

**WHAT FACILITATES AND HINDERS RECOVERY
FROM TRAUMATIC BRAIN INJURY:
A CRITICAL INCIDENT STUDY**

by

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ABSTRACT

Recovery from traumatic brain injury (TBI) involves more than just the physical dimension or just the time period in which a person is involved in a rehabilitation program. In fact it is during the post rehabilitation phase, with its concomitant changes in routine, that behavioural difficulties emerge and recovery becomes an ongoing process of adjustment. The purpose of this thesis was to discover what facilitates and what hinders recovery from traumatic brain injury (TBI) for late adolescents upon discharge from rehabilitation. The Critical Incident Technique (Flanagan, 1954) was employed to elicit the different resources that assist/encourage and hinder/discourage recovery from TBI as reported by the individual.

Six late adolescents with mild-moderate TBI were interviewed one to eight years after their injury. A total of 165 critical incidents were extracted and organized into 16 categories describing what late adolescents with TBI experienced to enhance their recovery. Following extensive validation procedures, the scheme of categories was found meaningful and useful for both counselling and research. In addition, the internal and external types of motivation involved within the 16 categories were discussed. It is hoped that the findings of this study will provide the groundwork for future research in developing assessment tools and treatment programs.

TABLE OF CONTENTS

ABSTRACT.....	ii
TABLE OF CONTENTS.....	iii
LIST OF TABLES.....	v
ACKNOWLEDGMENTS.....	vi
CHAPTER I: INTRODUCTION.....	1
CHAPTER II: REVIEW OF THE LITERATURE.....	5
WHAT IS TRAUMATIC BRAIN INJURY (TBI).....	5
Epidemiology.....	6
Severity of Injury.....	7
Prognosis.....	11
COGNITIVE SEQUELAE FOLLOWING TBI.....	12
Intellectual Performance.....	12
Attention.....	14
Memory.....	14
PSYCHOSOCIAL SEQUELAE FOLLOWING TBI.....	15
Behavior.....	16
Personality.....	17
DEVELOPMENTAL ISSUES IN TBI.....	18
Age at the Time of Injury.....	18
Age and Brain Plasticity.....	19
REHABILITATION.....	21
Assessment.....	21
Frontal Lobe Injury.....	22
Executive Functions.....	23
Cognitive Rehabilitation.....	25
RECOVERY FROM TBI – BEYOND REHABILITATION.....	27
Motivation and TBI.....	30
Theories of Motivation and TBI.....	31
Motivation in the Rehabilitative stage.....	33
Motivation and Other Medical Conditions.....	34
Current Study.....	38
CHAPTER III: METHODOLOGY.....	40
Participants.....	40
Procedure.....	41
Data collection: Interview procedures.....	44
DATA ANALYSIS.....	47
Extraction of incidents.....	48

TABLE OF CONTENTS

Forming the categories.....	50
Validation procedures.....	51
CHAPTER IV: RESULTS.....	54
Participants.....	54
Critical Incident Technique.....	55
DESCRIPTION OF THE CATEGORIES.....	56
Facilitative categories.....	57
Hindering category.....	69
Other relevant information categories.....	69
VALIDATION PROCEDURE.....	71
Participants' validation.....	72
Comprehensiveness of categories.....	73
Inter-rater reliability.....	73
Participation rate.....	76
Expert validation.....	77
Support of related literature.....	79
CHAPTER V: DISCUSSION.....	84
Conclusions.....	98
REFERENCES.....	101
APPENDIX A.....	108
APPENDIX B.....	110
APPENDIX C.....	114

LIST OF TABLES

TABLE 1: Demographic Information.....	54
TABLE 2: Information on sample from medical records.....	55
TABLE 3: Reliability of category system.....	75
TABLE 4: Participation rate.....	76

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CHAPTER I

INTRODUCTION

Brain injury is the great 'silent epidemic' of our times. It is generally agreed that for traumatic brain injury alone, there are 150 new cases a year per 100,000 people. This means that in Canada, 56,000 new cases occur each year. (In the United States there are 500,000 new cases each year). Of these cases, 9,000 Canadians (and 80,000 Americans) will have significant long-term rehabilitation needs (Higenbottam, 1998). In a blink of an eye an individual can sustain an injury that will forever change his or her life. Individuals who have sustained traumatic brain injury (TBI), which is an injury caused by any type of sudden external force upon the head and is typically accompanied by a range of complex physical, cognitive, behavioural, and emotional problems, face a long and difficult process of reclaiming their lives.

A recurring question in the literature has been whether the motivation of the individual with TBI influences not only the process of adaptation but also the actual recovery process (Prigatano, 1988). Motivation, and the effect it has upon TBI survivors, is presented as if everyone agrees on what it is. There seems to be an intuitive feeling for "motivation", and yet it escapes absolute definition (Cleveland, 1998). Although there is general agreement that motivation plays a key role in the process of recovery this has been investigated only in the rehabilitation setting (Maclean et al. 2000; Prigatano, 1988; Prigatano & Schacter, 1991; Prigatano, 1999). There is no evidence in the literature of TBI about what

specifically helps and/or hinders the enduring process of recovery beyond the rehabilitation setting.

When looking at the literature on motivation and TBI the trend for studies in rehabilitation settings is clear. This trend in research is explained by the necessity to enhance clients' motivation in order for them to comply with the provided therapies. There is no doubt that one of the critical stages in recovery from brain injury is established within rehabilitation programs. However, it is a faulty belief that recovery is achieved upon discharge. Individuals with TBI expect the return home to answer all their questions and self doubts, but then upon arriving home the realization that one has changed as a person occurs (Ottewell, 1998). Thus, it is during the post-acute phase, with its concomitant changes in routine and the post-crisis emotional slump, that behavioural difficulties emerge and recovery begins (Sherwin & O'Shanick, 2000). The question regarding the motivation to adjust to the emerging difficulties after returning home is yet to be answered.

Moreover, qualitative studies on TBI have shown that individuals with brain injury struggle to construct their new self. These studies indicate the incredible loss of identity, the loss of the person he or she knew as "self" (Cleveland, 1998; Nochi, 1998). While adults with TBI grieve over their loss of identity and struggle to bring back every piece of life prior to injury, adolescents with TBI are in the developmental stage of shaping one's identity. This process occurs while perceiving themselves as "different" and they may be painfully aware of their physical, cognitive, emotional, and behavioural changes, as well as

their loss of abilities. Therefore, enhancing the adolescent's psychological adjustment to the injury is critical in this developmental stage. Sherwin & O'Shanick (1998) indicate that the psychotherapist may also play the role of advocating for young individuals with TBI and help them to navigate the rehabilitative maze to access the services to which they are entitled.

From a personal perspective, the desire to conduct a thesis on TBI and its persisting recovery derives from my work with individuals who have sustained brain injury. The process of recovery does not follow a straight line which promises that the individual will reach the highest level of recovery. I was often exposed to the tremendous cycles of optimism and disappointment as individuals progressed or did not. Throughout this experience I realized that there is a way to learn about the strengths and weaknesses of recovery by allowing the individual to be the agent of the multiple resources that assist and encourage him or her to improve adjustment.

The purpose of this thesis is to discover what late adolescent individuals with mild-moderate¹ TBI identify as being helpful and not helpful for their recovery after discharge from rehabilitation. This study is not seeking the genesis of motivation, but uses critical incidents to identify objects, people, and actions that enhance and/or hinder the recovery from TBI. It is hoped that the data will extract information and generate categories that constitute motivational elements (e.g., friendship support; parental agenda.). It is clear that psychological work

¹ Mild- moderate TBI represents the current level of injury rather than the level assessed immediately post injury.

with individuals with TBI brings an inevitable challenge, however this cannot cancel the need for it.

CHAPTER II

LITERATURE REVIEW

WHAT IS TRAUMATIC BRAIN INJURY?

Traumatic brain injury (TBI) is called “the hidden epidemic” because the number of significantly impaired people is grossly under-represented in public health statistics and in the health record of the individual. It is estimated that 40% to 80% of the two million Americans who incur mild head injury each year develop a post-concussive syndrome. A working definition of concussion is a traumatic brain injury incurred through head impact or change of acceleration, or both, accompanied by some alteration in, or limited loss of, consciousness (Parker, 2001).

A head trauma must be sufficient to produce a disruption of the central nervous system to be of clinical significance to the pediatric neurologist, child psychologist, or other child practitioner. Several types of brain injury, with two broad classes, are generally accepted: penetrating injuries and non-penetrating injuries. Penetrating head injuries occur when an external object strikes the head, typically via acceleration-dependent forces, with sufficient strength to cause a depressed skull fracture and skull fragments. The second kind of penetrating head injury occurs when a missile penetrates the skull. Such a penetration can lead to the missile being lodged in the brain tissue or passing through it. Some individuals may show an immediate loss of consciousness; others may not lose

consciousness at the time of injury, but gradually progress into coma state over several hours (Snow & Hooper, 1994).

Non-penetrating head injuries do not involve any actual penetration of foreign material into the brain. These injuries can occur when the trauma to the head does not produce skull fracture, or the trauma generates a non-depressed, or linear, skull fracture. This type of involvement includes closed head injuries and concussions and, in general, accounts for over 90% of major pediatric head injuries (Menkes, 1985; as cited by Snow & Hooper, 1994).

Epidemiology.

In the United States, TBI accounts for nearly 40% of all deaths from acute injuries. The extent of TBI in the population is difficult to determine. Although the number of independent new hospitalized cases can be enumerated and the number of deaths attributable to TBI can be gauged, the number of persons with continuing neurological, behavioural, or cognitive impairment as a direct result of brain injury is very difficult to ascertain. In some respects, TBI prevalence is a measure of residual impairment or disability (Rosenthal, Griffith, Kreutzer, & Pentland, 1999). Approximately 52,000 deaths in the United States are attributed to head injury each year. Of those persons who died as a result of trauma and who had head injuries, the death certificate listed TBI as the cause of death for 87% (Marion, 1999).

For the population as a whole, men are approximately twice as likely as women to have a TBI. However, the ratio of male to female victims decreases to nearly equivalent in older ages, most likely because the most common cause of

TBI in this age group is falls, for which both sexes are at similar risk. Overall, the male:female ratio for TBI mortality is 3.4:1 which suggests that men also tend to suffer more severe injuries. The risk for TBI peaks between the ages of 15 and 30. Although population based studies have found varying overall incidences, the peak age for males and females is similar. The incidence of TBI in different age groups is closely related to the mechanism of injury. The incidence of TBI increases during the teenage years, when many young people begin driving. In addition, the use of alcohol and other drugs by teenagers contributes heavily to their high rates of head injury. Mortality rates from TBI are highest for those 15 to 24 years of age. Falls, assaults, and work-related accidents are other common causes of pediatric (i.e., from birth to age 17) head injuries. Based on the TBI database at the Medical College of Virginia, roughly 20% of TBIs occur in the pediatric group (Marion, 1999).

Severity of injury.

A severe TBI typically is operationalized by a Glasgow Coma Score (GCS) of less than 9 in the emergency department (Marion, 1999). However, the definition of severe TBI can vary among studies when prognosis is used to define severity. For example, any fetal TBI may be considered severe because of its cost to society, even if the individual with TBI was not hospitalized.

Lezak (1995) states that, although fewer than 10% of head trauma victims are severely injured, they present a major and growing social problem for the following reasons: their rehabilitation needs are so great and so costly, only a few return to fully independent living, and their disabilities create severe financial and

emotional burdens for their families. This population displays the full range of severity of dysfunction in every aspect of cognition. Attention deficits are common and can be exceedingly disruptive as the severely injured individual can be highly distractible, or unable to maintain directed or focused attention. Behavioural slowing, both of mental processing and response, are characteristics of severe TBI. Memory impairment usually consists of problems in the acquisition and retrieval of information. The recall of the severely injured individual is complicated by the effect of intrusions. In extreme cases, memory disorders may cause this individual to only be aware of what is currently presented to him. When injuries are predominantly frontal, the individual with severe TBI may perform well on time-limited, highly structured examination tasks but still be unable to function independently.

In a severely injured individual, the emotional alterations are predominantly intrinsically based. Reactive disturbances or compensatory changes in attitudes and affective response can have important effects. Premorbid predisposition may also enter the complex equation of why this behaviour occurs. The emotional changes generally involve either exaggeration or muting of affective experience and response. Social isolation is a common consequence of these emotional alterations, often because the apathy or the cognitive deficiencies keep the severely injured individual from socializing effectively. Other emotional and psychiatric problems are more common in the severely injured population than in the population at large, such as mania, paranoia, or a schizophrenic-like syndrome that can develop after head trauma (Lezak, 1995).

Mild injuries are defined as a GCS score greater than 12, no abnormalities on computed tomography (CT), no operative lesions, and a length of stay less than 48 hours. Parker (2001) indicates that mild brain injury accounts for 50% to 75% of all patients hospitalized with a brain injury. A high proportion of accident victims are seen in the emergency room and discharged, or may never even have a consultation in the acute period. Thus, the classification "mild" may be misleading.

Individuals with mild TBI are often not admitted to the hospital or referred for medical evaluation. Results of the National Health Interview Survey suggest that, of the 1,540,000 persons who sustained a TBI in 1991, 25% sought no medical care, and another 25% received care confined to outpatient clinics and offices (Marion, 1999). Because most cases of head injury involve less than 20-30 minutes of loss of consciousness (if any), and posttraumatic amnesia of only a number of hours (rather than days), they typically result in mild head injury (Lezak, 1995).

Lezak (1995) describes the triad of neuropsychological dysfunctions that usually appear within the first few days after injury. First, there are attention deficits which refer to slow reaction times in the acute stage, and provide evidence of slowed mental processing including: poor concentration, heightened distractibility, difficulty doing more than one thing at a time, and complaints of impaired "short-term memory". Second, there are verbal retrieval problems which refer to moderate to severe communication or perceptual disturbances that ultimately clear up or remain as subtle defects that are not always apparent to

casual observers. However, after the acute symptoms have subsided, most head trauma individuals, even some who have sustained severe injuries, tend to show remarkably little deficit on verbal tests that measure over-learned material. Third, there is emotional distress which refers to emotional alterations in which fatigue may be the chief cause. The activities that are performed frequently throughout a normal day become effortful after the injury, particularly during the first weeks or months. Lezak (1995) also states that there is general agreement about the neurobehavioural disorders associated with mild head injury in the acute stage, but considerable disagreement regarding their duration.

Moderate TBI accounts for 8% to 10% of all head injuries with levels of damage that are neither mild nor severe. The criteria for moderate injuries are admission to the hospital for at least 48 hours with a GCS score of 9 to 12 or a higher GCS score together with operative abnormal CT findings. Although the nature and duration of symptoms varies widely within this group, almost all patients in one large study continued to suffer significant disturbances at three months post-injury including the 38% making a "good recovery" on the Glasgow Outcome Scale (Lezak, 1995). Headaches, memory problems, and difficulties with everyday living are the most common complaints.

Lezak (1995) indicates that moderate TBI individuals can, and for the most part do, function independently. Many return to work, yet they tend to differ from intact persons, and from how they once were, in that most exhibit behavioural traces of localized frontal and/or temporal bruising. Frontal lobe problems, in particular, tend to show up in subtle ways in the moderately impaired

person who, nonetheless, lives independently, works steadily, and maintains family relationships. Frontal damage can be suspected in those who have lost some spontaneity or some capacity to initiate activities. Individuals with diminished initiative and spontaneity typically return to their usual occupations and conduct their routine affairs without difficulty, but they no longer plan for non-routine activities.

