Relationships between Changes in Coping Strategies and Community Integration Status at 6 and 12 Months after Traumatic Brain Injury

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Abstract

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The purpose of this prospective cohort study was to determine the relationships between changes in coping strategies and community integration at 6 and 12 months post traumatic brain injury (TBI). Seventy-one participants were adult significant others (SOs) (family members/friends) of people with TBI. SOs, proxies for TBI patients, completed coping and community integration questionnaire to describe TBI patients’ pre-injury status immediately post-injury as baseline information. Followed-up interviewed were completed at 6 and 12 months. Results showed that increased emotional preoccupation coping from baseline to 6 months were significantly associated with decreased productive activities and decreased social integration at 6 months and 12 months and modestly associated with decreased home integration at 12 months. Multivariable regressions showed that changes in emotional preoccupation coping from baseline to 6 months contributed significantly to social integration and productive activities above and beyond demographic factors and injury severity. Implications for cognitive rehabilitation are discussed.
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List of Abbreviations

CHART: Craig Handicap Assessment and Reporting Technique

CHIP: Coping with Health and Injury Problem scale

CIQ: Community Integration Questionnaire

CISS: Coping Inventory for Stressful Situations

CSI: Coping Strategy Indicator

DRS: Disability Rating Scale

GCS: Glasgow Coma Scale

ICC: Intraclass Correlation Coefficient

ICF: International Classification of Functioning, Disability and Health

LOC: Loss of Consciousness

PTA: Post Traumatic Amnesia

SOs: Significant Others

TBI: Traumatic Brain Injury

WOC: Ways of Coping Questionnaire
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1.0 Introduction

Individuals sustaining traumatic brain injury (TBI) frequently have poorer outcomes and, overall, experience a reduced quality of life relative to a healthy population (Pagulayan, Temkin, Machamer, & Dikmen, 2006). Often, they have poor community integration status, which has been defined as “active participation in a broad range of community involvements,” (Willer & Corrigan, 1994 page 653), due to changes in their physical condition (Maas, Stocchetti, & Bullock, 2008), cognitive impairments (Hochstenbach, den Otter, & Mulder, 2003), and/or emotional or behavioural issues (Chamelian & Feinstein, 2006). Coping strategies play an important role in managing these changes as individuals have to deal with new and different demands. Coping has been defined by Lazarus and Folkman (1984, page 445) as a person’s “constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person”. Outcomes post TBI may be influenced by whether individuals with TBI are able to select and use the most suitable coping strategies for adapting to these changes.

Multiple factors related to coping strategies have been explored in previous research. Time since injury (Hepp, Moergeli, Buchi, Wittmann, & Schnyder, 2005), level of education (Tomberg, Toomela, Pulver, & Tikk, 2005), sex (Willer, Allen, Liss, & Zicht, 1991), self-awareness (Kortte, Wegener, & Chwalisz, 2003) and severity of cognitive impairments (Krpan, Levine, Stuss, & Dawson, 2007) have been suggested as influencing the use of different types of coping strategies. We also know that certain factors which include work history, injury severity, length of post-traumatic amnesia, and early cognitive status are important predictors of post-morbid community integration status and measures of overall outcome (Dikmen, Ross, Machamer, & Temkin, 1995; Fleming, Strong & Ashton, 1998). However, due to the complex nature of these outcomes and of TBI itself, the determinants of outcome have yet to be fully explored. Among these are changes in coping strategies in the first year post injury and the association between the changes in coping strategies and community integration status.

The present study employed a prospective cohort method to determine: 1) whether coping strategies change following TBI over 12 months, 2) the association between changes in coping strategies and community integration, 3) the association between demographic factors and
community integration and 4) to determine if changes in coping strategies in the first 12 months contribute additional variance in community integration status at 6 and 12 months over and beyond the demographic factors and injury severity. To allow collection of information about pre-morbid coping, data were collected from the significant others of TBI patients. The results were expected to enrich our understanding of recovery following TBI, provide evidence as to whether we need to address changes in coping strategies during the recovery, support efforts aimed at improving rehabilitation efforts, and thereby improve long-term functional outcomes and overall quality of life. In addition, verifying the influence of coping strategies on community reintegration might have important implications for clinical practice. For example, clinicians may foster change in individual coping strategies through treatment, and through this facilitate the community integration process by teaching more adaptive coping strategies.

The thesis is organized as follows. Chapter 2 (Background) provides an overview of TBI, a discussion of coping behaviour theory, and a review of the literature on coping and TBI. The Method chapter (3) includes sections on the design, sample selection, measures, procedure, and statistics analysis. Results are presented in Chapter 4 and Chapter 5, the Discussion chapter, includes implications for rehabilitation, limitations and suggestions for future study.
2.0 Background

This chapter reviews the literature related to TBI and coping behaviour theory. Sections 2.1 through 2.5 provide an overview of the definitions, classification, pathophysiology, epidemiology, symptoms and sequelae of TBI. Section 2.6 focuses on coping behaviour theory, definitions and classification of coping strategies and the differences of coping strategies between pre and after TBI. Literatures for this section were based on searches via MEDLINE, PsycInfo, Scopus and Google Scholar in the time period from 1995 to 2012.

2.1 Definition and Classification of Traumatic Brain Injury

Traumatic brain injury (TBI) is a serious public health problem for the entire world. TBI is damage to the brain due to an external mechanical force, such as rapid acceleration/deceleration in transportation related accidents, or impact to the head (Maas et al., 2008). Each year, TBI causes a considerable number of deaths and permanent disabilities.

TBI can be classified as mild, moderate or severe (Saatman & Duhaime, 2008). There are three main methods for determining the severity of TBI. The Glasgow Coma Scale (GCS), the most common system, quantifies level of neurologic functioning on a scale of 3–15 based on verbal response, motor response, and eye-opening (McDonald, Jaffe, & Fay, 1994). A total score of 3-8 for the 3 sections indicates severe TBI; a score of 9-12 indicates moderate TBI; and a score of 13-15 indicates mild TBI (Department of Defense and Department of Veterans Affairs, 2008). Duration of loss of consciousness (LOC) is another measure of the severity of TBI. Victims may lose consciousness for only a few seconds or minutes, or not at all, based on the severity of injury. The severity is based on the time period of loss of consciousness; mild: LOC less than 30 minutes; moderate: LOC 30 minutes to 24 hours; severe: LOC of greater than 1 day (Department of Defense and Department of Veterans Affairs, 2008). Post-traumatic amnesia (PTA), a condition in which memory is disturbed or lost (Lee, 2007), has been proposed as the best measure of TBI severity (Rao & Lyketsos, 2000; mild: PTA less than 1 day; moderate: PTA 1 day to 7 days; severe: greater than 7 days, Department of Defense and Department of Veterans Affairs, 2008). The duration of PTA usually correlates well with the GCS although it may be overestimated (for example, if the patient is under the influence of drugs or alcohol) or
underestimated (such as, if some memories come back before continuous memory is regained) under certain conditions (van der Naalt, 2001). After PTA, the injured individual, appearing to be awake, behaves in an uncharacteristic manner. The person may be unable to remember what happened a few hours ago, or even a few minutes ago (Cantu, 2001). PTA may be either short term, or longer lasting (over a month), but normally is not permanent. PTA begins at the time of the injury and includes the coma period. It does not end until the individual is able to continuously report events accurately (van der Naalt, 2001).

2.2 Pathophysiology of TBI

The typical classification of injury processes includes primary injury (occurs at the time of force transmission) and secondary injury (subsequent to the primary injury). In TBI, primary injury is caused directly through the mechanism and forces of the accident or event causing the injury (Keel & Trentz, 2005). The resulting brain damage can be focal or diffuse, based on specific location or whether it can be visualized on brain imaging. It is common for both focal and diffuse damage to occur as the result of the same event (Lovell & Franzen, 1994). A focal TBI usually is caused by sudden contact, for example a penetrating wound (a gunshot). Diffuse injury usually is caused by a sudden acceleration/deceleration trauma (Werner & Engelhard, 2007). The primary injury usually causes structural changes, such as epidural or subdural hematoma, subarachnoid or intraventricular hemorrhage, and/or cerebral contusion (Werner & Engelhard, 2007).

Secondary injuries occur as a consequence of the initial injury (Gennarelli & Graham, 2005). Most secondary injury occurs within the first 12-24 hours after injury, but may also occur during the first 5 - 10 days if the initial injury is very severe (Granacher, 2007). Secondary injury includes cerebral oedema, hemorrhage, seizures, infection and refers to the delayed pathophysiological consequences of TBI (Keel & Trentz, 2005). The relative contribution of primary and secondary injury to the clinical manifestations of TBI has not been well explored (Granacher, 2007).
2.3 Epidemiology of TBI

The prevalence (the number of existing cases) of TBI is not easily documented, because most cases (such as mild TBI) are not fatal, and patients may not have been hospitalized. Estimates usually are based on existing disabilities.

