?

1. There have been changes in their physical abilities/health

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

2. There have been changes in their cognitive (eg. memory, attention, concentration) abilities

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

3. They now have emotional (eg. irritability, anger, depression, anxiety, apathy) difficulties

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

4. The amount of their social contact has changed

Yes ___
No ___

If yes, how much distress does this cause you?

1	2	3	4	5
none				very great

5. Overall, how much do the changes that have occurred in _________ distress you?

1	2	3	4	5	6	7
none						very great

Appendix D

WAIKATO AREA HEALTH BOARD

Our ref: AC/LC

7 September 1992

Dr J Havill
Intensive Therapy Unit
WAIKATO HOSPITAL

Dear Jack

HEAD INJURY STUDY - INTENSIVE THERAPY UNIT PATIENTS (135)

I advise that the above proposal was approved by the Committee on Ethics, at its meeting on 7 September 1992.

You will note that you are required to submit a final report in 1996 in accordance with the requirements of the Department of Health Standard for Hospital and Area Health Boards' Ethics Committees.

Yours sincerely

A J Sinclair
ACTING GENERAL MANAGER