Specific behavioural deficits after a moderate injury may include an altered ability to express emotions. Prefrontal injuries can dull the patient's affect and blunt the emotions. Right-hemispheric lesions may cause a diminished capacity to recognize facial expressions and emotions in others or an inability to appreciate the emotional "tone" of the situation. Moreover, diffuse brain damage often leads to impulsivity and disinhibition. The inability to monitor or regulate behaviour may be manifest as verbal or physical acts that violate social norms. Exaggeration of undesirable premorbid personality traits is common. Denial of these verbal and physical acts also is common and can be a significant problem during rehabilitation owing to its effects on motivation and compliance with treatment (Marion, 1999).

Prognosis.

The ultimate goal of treatment for TBI is to restore or preserve normal neurologic function (Marion, 1999). It is worth noting that prognosis is complicated by the lack of uniformly accepted terminology to describe outcomes after a TBI. For example, some studies have used duration of coma as a key prognostic variable without clearly defining how they determined this variable,

other studies use the term “vegetative state” interchangeably with “coma”, and still other studies use the five-category Glasgow Outcome Scale but use different ways of collapsing the categories from five to two categories.

The brain is our most complex and vulnerable organ. The brain is the operations center and network coordinator for who we are, the way we think, the way we feel, and the way we act. An injury to the brain can change everything about us in a matter of seconds. A range of complex physical, cognitive, behavioural, and emotional problems define the nature of traumatic brain injury and will be discussed under the headings of cognitive and psychosocial sequelae.

COGNITIVE SEQUELAE FOLLOWING TBI

A variety of neurocognitive outcomes have been advanced with respect to children and adolescents with non-penetrating types of brain injuries. These outcomes, particularly for the closed head injury person, span intellectual, motor, attention, language, visual perceptual, memory, and academic functional domains (Snow & Hooper, 1994). It is important to note that the literature is consistent in presenting the severe TBI group’s performance as clearly the poorest, whereas the mild and moderate TBI groups are closer in their results with an advantage to the mild TBI group (Ylvisaker, 1998). The focus here will be on intellectual performance, attention, and memory.

Intellectual performance.

Numerous studies exploring the possibility of a decline in the level of intellectual performance following a TBI reveal a clear trend in that direction.

Ewing-Cobbs et al. (1998) indicates that the studies conducted on intellectual recovery in school-aged children and adolescents have used the Wechsler scales. The author also stresses that the frequent findings of lower Performance IQ than Verbal IQ scores after severe TBI may, in part, be an artifact of the subtest format of the Verbal and Performance scales. The Verbal scale generally assesses previously learned information such as vocabulary, fund of knowledge, mental arithmetic computation, and social reasoning. Owing to the highly structured tasks and relatively limited response requirements of the Verbal scale, children with significant acquired language impairments might score within normal limits. In contrast, the Performance scale consists of five timed subtests that require the child to problem solve using novel materials; additional points are given for rapid response times. Consequently, when lower Performance than Verbal IQ scores are obtained, additional assessment is necessary to identify whether lower scores are related to task demands for visuospatial analysis, problem solving, attention, motor skills, or response speed.

Levin and Eisenberg (1979; as cited in Ewing-Cobbs et al., 1998) evaluated intellectual function at least 6 months after closed head injury using the age-appropriate Wechsler scale in 30 children and adolescents age 6-18 years. Intelligence test scores of less than 70, which indicated intellectual deficiency, were present in only a subgroup of the most severely injured patients. Children with mild to moderate closed head injuries did not exhibit deficient IQ scores 6 months or more after injury. Median Verbal and Performance IQ scores were in the average range for all severity groups.

Attention.

Despite the importance of attentional functions for successful completion of both cognitive and socially based tasks, few studies have examined attentional abilities after TBI. Kaufmann and colleagues (1993), using a computer-assisted adaptive-rate continuous performance test, evaluated 36 patients aged 7-16 years at the time of injury. This continuous performance test required the subjects to press a key at the onset of a target and not to respond to distracters presented on the computer screen. After either errors or responses with a long latency, the computer slowed the rate of presentation. Therefore the mean interstimulus interval for each of the four trial blocks provided an index of attentional efficiency. Six months after TBI, patients with severe injuries scored lower than those with mild or moderate injuries. Young, severely injured children had the greatest impairment on the continuous performance test.

Memory.

Despite the high degree of interaction between memory functions and attentional efficiency, a variety of memory deficits typically can be seen in children and adolescents following a severe TBI, particularly in children suffering from closed head injuries (Fennell & Mickle, 1992; as cited in Snow & Hooper, 1994). Bassett & Slater (1990) showed deficits in immediate and delayed recall of story passages and visual reproductions in their sample of severely injured adolescents; however, these deficits were not manifested in their mildly injured or age-matched normal controls. Ylvisaker (1998) states that, similar to other

functional domains, memory deficits secondary to mild and moderate brain injuries are less clear, especially over the long term.

While the neuropsychological consequences of TBI have been well documented in the literature, it is less clear whether these consequences persist after the injury. For example, Millis et al. (2001) sought to describe the cognitive functions that are likely to be impaired in the long term after brain injury. The authors were also interested in examining the neuropsychological recovery from 1 year to 5 years after injury. For the purposes of this analysis, performance on 15 neuropsychological tests, which assessed a broad range of cognitive abilities including attention, language, memory, visuoperception and construction, psychomotor speed, and problem-solving, were examined. Literal interpretation of these test scores suggests that neuropsychological outcome 5 years after TBI may range from severe impairment to no measurable impairment in a variety of cognitive functions. The authors found that a substantial proportion of individuals with moderate to severe TBI continue to show impairments in learning and memory; however, they stated that caution must be exercised in interpreting the data because of the non uniformity of currently available neuropsychological test norms. The authors concluded that neuropsychological recovery after TBI is not uniform across individuals and neuropsychological domains (Millis et al., 2001).

PSYCHOSOCIAL SEQUELAE FOLLOWING TBI

The presence of any significant brain impairment is likely to compound the effect of pre-morbid emotional or characterological difficulties, family or

environmental stressors, and other preexisting social or psychological concerns. Due to a decrease in problem solving ability, frustration tolerance, and general cognitive flexibility, concerns that were manageable pre-injury may become overwhelming post-injury. In addition to these concerns, the amount of social disruption and isolation related to an individual losing his or her job, the loss of contact with familiar social and friendship networks, and the impact of an ambiguous "new role" in the community may be considerable (Kreutzer & Wehman, 1990).

Severe injury often produces devastating permanent cognitive disabilities. In addition to these cognitive changes, individuals with TBI often experience social and emotional changes such as impulsivity, disinhibition, lack of insight, altered attention span, irritability, poor anger control, aggression, anxiety, low frustration tolerance, and sleep disorders (Marion, 1999).

Behaviour.

Fletcher and colleagues (1990; as cited in Ewing-Cobbs et al., 1998) examined the behavioural sequelae during the first year after injury in children and adolescents with mild, moderate, or severe TBI. They were categorized on the basis of the lowest Glasgow Coma Scale score and initial CT scan findings. The Vineland Adaptive Behaviour Scales and the Child Behaviour Checklist, which used the parents as the informants, were completed as soon after the injury as possible and again at 6 and 12 months after the injury. The baseline assessment was completed to indicate the child's level of functioning before the injury. Patients with severe TBI developed adaptive behavioural disturbances during the

first 6 months after injury, and these persisted over the 12-month follow-up interval on the Vineland scales (Ewing-Cobbs et al., 1998). However, there was no evidence of behavioural disturbances following moderate and mild TBI.

In an early study, Thompson (1974) found that 84% of family members surveyed complained of personality, behavioural and emotional changes in their loved one with TBI. During the subsequent 25 years, problematic social interaction after TBI has continued to be linked to difficulty maintaining employment, living independently and maintaining satisfying relationships with friends (Ylvisaker & Feeney, 2000).

Personality.

Ylvisaker & Feeney (2000) discussed the injury-related contributors to social disability after TBI. They indicate the two classical front-limbic behaviour syndromes that are linked directly to the injury: the pseudo-psychopathic and pseudo-depressed personalities. The pseudo-psychopathic personality, associated with orbit-frontal lesions, includes some combination of transient or persistent disinhibition, impulsiveness, lability, reduced anger control, aggressiveness, sexual acting out, perseveration and generally poor social judgment. The pseudo-depressed personality, associated with prefrontal lesions, is characterized by some combination of reduced initiation, apathy, lack of drive, loss of interest, lethargy, slowness, inattentiveness, reduced spontaneity, unconcern, lack of emotional reactivity, dullness, poor grooming and perseveration.

Indirectly linked to the injury are a variety of communication and behavioural challenges that may be secondary to cognitive impairment. Impaired

social perception and emotional modulation can interfere with social reintegration as the individual misinterprets the behaviour of others and responds accordingly. Similarly, a friendly comment about appearance or about a personality trait can be interpreted as an invitation, with a sexual misadventure the unfortunate result (Ylvisaker & Feeney, 2000)

Finally, after severe TBI in children and adolescents, virtually any outcome is possible, depending on a large number of factors, most notably the characteristics of the children and their families before the injury and its nature and severity. Some children enjoy a remarkably favorable outcome, succeeding in school and social life with few special services or supports. Others experience severe and persistent disability across a wide range of functional domains.

DEVELOPMENTAL ISSUES IN TBI

Age at the time of injury.

The relationship between age at the time of TBI and subsequent cognitive outcome is controversial. In a functional outcome study of 243 patients admitted to a rehabilitation hospital, age at the time of TBI proved to be the most important predictor of recovery (Katz & Alexander, 1994; as cited in Marion 1999). However, Chadwick et al. (1981) found that age at injury was not predictive of long-term outcome, related to severity of cognitive sequelae or related to the rate of cognitive recovery (as cited in Ewing-Cobbs et al., 1998). It is possible that different skills are more vulnerable to impairment at different points during development. Some studies of language and memory after TBI of differing

severity were consistent with the hypothesis that skills in a rapid stage of development at the time of brain injury were more adversely affected than more automated and over learned skills. Moreover, the duration of coma seemed to be independent of age, but the duration of post traumatic amnesia lengthened with age (Ewing-Cobbs et al., 1998).

Ewing-Cobbs et al. (1998) states that more longitudinal neuropsychological, psychosocial, and educational studies that evaluate outcomes are needed to address the important possibility of delayed deficits. In particular, social and behavioural domains may be more likely than cognitive domains to be characterized by delayed acquisition of normal functions over several years.

Age and brain plasticity.

It has long been assumed that youth confers an advantage in outcome after brain injury, an assumption that may partially explain the slow development of programs for children with TBI. Investigators and clinicians have increasingly highlighted the possibility of delayed consequences of brain injury in young people. That is, a specific injury may not manifest itself functionally until later in development when the function associated with that part of the brain is expected to mature. The mounting evidence that young children may be *more* rather than less vulnerable than older people in certain critical areas of functioning is sobering and should motivate rehabilitation professionals to redouble their efforts for this group (Ylvisaker, 1998).

Donders & Strom (2000) investigated the neuropsychological deficits in children who have experienced brain injury with comparison to those who have

an additional pre-existing psychiatric disorder. In this study, 20 children between 9 to 16 years of age, had to meet the criteria for the severity of injury and the absence of any pre-injury neuropsychological injury. These participants were selected from a 5-year series of consecutive rehabilitation referrals. The sample was divided into 10 children with prior primary psychiatric diagnosis and 10 children who had no pre-existing psychiatric histories. The post-injury average test scores of the psychiatric group were almost identical to those of the non psychiatric group. The authors conclude that even after such an injury as moderate to severe brain injury, the neuropsychological profile of the pre-existing psychiatric group mimics that of brain injured children without psychiatric histories.

Ylvisaker, Szekeres, & Feeney (1998) indicate the immediate and delayed consequences of TBI in adolescence at different stages of development. Common delayed symptoms related to earlier injury at the middle adolescence stage are: continued rigidity and dependence on external control (while peers become increasingly flexible and autonomous), hypersexuality, social withdrawal, increasing academic failure due to the cumulative effect of new learning problems, difficulty achieving communicative effectiveness in varied social settings, and general difficulty with divergent thinking.

The common delayed symptoms related to earlier injury in the late adolescence stage are: retention of concrete thinking and rigid responding, immature social skills, continued dependence on cliques while peers move on, continued dependence on same gender peers for support, relations with opposite

gender possibly characterized by hypersexuality, possible perception of differences between self and others as representing a psychiatric problem, and possible failure in college or on the job due to the elimination of the supports provided in high school.

REHABILITATION

It is important to note that much of what is presented in this section relates to both pediatric individuals and adults with TBI.

Assessment.

One of the most important factors in early treatment decisions and in long-term outcome after head injury is the patient's initial level of consciousness, as defined by the Glasgow Coma Scale (GCS; Teasdale & Jannett, 1974) score. The GCS provides a quantitative measure of eye opening, motor response, and verbal response. Ratings range from a low score of 3 to a high score of 15. In general, a GCS score of 8 or less is indicative of a severe brain injury, scores of 9 through 12 reflect a moderate level of severity, and scores of 13 to 14 indicate a mild brain injury. A score of 15 likely reflects the lack of an altered state of consciousness.

One of the most useful clinical measures of severity of injury is the duration of post traumatic amnesia (PTA). PTA is the amount of time following brain injury that an individual experiences difficulties learning and retaining new information. During this time, the individual is conscious and functioning and is capable of responding in a relatively reliable manner. PTA ends when the individual's essentially memories are restored (Snow & Hooper, 1994). The PTA

typically lasts approximately four times as long as coma, and four times as long as loss of speech. It has been shown that the duration of PTA correlates directly with objective neurobehavioural findings, such as personality change, psychiatric disability, and inability to return to work (Marion, 1999).

A very useful tool for assessing PTA is the Galveston Orientation and Amnesia (GOAT; Levin, O'Donnell, Grossman, 1979). The GOAT is a practical scale to assess cognition after head injury. A score of 66 or less (maximum score of 100) indicates that the patient is not encoding new memories for daily events and thus has persisting PTA. Scores from 66 to 75 are considered borderline whereas a score above 75 typically correlates with consistent day-to-day memories and is helpful in determining the end of PTA. The duration of loss of consciousness is a useful supplement to the GOAT when this information can be obtained from witnesses to the injury, emergency medical service personnel, or police reports (Marion, 1999).

Frontal lobe injury.

The interface between the skull and the brain also affects the different kinds of brain damage that can be seen. The brain tends to be more tightly packed in the posterior regions of the brain and more loosely packed in anterior regions. As a result, the interior surface of the skull tends to be smoother, whereas an increased number of bony lumps can be found in the anterior regions. Consequently, the frontal and temporal lobes are the cortical areas most likely to be damaged, regardless of the site or direction of the initial impact (Snow & Hooper, 1994).

The most common cognitive deficits after TBI are impairment of arousal, attention, and concentration. Short-term memory loss also may occur, either due to direct effects on memory function or secondary to poor attention and concentration. Given the high incidence of frontal-lobe involvement, disturbances of executive functions also are common. These include difficulties with planning, sequencing, judgement, and impulsivity. Specific deficits in cognition depend upon the location and severity of the ` as well as upon premorbid factors such as level of education (Marion, 1999).

Executive functions.