About 1.4 million people reported for medical care for a TBI each year in the United States from 1995 to 2001 (National Center for Injury Prevention and Control, 2006). The analysis also found that around 3.6 percent of people with TBI died from their injuries, 17 percent were hospitalized, and 80 percent were treated and released from the emergency department (National Center for Injury Prevention and Control, 2006). Another study showed that 1.1 percent of the total population of people in the United States live with long-term disability resulting from TBI (Zaloshnja, Miller, & Langlois JA, Selassie, 2008). It is estimated that at least 5.3 million Americans are living with disabilities resulting from TBI (Kraus & McArthur, 1996).

Falls, motor vehicle accidents and being struck by objects are the major causes of TBI (Summers, Ivins, & Schwab, 2009). Almost half of TBI related deaths and hospitalizations are because of vehicle accidents, 25% of injuries are related to falls, and around 16% are due to other violent acts (Thurman, Coronado & Salassi, 2007). The major risk factors for TBI in the United Stated are age, sex, and low socioeconomic status (Langlois JA, Rutland-Brown, & Wald, 2006). People at the extremes of age have the highest incident rates: 900 per 100,000 for those younger than 10 years and 659 per 100,000 for those older than 74 years (Langlois et al., 2006). Adults aged 75 years and older have the highest rates of TBI-related hospitalization and death. For sex, the rate among men is almost twice that of women (Guerrero, Thuman, & Sniezek, 2000). Also, mortality rates among males (between age 15 and 24) are almost 3.4 times higher than females (33.0 per 100,000 males and 9.8 per 100,000 females) (Langlois et al., 2006).

The long-term economic impact is serious because TBI occurs most commonly in young adults (Thurman, Alverson, Dunn, Cuerrero, & Sniezek, 1999). The total cost of TBI is not easy to estimate because there is limited research about the direct costs of medical treatment. In addition, it is difficult to collect data about the costs of extended rehabilitation, and lost productivity because various tasks may be performed by different agencies, facilities, or personnel.
Nevertheless, in 2000, costs were estimated to be $60 billion per year in the United States, including about $51.2 billion in lost productivity (Finkelstein, Corso, & Miller, 2006). These estimates did not include the costs of the long-term impairments and disabilities of TBI survivors, and also excluded the monetary value of lost quality of life of TBI survivors and the productivity losses of their family members and caregivers (Corrigan, Selassie, & Orman, 2010).

2.4 Symptoms and Signs of TBI

Signs and symptoms are diagnostic "tools" to determine the condition of patients. Any subjective evidence of disease is called a symptom. In contrast, a sign is objective evidence of disease.

Symptoms are dependent on the type (diffuse or focal), severity and location of the TBI (Arlinghaus, Shoaib, & Price, 2005). Mild TBI is defined as the result of the forceful impact of the head causing a brief change in mental status or loss of consciousness for less than 30 minutes, Glasgow Coma Scale of 13 to 15 while MRI and CT scans are often normal (Iverson, 2005). Generally, physical symptoms of mild TBI include headache, vomiting, dizziness, balancing difficulty, lightheadedness, and fatigue or lethargy (Ponsford et al., 2000). Emotional and cognitive symptoms include behavioural or mood changes, confusion, and difficulty concentrating or thinking (Ponsford et al., 2000). Mild TBI symptoms may be seen in moderate and severe injuries as well. Fifteen percent of people with mild TBI have symptoms that last one year or more, normally referred to as a post concussive syndrome (Arlinghaus et al., 2005). Also, mild TBI is the most prevalent TBI and can be easily missed at time of initial injury due to its relatively minor symptoms (Moppett, 2007).

Moderate TBI is defined as a brain injury resulting in a loss of consciousness from 30 minutes to 24 hours and a Glasgow Coma Scale of 9 to 12 (Department of Defense and Department of Veterans Affairs, 2008). Severe TBI is defined as a brain injury resulting in a loss of consciousness of greater than 24 hours and a Glasgow Coma Scale score of less than 9 (Department of Defense and Department of Veterans Affairs, 2008). About seventeen percent of TBI patients with moderate to severe TBI sustain disabilities, and thirty percent die (Gargollo & Lipson, 2007). The factors that influence outcomes of moderate to severe brain injury include
the severity of initial injury, rate of physiological recovery, functions affected, and available resources to assist recovery (Dikmen, Machamer, Powell, & Temkin, 2003). In moderate to severe TBI, the symptoms are more severe than mild TBI. The physical changes include chronic pain, sleep disorders, fatigue, impaired appetite, and dysregulation of body temperature (National Institute of Neurological Disorders and Stroke, 2008). Also, in moderate to severe TBI, the common long-term neuropsychological symptoms include changes in social behaviour, social judgment deficits, and cognitive changes (National Institute of Neurological Disorders and Stroke, 2008).

Amnesia is a sign occurring in TBI survivors. The degree and location of injury affect the severity of memory problems. The amnesia resulting from a trauma may be retrograde (loss of memories shortly before the injury) or anterograde (problems with generating new memories after the injury), or both (Lee, 2007).

Trouble sleeping is another sign in TBI survivors. Many people with TBI report having trouble sleeping at night (Ouellet, Beaulieu, & Morin, 2006) and/or being vulnerable to fatigue during the day (Shekleton, 2010). For individuals with TBI, poor sleep is a more serious problem than in a healthy population. Study has reported that trouble sleeping at night could be related to higher levels of anxiety and has a negative effect on rehabilitation process and outcomes after TBI (Shekleton, 2010).

2.5 Sequelae of TBI

Sequelae mean any abnormal condition or disease related to or arising from a pre-existing disease. Some individuals with mild TBI and most moderate and severe TBI survivors have long-term physical and neurobehavioural sequelae (McAllister, 2008). In order to describe the complexity of TBI sequelae (cognitive, emotional, communicative and physical issues) and their impact on individuals’ daily life, a more universal framework is needed, such as the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001).

The ICF is a model that classifies disability and health at individual and general population levels. It has three main domains: body structures/functions, activities and participation (World Health Organization, 2001). Within the ICF, disability is defined as ‘an umbrella term for
functional impairments, limitations in activities and restrictions in participation’ (World Health Organization, 2001). The ICF model describes interactions among the health condition, body function and structure, activities, participation, environmental and personal factors. All of these components are inter-related and influence each other. Factors within body functions/structures, environmental (external) and personal factors theoretically influence adherence to participation (World Health Organization, 2001). The ICF model suggests that pre-morbid personal factors should be included in investigations of recovery.

Seizures, dizziness, and headaches are common physical sequelae after TBI. Seizures are rarely seen in a mild TBI population, but 14 to 53 percent of survivors with moderate to severe TBI experience post-traumatic seizures (Yablon, 1993). Post-traumatic dizziness occurs in 20 to 65 percent of TBI individuals and remains for several months (Duong et al., 2004). Evidence shows that post-traumatic dizziness may be related to psychological factors after brain injury (Chamelian & Feinstein, 2004). Headache is another common sequelae (from 18 to 93 percent) among people with TBI (Bazarian et al., 1999). Post-traumatic headache (PTHA) is usually self-limited but it may become chronic. Similar to the general population, chronic PTHA after TBI can be related to emotional instability (Walker et al., 2005).

In addition to physical symptoms, persistent cognitive deficits are frequent complaints of TBI patients (Hochstenbach et al., 2003; Chamelian & Feinstein, 2006). They are the major factors that affect independent living, social re-adaptation, family life, productive activities (Cicerone et al., 2000) and overall quality of life (Pagulayan, Temkin, Machamer, & Dikmen, 2006).

Cognitive changes following TBI include problems in memory (Hall & Chapman, 2005), learning, reasoning and executive function (Lehtonen et al., 2005; Arlinghaus et al., 2005; Krpan et al., 2007). One study evaluated 79 mild TBI patients 6 months post TBI using the Rivermead Postconcussional Symptoms Questionnaire and found that 39 percent of patients reported cognitive complaints (Stulemeijer, Vos, Blijenberg & Van der Werf, 2007). As well, emotional instability, personality changes, lower education levels and physical dysfunction were related to cognitive deficits (Stulemeijer et al., 2007).