Executive problems, which are often associated with frontal lobe damage, are also common after brain injury. This includes the individual's difficulty to move flexibly from task to task, perhaps even doing very little or alternatively persisting with a task long beyond the point at which they need to engage in it. From a practical, everyday vantage point, executive functions include (1) having some sense for one's strengths and weaknesses, (2) knowing what is easy and what is hard to do, thereby being able to set reasonable goals for oneself, (3) planning and organizing behaviour to achieve the goals, (4) initiating goal-directed behaviour, (5) monitoring one's behaviour, and (6) flexibly shifting sets, thinking strategically, and solving problems in the event of obstacles (Ylvisaker, Szekeres, & Feeney, 1998). In this broad sense, development of executive functions is critical in achieving any meaningful goals in life that require effort.

From a rehabilitation perspective, the way the client is engaged with the daily activities is very much goal-directed. The day ideally begins with the

children actively involved in making their plan for the day (e.g., placing photographs of themselves, engaged in scheduled activities, on a planning board that can later be used for reorientation throughout the day). The children's day ends with a review of the day's activities, made meaningful because a concrete product has to be generated. Over the course of the day, staff and family members can begin each new activity following the structure of a general executive system routine. For the adolescents with TBI, the executive function term refers to "self-coaching". They are encouraged to consider themselves both player and coach. As coach, they set goals for themselves, identify obstacles, formulate game plans, give themselves instructions, and evaluate their own performance. The therapists try to move into the background and play the role of consultant and cheerleader (Ylvisaker, Szekeres, & Feeney, 1998).

Gauggel & Fischer (2001) examined the effectiveness of goal setting in brain-injured patients with a simple motor task. Forty-five brain-injured patients were randomly assigned to two groups where one group received a "do your best" goal and the other group received a specific, high goal. An assessment of intellectual functioning and mood was carried out to provide an estimate of the cognitive and affective impairment. No significant group differences were found with respect to intellectual functioning, memory or executive functions. The high goal group was asked after the fourth trial to improve their performance by 20% - to complete the task faster, whereas the "do your best" group was told to work as fast as possible. The authors found a significant goal setting effect indicating that the brain-injured patients with a high, specific goal performed better than patients

with an easy goal. Furthermore, goal setting not only positively affected motor performance but also led to an enduring improvement.

Cognitive rehabilitation.

It has been customary in the TBI literature to describe cognitive recovery in terms of qualitatively distinct stages. As descriptions of cognitive development in children have evolved from stages to continuity, so have descriptions of recovery after TBI. That is, recovery is often characterized by bursts of progress and can be seen more as a continuum than as a sequence of a small number of abruptly changing, qualitatively distinct stages. Accordingly, Ylvisaker, Szekeres, & Feeney (1998) highlight three roughly distinguishable phases of rehabilitation, which are not associated with specific lengths of time. Notably, they suggest that the term 'improvement' is preferable to the term 'recovery', since the latter term carries a suggestion of a return to normalcy which is rarely a realistic expectation after severe TBI.

The early phase of improvement includes the period from early medical stabilization to consistent responsiveness to environmental events. The focus of intervention during this phase is to control sensory stimulation so as to prevent the negative effects of sensory deprivation and sensory overload and to channel recovery by providing specific sensory and sensorimotor stimulation that is consistent with the individual's ability to process stimulation and to respond. The transition to the middle phase occurs when the individual gives evidence of consistent comprehension of simple language and appropriate use of everyday objects.

The middle phase of improvement is the period during which the individual is alert and generally responsive but is, to some degree, confused, disoriented (relative to age expectations), unable to process information in depth, unable to remember information effectively from day to day, and generally unable to maintain effective and appropriate social interaction. The focus here is on reducing confusion through careful environmental structuring, gradually and systematically improving general information-processing abilities by controlled use of activities of daily living and familiar academic and recreational activities.

In the late phase of improvement, many children and adolescents recover to the point at which they are generally oriented, goal directed, and purposeful (relative to age expectation). Learning new information and skills may still be difficult and processing efficiency may deteriorate precipitously with increases in cognitive demands or psychosocial stress. The focus in this phase is on increasing independence and enhancing individual's strategic behaviour so that they can compensate for ongoing cognitive deficits.

In this respect, when looking at the cognitive rehabilitation following TBI through the lens of continuity rather than a serial progression from one cognitive component to another, it provides more space for the motivation construct to change its "size and shape" according to the presented cognitive state on the continuum. Therefore, it enables the individual with TBI to have more flexibility and freedom to improve his or her adjustment upon the availability of the resources that enhance and/or hinder this movement.

RECOVERY FROM TBI – BEYOND REHABILITATION

With respect to the outcomes of traumatic brain injury in the rehabilitation stage, early intervention is critical to maximize a person's recovery from TBI. Functional outcomes for the brain injury survivor can be improved through early onset of rehabilitation in the acute recovery stage. In some hospitals, a specialist consult is an automatic order for brain injury patients upon admission. The consult typically includes evaluations by physical and occupational therapists, speech-language pathologists, and a psychiatrist. Following a serious brain injury, most recovery seems to occur within the first six months, making revision of treatment plans and goals critical to ensure that rehabilitation time is efficiently used.

Rosenthal et al. (1999) state in their discussion about treatment approaches that outcome is defined as a measurable functional level directly related to spontaneous recovery and therapeutic intervention. Factors that influence recovery outcomes include age, site and size of the brain lesion, extent of diffuse injury, pre-morbid skills, behaviour and intelligence, genetic inheritance, neural plasticity, nutritional history, environment, post-morbid emergency care, family involvement, rehabilitation and medical management, and available resources and support services.

Consequently, the term recovery in the rehabilitation context refers to the establishment of self functioning. Function refers to a deliberate action or activity needed for self-care and mobility (Rosenthal et al., 1999). On initiating a therapy service, the clinician evaluates the TBI patient and then establishes a set of

relevant functional goals. These goals should describe an objective level of physical abilities that mark a progression toward independence and safety in mobility and self-care activities, including bathing, dental hygiene, feeding, grooming, and dressing. When designing a treatment plan to focus on recovery, cognitive, emotional, behavioural, communicative, and family issues must also be assessed because they play an integral role in the patient's ability to tolerate and benefit from therapy.

According to Sherwin & O'Shanick (2000), the recovery period begins upon discharge from the acute medical setting and the commencement of the rehabilitation. It is during the post-acute phase, with its concomitant changes in routine and the post-crisis emotional slump, that behavioural difficulties emerge. The authors create a list of recommendations for the recovery stage. Among those is one that involves adolescents in consultation during rehabilitation, encouraging them to set goals they want to accomplish. These goals can foster feelings of independence as well as motivate them to try harder and adhere to the program longer.

Research that sheds some light on the definition of recovery from TBI is Lewington's (1996) study. Lewington examined the meaning of recovery as lived by persons who have sustained TBI. She interviewed seven adults long after their injury (i.e., 3 to 10 years post injury) and asked them about their experience of recovery from TBI. She discovered four parts that constituted a pattern of recovery from brain injury: Trauma (a time of disorientation following the traumatic event), Deconstruction of the old story (a time of personal devastation

over the realization of the lost roles), Construction of a new story (a time of being propelled to overcome the negative evaluations and to find a path to renewed self acceptance), and Recovery (a time of meeting the challenges that are simply part of life's journey and therefore achieving re-orientation to life). She indicated that the participants in her study experienced a movement through these four parts that is cyclical, although the story always begins with a trauma.

While little is known about the recovery patterns of TBI there is evidence to describe the quality of life (QOL) following TBI. Dawson, Levine, Schwartz and Stuss (2000) investigated the QOL following TBI at four years post-injury and also sought to determine whether the injury severity can predict QOL. After classifying the subjects into categories of severity (mild, moderate and severe), the authors administered quality of life measures, in particular Flanagan's (1982) Quality of Life Scale. Flanagan's QOL includes 15 domains that subjects are asked to rank, first in terms of importance to QOL and then in terms of how well their needs are being met. Out of the 15 domains, the six most important for TBI subjects were: health, close relationship with a significant other, relationships with family, relationships with close friends, work, and learning or improving one's knowledge. TBI subjects reported their overall QOL as good, with 18.4% reporting it as poor or fair, 38.8% as good, and 42.8% as very good or excellent. The moderate TBI group scored the highest in the overall QOL (Dawson, Levine, Schwartz & Stuss, 2000). The authors suggest that further exploration of these and other factors will be necessary to obtain a better understanding of QOL

following brain injury and to identify variables that may be amenable to rehabilitation so that outcomes can be improved.

Yelvisaker (1998) stresses that the growing body of evidence that family, school, and social supports have a powerful impact on long-term outcome should inspire rehabilitation and education professionals and, at the same time, foster a sense of profound obligation to positively influence outcome. Outcome is not the inevitable unfolding of biological consequences of the injury. Rather, it is an ongoing journey, powerfully influenced by intelligent decisions made by many people along the way. This includes ensuring that the people who make the greatest difference in the long run, including family, school personnel, and friends, are fully oriented, trained and supported so that they can play their role as effective supports for the individual.

Motivation and TBI

Persons with TBI have been shown to underestimate the severity of their cognitive and behavioural impairments resulting from TBI. Prigatano (1999) stated that many TBI patients have a poor conscious representation of their functional disabilities. They often overestimate their behavioural competencies compared to what their relatives report. Prigatano further admonishes not to confuse impaired self-awareness with denial. He explains that impaired self-awareness literally means an individual lacks a subjective or phenomenological experience of impaired functioning, whereas in denial of disability there is a partial conscious representation of altered function. Consequently, patients with

impaired awareness may be poorly motivated to comply with therapies to address deficits that they do not believe exist. In this respect, the motivation construct is crucial in order to benefit from what rehabilitation has to offer.

Impaired awareness has also been hypothesized to limit patients' eventual functional outcomes by decreasing motivation for treatment and resulting in selection of inappropriate long-term goals. Sherer et al. (1998) investigated the association between impaired awareness and employment outcome. Their sample included 66 persons with TBI, with a mean age of 31.7, who were administered the Awareness Questionnaire. A family member/significant other who knew the patient well and the clinician most familiar with the patient both completed the Awareness Questionnaire. Employment status was examined an average of 30.2 months post injury. At this point, 30 patients were competitively employed, 3 were in modified jobs, 11 were in school, 5 were in volunteer jobs, and 17 were unemployed. The results of this study indicated a positive relationship between accurate self-awareness of functioning after TBI and favorable long-term employment outcome (Sherer et al., 1998).

Theories of motivation and TBI.

Prigatano (1999) wrote about motivation and awareness in cognitive neurorehabilitation and presents two motivational theories with respect to TBI. In the first theory, motivation refers to the complex feeling states that parallel hierarchical goal-seeking behaviour. As such, it can be described as the arousal component of behaviour that influences attention and thereby helps in the selection of a plan of action (Simon, 1994; as cited by Prigatano). This arousal

component has long been known to relate to performance. Moreover, this phenomenon is clearly seen in neuropsychological rehabilitation: if individuals are hypoaroused or not very motivated, their performance is often poor. If the arousal level is too high, people often do worse on various cognitive tasks. Thus, motivation is a double-edged sword; too little or too much can be detrimental to patients and to the rehabilitative process. An optimal level of arousal, however, seems to be necessary. The second theory refers to how incentives influence performance. Parente (1994) has documented that TBI individuals may perform better on learning and memory tests given the right incentives. Using a \$100 incentive, he showed that TBI patients would perform better on such demanding tasks than if no incentive was given. He also remarked that perhaps some of the deficits of TBI patients really reflect continuing motivational disturbances, so if the right incentive can be established then the motivational disturbances can be overcome (as cited in Stuss & Winocur, 1999)

However, Bernstein & Ruiters (2000) suggest that individuals who have sustained mild TBI may be unable to overcome subtle deficits in information processing, even when motivated to do so. Seventy-one psychology students with an average of 6.4 years after injury, completed three questionnaires assessing general health, head injury, and a wide variety of cognitive, emotional, and physical complaints. In addition, the subjects were subdivided into two groups: those receiving a psychological manipulation aimed at increasing motivation level and those receiving no such manipulation. Participants with mild TBI performed no worse than matched controls on a set of highly demanding neurocognitive

measures. However, when motivated to do their best, controls' performance improved on two out of five measures, whereas the mild TBI group's performance was either unaffected or hindered.

Motivation in the rehabilitative stage.

The research on motivation and TBI is fairly limited. Although previous research in the field of neurology and rehabilitation has recognized the importance of motivation in the recovery process from brain injury, none of these presented studies appear to be well integrated. No suggestions have been offered as to what motivates the individual with TBI to recover. The following research by Cleveland (1998) attempts to shed some light on this discrepancy.

Cleveland (1998), in her research on motivation in rehabilitation for individuals with TBI, sought to discover the structure and the essence of the rehabilitation experience of individuals recovering from brain injury. The author conducted two preliminary studies that formed the basis for her main study. The first preliminary study suggested that the motivating force for all survivors of TBI is a reconstruction of self. The second preliminary study suggested the need for reconstruction of self and the identification of three stages of recovery: acute, discharge, and compensatory strategies. Cleveland examined how the individual with TBI moves from one recovery stage to another while reconstructing self. The author stressed that motivation lies somewhere in the relationship of our cognitive awareness to our responses to emotions. Motivation is often the term used to describe the transformation of our emotional response (feeling) to a volitional response (action). In this study, the outcome of motivation was engagement in

rehabilitation programs. The findings suggested that engagement was achieved as a result of the interaction created by four contextual categories: perception of self, perception of recovery, vision, and personal interactions. Consequently, the author has chosen to label the central phenomenon of her study 'momentum'. This momentum is generated from the interaction of the above named categories that propels the individual into personal commitment of action and effort in his or her rehabilitation (Cleveland, 1998).

Motivation and Other Medical Conditions

Unfortunately, very little has been written about the notion of motivation in the TBI population. Because motivation is a central concept in this thesis, it seems essential to look to other patient groups in which motivation may be particularly important. One such group is substance abusers. Tims, Melnick, and De Leon (2001) stated that two basic types of motivation, external and internal, have an impact on recovery from substance abuse. External motivation is generally defined as perceived outside pressures or coercion to change, or to enter and/or remain in treatment. The sources of coercion are usually legal, family, or employment pressures, although health concerns may also qualify. Internal motivation refers to pressures to change that arise from within the individual. These pressures are typically negative self-perceptions concerning drug use, and the desire for a more fulfilling lifestyle. With respect to TBI, it is possible that extrinsic motivation is manifested within the rehabilitation context. In this context, multiple therapy programs (e.g., physiotherapy, occupational, language)

are imposed on the TBI individual. The intrinsic motivation is required upon discharge from the rehabilitation centre. At this stage, the individual with TBI is self functioning, to some degree, and is likely to self-negotiate his or her persistence to improve readjustment.

Regardless of the initial source of motivation (external or internal), stable recovery appears to depend on the continuing influences of intrinsic motivational factors. Although external pressure may influence internal motivation, it cannot substitute for it in the recovery process. External motivation is more adequately characterized as external *pressure* to further distinguish it from the internal motivational variables underlying recovery. These variables refer to certain cognitions and perceptions expressed in self-statements concerning drug-use behaviours. Thus, the cognitive/perceptual elements of motivation (e.g., “tired of drug life”) are separate from the behavioural elements of motivation (seeking treatment) (De Leon, Melnick, & Times, 2001).

The role of motivation in substance users has been considerably illuminated by clinical efforts to enhance motivation for change in general and for treatment in particular. Research focuses on various approaches that directly or indirectly attempt to increase the likelihood that individuals will enter and/or remain in treatment. Prominent among these is the work of Miller et al. (1991), who have developed a collection of counselling strategies termed Motivational Interviewing. Motivational Interviewing demonstrates the effectiveness of various brief interventions (e.g., psycho-therapy, skills training, conditioning) in reducing problem drinking. These interventions were presumed to be motivational in that

they altered decisions and commitments to change. The active elements of these interventions were identified (e.g., feedback, advice, empathy) and organized into strategies to help people address their ambivalence about change (De Leon, Melnick, & Times, 2001).

De Leon (1996; in De Leon et al, 2001) has formulated the Integrated Recovery model which is a ten-stage paradigm describing the recovery process of serious substance abusers treated in long-term treatment centre. Four of the six pretreatment stages focus on motivation and readiness which speaks to the importance of these concepts.

Moreover, this research on substance abuse sought to clarify the contribution of motivation in treatment and recovery. The research suggests that the role of motivation in recovery reflects a complex interaction between subgroups of substance abusers and treatment intensity. For some substance abusers, high motivation alone will result in positive outcome regardless of treatment intensity; for others high motivation plus some minimal treatment will sustain recovery; and for still others, high motivation plus intense treatment is needed to sustain recovery. Nevertheless, recovery theory consistently accounts for two types of influences – motivation to change, and a readiness to take action based on that motivation (De Leon, Melnick, & Times, 2001).

Another study that provides useful information on motivation involves stroke patients. In a qualitative study using semistructured interviews, Maclean, Pound, Wolfe, and Rudd (2000) sought to explore the attitudes and beliefs of 22 stroke patients identified by professionals as having either “high” (14 patients) or

“low” (8 patients) motivation for rehabilitation. The interviews were conducted six weeks after the stroke and covered topics such as confidence about making a good recovery, ideas about important factors in recovery, and ideas about the nature and purpose of rehabilitation. While all of the patients thought rehabilitation played a role in their recovery, high motivation patients believed that rehabilitation had the most important means of recovery and sought to accord themselves an active role in rehabilitation. Most of the high motivation patients thought that progress in rehabilitation meant developing independence in activities of daily living, while few low motivation patients related this goal to success in rehabilitation. This study found that information from professionals about rehabilitation, comparisons with other stroke patients, and the desire to leave hospital had a positive effect on motivation. Accordingly, the authors concluded that the differences in beliefs between the two groups of patients seemed to be influenced by the environment in which the patient is rehabilitated. The authors also indicated that further research into the determinants of motivation (i.e., to how patients themselves categorize motivation) is required.

It is clear that motivation is a complex and multifaceted concept. Nevertheless, in the context of other medical condition (e.g., substance abuse, vascular disease) the means of motivation becomes more clear. In this context, the individuals who are ready to stay away from the drug or to recover from a health threat, are asked to accord themselves with re-adjusting to the new reality. In other words, they seek the motivation to make this change in lifestyle and to take action based on that motivation. It can be seen as a persisting self-negotiation to

avoid returning to previous lifestyle. With respect to TBI, the individual may be persistently self-negotiating on how to move forward in the enduring process of recovery. Thus, it is essential to recognize the importance of motivation in the recovery process from brain injury.

Current Study

Clearly, the topic of motivation in TBI has not been thoroughly studied, and only one study appears to have examined motivation to recover. While Cleveland's (1998) study has examined the meaning of motivation for the individual with TBI within rehabilitation, no studies appear to have examined motivation to recover while re-entering the community, or specifically what helps and hinders in the recovery or improvement process. One reason for this may relate to self-awareness and cognitive impairments following TBI and a hesitancy to rely on participants with TBI to provide the required information. However, as mentioned before, it is still not clear to what extent such impairments exist in mild and moderate TBI long after the injury has occurred.

In spite of the overwhelming research on the phenomenon of TBI and its multiple and complicated consequences, little is known about the process of recovery in the individual with TBI. Elaborating on Sherwin & O'Shanick (2000) definition of recovery, this thesis will view recovery as an ongoing personal journey where adjustment is perpetually established. The research on TBI is not complete without discovering the different resources that assist and encourage the TBI individual to improve his or her recovery and the obstacles that hinder

recovery. This can be done by conducting a study that integrates the perspective of the adolescent with TBI into the enduring self-journey of recovery.

The specific objective of the current study is to discover what late adolescents with mild-moderate TBI identify as being helpful (motivating) and being hindering (unmotivating) for their recovery after discharge from rehabilitation. Specifically, this thesis will ask participants:

- 1) What has assisted and encouraged recovery following discharge from rehabilitation?
- 2) What has hindered and discouraged recovery following discharge from rehabilitation?

CHAPTER III

METHODOLOGY

Participants

Study participants were recruited through the G.F. Strong Rehabilitation Centre in Vancouver, BC. A designated person at the Centre sorted through the health records and identified the individuals who met the inclusive criteria. Letters of invitation (see Appendix A) to participate were mailed out to the selected individuals. Given the slow reply to the letters, the staff at the Centre conducted follow-up phone calls. The potential participants who were interested in the study responded back to the researcher by phone. The individuals included in the study had to meet all of the following criteria: (1) participants are either male or female, between the ages of 16 and 25²; (2) he/she sustained a mild-moderate brain injury as indicated in his/her medical record held by the G.F. Strong Rehabilitation Centre³; (3) he/she may or may not have participated in the inpatient rehabilitation program; (4) he/she must be a minimum of 1 year after injury; (5) he/she must be

² The maximum age was extended from 19 to 25 following the low reply rate from an already limited group of people. This extension of age was still in accordance with the term 'late adolescence'.

³ Originally, individuals with a mild-moderate brain injury were sought; however, the level of mild to moderate was removed from the consent form and subsequent letters of invitation when became clear that potential participants' parents' perceptions of the severity of their child's head injury and the reported severity of injury in the health records differed considerably. Parents tended to believe their child's injury (probably based on initial intake information after the injury) was more severe than indicated by the Centre's records (which are also based on status of injury upon release from hospital).

able to understand the researcher's questions and the researcher must be able to understand the participant's responses.

A total of six volunteers (four men and two women) ages 16 to 24 participated in this study. It was originally hoped to obtain a sample of 10 to 15 individuals; however, the researcher experienced unexpected difficulties in obtaining this sample. First, it seemed that the potential participants may not have been motivated enough to initiate a phone call to the researcher. Low motivation is certainly a characteristic of individuals with TBI according to the literature (Prigatano, 1988; Cleveland, 1998). The staff at the Centre expressed concern that the potential participants were not familiar with the researcher's name (which appeared on letters of invitation) which might have affected low participation rates. Second, there was a discrepancy between the Centre's records of current level of TBI and the patient's (or their parents') knowledge of their current level which may have resulted in a self-selection bias where some participants decided they were not eligible to participate. This discrepancy was identified by some of the parents as well as by the Centre's rehabilitation staff.

Procedure

The major considerations in selecting a qualitative approach for the present study were threefold. First, the researcher was interested in providing a map of what helps and what hinders adolescents, who sustain traumatic brain injury (TBI), in their recovery process. Second, the researcher was interested in giving these adolescents a "voice" regarding what facilitates the process of recovery from TBI while integrating their perspective. The third reason refers to

the role of motivation in recovery. TBI has only recently become the focus of intense research. Very little is known about individuals' motivation in relation to recovery from TBI. The extensive knowledge on TBI is focused more on the cognitive, affective, and behavioural outcomes and less on the process of recovery. By recovery, I am referring to the inevitable unfolding of biological consequences of the injury throughout an ongoing journey, powerfully influenced by multiple resources along the way. It seems that more efforts have to be made in the direction of advancing recovery from TBI, whether through education on how to cope with the challenges that arise, or through having the information necessary to create a model of motivation to foster recovery. The present study is intended to contribute to the field of counselling and treatment by providing information about what helps people who sustain brain injury not only to deal with the arising challenges but also to move forward in their enduring recovery.

The specific qualitative approach used in the present study is the Critical Incident Technique (CIT). CIT is an exploratory qualitative method of research. This technique originally was developed by John Flanagan (1954) during World War II in order to identify effective pilot performance. However, the technique has been extended to study psychological states (Norman et al., 1992; Wilde, 1992). Flanagan (1954) stated that the CIT consists of a set of procedures for collecting direct observations of human behaviour in such a way as to facilitate their potential usefulness in solving practical problems and developing broad psychological principles (p.327).

Participants selected for a CIT study have to be in a position to observe or experience relevant facilitators or hindrances and be capable of articulating their experiences. The emphasis is on incidents which are critical to, or significantly affected, motivation to recover (Woolsey, 1996). Upon completion of interviews, critical incidents are extracted from accounts and then grouped by similarity to form a set of categories that encompass the events. These categories provide a comprehensive list of what facilitates and/or hinders the investigated psychological condition. This categorical map can be used for the development of theory, for test construction, for practical programs, and for further research to refine, extend, or revise the categories (McCormick, 1994).

This study followed the five steps of a critical incident study: (1) determine the aim of the activity to be studied; (2) set plans, specifications, and criteria for the information to be obtained; (3) collect data; (4) analyze the thematic content of the data; and (5) report the findings (Flanagan, 1954). The first step is to identify the purpose of the study in a clear and simple way. This occurs through consulting the theoretical and empirical literature as well as experts in the specific field the researcher is trying to investigate. Setting plans refers to who will make the observations, which individuals or activities will be observed, and which specific experiences or behaviours will be investigated. Collection of the incidents takes place through the use of questionnaires or interviews. Next the data is transcribed, making sure to add nonverbal cues which can clarify the reported incident (Alfonso, 1997). Analyzing the data consists of inductively studying the thematic nature of the description of the identified

incidents. While the process of analyzing the data is mostly subjective, it is still aimed at providing a detailed and valid description of the activity that is being studied. The categories are tentatively formed by sorting the incidents into clusters that appear to be similar and labeling them with descriptive titles. According to Alfonso (1997), a process of redefinition of categories and reclassification of incidents needs to occur until all incidents are represented.

Data Collection: Interview procedure

For the purpose of data collection two interviews occurred. The first interview was conducted to elicit critical events that facilitated and/or hindered recovery from TBI. The second interview was a follow-up interview conducted for validation purposes.

The first interview was divided in two parts. The first portion was aimed at clarifying the nature of the study and providing time to establish rapport. This orientation was an attempt to communicate the aim or the nature of events to be reported. The researcher was aware of presenting the aim of recovery without implying to know how the participants would define it. Subsequently, the researcher and the participant discussed the nature of the study, and clarified the nature of events to be reported. The following statement was used:

Hello, X. Thank you for willing to meet with me today. As I mentioned to you on the phone, the purpose of this study is to find out what helps people with brain injury in their recovery. My intention is to meet with individuals like you, so that you can tell me what has helped and/or hindered this process. My goal is to come up with a comprehensive map of what encouraged you and discouraged you in your recovery, so that other people can learn

from your personal experience. In order to do that I need your help, and so I appreciate you being here today.

The next step was to present to the participants the consent form explaining the purpose of the study, the type of questions to be asked, confidentiality and their option to withdraw from the study at any given time (see Appendix B). Upon reading this form the researcher offered to clarify any questions the participants might have had. The form was signed by the participant. In one case, the participant was under 19 years of age and therefore the parent was also asked to sign the consent form. Next, the participants were also asked to complete a demographic questionnaire requesting their age, sex, education, employment before and after injury, and time post injury (see Appendix C).

The second part of the first interview consisted of eliciting critical events that facilitated or hindered recovery from TBI. This part of the interview was approximately one hour in length and was tape-recorded with participants' consent. All interviews took place at the participants' home following their request. Participants were asked to think back over the time since the injury occurred and to describe critical incidents according to the following statement:

When someone did or said something that in your judgment was very encouraging or very hindering, then that incident may be considered critical. In the same respect it could be an object or environment that did something that was in your judgment very encouraging or very hindering to recovery. It could also be a self-initiated action.

The researcher's role as an interviewer was to listen carefully to ensure that the events were complete and accurate. While listening to the participant's

description, the interviewer was attentive to what led up to the incident, what actually happened, and what was the resulting outcome. The interviewer utilized active listening skills; that is, listening, probing, and reflecting. Moreover, when the participant finished the description the interviewer summarized what has heard. The summary statement was crucial to ensure that the interviewer actually understood the speaker, and that the described incident included the source, the action and the outcome. With some participants, the use of focusing was necessary because they became caught up in telling irrelevant detailed stories or in repetitiveness. In cases where the participant reported insufficient information for a critical incident, (e.g., “mom was a huge help”) the interviewer probed further to clarify the response (e.g., “can you think of an example where she was very helpful” and/or “How did you know it was helpful?”). An example of the form of dialogue is as follows:

Interviewee: I was in the hospital and I came across J.C who is a sports columnist and he was in the same trauma unit as I was and I was just really down about myself and I just thought “I am never going to get better” so he got my attention and started talking to me about his life.

Interviewer: so I’m hearing you saying that this sudden encounter with J.C helped you in your recovery?

Interviewee: yeah definitely. Just talking to him he was such an interesting man and I saw the passion he had through his career.

Interviewer: It sounds like a very special moment. Can you tell me what went through your mind or what did you feel following this encounter?

Interviewee: I felt inspired. I told myself “this is what I want to do” to work in broadcasting.

In this example, the source of the critical incident was “the encounter with J.C”, the action was “engaging in conversation with J.C because feeling down” and the outcome was “feeling inspired and stating future interest”.

When the participants were not able to recall any new incidents, the researcher proceeded to ask them about wishful thoughts to facilitate their recovery. The question was: “What would be helpful to you in your recovery that has not happened yet?” (Catapia, 2001). The interview ended when the participants were not able to recall any new incidents.

The second interview occurred within three months of the first interview. Data had been partially analyzed by this time and the researcher explained that the purpose of the second interview was to check the current categories with the participant. The researcher briefly explained to the participant the process in which the helpful and unhelpful critical incidents were extracted to form possible categories. To check the possible categories that had been generated, the researcher used the following procedure. First, the researcher read the recorded incidents and invited the participant to modify any part that did not fit with his/her experience. Second, the researcher asked for the participant’s agreement/disagreement with the category under which the recorded incidents had been placed. Finally, the participant was invited to add new incidents that might have occurred since the first interview.

DATA ANALYSIS

The analysis of the incidents involved three steps. First, events were extracted from the transcripts and recorded on cards, with one incident per card. Second, incidents (on cards) were grouped according to similarity to form categories. Third, these categories were subjected to reliability and validity procedures.

(1) Extraction of the incidents

The researcher tape-recorded, transcribed, and assigned a code number to each of the six interviews. Throughout the transcription work, the researcher used an electronic highlighter to identify a potential critical incident. This involves highlighting everything resembling an event. The helpful incidents were color-coded separately from the unhelpful incidents. This process provided an initial feel for the described critical incidents. The researcher read carefully through each transcript and followed the procedure suggested by Woolsey (1986).

- (1) Both helpful and unhelpful incidents were identified by (+) or (-) respectively on the left margin of the transcript.
- (2) Any specific incident was counted only once even when the participant returns to the same incident several times in the course of the interview.
- (3) Each report of a critical incident typically consisted of several meaning units. A meaning unit might vary in length from one sentence to one paragraph, but it must contain a complete and clear idea marked by a transition in meaning. In several cases, the meaning unit in this study referred to a shift in emotion or thought in relation to the process of

recovery presented by the participant.

- (4) A descriptor of each relevant meaning unit was created by the researcher and written on a Memo-Note attached to the right margin of transcript. A descriptor could be a phrase or a sentence that accurately captures the meaning of the unit. For example: "My friend helped me with reading".