Language issues are commonly seen following TBI as well (Kreutzer, Gervasio, & Camplair, 1994). Some people experience difficulty with aspects of communication that may involve voice, speech, language, hearing, cognition and erroneous expression. These problems can cause
frustration, and misunderstanding by people with injury, as well as family members, caregivers and medical personnel (Kreutzer, Gervasio, & Camplair, 1994).

TBI also can cause emotional or behavioural problems and changes in personality (Zink, 2001). Emotional adjustment following TBI appears to be influenced by a number of factors, including lesion location, injury severity (Deb, Lyons, Koutzoukis, Ali, & McCarthy, 1999), social support (Pelletier & Alfano, 2000), pre-morbid personality (Rochat et al., 2010) and level of education (Deb et al., 1999). Behavioural symptoms following TBI include impaired anger control, impulsiveness, lack of initiative, and personality changes (Arlinghaus et al., 2005). TBI patients and family members frequently described the changes in emotion and strategies as causing them to be a different person after their TBI particularly related to reported impulsiveness (Rochat et al., 2010), irritability and affective instability (Fleminger, 2008).

At the participation level, TBI can lead to disruptions in higher-level functions of everyday life, including social relationships, independent living, employment, and leisure activities which are important components of community integration. Community integration has been defined as “active participation in a broad range of community involvement,” (Willer & Corrigan, 1994, p. 653). Traditionally the three main areas of community involvement are social and leisure activities, work or other productive activity, and independent living (Willer & Corrigan, 1994).

Leisure activities are important to improve physical fitness, re-build self-esteem, seeking relationships, and increasing life satisfaction (Specht, King, Brown, & Foris, 2002). Individuals with TBI often experience limitations in their leisure participation. A study reported that among individuals with TBI after 3 to 5 years, 60% had difficulties in leisure activities participation (Dikmen, et al., 2003). A large number of people with TBI still experience reduced leisure participation over extended periods of rehabilitation (Harrison-Felix, Whiteneck, DeVivo, Hammond, & Jha, 2004).

Research has found that people with TBI often experience limitations in social functioning, especially following severe TBI. The results of one study show that difficulties in social functioning can continue for up to 15 years after injury, depending on the severity of TBI (Schwab, Grafman, Salazar, & Kraft, 1993). Social functioning deficits also include difficulties in filling roles such as worker or student. Employment has received the most attention of all as an aspect of social functioning. Poor productivity outcomes not only represent a public
economic burden but also a reduction in personal meaning for those who are unable to restart these roles (Oppermann, 2004). One study found that only 34% of people with TBI were stably employed, while 27% did not have stable employment, and 39% were unemployed (Kreutzer et al., 2003). Furthermore, employed patients with TBI earned less than employed trauma controls after injury, and in the TBI group, increasing length of coma was related to decreased income (Dikmen, et al., 1995).

Although important, there is limited research on the key variables following TBI that are related to return to work/school. To date, investigations of the essential factors of psychosocial outcomes following TBI (such as going back to work) have focused on demographic and injury severity variables (Dawson, Levine, Schwartz, & Stuss, 2004). In general, the level of severity and age influence outcomes although there is evidence to suggest that the relationship of injury severity to outcome is not linear and varies over time (Dawson et al., 2004). It is important to further explore other factors that could influence returning to work and/or school which in turn may result in better community reintegration. Identifying the factors influencing one important component of community reintegration (returning to work/school), may not only improve the rate of returning to work and/or school, improve the reduction in personal meaning, and reduce the economic burden, but it also may help TBI people to have better community integration status.

Coping strategies may be one of the most important factors in managing the cognitive and emotional/behavioural changes which impact the day-to-day life of persons with TBI (Lazarus & Folkman, 1984). In other words, coping strategies may be one of the essential factors influencing the participation (such as community integration status) of TBI survivors. There is reason to hypothesize that coping will impact community reintegration because according to the ICF model, personal factors (coping strategies) theoretically influence adherence to participation (community integration status). Thus, this thesis explores the relationship between changes in coping strategies and community integration status after TBI. Recent studies have indicated that the way TBI patients cope with the negative aspects of the trauma and problems in everyday life has a major influence on the rehabilitation process (Anson & Ponsford, 2006a). But what are coping strategies? How are coping strategies classified? What is known about coping strategies after TBI? What is not known? These questions are addressed below.
2.6 Coping Strategies Theory and TBI

Coping is defined by Lazarus and Folkman (1984, p. 445) as a person’s “constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person”. There are two concepts often confused in the coping literatures: coping styles and coping strategies. Generally, the difference between coping styles and coping strategies is characterized in terms of trait and state. Traits (coping styles) are distinguishing characteristic of a person that differ across individuals and are relatively stable over time. In other words, coping styles are based on individuals’ personality and ways of dealing with life stressors, events or illness. Coping styles have been defined as “efforts to reduce the negative impacts of stress on individual well-being” (Edwards, 1988, p. 235). Coping styles include thoughts, faiths and strategies that result from the experience of stress and express independently of the type of stressor (Edwards & Cooper, 1988). The coping styles adopted to deal with a stressful event have the potential to influence psychological adjustment (Godfrey, Knight, & Partridge, 1996) because adjustment is affected by how well people are able to control their lives.

Coping styles are stable over time and context but are influenced by personality traits. Individual differences in personality, demographic factors (such as age, sex, level of education) and cognition affect the way people deal with stress (Mroczek & Almeida, 2004). For example, one study found that older participants used a more religious coping style which includes considering diseases as fate and looking for meaning in illness (Herrmann, Curio, & Petz, 2000).

While one study found a non-significant association between coping styles and time since brain injury, this study only assessed participants within one year of injury (Kortte, et al., 2003). Coping styles may also change after one year. Different pre-morbid coping styles in an individual also have been reported to influence post-injury coping styles and adjustment (Godfrey, Knight, & Partridge, 1996). The influence of pre-morbid coping style has significant implications for the younger TBI population who may not have enough opportunities to build adaptive coping styles before the injury (Godfrey et al., 1996). Thus, it may be that younger adults with brain injuries have lower levels of adaptiveness, active coping styles and higher levels of non-productive (such as wishful thinking, worry, self-blame, and ignoring the problem).
and avoidant coping. Also, individuals who are more aware of their illness (brain injury) report higher levels of depression and anxiety (Wallace & Bogner, 2000).

In contrast, state (coping strategies) usually refers to the present condition of a system or existence; for example, the condition of a person with respect to circumstances or attributes. In other words, coping strategies are influenced by external factors, environment differences, knowledge acquired or other factors gained through life experiences. Coping strategies are the strategies selected by people to help them deal with stressors arising in specific situations. For instance, people with hearing loss develop coping strategies such as wearing a hearing device for different listening situations. Coping strategies are commonly classified in two broad categories: problem-focused coping strategies and emotion-focused coping strategies (Lazarus & Folkman, 1984). Problem-focused coping is defined as “doing something to relieve the problem” (Lazarus & Folkman, 1984, p.44). Problem-focused coping strategies are those that deal directly with a situation, such as collecting more information or skills to control the situation. Problem-focused coping strategies include defining the problem, generating alternative solutions, weighing the alternatives, choosing among the alternatives and acting upon them (Lazarus & Folkman, 1984). In contrast, emotion-focused coping is defined as “oriented toward emotion regulation” (Lazarus & Folkman, 1984). Emotion-focused coping strategies regulate the emotional reactions rather than changing the stressful situation itself and include suppression of emotions, reassuring thoughts, and dealing with situations more easily (Cook & Heppner, 1997). People with TBI who use more emotion-focused coping strategies have been reported to have worse psychosocial outcomes (Milia, Powell, & Torode, 1995) and poorer cognitive performance (Krpan et al., 2007; van den Bosch & Rombouts, 1997). Since emotion-focused coping strategies have been repeatedly linked to negative outcomes following the post-acute stages of TBI, they are often considered to be maladaptive.

Problem-focused and emotion-focused coping strategies are often used together. At times using them together can be an advantage for dealing with events as both coping strategies reduce pressure and provide skills to deal with the stress more easily. At other times, using both coping strategies can be a disadvantage, for example learning more information about an illness could cause anxiety and stress (Taylors, 1989).
Although coping strategies are not considered to be good or bad, there is empirical evidence to suggest that specific coping strategies are more likely to be associated with different responses of adjustment to disability (Smedema, Catalano, & Ebener, 2010). One positive coping strategy is hope which can be defined as “a positive motivational state that is based on an interactively derived sense of successful agency and pathways” (Snyder, Irving, & Anderson, 1991, page 287). Hope has been found to be related to better well-being, better outcomes and less mental health symptoms (Irving et al., 2004). Another important positive coping strategy is humor which is defined as “the ability to appreciate or express that which is funny or amusing” (Burkhead, Ebener, & Marini, 1996, p. 51). One study shows that humor is an effective and positive coping strategy for the members of families who have children with a disability (Rieger, 2004). In contrast, negative coping strategies (such as worry, self-blame, and ignoring the problem) can lead to negative outcomes which include poorer health, worse well-being (Wollaars, Post, van Asbeck, & Brand, 2007), depression (Turner, Jensen, & Romano, 2000) and greater levels of disability (Woby, Watson, Roach, & Urmston, 2004).