In this examination, the critical incidents were identified by: (1) the source, which indicated who was involved and the context of the event, (2) the action taken, which explained what has happened, and (3) the outcome, which described the effect that followed the incident. By ensuring that each critical incident encompassed the above criteria, it was possible to delete vague statements and sharpen the occasionally rambling language of participants without losing the core meaning of the event.

Finally, the researcher recorded each critical incident onto index-cards, coded by participant number and incident number (e.g., index-card number 3.5 refers to incident number 5 of participant number 3). Incidents that could not be identified by the source, the action, and the outcome were still recorded on index-cards and were set aside. These incidents were re-checked and clarified with the participants during the second interview.

After this process, 165 complete incidents were obtained. It should be noted that the incidents were varied in clarity and format; some were in detailed and narrative form while others were vague in their wording. The process of

extracting incidents was straightforward after following the above mentioned guidelines.

(2) Forming the categories

After the incidents were extracted and recorded onto index cards indicating the three component parts (source, action taken, and outcome), the researcher highlighted the action mentioned on the index card. The focus of sorting incidents into similar groups in order to produce categories was based on the action taken (e.g. "I was getting physically better and so my dad took me on field trips; we're getting adventurous like we used to do before the accident has happened"). The researcher had to exercise her own judgment in cases where it was necessary to reword and/or paraphrase the action taken, because participants tend to speak with varying degrees of clarity. In such cases, the researcher notified the participant during the second interview. These groupings then became the basis of the evolving categories. Once a tentative facilitating category system had been established, categorization was reviewed by a member of the thesis committee (R.M.) and as a result, refined and revised. The second round of categorization was reviewed by the participants, during the second interview, who checked the fit between incident and category.

In the case of a strong emotional response on the participants' part, a list of counselling resources such as the Crisis Centre phone number, Brain Injury Association Vancouver, and some counselling agencies was to be provided to the participants. There was no need to pursue this provision.

(3) Validation procedure

The categories were assessed in six different ways answering six different types of questions regarding the soundness and trustworthiness of the category system. In this study, the researcher initially needed to determine whether the descriptive accounts appeared accurate and whether they are well represented by the category under which they have been classified. A second interview with the participants was conducted to answer this question. Two participants added information to the recorded incidents in order to enhance their accuracy. Five participants moved one recorded incident to a different category that they found more representative of that incident. The reclassification was always followed by a joint discussion. This process was not only to increase validity but was also indicative of participants' involvement in the research.

The second question considered the saturation point and comprehensiveness of the categories. Following McCormick (1994), approximately ten percent of the incidents (i.e., 15 incidents provided by three participants) were left unexamined until all the categories were formed. In this study, the 15 incidents initially were set aside for lacking the necessary clarity. During the second interview, these incidents were re-visited with the participants to attain clarity on the three parts: the source, the action taken, and the outcome. The category system would be considered comprehensive if the 15 incidents could be classified under the existing categories.

The third question referred to the consistency of the categories among different people. Two independent judges were asked to participate. Both judges

were doctoral students in the Counselling Program at the University of British Columbia. On separate occasions, each judge was provided with a brief description of the categories and then asked to place a sample of 17 incidents (approximately 10%) under appropriate categories. Each judge received a different set of 17 incidents. By comparing the placement of incidents by judges with the original placement of incidents while forming categories, the number of hits and misses could be summarized statistically as a percentage of agreement. Flanagan (1954) recommended a 75% level of agreement or more to consider a category system to be sufficiently reliable for use. A high level of agreement indicates that different persons can use the categories to categorize incidents in a consistent or reliable way (McCormick, 1996)

The fourth question referred to the participants' rate in each category. To form a category, the researcher must identify a significant similarity among a group of incidents reported by different people. The researcher asked how frequently a category occurred among the participants. If all six participants reported similar events placed under the same category, it indicated high validity for that category. Participation rate for each category is obtained by the number of participants reporting a category of event divided by the total number of participants.

The fifth question referred to the relevance and usefulness of a category of event for facilitating and/or hindering recovery from TBI. Previous research using CIT suggested expert validation of the categories (McCormick, 1994; Alfonso, 1997; Butterfield; 2001). This was done by asking two psychologists

with rich experience in working with TBI adolescents to judge the relevance and usefulness of the categories. These experts were asked to comment on the completeness of the categories in each of the two groups (helpful and unhelpful critical incidents) and to provide feedback on each category and its relevance to the practical therapy. The experts indicated their own familiarity with specific categories that were manifested through their practice.

Finally, it is very important to assess the category system in relation to other research that has been conducted in the field of recovery from brain injury. As indicated earlier, very little is known about what facilitates and/or hinders recovery from TBI; that is, what encourages or motivates adolescents who sustain TBI to recover. Nevertheless, the category system obtained in this study was assessed through one significant study which focused on the process of recovery from TBI (Lewington, 1996).

CHAPTER IV

RESULTS

Participants.

Six individuals, four men and two women, who have sustained a traumatic brain injury (TBI), took part in the study. All participants expressed a keen interest to speak about their recovery. The age of the participants ranged from 16 to 24 years old. The mean age was 20.5 years. All were high school students at the time of the injury. Most currently have some post secondary education. Further demographic information about the participants is presented in Table 1.

Table 1: Demographic information

Participant #	Sex	Age	Education	Employment pre - injury	Employment currently
1	F	19	Post Secondary	Student. Employed P/T	Student. Unemployed
2	M	16	High school	Student	Student
3	M	19	Post Secondary	Student. Employed P/T	Student. Unemployed
4	M	22	Post Secondary	Student. Employed P/T	Student. Unemployed
5	F	24	Post Secondary	Student.	On/Off work placements
6	M	23	Post Secondary	Student.	Student.

Note: Post Secondary = college studies.

Available information was obtained from the participants medical records at the G.F.Strong Rehabilitation Centre with the participants' permission and is presented in Table 2. All participants sustained closed head injury. The time post injury ranged from 1 to 8 years. The mean time was 4.38years.

Table 2: Information on sample from medical records

Participant #	Glasgow Coma Scale	Duration of coma	Time post injury
1	10 dropped to 3	~4 days	1.10years
2	6	~4 days	1year
3	7	~2 weeks	2.3years
4	4	~3 weeks	4.11years
5	3 shifted to 4	~4.5 weeks	8.4years
6	3	~5.5 weeks	8.4years

Note: Scores on the Glasgow Coma Scale range from 3 to 15. Score of 8 or less indicative of severe brain injury, 9 to 12 indicates a moderate level of severity, 13 to 14 indicates a mild level of severity, and a score of 15 reflects no altered state of consciousness. These scores appear to have been obtained upon entry to hospital.

Critical Incident Technique.

A total of 165 critical incidents concerning what facilitates and what hinders recovery from TBI following discharge from rehabilitation were identified. Participants reported on more facilitating events (78.8%) than on non-facilitating events (21.2%). The 165 critical incidents were classified into 16 categories: 13 facilitative, 1 hindrance, and 2 categories that fall under other relevant information. The purpose of this research was to elicit critical incidents

that facilitated and/or hindered the process of recovery. However, it was discovered that only 7 of the 31 critical incidents reported as unhelpful events were actually hindering the recovery, while the remaining 24 critical incidents were more negative (e.g., irritating or disappointing) experiences than hindrances per se. Therefore, these 24 critical incidents formed on of the categories under other relevant information. An additional four critical incidents resulted from a specific question about what would be helpful to the participants in their recovery that has not happened yet. This relatively neutral category was also included under other relevant information. It was the researcher's primary concern not to impose data into categories that were discovered to be inappropriate.

In this chapter, the 16 categories are first described following the validation procedures employed for the categories.

DESCRIPTION OF THE CATEGORIES

This section will present each of the 16 categories by providing a brief description of the category, examples of incidents in the category, a numerical indication of the incidents included in the category, and the number of participants contributing to each category. For each example, there is a number attached in brackets indicating its index card number. The 16 categories are presented in the following order: 13 facilitative, 1 hindrance, and 2 other relevant information categories. The facilitative categories are presented in random order as there was no attempt to rank them in order of importance.

All of the incidents describe what has facilitated and hindered recovery from TBI for the late adolescents who participated in the study. The generic term “recovery” was used in this study as no attempt was made to define recovery in terms of one part of the person, be it physical, mental, emotional, or spiritual. Recovery was viewed as an ongoing personal journey where adjustment is perpetually established (Sherwin & O’Shanick, 2000). This view of recovery was spontaneously confirmed by the participants and will be discussed in the Discussion chapter.

Facilitative Categories

Constancy of Support (17 incidents, 5 participants)

This category refers to the various sources of support which were available for the participants throughout their recovery. This category does not necessarily include incidents that involved obtaining direct help or support from others, but incidents in which the individual was aware of others’ unconditional availability. The described support would come from parents, siblings, friends, and therapists. Participants described feeling nervous, afraid, and anxious about life following this traumatic event of their injury; “What is going to happen to me?” Participants described the received support as something beyond the regular, daily used word ‘support’. The family and social support was available on a continuous basis over time; was congruent in terms of both words and actions; and provided hope for the participant in times of pessimism. For these additional qualities this category is seen as a distinctive type of support.

Examples

The company that kept coming in from other people helps you to try more. I mean instead of doing it just for me, I think that subconsciously I did it for other people. It is when everyone else was hoping for me. [4.11]

The G.F.Strong rehab centre helped me to feel myself. The staff pushed me to do the most I could, and it was tough but they did not give up on me, they were very persistent and caring. [1.6]

My family, the efforts that they put in making me better...always being there for me...basically always give me a lot of hope, reassuring me that everything will be okay. [1.7]

Gaining Perspective (9 incidents, 3 participants)

This category refers to gaining perspective over traumatic experience.

Participants expressed their struggle to comprehend the trauma. Gaining perspective means that the participants realized the significance of the event. Not only was it a serious experience but they have survived it. For some participants, the perspective over traumatic injury was obtained through meeting with other inpatients who sustained a higher severity of injury. Participants described feelings of being fortunate to stay alive, winning a second chance, and feeling that it could have been worse. This category refers specifically to the experienced trauma and therefore occurs at the early stages of recovery.

Examples

I remember this unexpected encounter with one of the nurses at the VGH. She recognized me. She run over and hugged me. She started crying "we thought you were dead". I was thinking this is really weird, I was dropping

off a friend for stitches and this woman was telling me how they all thought I was going to die. So I was alive and I was not supposed to...just hearing that was scary but helped me understand that it was serious. I wanted to do something to survive. [2.18]

After I came out of my coma my mom introduced me to M. whose husband has been in coma for over 3 months. I often go and visit him. When I see him I understand how lucky I am to have recovered. [4.28]

I met with a lot of the in-patients. Talking to them, hearing their stories and what they had to go through made me think "Gees I do not have it that bad at all". [1.20]

Challenging Opposing Forces (8 incidents, 5 participants)

This category involves incidents that encompass both the positive and the negative or the helpful and the unhelpful at the same time. The participants engaged in somewhat emotionally charged activity to facilitate their recovery. In other words, they did something to enhance their recovery (e.g., grieving the loss) accompanied by a less expected challenge (e.g., depression). The outcome of challenging opposing forces seemed similar to a "double-edged sword".

Participants described the difficulty of holding opposing feelings but, at the same time, indicated feeling content. For the participants who reported these incidents of challenging opposing forces, they tended to occur on a single occasion rather than be a continuing experience.

Examples.

It was a good thing to process the loss. To let myself think about where I would be today had the accident never happened? At the same time it was bad, because the depression kicked in. I felt as if I am dealing with two things against each other. [5.1]

Coming back from the assault means [to youth] that I am known for the guy who got beaten-up and that does not feel good at all. But at the same time, I come back strong, I am the guy who was beaten-up and beat it. I stood up to it. [3.14]

Re- encountering my “old” Self (11 incidents, 4 participants)

This category refers to the activities participants had engaged in prior to the traumatic injury. These pre-injury activities were highly significant in the participant’s life. Before the injury, the participants integrated these activities into their own identity. Participants described meaningful activities and even roles taken prior the traumatic injury, which were “forgotten” after the injury. For some participants, the first basketball game or volleyball game after the injury indicated that they were back to being “normal”. For other participants, this category was more about being independent again. Participants described feelings of excitement, nervousness, and feeling encouraged while re-encountering these parts of the “old” self.

Examples.

Playing basketball for the first time since the accident...it was at the G.F.Strong rehab. Centre. I, my two friends and one of the janitors played the game. I felt like I’m back to being “normal”. [4.6]

Being out of my parents’ house was definitely important for me. Even when I was living with my brother or with my girlfriend they had their own lives so they could not do things for me. I had to take care of my self by myself. [5.16]

When I was physically getting better, I, my dad, and my step mother would go on field trips as we have done prior to the accident. We would go around the province on back roads and camps. I remember feeling safe and confident in myself. [6.14]

Having things that made me feel as if I am back into my life was very helpful. When I got back into school, studying and being around my friends was helpful. [2.6]

Gaining a New Understanding of Myself (17 incidents, 6 participants)

This category refers to the process of one's understanding of self in relation to the traumatic injury. Participants described their process of learning about who they are at the current time, following the injury. This self understanding incorporates one's strengths and weaknesses in relation to the injury. For some participants, gaining a new understanding of who they are resulted in self-acceptance, while for others it was still in progress. The majority of self-understanding incidents occurred through a therapeutic relationship (i.e., counselling, occupational therapist) as reported by the participants.

Examples.

When I was coming out of the Rehab. Centre, I knew I can never be who I was. I can never do what my brother does; I can never be like my sister. It has been a struggle accepting that I am different. I am permanently different. [5.10]

I have come to realize that my scars on my body, as of now are the scars of my battle. I know that what I have gone through made me a beautiful person, because I went through it. [1.10]

If we go party and someone gets drunk they look for me because I'm the sober kid now. I'm their designated driver. The injury has changed who I am. No longer am I the crazy kid who gets up on the roof of the house,

make up the speech, and yells at the cops, now I am the guy down on the ground, who is helping out. This is good for me. [2.4]

When I went back to the party scene I felt nervous with all the people around me. People I did not know. I was telling myself “relax, you are just different now; you are more mature, just stay away from them and go talk to other people” I dealt with it through understanding myself, understanding that I am different now. [3.1]

Obtaining Life Attitude (10 incidents, 5 participants)

This category involves getting beyond one’s own negative experience and developing a different view of life events. Obtaining life attitude means that the individual is able to articulate the negative experience (i.e., traumatic accident) while adding to it another meaning. This meaning might serve as a positive outlook or a learning experience. Participants saw these negative experiences as something that they could not change, therefore they felt the need to move forward, away from that experience, without erasing it. Many of the participants described feelings of sadness, depression, and anger for what has happened, and through that realizing: “I cannot affect the past but the future”. Participants delivered their obtained life attitude through a quotation, an expression, or a statement. This category is distinctly different from gaining perspective because it refers to a world view or philosophy of life being exercised throughout the recovery.

Examples

The attitude that the person has for the recovery is probably equally a factor in the recovery than anything else. The one consistent thing is that my attitude has always been positive. [4.15]

My favorite quote is from James Dean: “Dream as if you will live forever. live as if you will die today”. I live it up to each day. [1.8]

You do not look back and try to change things because what happened has happened and you can’t change it. All you can affect is the future. The accident was not a happy event in my life, but it allowed me to experience life in a different way or have a different view on life. [4.16]

Engaging in Goal-directed Activity (12 incidents, 5 participants)

This category refers to the intentional engagement in activities aimed to facilitate recovery. Participants described engaging in somewhat challenging activities in accordance to their own personal goals. The goals ranged from getting back into a party scene to discovering a future career. These goal-directed activities for some participants involved a short term intentional engagement, while for others it was a long term engagement. Participants described feelings of self-challenge, stubbornness, and self-focus resulting in their own sense of purpose. The activities included solving math problems, weightlifting, or going through work placements while being conscious of their limitations.