Sex may be a factor that influences coping strategies following TBI (Willer, Allen, Liss, & Zicht, 1991). Research has found that females use more emotion-focused coping strategies, whereas males report using more problem-focused coping strategies (Willer et al., 1991). However, this study used a small sample size (31 participants) and measured coping via group discussion instead of using a coping measure with demonstrated reliability. Other research which did use a questionnaire with demonstrated validity and reliability (Freiburg Questionnaire on Coping with illness) recruited a larger sample size (58 TBI participants) and did not find an association between sex and coping strategies (Herrmann et al., 2000).

Research has found that coping strategies can be influenced by time since injury (Kortte et al., 2003) although there is disagreement on this point (Curran, Ponsford, & Crowe, 2000). With increased time since injury, individuals with TBI tend to use less active, problem-focused coping strategies meanwhile using more passive, emotion-focused coping strategies (Kendall, Shum, Lack, Bull, & Fee, 2001). Using less effective active, problem-focused coping strategies or using more passive emotion-focused coping strategies may be related to the stress frustration, helplessness, and depression that arise from chronic sequelae after acquired brain injury (Kendall et al., 2001). Other research found that coping strategy responses differ at different
phases of rehabilitation (Ptacek & Pierce, 2003). This may be because of different experiences after injury and the way those experiences are differently represented (Ptacek & Pierce, 2003).

One of the biggest problems in these studies is the lack of a longitudinal design. As such conclusions addressing the changes in coping strategies over time since TBI are hypothetical.

Other research has used longitudinal, prospective experimental designs to investigate coping strategies in TBI. One longitudinal study that followed 31 patients with TBI repeated observations of the same variables on average 5.7 years after onset reporting that high education level was associated with the use of adaptive active problem-focused coping (Tomberg, Toomela, Ennok, & Tikk, 2007). This research also reporting that social support, satisfaction with support, health-related quality of life and resuming work did not improve significantly after a rehabilitation process (Tomberg et al., 2007).

Curran et al. (2000) found a significant association between the type of coping strategies used and psychological adjustment. In their study, eighty-eight participants who had sustained a TBI 1 to 5 years previously were interviewed. Nonproductive coping (wishful thinking, worry, self-blame, and ignoring the problem) which can be considered emotion-focused coping was associated with higher levels of anxiety and depression (Curran et al., 2000). In contrast, adaptive coping (dealing with the problem in an active manner) which can be considered problem-focused coping was associated with lower levels of anxiety (Curran et al., 2000). Demographic factors, time since injury and type of injury were not significantly associated with anxiety or depression (Curran et al., 2000). Thus, the choice of coping strategies had a potentially greater influence on psychological outcomes than demographic factors, severity of injury, and type of brain injury.

Other research also has found a relation between coping strategies and psychological outcomes following moderate to severe TBI in 24 participants (Kendall et al., 2001). These authors found that continuing use of active problem-focused coping strategies was associated with higher self-esteem and had a positive effect on the coping outcomes (Kendall et al., 2001). In contrast, the continuing use of passive emotion-focused coping strategies was associated with lower self-esteem and had a negative effect on the rehabilitation process (Kendall et al., 2001). This suggests that using more active problem-focused and avoiding use of passive emotion-focused coping strategies has a potentially positive effect and results in better psychological outcomes.
The cognitive sequelae of TBI, which include difficulties in concentration, memory, language, executive function, generating ideas, and ease in adapting to new situations, may influence coping strategies (Bryant, Marosszeky, Crooks, Baguley, & Gurka, 2000). Bryan et al. hypothesized that the poor memory, inappropriate judgment, and problem-solving deficits of TBI survivors may influence the selection of suitable and adaptive coping strategies for managing a new situation after injury (Bryant et al., 2000). These cognitive deficits may cause individuals with TBI to use more avoidant coping strategies (Bryant et al., 2000). However, not all research has supported this idea. For example, Curran et al (2000) found no differences in selecting coping strategies between persons with TBI and participants with orthopedic conditions to deal with the events. One of the limitations of this report is that cognitive complaints were measured by self-report instead of objective assessment which may cause the results to be inaccurate (Curran et al., 2000). One other study using objective measures for memory (Crawford version of the Rey Auditory Verbal Learning Test), coping (Coping Scale for Adults), and executive functioning (Six Elements Test from the Behavioural Assessment of the Dysexecutive Syndrome) also found no effects of cognitive performance on choice of different coping strategies (Anson & Ponsford, 2006a).

Krpan et al (2007) found the relationship between executive function (a term for cognitive processes such as, planning, making decision, and judgment) and coping strategies at 1-year post TBI. In this research, 21 TBI participants and 15 control participants were tested. The authors found that higher levels of executive function was related to the use of more problem-focused coping strategies in the TBI group whereas, lower executive performance was related to the use of more emotion-focused coping strategies (Krpan et al., 2007). This research also showed that performance on a composite measure of executive function contributed significantly to the use of problem-focused coping strategies beyond that explained by pre-morbid intelligence and injury severity.

2.7 Summary

To date, multiple factors associated with maladaptive coping strategies following TBI have been explored in previous studies. At the demographic level, research indicates that having a TBI at a younger age results in lower levels of adaptive, active coping styles, and use of less religious coping strategies (Godfrey et al., 1996). Women use more emotion-focused coping strategies,
whereas men use more problem-focused coping strategies (Willer et al., 1991). Also, some studies have reported that well-educated people more often use active problem-focused coping strategies (Tomberg et al., 2005).

There are some injury related factors that need to be mentioned. One study found the use of active problem-focused coping strategies to be most common in the acute phase after brain injury and that emotion-focused strategies emerged later, further, using emotion-focused strategies in the acute phase and problem-focused strategies in the chronic phase was most beneficial for the adjustment process (Hepp et al., 2005). Some researchers found that although coping styles did not influence quality of life in the acute or post-acute phase (within 6 months), they were important determinants of quality of life in the chronic phase (after 6 months) (Darlington et al., 2007).

Cognitive impairments following brain injury could interfere with the ability to use a problem-focused approach to coping, resulting in using more emotion-focused coping strategies (Krpan et al., 2007). People with cognitive deficits may have problems implementing adaptive coping strategies due to having problem-solving deficits which are common in TBI survivors (Bryant et al., 2000). Also, a study found that better executive performance was related to the use of problem-focused coping in TBI patients. In contrast, lower executive performance was related to the use of emotion-focused coping (Krpan et al., 2007).

Finally, the relationship between coping and outcomes is important to keep in mind. Positive coping like hope and humor was associated with better well-being, better therapeutic outcomes and less mental health symptoms (Irving et al., 2004) and positive responses of adjustment to disability (Smedema, Catalano, & Ebener, 2010). Using negative coping strategies can result in negative outcomes such as a poorer quality of life and greater levels of disability (Woby, Watson, Roach, & Urmston, 2004), because use of negative coping strategies is a significant predictor of depression (Turner, Jensen, & Romano, 2000). Passive, emotion-focused coping strategy was associated with poorer self-esteem (Kendall et al., 2001), poor self-awareness (Kortte et al., 2003) and negative rehabilitation process (Kendall et al., 2001). And the choice of coping strategies can have a potentially greater influence on psychological outcomes (Curran et al., 2000).
In this background chapter, I have discussed the definition, classifications, symptoms, signs, and sequelae of TBI and compared the differences between pre-injury and post injury in physical, cognitive and emotional aspect. Also I have reviewed coping strategies’ definitions, classifications and the relationship between coping strategies and the cognitive, emotional changes after individuals acquire TBI. Based on the literature I have reviewed, I found that there are still some questions that need to be answered. For example, how do coping strategies change after TBI within 12 months? What is the association between the changes in coping strategies and community integration? This thesis will inform these questions.

2.8 Purpose and Objectives

The purpose of this study was to examine whether coping strategies change, the relationship between change in coping strategies and community integration status, and the relationship between demographic factors and community integration status at 6 months and 12 months after TBI. Based on ICF model, I hypothesize that changes in coping strategies occur after TBI and the community integration status will be impacted by both changes in coping strategies and demographic factors (such as age, sex and level of education).

The specific objectives are 1) whether coping strategies change following TBI over 12 months, 2) the association between changes in coping strategies and community integration, 3) the association between demographic factors and community integration and 4) to determine if changes in coping strategies in the first 12 months contributes additional variance in community integration status at 6 and 12 months over and beyond the demographic factors and injury severity.
3.0 Method

3.1 Design and Participants

This study was a secondary analysis of data derived from a prospective, cohort design. Participants, adults who had sustained a TBI, were recruited consecutively over 11 months (February 2002 – January 2003) immediately post injury following admission to Sunnybrook Health Science Center, Canada’s largest trauma centre. All participants were asked to identify a significant other (SO), that is a close family member or friend able to provide information about their day-to-day life and behaviours. If people with TBI did not have sufficient cognitive status at baseline (could not identify an SO), then their identified decision maker was asked to indentify an SO. SOs were interviewed at baseline regarding the TBI patients’ pre-injury coping strategies and community integration status. After 6 and 12 months post injury, SOs were re-interviewed. Ethics approval for this study was obtained through the Ethics Review Boards at Baycrest and the Sunnybrook Health Science Center. TBI and all participants provided informed, written consent prior to becoming involved in the study (See Appendix 7.1).

These data were collected as part of a larger study concerned with the stability of particular psychological factors following TBI including coping (reported here), locus of control, life attitude, and community integration (Dawson, Stuss, Winocur & Schwartz, 2001-4).

Inclusion criteria for people with TBI were: English speaking, non-penetrating traumatic brain injury and at least 16 years of age. The exclusion criteria were: prior significant neurological or systemic disease, (in order to ensure that factors secondary to TBI were not influencing pre-injury coping strategies), prior hospitalization for psychiatric disease, prior significant substance abuse, and/or developmental cognitive disabilities. Patients were considered to have a brain injury if one or more of the following criteria were met: Glasgow Coma Scale score of less than 15, recorded loss of consciousness, recorded post traumatic amnesia, and abnormal image on a CT scan (Jennett & Teasdale, 1981; Jennett et al., 1981; Levin, Benton, & Grossman, 1982). Eligibility criteria for SOs were English speaking, age 18 years or higher, and willing to complete questionnaires at each time point.
3.2 Measures

Demographic (age, sex, level of education) and injury severity (6 hour GCS score) information were obtained from TBI patients’ health records. SOs were asked to provide socio-demographic information about themselves (age, sex, level of education, and relationship to person with TBI) at the baseline interview.

Coping strategies were measured by the Coping with Health and Injury Problem scale (CHIP) (Endler, Parker and Summerfeldt, 1998b). The CHIP is a self-report questionnaire developed by Endler and colleagues in 1998 to assess how people cope with specific health problems. It includes 4 sub-scales of 8 items each and each item is rated on a five-point Likert-type scale ranging from (1) “Not at all” to (5) “Very much” (Endler et al., 1998b). The range of scores for each sub-scale is 8 to 40. The four sub-scales are distraction coping, palliative coping, instrumental coping, and emotional preoccupation coping strategies respectively (Endler et al., 1998b). Sample items from each scale can be found in Appendix 7.2. Distraction coping strategies are those aimed to distract from the health problem such as seeking the company of others and/or thinking about pleasant experiences instead of focusing on the health issues. Palliative coping strategies include using self-efforts to alleviate the unpleasantness of the health problem and its sequelae including getting lots of rest, and improving the environment for comfort. Instrumental coping focuses on various strategies to deal directly with the events, for example, trying to acquire health advice and knowledge. Emotional preoccupation strategy focuses on the negative emotional consequences of the health problems, such as negative thoughts and gets frustrated (Endler et al., 1998b). Further, as illustrated below in figure 1, in the CHIP, distraction, palliative and emotional preoccupation coping can be considered as emotion-focused coping strategies and instrumental coping can be considered as problem-focused coping strategy.
Figure 1. Category of the CHIP

CHIP

Emotion- focused Coping Strategy

Distraction- aimed to seek the company of others and /or thinking about pleasant experiences instead of focusing on health problem.

Palliative- Describes the “self-help” responses utilized to alleviate the unpleasantness of the situation.

Emotional Preoccupation- individual focuses on the emotional consequences of the health problem.

Problem- focused Coping Strategy

Instrumental- Focuses on various strategies used to deal directly with the illness.

To measure whether participants may have misunderstood the instructions and/or responded carelessly or randomly, the CHIP includes an Inconsistency Index that represents the consistency of the responses. This Index consists of eight pairs of questions (two pairs for each of the four subscales) that have similar content. The Inconsistency Index is calculated as the sum of the absolute values of the different response to each pair (Endler et al., 1998b). If the Inconsistency Index score is 10 or greater, the results of the other scales should be interpreted more cautiously (Endler et al., 1998b).

The CHIP is considered to be a valid measure of adults coping responses to specific illness or health events (Endler et al., 1998b) and has been used successfully with adults with chronic pain (Hadjistavropoulos, Asmundson & Norton, 1999), cancer patients (Endler, Courbasson & Fillion, 1998a), and heart disease patients (Karademas, Zarogiannos & Karamvakalis, 2010).

The reliability of the CHIP has been reported through internal consistency, and test-retest reliability. First, the Cronbach’s alpha coefficient of the CHIP was tested in three age groups (18-29, 30-49 and 50 or older) and in both genders (Endler & Parker, 2000). The range of Cronbach’s alpha among these groups was 0.66-0.84 indicating acceptable to good internal consistency for these samples (Cortina, 1993).
Test-retest reliability was evaluated by Endler and colleagues (1998b). In their study, they tested 160 (110 women and 50 men) participants with cancer twice with an interval of two weeks. The range of test-retest reliability coefficients was 0.75-0.85 in men and 0.64-0.82 in women (Endler et al., 1998a). This indicated the test-retest reliability for CHIP was acceptable for both genders (Cortina, 1993).

Determining the construct validity of the CHIP (or any other coping scale) is difficult because there is no gold-standard measure of coping and different scales have been designed to reflect different theories and views of coping. Nevertheless, studies of construct validity have been undertaken and results are reported below.

To test the construct validity of the CHIP, scores were compared with two other measures of coping (Endler et al., 1998b). The first was the Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1999). The CISS is designed to measure coping styles under specific stressful situations and to help to understand the relationship between that individual’s coping style and personality. The 125 men and 167 women completed both the CHIP and the CISS. The results showed that the correlations between the CHIP emotional preoccupation scale and the CISS emotion-oriented scale (0.61 for male and 0.60 for female; p<0.05) (Endler & Parker, 2000) were strong (Cohen, 1988); correlations between the CHIP palliative scale and the CISS avoidance-oriented scale and distraction scale (0.36 for male and 0.32, 0.42 for female respectively; p<0.05) were weak; and correlations between the CHIP distraction scale and the CISS avoidance-oriented scale (0.54 for male and 0.55 for female; p<0.05) were moderate (Endler & Parker, 2000). Similar results were reported in another study with patients with chronic pain (Summerfeldt & Endler, 1998) with the same two questionnaires. These findings suggest that the emotional-preoccupation scale of the CHIP and the emotion-oriented scale of the CISS are measuring similar constructs. Other comparisons between sub-scales on these measures suggest that different constructs are being tested.

In another study of construct validity, 186 people (76 men and 110 women) completed the CHIP and the Coping Strategy Indicator (CSI) (CSI; Amirkhan, 1990). The CSI is designed as a self-report measure of situational coping embracing the strategies of avoidance, problem solving and seeking social support. There were moderate correlations found between the CHIP instrumental scale and the CSI problem solving scale (r= 0.41) (Endler et al., 1998b). The CHIP
palliative and emotional preoccupation scales were moderately associated with CSI avoidance scale (r= 0.46; r= 0.39); and a moderate correlation was also found between the CHIP distraction scale and the CSI seeking social support subscale (r=0.42) (Endler& Parker, 2000). These findings suggest that the instrumental scale of the CHIP and the problem solving scale of the CSI, palliative and emotional preoccupation scales of the CHIP and the avoidance scale of the CSI, distraction scale of the CHIP and seeking social support of the CSI measure similar constructs.

Criterion validity of the CHIP was tested by comparing the coping strategies of adults with chronic disease and acute disease (Endler et al., 1998a) by using analysis of variance (ANOVA) for the mean scores for the four CHIP scales. The results showed an interaction with group was significant in the palliative scale; the chronic group scores were significantly higher than acute group in instrumental scale and the acute group scores were significantly higher than chronic group in the emotional preoccupation scale (Endler & Parker, 2000).