Examples.

Having short term goals helped me a lot. I wanted to go back into driving. My parents said “once you get 100 hours driving with us then you can have the car”. We are pretty close to that, now I am at 85 hours. [2.2]

When I came back I did not really know how to be in a party scene. That was a goal, to learn how to get myself back into it. I was working on feeling comfortable to get around and talk to people. [3.17]

Obtaining Help from Others (10 incidents, 3 participants)

This category refers to integrating others in the process of recovery. This means accepting one's need for help whether it is physical, emotional, or spiritual. Participants allowed others to provide that help, and ultimately sought out the required help. For some participants, the connection to their spiritual side or to their passion in life had originated in obtaining help from others. Participants described the initial discomfort in having the need. Once the help was obtained, feelings of gratitude and appreciation arose. Obtaining help from others took different forms: Help as integrating alternative treatments; Help as an emotional support; Help in getting inspired; Help in re-connecting to different sides of the self (i.e., spiritual, physical).

Examples.

My dad and his wife took me on a two weeks adventure. We kayaked around the Queen Charlotte Island. I could not get the paddle exactly in the right angle so I was a bit slower in the group. My dad would kayak next to me and talk me through it. Having him there was helpful. [6.1]

After the accident our priest came to see me at the hospital. He talked to me about the aspects of life. He gave me this positive vibe. I began to like to go to church. He helped me to have that connection with god. [1.18]

Before the accident I did not need help, I was very intelligent. I could do things on my own! After the accident I had to accept that I need these people. I need their help. It was very hard to adjust to that and to accept it. [5.9]

Pacing Oneself (7 incidents, 3 participants)

This category refers to the return home after the discharge from the G.F.Strong Rehabilitation Centre. Participants needed to slow their pace down while re-adjusting to their lives. They saw this as a transition time where all taken

activities should be considered appropriately. The incidents involved in this category integrated the feeling of “I want to take it easy” and the action of “taking one step at a time”. Pacing oneself should not be confused with the concept of strategy as it was not seen as a skill in terms of organizing and doing something or as a plan of action. Pacing oneself occurred spontaneously throughout the recovery.

Examples.

I will try to finish my diploma within a year, but if it takes me eighteen months or two years I am not dead yet so it is not a big worry. I am not rushing my life anymore. I have shifted my studies to part time basis. I want to achieve good grades without getting stressed about it. [4.27]

I had to take it time by time, just like every inch along the way. I could not say “this is what I’m going to do for the next year” I had to think of every time as it pops out. [2.12]

Developing Practical Techniques and Skills (9 incidents, 3 participants)

This category refers to finding helpful ways to deal with the outcomes following brain injury. The incidents involved in this category incorporate helpful ways to deal with memory loss, anger for what has happened, continuous stress, and slow speech. The participants described feelings of frustration and getting upset before having these techniques, while feeling more in control over the situation when using these techniques. For some participants, these techniques were acquired through their relationship with a counsellor and/or occupational therapist. Other participants developed these techniques on their own as they have learned more about themselves in relation to the injury.

Examples.

I love poetry. When I was at the G.F.Strong I had my notebook to write poems. Today I keep it near my bed and write whenever I feel anger and disappointment. It helps me realize how I truly feel. [4.1]

When I am stressed or feeling down, I try to visualize that I am in a bubble. Every thing in the world is outside of that bubble. I tell myself "okay E. you are in this bubble and you have to figure out what you want to do, what is going to be the best for you right now" [1.16]

My agenda is my bible. If I lose it I'm gone. I write everything down: school work, coffee with friends, and just every detail. I have to otherwise I over book myself. It helps me to organize my life and also not to take too many things upon myself at once. [1.34]

School is not as good because of my memory problems. Today I am meeting with one of my class mates and we are going over the school material together. Studying with someone else helps me to make connections between the [theoretical] material and things that happen in life. [4.25]

Recognizing the Success/es (6 incidents, 4 participants)

This category refers to recognizing one's own successes throughout the recovery. The meaning of success is manifested through graduating from high school, receiving high grades, establishing a new circle of friends, or simply feeling improvement. Participants described feeling empowered and accountable for their own progress. While acknowledging receiving help from others, participants discovered their own power to make their recovery better.

Examples.

The fact that I am able to progress and learn something new everyday, gives me the feeling of I am improving! I am getting better! [4.8]

After my graduation I realized that I did well. I realized that I am the only one who can make it better. Of course I can get help from other people, but I am the only one who can make myself better. [1.13]

I had a test today about how to make sweet dough. There are so many small details to remember. I got 80% and it's great. It feels really rewarding that I found something to fall back on, so to speak, and that I am also good at it. [6.3]

If there were 10 "normal" people in front of you and I was one of them I do not think you will be able to say "she is the one who had the accident". It makes me feel good about my recovery. [5.12]

Physical / Sensory Experiences (12 incidents, 5 participants)

This category was intentionally broadened to encompass physical exercising (i.e., attending the gym), sensory activities (i.e., cooking, listening to music), and physical therapies (i.e., attending massage therapy). Most participants attended the gym initially to enhance their physical recovery, but then it became a rejuvenating activity. A few participants were drawn to activities that trigger the senses such as cooking, for it made them feel relaxed. Other participants sought physical therapies to enhance their physical and emotional strength. The interconnectedness between the physical, the emotional and the mental was evident in the reported incidents. The incidents were either self-initiated by the participants or offered to them by their parents or friends.

Examples.

When I was living with my roommate, I didn't want to buy bread, so I was searching for a recipe in a magazine I was subscribed to. I just followed the instruction and it was easy. The bread came out very good. I felt good

about myself. I think that if anything could inspire me it would be the smell of fresh baked bread. [6.5]

I love music, especially country music. It has a lot of meanings to it. It reminds me of people or scenarios, like a play of what I have. If I was ever grumpy on something I would pick a song and listen to it. It is very therapeutic for me. [1.5]

Physical exercise helped me a lot in my recovery. Whether I go for a workout, for a run or do boxing, I feel energized. Every physical thing I have ever done helped me release the stress and anger I had. Physical exercise helped me recover but also helped me to feel more confident with myself. [3.10]

Taking Care of Others (2 incidents, 2 participants)

This category refers to one's expansion of self care towards others, specifically one's pets. Although this category includes only two incidents they were significant enough to form a separate category. Taking care of others facilitated the participants' recovery for it had shifted their attention to someone or something beside themselves. Participants had to remember to do certain things that were not about themselves. They described feeling relieved to experience this shift in focus, and also feeling happy about making the pet happy.

Examples.

My cat is another thing I have to remember. I have to feed her and take care of her. It is such a relief to not have to think about myself. There are so many things about me that I have to remind myself throughout the day, so now it's not about me it's about someone else. [5.18]

When my parents would go on holidays I would take our dog and at least one of their cats over to my place. It would be a lot of work taking care of them. Feeding them and taking the dog out for a walk. It would make me happy to make them happy. [6.13]

Hindering Category

Lacking the Necessary Support (7 incidents, 5 participants)

This category refers to one either receiving inappropriate support or experiencing a decline in their existing support. Participants described events where friends would suddenly stop their visits or healthcare professionals who made discouraging comments. Participants indicated feeling lonely, discouraged, and fearful which, in turn, hindered them in their recovery. This category is complementary to the category “Constancy of support” which emphasizes the significance of support in one’s life.

Examples.

I remember one time when one of the doctors came in. He asked me to count backwards from 100 subtracting 7 each time. I sat there and kept messing up the numbers and he said “Oh that’s not good”. That comment scared me because I did not know what is going to happen to me. [2.21]

After the accident everybody was coming to visit me at the hospital, all the people that have known me. As soon as I was transferred to the G.F.Strong I was forgotten about by most of them. Then when I returned home I had even less visitors. I realized that most of them were just acquaintances to me. To a certain degree that had a negative impact on my recovery. [4.23]

Other Relevant Information Categories

Facing the Outcomes / Living with Loss (24 incidents, 5 participants)

This category includes incidents which had discouraged the participants in their recovery. Following the traumatic brain injury, the participants were left with multiple outcomes that have left a permanent mark on their lives. Anger

outbursts, impulsivity, poor judgment, and slow cognitive processes are just a sample of the most challenging and serious effects with which the participants are faced. The reported outcomes of these incidents are congruent with the literature on traumatic brain injury. Moreover, part of the injury outcomes is the loss of a role taken by the participant prior to the injury. Participants described feeling devastated after realizing that they cannot become a doctor or a baseball pitcher. Living with the loss raised feelings of sadness and depression among the participants.

Examples.

The biggest and quite crucial one is not being able to drive. A normal 24 years old has a license and has a car, and I don't. I won't. I think that this is probably the biggest disappointment. [5.22]

I don't have much free time right now. In my room I have this long list of things that need to get done and I don't find the time. It makes you think "damn! I have got brain injury and it slows me down" sometimes I wish I could get it done faster. It would make everything easier. [3.22]

I have anger problems. I can get angry really fast. I can get into this crazy moment and my eyes and my face look like I almost see disaster. I have this weird look on my face; it's not a nice look. It does not even look like me. [1.24]

My voice is slow and my speech is slurred. It makes it more of a social problem. I think women get scared by the image of a big guy who has a low speech. I may be perceived how I don't want to be by some people. [6.24]

I remember baseball as being the pitcher, everyone was depending on me. I was always good. After the accident I was not relied upon the same way. The accident changed the whole aura around [the experience of] playing baseball. [4.21]

Envisioning Normalcy (4 incidents, 4 participants)

This category is based on participants' response to the question "what would be helpful to you in your recovery that has not happened yet?" Most of the reported incidents included in this category were related to companionship. Participants described the need to have someone meaningful in their life with whom they could also share their traumatic experience. For other participants, the wish to have their own place or to earn their own money was considered helpful once it occurs. Participants described feelings of desire to attain features of life that most people their age strive for. It is worth noting that the two remaining participants, who did not report on critical incidents here, appeared to have attained those features of life.

Examples.

It would be very helpful to have somebody new in my life. Somebody that I could share my experiences with, that could understand or find what I'm saying as meaningful. Somebody that I feel comfortable enough to be around and to open up could be helpful. [4.24]

It is hard not to have my own place. I would love to move out of this house but it is financially hard because my school is Mon.-Fri. and so I don't have time to work. [1.21]

One thing I really want to go back into is working. It would be very helpful to make my own money because it means I am doing something with my time plus it is good to have pocket money. [3.24]

VALIDATION PROCEDURES

Six approaches were employed in this study to assess the validity of the category system: (1) Participants' validation, (2) Comprehensiveness of categories, (3) Inter-rater reliability, (4) Participation rate, (5) Expert validation, and (6) Literature support. The employment of multiple and various procedures suggested that each approach was necessary but insufficient by itself.

(1) Participants' Validation

One of the considerations taken by the researcher to study recovery from brain injury was to incorporate the participants' perspective. As Alfonso (1997, P. 121) indicated, "it seems important to treat participants as experts in their history and individual perspective of the world". In order to stay true to the researcher's intention of integrating participants' expertise in their recovery, it was necessary to present the category system to the participants and to use their feedback for assessing the validity of the categories.

This examination, as mentioned in the previous chapter, took place in the second interview. First, the researcher sought the participants' agreement regarding their descriptive incidents on what facilitated and hindered their recovery; that is, were they accurate? Two participants added information to the recorded incidents to enhance their accuracy. Second, the researcher asked the participants to review each category and provide feedback on whether that category was a trustworthy representation of their reported incidents. Five participants each moved one recorded incident to a different category that they found more representative of that incident. The reclassification was always followed by a joint discussion. This process not only increases the descriptive

validity (intended for avoiding distortion of the reported data), but also indicates participants' involvement in the research. One participant was not available for a second interview which might have affected the completion of this examination.

(2) Comprehensiveness of Categories

To determine whether the category system was reasonably complete or comprehensive, the researcher withheld 15 incidents (approximately 10% of the 165 incidents) until the categories had been formed (McCormick, 1994; Alfonso, 1997). In this research, the 15 incidents were initially left unexamined because they were unclear. In the second interview, the researcher read those incidents to the participants and asked for further information to attain clarity. All of the 15 incidents were revised to include the source, the action taken, and the outcome of each incident. At this point, these incidents were examined and classified. It was expected that if the incidents could be placed within the existing categories, the category system would be considered comprehensive. All 15 incidents were classified within 15 of 16 existing categories; the category "Envisioning Normalcy" was not included in this examination because it emerged in response to the final structured question. This examination seemed to be the closest available way to see if the categories which have emerged from this study can accommodate "new" incidents. These were "New" in the sense that they were not included in the initial process of forming the categories.

(3) Inter-rater Reliability

Once the categories were developed, it was necessary to determine whether it was reliable for use with different raters. Can different people use this

category system in a consistent way? According to Anderson and Nilsson (1964), one way to determine reliability is by the degree of agreement of independent judges using the category system. This is attained by percentage agreement. Flanagan (1954) suggested that a category system should attain at least 75% agreement. Anderson and Nilsson (1964) suggest that a category system is acceptable if independent raters can correctly classify 75%-85% of the incidents into the categories.

In this study, separate samples of incidents were drawn from the pool of 165 for each judge. The two samples each consisted of 17 incidents chosen by the researcher. The sample size constituted approximately 10% of the incidents reported, which was suggested by McCormick (1994). The researcher selected two separate samples to avoid overlap in incidents reported and provide separate tests of reliability. The selection for both samples was influenced by the researcher's high confidence that certain incidents easily represented by their category (i.e., #1.7 in constancy of support) and the researcher's low confidence in same incidents that were less obviously represented by their categories (i.e., #2.20 in challenging opposing forces). These 17 incidents represented at least one incident from each category. The first judge received two incidents from the category "Gaining a new understanding of myself" and the second judge received two incidents from the category "Re-encountering my "old" self".

Two independent judges participated in this procedure; both were doctoral students in the Department of Educational and Counselling Psychology and Special Education at the University of British Columbia. On two separate

occasions, the judges were provided with a brief written description of each category by the researcher and with 17 number-coded index cards, on which the incidents were recorded. The two judges were asked to place each of the index cards in the categories that they felt were most appropriate. Both judges completed this work independently in their leisure time without the researcher being present. Both judges categorized 16 of 17 incidents in the same category as the researcher. The one incident that was categorized differently by each judge represented two different categories: “Gaining a new understanding of myself” [5.10; mis-categorized as “Facing the outcomes”] and “Re-encountering my “old” self” [5.6; mis-categorized as “Engaging in goal-directed activity”]. Both judges reported on taking approximately 60 minutes to place the incidents. Table 3 represents the percentage of agreement between the researcher’s and each judge’s placement of the incidents in the categories.

Table 3: Reliability of category system

Judges	Percentage Agreement
Doctoral student #1	94%
Doctoral student #2	94%
Average Inter-rater reliability	94%

The relatively high percentage of agreement between the researcher and each of the independent judges’ suggests that the categories are clear enough to provide a reliable (i.e., consistent) classification by different raters.