The CHIP was selected for use in this study because it has been used in several different populations and had several studies supporting its reliability and validity. It has stronger psychometric properties than the more frequently used Ways of Coping Questionnaire (WOC) (Folkman et al, 1988). The test-retest reliability of the WOC has not been reported (Ender et al, 1995) and its demonstrated reliability in people with a specific illness has been challenged (Waller, 1989). Further, we hypothesized that the CHIP with its 32-items would be easier to complete than the 64-item WOC. Most importantly, the CHIP was selected as it asks specifically about coping with a health problem, the focus of this study, whereas the WOC asks about coping with a specific stressor within the week prior to the interview. Thus, the CHIP is evaluating dispositional coping rather than situational coping (Ptacek & Pierce, 2003). In addition, in the WOC, some of the items are not applicable to individuals dealing with particular health issues (such as TBI).

Community integration was measured using the Community Integration Questionnaire (CIQ) (Willer et al., 1993). The CIQ was designed specifically for individuals with TBI. The CIQ consists of fifteen items relevant to living and working and has 3 subscales: home integration which has 5 items resulting in scores ranging from 0 to 10, social integration which has 6 items resulting in scores ranging from 0 to 12, and productive activities (including employment,
school and volunteer work) with 4 items and scores ranging from 0 to 7. The total score can vary from 0 to 29 (Willer et al., 1993). It can be completed by the individual with TBI or a proxy (Willer, Ottenbacher & Coad, 1994) via face-to-face interview or via telephone (Dijkers, 1997).

The internal consistency of the CIQ was evaluated in several studies. The range of Cronbach's alpha for the total score is 0.76 to 0.84, for home integration is 0.84 to 0.95, for social integration is 0.65 to 0.83, and for productivity is from 0.26 to 0.35 (Willer et al., 1994; Corrigan & Deming, 1995). The Cronbach's alpha of the social integration and productive activity subscales were lower than the total score and home integration, possibly because these subscales are not unitary. The productivity subscale includes work, study, volunteering, and travel and the social integration subscale includes both socializing at home and away from home as well as with family and with friends.

The inter-rater reliability of the CIQ has been reported in correlations of ratings made by TBI patients and family members. The correlation between TBI patients and family members were Home Integration $r = 0.81$, Social Integration $r = 0.74$, Productive Activities $r = 0.96$, and total score $r = 0.89$, $p< 0.01$ (Willer et al., 1993). Another study achieved similar results. The CIQ inter-rater was tested through 148 TBI patients and their significant others, the correlations between patients’ and family members’ response were acceptable for all three CIQ scales (Tepper, Beatty & DeJong, 1996). This indicated that family members and TBI patients provided similar descriptions of patients’ community integration through the CIQ.

However, according to studies, the intraclass correlation coefficient (ICC) which is a more appropriate measure resulted in much lower numbers (Tepper et al., 1996). Proxy respondents tended to provide lower scores than the patients themselves did (ICC= 0.65 for social integration and ICC= 0.81 for productivity subscale), especially for the home integration subscale (ICC= 0.43) (Tepper et al., 1996). Sander et al (1997) found similar results: for in home integration there is a lack of agreement between people with TBI and their proxies. That may be explained by the results of the Tepper et al (1996) study, where most of the participants (TBI patients) were males who did not want to participate in home activities at all, or they have different definitions for home activities compared to their SOs. Further, it may be because TBI patients
with poor ability to perform and to communicate that could cause less satisfaction of family members, which may result in different responds.

The test-retest reliability coefficient (Pearson correlation coefficient) was reported by Willer and colleagues (1993) in a study of 16 participants with severe TBI and 16 proxies with an average of 10 days between assessments. The value for the CIQ total scores was \( r = 0.91 \) for TBI individuals and \( r = 0.97 \) for their family members. Reliability coefficients in each subscale were \( r = 0.93 \) for TBI individuals and \( r = 0.96 \) for SOs in home integration; \( r = 0.86 \) for TBI and \( r = 0.90 \) for SOs in social integration and in productive activities, \( r = 0.83 \) for TBI and \( r = 0.97 \) for family members (Willer et al., 1993). Also, the range of ICC across 3 domains were reported by other studies which were 0.81–0.91 (total scores), 0.71–0.90 (home integration), 0.66–0.86 (social integration) & 0.63–0.83 (productivity) (Cusick, Berhart & Mellick, 2000; Willer et al, 1994; Seale et al., 2002) which were generally acceptable to good. It means family members and TBI patients respond similarly through the CIQ and its demonstrated reliability is acceptable, thus the CIQ can be used via proxies’ response.

Criterion validity has been reported by Willer and colleagues (1993) using a small sample of 16 people with TBI and their proxies to indicate the scores of the CIQ correlated with scores on the Occupation subscale of the Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck et al., 1992). The CHART was designed to measure the degree of impairments and disabilities after rehabilitation. The CHART subscales of physical independence, mobility, economic self-sufficiency are indirectly related to the concept of community integration; in contrast, the subscales of occupation and social integration are directly related to community integration. The CIQ and the CHART are both measure the community integration, but were designed for different population. Total CIQ scores correlated with total CHART scores \( (r=0.62, p<0.05) \), the CHART occupation subscale correlated with all the CIQ subscales and especially with the CIQ productivity \( (r=0.55) \), the CHART social integration subscale correlated with the CIQ \( (r=0.35) \), however, the relationship between the CIQ scores and scores on the CHART Social Integration scale was not significant \( (p>0.05) \) (Willer et al. 1993). The relationships were weak in some correlation, perhaps because of the small sample size and sampling fluctuations (Dijkers, 1997) or may be because the comparisons between sub-scales on these measures suggest that different constructs were being tested.
Another study explored the relationship between the CIQ and the Disability Rating Scale (DRS) with 70 TBI patients. The DRS was designed to assess functional changes in persons with moderate and severe TBI in an inpatient rehabilitation setting (Rappaport et al., 1982). It includes 4 domains which are Arousability, Awareness and Responsibility, Cognitive Ability for Self Activities (feeding, toileting and grooming), Physical Dependence on Others, and Adaptability (employability). Results showed that the relationships between the CIQ home domain correlated with the DRS in level of functioning (r= -0.46), and employability (r= -0.38) (Zhang et al., 2002). The CIQ social domain correlated only with total DRS score (r= -0.25). The total CIQ score correlated with the DRS in all domain scores (range: r= 0.24– 0.43) but the arousability subscale. The productivity domain of the CIQ did not correlate with any the DRS domain or total rating (Zhang et al., 2002) which may be because of potential response bias among TBI survivors or because different constructs are being tested (the CIQ productivity subscale is not unitary). An other study found the correlation between the level of function subscales of the DRS and both the CIQ home integration (r= 0.46) and CIQ total (r= -0.47); correlation between the DRS level of employability and the CIQ productivity (r= -0.58) and the CIQ total (r= -0.58) (Sander et al., 1999).

Some correlation scores between the CIQ and the DRS are higher than others. That may be because subscales that focused on similar areas of function (social integration) would be more highly correlated than scales that measure different areas of function (such as home integration compare with employability).

The CIQ was selected for this study as it is a widely used measure of community integration, and shows good reliability between patients and their proxies. Its brevity (15 items) and clarity also make it a good choice.

### 3.3 Procedures

Eligible persons were identified by a research assistant at admission to Sunnybrook Health Science Center. Potential participants and/or their family members were provided with the information about the study and asked to be part of the study. Participants in the study were asked to provide contact information to arrange for follow-up interviews. At 6 and 12 months post-injury, participants were re-interviewed at the Baycrest Hospital. If persons could not come
to Baycrest, data were collected via interviews at the person’s home, via telephone interviews, or via mailed questionnaires.

### 3.4 Statistical analysis

All variables were examined for their underlying distribution to determine if parametric or non-parametric statistics could be employed. Skewness and kurtosis were evaluated.

Descriptive statistics were used to describe participants’ demographic, injury-related and coping characteristics at each time points. For objective 1, to test whether coping strategies change across time, repeated measures analysis of variance (ANOVA) was employed. Planned contrasts between baseline and 6-month coping, and 6-month coping and 12-month coping, and baseline and 12-month coping strategies were investigated.

For objective 2 which sought to determine the relationships between changes in coping strategies and community integration status, 6-month coping scores minus baseline coping scores were calculated to represent the changes in coping between baseline and 6-months. Similarly, 12-month coping scores minus 6-month coping scores were calculated to represent the changes in coping from 6 months to 12 months. As these variables were normally distributed, to determine the relationships to community integration, correlational analyses (Pearson’s r) were used.

For objective 3, to determine the relationships between demographic factors and community integration, Spearman correlation coefficients were used as the variables age, and 6 hours GCS scores were not normally distributed (See Appendix 7.3). T-tests were used to determine the relationship between sex and community integration.

For objective 4, to determine if demographic factors, injury severity and changes in coping strategies contributed unique variance to community integration status post TBI, multivariable regression analyses were performed. I conducted multivariable regression analysis with community integration status scores as the dependent variables. Since only changes in emotional preoccupation coping strategies correlated to community integration status, changes in emotional preoccupation coping strategies was considered as a predictor variable. Thus, the
predictors included in the model were: age, sex, injury severity, and changes in emotional preoccupation coping strategies.

As this is the first study to investigate changes in coping prospectively in a cohort of individuals with TBI, the p-value was set at 0.05. The data were analyzed using STATA 11® for Windows.
4.0 Results

Of 145 people with TBI recruited at baseline, 71 with identified significant others (SOs), completed all the questionnaires at each time point (baseline, 6 and 12 months) and were used as participants in this study. Among the SOs, there were 24 parents, 25 spouses (3 common-law), 12 siblings, 5 friends, 3 children (adult), and 2 boy/girl friends (adult).

TBI patients’ injury severity was based on 6-hour GCS scores. According to standard criteria (Teasdale & Jennett, 1974), 44 of the TBI participants had mild TBI (GCS 13–15), 15 had moderate TBI (GCS 9–12) and 12 had severe TBI (GCS 8 or less). There were no significant demographic differences between TBI participants with identified SOs and TBI participants without identified SOs. See Table 1 for TBI participants and those with no identified SOs demographic characteristics.

Table 1. Demographic characterization of TBI participants with and without identified SOs

<table>
<thead>
<tr>
<th></th>
<th>TBI Participants with SOs (n=71)</th>
<th>TBI Participants Without SOs (n=74)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td>Male</td>
<td>51</td>
<td>50</td>
</tr>
<tr>
<td>Mean Age in years (SD)</td>
<td>33.83 (15.18)</td>
<td>29.42 (11.82)</td>
</tr>
<tr>
<td>Mean Years of Education (SD)</td>
<td>13.13 (2.70)</td>
<td>13.11 (2.54)</td>
</tr>
<tr>
<td>Injury Severity – 6 hour GCS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild (13–15)</td>
<td>44</td>
<td>54</td>
</tr>
<tr>
<td>Moderate (9–12)</td>
<td>15</td>
<td>8</td>
</tr>
<tr>
<td>Severe (&lt;9)</td>
<td>12</td>
<td>12</td>
</tr>
</tbody>
</table>

Note. GCS= Glasgow Coma Scale scores
SD= Standard Deviation
4.1 Changes in coping strategies across time (Objective 1)

Descriptive data for each of the four subscales on the CHIP are shown in Table 2. As previously mentioned, all data are proxy. That is, SOs reported their perception of their loved ones’ coping strategies at each time point. Baseline data represent TBI participants’ pre-morbid coping as these data were collected shortly after TBIs were sustained while these individuals were patients on the trauma unit. At this time point, SOs were asked to comment on their loved ones’ pre-injury coping strategies status.

Table 2. Mean scores and standard deviation of four coping strategies in CHIP at 3 timeline (n=71)

<table>
<thead>
<tr>
<th>CHIP Subscales</th>
<th>Baseline Mean (SD)</th>
<th>6 Months Mean (SD)</th>
<th>12 Months Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distraction</td>
<td>24.17 (7.07)</td>
<td>26.23 (6.60)</td>
<td>22.79 (7.06)</td>
</tr>
<tr>
<td>Palliative</td>
<td>25.91 (6.51)</td>
<td>26.25 (5.96)</td>
<td>26.27 (6.09)</td>
</tr>
<tr>
<td>Instrumental</td>
<td>26.47 (7.53)</td>
<td>27.85 (7.64)</td>
<td>25.41 (7.22)</td>
</tr>
<tr>
<td>Emotional Preoccupation</td>
<td>21.07 (7.63)</td>
<td>24.06 (8.35)</td>
<td>21.52 (8.93)</td>
</tr>
</tbody>
</table>

Note. SD= Standard Deviation

To assess whether coping strategies change at 6 months and 12 months after acquired TBI, repeated measures analysis of variance (ANOVA) was employed comparing 6 month scores to baseline, 12 month scores to baseline and 12 month scores to 6 month scores (See Table 3). Analyses revealed statistically significant increases in distraction coping from baseline to 6 months (2.06; p= 0.01) and decreases from 6 months to 12 months (-3.44; p< 0.0001); significant decreases in instrumental coping from 6 months to 12 months (-2.44; p= 0.01); significant increases in emotional preoccupation coping from baseline to 6 months (2.98; p< 0.0001) and decreases from 6 months to 12 months (-2.53; p< 0.0001). Changes in four coping strategies were not significant from baseline to 12 months.
Table 3. Changes in coping strategies from baseline to 6 months, from 6 months to 12 months and from baseline to 12 months (n=71)

<table>
<thead>
<tr>
<th>CHIP Subscales</th>
<th>B to 6 months (P value)</th>
<th>6 to 12 months (P value)</th>
<th>B to 12 months (P value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distraction (F= 2.64)</td>
<td>2.06 (p=.01)</td>
<td>-3.44 (p&lt; .0001)</td>
<td>-1.10 (p=.16)</td>
</tr>
<tr>
<td>Palliative (F= 1.93)</td>
<td>0.35 (p=.64)</td>
<td>0.01 (p=.99)</td>
<td>0.36 (p=.62)</td>
</tr>
<tr>
<td>Instrumental (F= 2.03)</td>
<td>1.37 (p=.12)</td>
<td>-2.44 (p=.01)</td>
<td>-1.07 (p=.22)</td>
</tr>
<tr>
<td>Emotional Preoccupation (F= 2.47)</td>
<td>2.98 (p&lt; .0001)</td>
<td>-2.53 (p&lt; .0001)</td>
<td>0.45 (p=.61)</td>
</tr>
</tbody>
</table>

Note. B= Baseline; F= F value
Positive number indicates increase from one time point to another
Negative number means decrease from one time point to another

4.2 Relationships between changes in coping strategies and community integration (Objective 2)

Changes in coping (6 months minus baseline; 12 months minus 6 months) were compared to 6-month and 12-month community integration status respectively (See Tables 4 & 5) using Pearson’s correlation coefficients. The results showed that increases in emotional preoccupation coping strategies from baseline to 6 months were significantly associated with decreases in both productive activities (r= -0.36; p< 0.0001) and social integration (r= -0.43; p< 0.0001) at 6 months which means individuals with TBI were using fewer emotional preoccupation coping strategies at 6 months post-TBI relative to baseline, were more likely to be back to work or school and had greater social integration at 6 months.
Table 4. The relationships between changes in coping strategies (from baseline to 6 months) and community integration at 6 months (n=71)

<table>
<thead>
<tr>
<th>CHIP Subscales</th>
<th>Home integration (P value)</th>
<th>Social integration (P value)</th>
<th>Productive activities (P value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distraction</td>
<td>( r = 0.00 ) (p=.99)</td>
<td>( r = 0.14 ) (p=.25)</td>
<td>( r = -0.19 ) (p=.12)</td>
</tr>
<tr>
<td>Palliative</td>
<td>( r = -0.07 ) (p=.55)</td>
<td>( r = -0.09 ) (p=.48)</td>
<td>( r = -0.23 ) (p=.06)</td>
</tr>
<tr>
<td>Instrumental</td>
<td>( r = -0.04 ) (p=.71)</td>
<td>( r = 0.03 ) (p=.81)</td>
<td>( r = -0.03 ) (p=.81)</td>
</tr>
<tr>
<td>Emotional Preoccupation</td>
<td>( r = -0.17 ) (p=.15)</td>
<td>( r = -0.43 ) (p&lt; .0001)</td>
<td>( r = -0.36 ) (p&lt; .0001)</td>
</tr>
</tbody>
</table>

Note. \( r = \) Pearson’s correlation coefficient

This relationship was maintained at 12 months. That is, increases in use of emotional pre-occupation coping strategies between baseline and 6 months were significantly associated with reduced productive activities (\( r = -0.32; \text{p}< 0.0001 \)) at 12 months and reduced social integration (\( r = -0.37; \text{p}< 0.0001 \)) at 12 months and approached significance in relation to home integration at 12 months (\( r = -0.23; \text{p}= 0.06 \)). This means that individuals with TBI were using fewer emotional preoccupation coping strategies at 6 months post-TBI relative to baseline, were more likely to be back to work/school and had greater home and social integration at 12 months. There were no statistically significant relationships between changes in coping strategies (from 6 months to 12 months) and community integration at 12 months (See Appendix 7.4).