(4) Participation Rate

Participation rate refers to the number of participants reporting a category divided by the total number of participants. Borgen and Amundson (1984) suggested that a 25% participation rate could be considered sufficient to support the validity of the categories. The participation rate ranged from a low of 33% (Taking care of others) to a high of 100% (Gaining a new understanding of myself). Table 4 provides the frequency and participation rate for each category. Frequency indicates the number of participants reporting an incident in a category. Participation rate is the percentage of participants reporting an incident in the category. This examination suggested that certain categories (e.g., Constancy of support) are “stronger” categories than other categories (e.g., Taking care of others). However, the rate of participation rates is constant with the high variation within the general population with traumatic brain injury; this is, there are no two identical traumatic brain injuries, and the experience of TBI is unique to each individual.

Table 4: Participation rate

Categories	Frequency	Participation Rate
Facilitative:		
Constancy of support	6	100%
Gaining new understanding of myself	6	100%
Challenging opposing forces	5	83%
Engaging in goal-directed activity	5	83%
Obtaining life attitude	5	83%
Physical/sensory experiences	5	83%

Recognizing the success/es	4	66%
Re-encountering "old" self	4	66%
Gaining perspective	3	50%
Pacing oneself	3	50%
Obtaining help from others	3	50%
Developing practical techniques and skills	3	50%
Taking care of others	2	33%
Hindering:		
Lacking the necessary support	5	83%
Other:		
Facing the outcomes/ living with loss	5	83%
Envisioning normalcy	4	66%

(5) Expert Validation

Another test for soundness used in this study was expert validation. It is considered important to put the category system into the context of the field. This test was obtained by asking experts in the field to determine whether or not these categories are valid and useful to them (McCormick, 1994; Alfonso, 1997). Experts were asked to include their relevant experience while reviewing the findings presented to them. In particular, they are asked to comment on each category as to what extent it is seen in the practical context of therapy.

In this study, the researcher approached two psychology professionals in the field of brain injury. The first expert was a registered psychologist in private practice who has more than 10 years experience in providing therapy to clients who have sustained brain injury. The researcher met with this expert for nearly

two hours. Throughout this meeting the researcher briefly explained the study and provided three pages of description on the 16 categories. The expert was asked to review each category description and to comment on whether it was manifested in the practical context of therapy. The expert confirmed each of the 16 categories as useful and valid to therapy practice. In addition, the expert expressed appreciation of participants' accommodative stage in their recovery. In other words, the category system indicated to the expert that the participants' movement in their recovery was beyond the traumatic experience.

The second expert used in this study was a clinical psychologist who conducts neuropsychological assessments to the adolescents and young adults with TBI who were admitted to the G.F.Strong Rehabilitation Centre. This expert has been working with individuals with brain injury for more than 10 years. The researcher met with this expert for 30 minutes, explained the study and provided three pages of description on the 16 categories. The expert was asked to review each category description and to comment on whether it was manifested in the practical context of therapy. The expert provided her feedback in writing next to each category and then delivered it back to the researcher. The expert indicated in writing that each of the categories is relevant for practical counselling therapy. However, the expert highlighted two categories that would be more challenging to individuals with severe frontal lobe injuries because of damage to executive functions (i.e., initiation, planning). These categories are: "Engaging in goal-directed activity" and "Developing practical techniques and skills". She also indicated the importance of "Gaining a new understanding of myself" and

“Obtaining help from others”. The expert was surprised to read that sensory activities were reported as facilitating recovery. Taken as a whole, the expert expressed her appreciation of these categories and recommended that the results be presented to the interdisciplinary team for traumatic brain injury at the G.F.Strong Rehabilitation Centre.

The experts’ feedback on the 16 categories provided evidence supporting the validity of categorical system for the practical context of therapy with persons who have sustained traumatic brain injury. This examination provided a link between research and the practical therapy.

(6) Support of Related Literature

This was the final test used in this study to assess the validity of the categories. The purpose in assessing the category system through previous research was to obtain a relative support for the soundness of the categories. This section will be limited to a comparison of the findings of the present study to another study dealing specifically with recovery from TBI. An expanded discussion of the findings of the present study that embeds them in the broader literature will take place in the Discussion chapter. Thus, the present assessment was conducted using a significant study by Lewington (1996). The researcher in the present study found that the categories were interrelated and mutually affected one another to different degrees. For example, the category “Challenging opposing forces” provided information to the participants about their abilities after the injury which was also became evident in the categories “Pacing oneself” and “Gaining a new understanding of myself”. Moreover, indications of one’s

“new” abilities led the participant to engage in appropriate behaviours such as that seen in the category “Engaging in goal-directed activities” and in “Developing practical techniques and skills”. Thus, the comparison of the categorical system developed in this study to Lewington’s (1996) research is presented as a whole rather than by separating the categories and comparing each category to her research. This also fits with Lewington’s findings that recovery from brain injury is a process that is cyclical more than linear and is influenced by interrelated themes and constructs. It is important to note that Lewington’s role in this section was based purely on her research; that is, to compare this study’s results with her study’s results. Therefore, Lewington played two roles in the validation process using two different expertises: (1) psychologist and (2) researcher.

Lewington (1996) studied the meaning of recovery as experienced by seven adults who sustained TBI. She discussed four parts that constituted a pattern of recovery from brain injury: Trauma, Deconstruction of the old story, Construction of a new story, and Recovery. She indicates a movement through the four parts that is linear only to the extent that the story always begins with a trauma.

The theme “Trauma” is seen in the category “Gaining perspective” over the traumatic injury. This category included incidents during which participants’ felt the need to grasp the shocking experience. Gaining perspective provided glimpse of understanding over the “what the hell has happened?” experience.

Lewington’s theme of “Deconstruction of old story” was seen in the categories of “Gaining a new understanding of myself”, “Challenging opposing

forces”, “Facing the outcomes/Living with Loss” and “Re-encountering my old self”, found in the present study. These categories referred to the participants’ experiencing themselves in a different light; that in a light that emphasizes the core of their traumatic brain injury. This is the loss of meaningful parts of themselves. Lewington indicated that this is a time of personal devastation where in the present study participants expressed ambivalent feelings. On one hand they felt frustrated and sad and, on the other hand, they felt challenged to deal with that negative spot light.

The next theme in Lewington’s study is the “Construction of a new story” which refers to the person being propelled to overcome the negative evaluations, be it theirs or others, and to find a path to renewed self acceptance. Feelings of surprise, excitement, pride, hope, relief, and determination arise. The category “Obtaining life attitude” in the present study seemed to mark the beginning of this theme. Participants in the present study found it crucial to deliver the message of “I cannot affect the past but the future”. At this time participants were somewhat accepting of self as now and had begun to discover new elements of themselves as well as new roles to take on. This occurred without necessarily abandoning the “old” parts of self. This is not the case for persons with severe TBI who have completely lost their sense of self and therefore are required to create a new one, as noted by Lewington in our meeting. The participants in the present study, however could still connect to their “old” parts of self. This was manifested through the categories of “Engaging in goal-directed activity” (i.e., “if you follow the thing that you most passionate about like my love of music you are setting up

a goal with what you want to do” [1.1]); “Obtaining help from others” (i.e., “K. has been my best friend since kindergarten so we go way back...moving in to her place helped me ‘cause she would remind me of things to do”[5.7]); “Physical/sensory experiences” (“with my physiotherapist I was able to slowly go to weightlifting...”[4.18]), “Pacing oneself”(“when I came back to school I didn’t go out for a while...I need time off” [2.5]), “Developing practical techniques and skills”(i.e., “I love poetry...when I was at the rehab. Centre I used to write less because my hand writing wasn’t neat enough...but today I write whenever I feel anger ...” [4.1]) and “Recognizing the success/es” (“If there were 10 “normal” people in front of you and I was one of them I do not think you will be able to say “she is the one who had the accident”)

The last theme in Lewington’s study is “Recovery” which refers to meeting the challenges that are simply part of life’s journey. The person achieves a re-orientation to life as it is accompanied by feelings of comfort. The researcher in the present study could not identify a specific category that fit into the “Recovery” theme. However, it became apparent that this theme is actually manifested throughout the whole categorical system. Moreover, the participants in the present study expressed their continuous movement towards self-satisfaction. None of the participants identified a satisfying end point throughout their recovery process. The possible category to explain this is “Envisioning “normalcy” which discussed the wishful thoughts the participants still held, whether these would bring them to a complete or temporary satisfying point or not.

In summary, Lewington's study provided a useful assessment tool for the categories emerged in the present study. Her study was particularly useful in relation to the generic term "recovery" which was purposely left undefined in the present study. Lewington's findings provided a general framework to the categories developed in the present study when looking at the process of recovery from brain injury. Further implications of her study to the present study are discussed in the Discussion chapter.

CHAPTER V

DISCUSSION

In a blink of an eye an individual can sustain an injury that will forever change his or her life. Life following a traumatic brain injury (TBI) is typically accompanied by a range of complex physical, cognitive, behavioural, and emotional problems followed by the long and difficult process of coping with these changes. The recovery of the brain from TBI is still a puzzle. On the one hand, recovery depends on the location and extent of the damage, and whether the damage is permanent or temporary. On the other hand, a seemingly “mild” injury, where there is a brief loss of consciousness after a blow to the head, could permanently affect behaviour. Thus, the results of a brain injury are both predictable, and to a certain extent, unpredictable.

The purpose of this thesis was to discover what facilitates and what hinders recovery in late adolescents who currently have a mild-moderate TBI. The recovery time period of interest was the time after discharge from the rehabilitation centre. In total, 165 critical incidents were collected from six participants and organized into 16 categories based on the actions taken by participants to facilitate recovery. It is important to note that the two categories of other relevant information (i.e., Facing the outcomes/living with loss and Envisioning normalcy) acted as neither facilitating nor hindering, but still played a significant role in this study. Thus, further research may explicitly explore whether experiencing and/or expressing the thoughts in these categories are

helpful or hindering in the recovery process. Following extensive validation procedures to assess the categories (1) participants' assessment of accuracy, (2) comprehensiveness of the categories (3) consistency among different raters, (4) representativeness of the categories for the sample, (5) experts' assessment of relevancy to practical counselling therapy, and (6) support by existing literature on TBI, the scheme of categories was found meaningful and useful.

In this chapter, each of the 16 categories and its meaning to practitioners and/or researchers will be discussed, followed by a summary and brief discussion of the possible limitations of the study.

First, it needs to be noted that the participants reported far more facilitating events (78.8%) than non facilitating events (21.2%). A category describing the importance of having constant social and family support was reported by all participants. "Constancy of support" was not only reported as helpful to recovery but support was also described as hindering to recovery when it was absent or when it was inappropriately offered. This was reflected in the category "Lacking the necessary support" (which had an 83% participation rate). The importance of these complementary categories resides in the family, social, and care providers' invaluable presence throughout the recovery from TBI (Conoley & Sheridan, 1996). In the case of available but inappropriate support, the counsellor's role is to inform those involved as to the changes they should expect to see in the individual with TBI and then training them to provide the appropriate response to these overwhelming changes. However, it is more complicated when the individuals with TBI do not have any family members

around them to provide the necessary support. In such case, the role of a counsellor can be critical. For example, Sherwin and O'Shanick (1998) indicated that the psychotherapist may also play the role of advocating for young individuals with TBI and help them to navigate the rehabilitative maze to access the services to which they are entitled. Parker (1990) noted that some individuals with severe brain damage who received good rehabilitation services as soon as they were able to participate in a program, along with personal support, made a surprising recovery.

Another category, "Obtaining help from others" seemed to emerge from the available support system but occurred in the later stages of recovery. For individuals with TBI, it is not enough to have constant support available because they often will not take it or seek it out. This may be related to their lack of awareness of the extent of their deficits and their need for assistance and their difficulties initiating behaviours (Prigatano, 1991). In the present study, some participants seemed to accept their need for help (whether it is physical, emotional, or spiritual) at a more mature stage of their recovery when gaining a better understanding of themselves in relation to their injury. These participants allowed others to provide help and ultimately sought out the required help. The relatively low participation rate in this category (50% of participations) could be explained though by some of the participants' still having an inaccurate perception of their recovery (Cleveland, 1998) and not realizing when they need help. The information provided within this category could inspire counsellors and care providers on how to integrate others to facilitate recovery from TBI. For

example, qualifying the term “help” to take different forms and sizes according to the client’s needs could remove the negative association with this term; that is, that “help” does not necessarily mean losing or giving up one’s autonomy.

A related but more tentative category is “Taking care of others”.

Specifically, this category refers to the participants’ expansion of care from their self towards their pets. While only one-third of the participants contributed to this category, research in the field of counselling has begun to emerge concerning the unique connection that one can develop with pets more than other individuals. In the field of TBI, this type of research is significant for two major reasons: (1) taking care of pets facilitated recovery for two participants in this study by shifting the individuals’ attention to someone or something else beside themselves, and (2) having pets in one’s life could provide support for individuals with TBI who experience isolation from society. From a counselling perspective, this category could help counsellors obtain important information about the individual’s style of interacting with others. Cleveland (1998) used the construct “interactions” to describe part of the individual’s recovery from TBI. She further noted that relationships appeared to motivate individuals to engage in rehabilitative programs. In addition, perhaps having a pet that one could stroke would also provide good sensory stimulation (which relates to another category to be discussed later).

The category of “Gaining perspective” over the traumatic brain injury included incidents during which participants felt the need to grasp the shocking experience. Although only half of the participants in the present study reported on

their need to comprehend the traumatic experience, it is still a well recognized stage of recovery in the existing literature (Cleveland, 1998; Lewington, 1996; Rosenthal et al. 1999; Sbordone, 1990). Through the counselling process, a person with TBI could have a safe place to process this traumatic event. The counsellor could also create a peer support group during which the members share their experiences which might naturally provide the other members with a glimpse of understanding over the “what the hell has happened?” experience.

Gaining perspective fits in nicely with the category “Gaining a new understanding of myself” which all six participants reported as facilitating their recovery. The counsellor could use the information within this category to engage the individual in a unique process in which self revelations occur. These revelations could center around existential questions such as, “Who am I?”; “Who was I?”; and “Who am I becoming?” (Sherwin & O’Shanick, 2000). Throughout this engagement the counsellor’s main tool is basic listening skills accompanied by empathy. It is important to note that the participants gained an understanding about themselves which is also reflected in other categories (i.e., “Challenging opposing forces”) but the present category seemed to provide the groundwork from which other self-understandings could emerge.

There is growing evidence in TBI literature on the notion of “self”. Qualitative studies on TBI have shown that individuals with brain injury struggle to construct their new self. These studies indicate the incredible loss of identity, the loss of the person he or she knew as “self” (Cleveland, 1998; Nochi, 1998). In the present study, however, participants were able to report on events which

suggested the existence of important parts of their past and current selves. In other words, some participants not only identified parts of their past self but also re-encountered those parts of themselves through current actions (e.g., playing basketball after the injury). This process is reflected in the category “Re-encountering my “old” self” which was reported by 66% of the participants. Given that the present findings counter previous research but also do not apply to all of the participants in the present study, it seems that it is still unclear as to what role the notion of “self” plays in the mild to moderate TBI population; therefore more research need to be conducted on this matter.

It has been suggested that individuals with TBI are inclined to set unrealistic goals for their recovery for they are lacking (the necessary) awareness over their severity of injury and its outcomes (Prigatano, 1991; Rosenthal, 1999; Ylvisaker et al. 1999). The participants in the present study reported on events in which they have discovered new abilities following the injury which has also facilitated their recovery. This is reflected in two categories: “Challenging opposing forces” and “Engaging in goal-directed activity”, each reported on by 83% of the participants. In these categories, participants engaged in activities that could be perceived by outsiders as a recipe for disaster (i.e., attending a teenaged party or weightlifting) while, for the participants, it was more about self-challenge, stubbornness, and self-focus that resulted in a sense of purpose. For the counsellor, this means keeping an open mind while listening to the individual’s “unrealistic” self statements. The next suggested step is to work *with* the individual on a personal plan that consists of the goals; the functional steps to

attain these goals, the individual's perception of how well he/she would do, and a review of the plan after the action happened. Ylvisaker et al. (1999) indicated that characterizing the disability as it manifests itself in real-world-activities and then creating assessment tasks that are tested for validity against the real-world standard could be helpful for individuals with TBI who learn about their "new" world. Engaging in goal-directed activity could result in improvements in the participants' abilities even though they may not attain the desired goal (Gauggel & Fischer, 2001). The counsellor role is to be attentive to those "opposed forces" that could emerge as therapy progresses and to facilitate, in a safe way, the individual's process of working through those challenging activities.

As individuals with TBI expand their understanding of themselves in relation to the traumatic event (i.e., their new abilities, their limitations, and their present-future goals), it becomes clearer to them that the outcomes following the injury are permanent. This is reflected in the category "Facing the outcomes/living with loss" which indicates the participants' recognition of certain behaviours resulting from their brain injury (i.e., anger outbursts, impulsivity, poor judgment, and slow cognitive processes). This category had a participation rate of 83%. Interestingly enough, the participants described those outcomes or behaviours as negative (e.g., irritating, disappointing) events in their recovery rather than *hindering* their recovery. Counsellors can use the information provided by this category to help clients assign these experiences to the recovery process and not to the clients themselves. Specifically, the counsellor can validate their experiences and normalize them while providing "evidence" or examples

from the existing research on TBI, and then work on techniques to deal with those challenging behaviours.

The category “Developing practical techniques and skills”, which was noted by half of the participants, seemed to emerge after the participants recognized the inevitable outcomes of their injury. This category reflected the usefulness in having the practical tools to deal with the injury’s outcomes and therefore feel more controlled and less emotionally overwhelmed over the challenging situation. This category is also reflected in Cleveland’s (1998) third stage of recovery called “compensatory recovery”. This term refers to one’s realization (weeks, months, years after the injury) that some compensatory strategies must be developed to assist in routine daily activities. For counsellors, psychotherapeutic work would be incomplete without providing clients with the appropriate tools to deal with the challenging behaviours resulting from TBI. Moreover, professionals in the field of TBI may benefit by a creative workshop aimed at exchanging and generating new techniques on how individuals can better cope with the most challenging and serious effects of TBI.

The return home after discharge from the rehabilitation centre (in this case the G.F.Strong Rehabilitation Centre) raises mixed feelings for individuals with TBI. On the one hand, they want to rush back into their lives (i.e., school, friends) but, on the other hand, they experience the common physical symptoms after brain injury such as: persistent headaches, fatigue, and muscle spasms. In the present study, only half the participants reported on their need to slow their pace while re-adjusting to their lives. However, the need for pacing oneself upon the

return home is clear. The category "Pacing oneself" can be utilized to encourage individuals with TBI to be more attentive to what their body signals. Pacing oneself does not mean removing the individuals from their regular activities, but rather to instill more flexibility into their activities. Pacing oneself could also emerge throughout the recovery while engaging in goal-directed activity. For example, a client may enroll in one year diploma studies on a full time basis and later in the process realize that obtaining high grades takes longer (partially because of the injury outcomes) than was initially expected. This realization may result in practicing flexibility to make the changes needed, such as shifting courses from full to part time basis.

The category "Physical/sensory experiences", which had a participation rate of 83%, encompassed physical exercising (e.g., attending the gym), sensory activities (e.g., cooking, listening to music), and physical therapies (e.g., attending massage therapy). Previous research suggests that sensory experiences facilitate personal well-being (Nicol, 1997). However, in the literature on TBI, there is more indication of the usefulness of integrating physical therapy into the process of recovery (Tomberlin, 1990) and less on the importance of sensory experiences. Thus, it is suggested that future research is needed on the specific physical/sensory activities described in this category and their effect on the process of recovery from TBI. Counsellors might also encourage clients with TBI to take part in physical and sensory activities that were reported in this category and to self-monitor their usefulness for their recovery.

When the individual with TBI is introduced to the long and difficult process of learning how to cope with their “new” life following the traumatic event, it is important to understand that relativity underlies the term recovery. Thus, it is important to recognize and celebrate smaller successes along the way which represent relative recovery from the injury. In other words, success could be defined as achieving one of the elements that comprise the overall loss (e.g., playing basketball and/or coaching basketball) rather than as achieving the original (pre-injury) goal (e.g., becoming a competitive basketball player). This is reflected in the category “Recognizing the success/es” which was noted by two-thirds of the sample. This category indicates the importance of recognizing and ultimately owning the successes that are manifested in individuals’ behaviour. In the present study, the participants’ progress in their recovery is apparent through, and throughout, the 16 categories. Thus, progression in recovery from TBI is cyclical. The counsellor could use this category to exemplify to their clients the varying successes that need to be considered as they move forward in their recovery.

Lewington (1996), in her study on the meaning of recovery from TBI, mentioned the theme “Construction of a new story” as being part of recovery. This theme refers to people being propelled to overcome negative evaluations of their recovery and find a path to renewed self acceptance. Although the present study was not intended to discover the meaning of recovery, it could still be reflected in the category “Obtaining life attitude”, noted by 83% of the participants. For the lack of a better term, obtaining life attitude means that the

individuals were able to articulate the negative experience (i.e., traumatic event) while adding to it another affective meaning or viewpoint. It became apparent, that the described negative events, whether they referred to the traumatic event or to subsequent negative events, are perceived and dealt with differently than before the injury. There seems to be more of a focus on facing the present and future and moving on.

The present study also addressed the future tense (in addition to the past and present tenses) when asking about what facilitates and/or hinders recovery from TBI. The reported incidents in response to the question “what would be helpful to you in your recovery that has not happened yet?” included features of “normal” life (i.e., job, relationship). These features of “normalcy” are likely to be sought by the average young adult in the general population. Therefore, the category that emerged and reflected on these features was entitled “Envisioning normalcy”. Two-thirds of the sample expressed responses that fit within this category. Envisioning oneself in the future appeared to be important for the individual’s movement in recovery from TBI. This is in agreement with Cleveland’s (1998) findings. In her study, the term “vision”, which referred to one’s hopes and future goals, played a significant role in motivating individuals with TBI to engage in rehabilitative programs. For the counsellor, it is important to encourage individuals with TBI to discover their own vision; that is, their own hope/s for their future for it is a necessary connection to their present process of recovery. Envisioning oneself in the future may also serve as a motivator by itself for the individuals to maintain the progress in recovery.

In summary, it is important to note that these categories should be viewed somewhat on a continuum rather than in a sequential order. Moreover, the term recovery is manifested throughout the 16 categories as a relative and dynamic term. The continuous interaction among the categories suggests that the progression in recovery from TBI is not linear but cyclical.

Previous studies have shown that while cognitive deficits may alter the manner in which counselling is conducted, it is still a powerful tool to help individuals with TBI through the different stages of recovery (Parker, 1990; Sbordone, 1990; Sherwin & O'Shanick, 2000). Accordingly, the 16 categories developed in this study can be utilized not only to advance self-awareness and understanding of injury, but to also master and habituate compensatory strategies to cope with consequences and ultimately attain self acceptance and readiness to achieve realistic goals (Daniels-Zide & Ben-Yishay, 2000). Moreover, the counsellor can use the concrete names of the categories to provide empathic responses (i.e., "It seems that you are gaining a new understanding of yourself").

It is also worth noting that some elements of the categorical system developed in this study were found not only in the rehabilitation programs at the G.F.Strong Rehabilitation Centre, as indicated by the second expert, but also as part of an existing therapeutic program. The New York University Medical Centre Rusk Institute Brain Injury Day Treatment Program (Daniels-Zide & Ben-Yishay, 2000) appears to implement practical parts of the 16 categories developed in the present study. These parts include: gaining self-awareness and understanding of the consequences of the brain injury, mastering practical

strategies, and ultimately attaining self acceptance and a readiness to pursue realistic and achievable functional goals.

Another aspect to consider when reviewing the 16 categories is the types of motivation involved. As noted in the literature review chapter, there is general agreement that motivation plays a key role in the process of recovery within the rehabilitation setting (Maclean et al. 2000; Prigatano, 1988; Prigatano, 1999; Prigatano & Schacter, 1991). A review of the 16 categories developed in this study produced some interesting similarities to De Leon, Melnick, and Times' (2001) work. De Leon et al. (2001) distinguished external motivation from internal motivation in relation to recovery from substance abuse. External motivation is generally defined as perceived outside pressures or coercion to change, enter, and/or remain in treatment. Internal motivation refers to pressures to change that arise from within the individual. These pressures are typically negative self-perceptions concerning drug use and the desire for a more fulfilling lifestyle. In this present study, it became apparent throughout the formation of the facilitative categories that these categories provided the external motivation described by De Leon et al. A few examples are presented to illustrate this:

- Constancy of support – “The company that kept coming in from other people helps you to try more. I mean instead of doing it just for me, I think that subconsciously I did it for other people. It is when everyone else was hoping for me [4.11]”. Clearly, the participant’s supportive surroundings provided external motivation to recover
- Physical/sensory experiences – “My girlfriend would go with me for a workout. It was motivating to go with someone else. After the gym I’d feel sweaty and energized”. The friend provides external motivation to attend the gym, and perhaps to work hard which resulted in participant’s positive feeling.

In the above examples, it was an external force that pressed participants to engage in facilitative events. The participants' internal motivation was expressed through self-statements concerning their recovery. For example, "I got tired of asking myself where would I be had the accident never happened?" or "I can't affect the past... what happened has happened and I can't change it". For some participants, this element of internal motivation was followed by behavioural element of motivation such as, "I'll get depressed and then I'll just call my counsellor". Regardless of the existence of internal motivation or not (there were no formal assessments to determine that), it seemed that the participants in this study had different degrees of engagement with the different categories that might be related to internal motivation. This variation in internal motivation may be related to the participants' level of readiness. It is the readiness to take action that influences the motivation to make change (De Leon, Melnick, & Times, 2001).

The comparison of the categories developed in this study to the available research on motivation to recover from substance abuse (De Leon et al., 2001) is useful but insufficient to make definite conclusions on what motivates individuals with TBI to recover. Therefore, more research needs to be conducted on motivation and recovery from TBI after participating in rehabilitation programs while considering the facilitative, hindering and negative events reported in this study.

In addition, there is currently no theory on recovery from TBI following discharge from rehabilitation and what facilitates this process. The results from this study suggest the importance of developing a theory on the matter. The 16

categories describing what happened for participants in their recovery provide a framework for what late adolescents with TBI experienced to enhance their recovery. Thus, the 165 incidents reported in this study in which the source of the event, the action, and the outcome were considered, along with further research can provide the groundwork for developing a holistic theory. As mentioned earlier in this chapter, there are currently at least two rehabilitation programs in North America that practice holistic ideas (e.g., integrating the individual's physical, psychological, and educational needs), however neither suggest a theoretical base for this practice.

Conclusions

In summary, the 16 categories that emerged in this study reflect what late adolescents with TBI saw as facilitating and hindering their ongoing recovery. These categories were examined using several validation procedures and were found to be reliable, meaningful and useful. While the findings from this Critical Incident Study cannot be generalized, as is the case with any study using qualitative methods, it is hoped that these categories might help to describe the experiences of other individuals with TBI.

Nonetheless, there are four potential limitations of this study that need to be noted. First the sample size for this study is relatively small at six participants. According to CIT, the size of the sample is defined by the number of critical incidents obtained rather than the number of people interviewed. That is, the study is considered complete when one reaches saturation in the number of critical incidents. In this case, saturation was reached by the fifth participant. While the

six participants in this study provided important and useful information, a larger number of participants might have made the research more definitive.

A second possible limitation is the reliance on the participants' recollections while collecting the data. This limitation is especially relevant when working with a TBI sample with whom memory problems are likely to occur. Thus, it is possible that participants did not include some events which they had forgotten. One could also argue that they may have misremembered the events. While this may all be true, it still does not take away from the participants' recollection of events as facilitating and/or hindering their recovery. In other words, if one *recalls* an event and *considers* it as hindering to recovery then that is what seems most important, irrespective of whether this event (according to the significant other) is inaccurately described.

The third possible limitation lays in the way the central question about incidents that were facilitative and/or hindering was presented to the participants in this study (see p.45). The question asked about people, objects, environments or actions that facilitate and/or hinder recovery but did not consider or suggest that the participants' personal thoughts/insights might affect recovery. In fact, the analysis of the data did show that participants' insights or self-talk did play some role. Therefore, excluding this from the question might have limited the possible critical incidents which could have been reported by some participants.

The fourth possible limitation of this study relates to the researcher's involvement. The researcher was a vessel to the reported incidents which she then grouped into categories. It is possible that the researcher used language that she is

familiar with in order to name the categories. It must be recognized that the original text loses force as the researcher engages in re-processing the data. However, it must also be noted that validation procedures, such as participants' validation of the categories and inter-rater reliability, act as a check for the researcher's subjectivity.

Finally, it is important to recognize the potential benefit of the scheme of categories obtained in this study, particularly in light of the limited research on recovery from TBI after discharge from rehabilitation programs. It is hoped that this significant information may be of assistance to counsellors and may also generate more research on recovery from TBI post the rehabilitation phase.

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APPENDIX A
LETTER OF INVITATION

APPENDIX B

INFORMED CONSENT FORM

eligible to participate. Participation involves meeting with the co-investigator for an interview of up to 2 hours. The interview will take place at the participant's convenience. The interview will be audio-taped. During this interview, the participant will be asked to describe particular incidents which enhanced and/or hindered the process of recovery after discharge from the rehabilitation setting. If needed, a follow up meeting (max. of 20 min.) to confirm the accuracy of the interviewer's interpretations will be conducted within four months of the initial interview.

The following information (if available) will be requested from the G. F. Strong Rehabilitation Centre so that we may describe our study participants and the degree of their traumatic brain injuries accurately: your scores on the Glasgow Coma Scale and the Galveston Orientation and Amnesia scale, the duration of your post-traumatic amnesia, and whether you had an open or closed head injury.

Confidentiality

Any information resulting from this research study will be kept strictly confidential except in the following two cases: (1) if the participants disclose information about abuse that hinders their recovery, and/or (2) if the researcher is required to submit interview material under court request. Otherwise, the only individuals to have access to the raw data will be Dr. Anita Hubley, Revital Hayoun, possibly a transcription person, and the thesis committee (Dr. Rod McCormick and Dr. Bill Borgen). All documents and tapes will be identified only by code number and kept in a locked filing cabinet. Consent forms will be kept separately from the raw data. Participants will not be identified by name in reports or material relating to the study. Data will be coded and stored on computer disk for analysis during the study; no names or initials will be entered into any computer or on any disks.

Audio-taping

Each of the sessions will be audio-taped. By signing your consent below to take part in the study, you are also acknowledging that you know that audio-taping will be taking place. Participants will not be permitted to obtain or keep copies of any tapes or transcripts.

Remuneration/Compensation:

There will be no remuneration or compensation for participation in this study; however, a summary of the overall results of the study will be sent to the participants upon request.

APPENDIX C

PERSONAL INFORMATION QUESTIONNAIRE

Personal Information Questionnaire

Age _____

Sex _____

Education _____

Time since injury _____

Employment status at time of injury _____

Employment status at time of interview _____