Table 5. The relationships between changes in coping strategies (from baseline to 6 months) and community integration at 12 months (n=71)

<table>
<thead>
<tr>
<th>CHIP Subscales</th>
<th>Home integration (P value)</th>
<th>Social integration (P value)</th>
<th>Productive activities (P value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distraction</td>
<td>( r = -0.21(p = .09) )</td>
<td>( r = 0.08(p = .52) )</td>
<td>( r = -0.12(p = .32) )</td>
</tr>
<tr>
<td>Palliative</td>
<td>( r = -0.21(p = .08) )</td>
<td>( r = -0.19(p = .11) )</td>
<td>( r = -0.18(p = .14) )</td>
</tr>
<tr>
<td>Instrumental</td>
<td>( r = -0.08(p = .53) )</td>
<td>( r = 0.14(p = .24) )</td>
<td>( r = -0.02(p = .88) )</td>
</tr>
<tr>
<td>Emotional Preoccupation</td>
<td>( r = -0.23(p = .06) )</td>
<td>( r = -0.37(p&lt; .0001) )</td>
<td>( r = -0.32(p&lt; .0001) )</td>
</tr>
</tbody>
</table>

Note. \( r = \) Pearson’s correlation coefficient
4.3 Relationships between demographic factors and community integration status (Objective 3)

Relationships between demographic characteristics and community integration were examined using Spearman’s correlation coefficient, because the age and 6 hours GCS scores had non-normal distributions (See Appendix 7.3). To determine the relationship between sex and community integration t-tests were used.

A number of significant and marginally significant relationships were evident. At 6 months post injury, the results show that greater social integration was significantly associated with younger age (r= -0.30; p= .01), and a trend to higher levels of education (r= 0.20; p= 0.09). Higher levels of productive activities were significantly associated with younger age (r= -0.37; p< 0.0001). Also, greater home integration significantly associated with female sex and less severe patients (r= 0.29; p= 0.02) (see Table 6 & 7).

Table 6. Correlation between Sex and community integration at 6 and 12 months (n=71)

<table>
<thead>
<tr>
<th>Sex</th>
<th>HIN 6 Mean</th>
<th>HIN 12 Mean</th>
<th>SIN 6 Mean</th>
<th>SIN 12 Mean</th>
<th>PRO 6 Mean</th>
<th>PRO 12 Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>4.60</td>
<td>6.45</td>
<td>8.15</td>
<td>8.95</td>
<td>3.40</td>
<td>4.25</td>
</tr>
<tr>
<td>Male</td>
<td>2.54</td>
<td>2.88</td>
<td>7.58</td>
<td>7.40</td>
<td>3.46</td>
<td>3.98</td>
</tr>
<tr>
<td>P value</td>
<td>p=.01</td>
<td>p&lt;.0001</td>
<td>p=.42</td>
<td>p=.05</td>
<td>p=.91</td>
<td>p=.65</td>
</tr>
</tbody>
</table>

Note. HIN 6= 6 months Home Integration; HIN 12= 12 months Home Integration; SIN 6= 6 months Social Integration; SIN 12= 12 months Social Integration; PRO 6= 6 months Productive Activities; PRO 12= 12 months Productive Activities
Table 7. Correlation between demographic factors and 6 months community integration (n=71)

<table>
<thead>
<tr>
<th></th>
<th>Home integration (P value)</th>
<th>Social integration (P value)</th>
<th>Productive activities (P value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>r= -0.04 (p=.77)</td>
<td>r= -0.30 (p=.01)</td>
<td>r= -0.37 (p&lt;.0001)</td>
</tr>
<tr>
<td>Education</td>
<td>r= 0.18 (p=.14)</td>
<td>r= 0.20 (p=.09)</td>
<td>r= 0.03 (p=.81)</td>
</tr>
<tr>
<td>6 hour GCS</td>
<td>r= 0.29 (p=.02)</td>
<td>r= 0.08 (p=.51)</td>
<td>r= 0.14 (p=.26)</td>
</tr>
</tbody>
</table>

Note. r= Spearman’s correlation coefficient.

At 12 months post TBI, the results showed that better productive activity was associated with younger age (r= -0.46; p<.0001). Greater home integration was associated with female sex. Also, greater social integration was associated with younger age (r= -0.29; p=.02) and female sex (see Table 6 & 8).

Table 8. Correlation between demographic factors and 12 months community integration (n=71)

<table>
<thead>
<tr>
<th></th>
<th>Home integration (P value)</th>
<th>Social integration (P value)</th>
<th>Productive activities (P value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>r= -0.16 (p=.19)</td>
<td>r= -0.29 (p=.02)</td>
<td>r= -0.46 (p&lt;.0001)</td>
</tr>
<tr>
<td>Education</td>
<td>r= 0.00 (p=.97)</td>
<td>r= 0.20 (p=.10)</td>
<td>r= 0.12 (p=.32)</td>
</tr>
<tr>
<td>6 hour GCS</td>
<td>r= 0.14 (p=.24)</td>
<td>r= 0.06 (p=.62)</td>
<td>r= 0.01 (p=.94)</td>
</tr>
</tbody>
</table>

Note. r= Spearman’s correlation coefficient.

4.4 Multivariable Regression (Objective 4)

Regression variables were identified by using all variables associated with community integration status at p≤0.05 (See Table 6, 7 & 8). In addition, injury severity was included in all models because previous studies have shown it to be predictive of outcome (Fleming, Tooth, Hassell & Chan, 1999). To determine whether changes in emotional preoccupation coping strategies contributed uniquely to community integration status, age or/and sex, and injury severity were the first variables entered. If these models were significant, the emotional preoccupation variable was then added to determine if it accounted for additional unique variance. Tables 9, 10 and 11 show the results of the multivariate regression, the r-square for
each model and p value for each variable. Sex was coded as woman = 0, and man = 1. In total 12 models were built.

Models 1 and 2 have 6-month home integration as the dependent variable and models 3 and 4 have 12-month home integration as the dependent variable (See Table 9). As planned, in models 1-4, injury severity and sex entered first, and then changes in emotional preoccupation coping from baseline to 6 months was entered next. As can be seen, emotional preoccupation coping did not contribute significantly to explaining the variance in home integration at 6 or 12 months.

Table 9. Multivariable regression model of independent variables on Home Integration at 6 and 12 months (n=71)

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Model 1</th>
<th>Model 2</th>
<th>Model 3</th>
<th>Model 4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HIN 6 month</td>
<td>HIN 6 month</td>
<td>HIN 12 month</td>
<td>HIN 12 month</td>
</tr>
<tr>
<td></td>
<td>F=7.64 (p&lt;.000)</td>
<td>F=5.49 (p&lt;.000)</td>
<td>F=10.53 (p&lt;.000)</td>
<td>F=8.18 (p&lt;.000)</td>
</tr>
<tr>
<td></td>
<td>R-squared= 0.19</td>
<td>R-squared= 0.20</td>
<td>R-squared= 0.24</td>
<td>R-squared= 0.27</td>
</tr>
<tr>
<td>Injury Severity</td>
<td>Variable Coefficient (p-value)</td>
<td>Variable Coefficient (p-value)</td>
<td>Variable Coefficient (p-value)</td>
<td>Variable Coefficient (p-value)</td>
</tr>
<tr>
<td></td>
<td>0.18 (p = 0.02)</td>
<td>0.17 (p = 0.03)</td>
<td>0.14 (p = 0.17)</td>
<td>0.11 (p = 0.27)</td>
</tr>
<tr>
<td>Sex</td>
<td>-2.02 (p&lt;.000)</td>
<td>-1.98 (p&lt;.000)</td>
<td>-3.58 (p&lt;.000)</td>
<td>-3.51 (p&lt;.000 )</td>
</tr>
<tr>
<td>Coping (EP)</td>
<td>-0.04 (p = 0.29)</td>
<td>-0.04 (p = 0.29)</td>
<td>-0.07 (p = 0.09)</td>
<td>-0.07 (p = 0.09)</td>
</tr>
</tbody>
</table>

Note. EP= changes in emotional preoccupation coping strategies from baseline to 6 months
HIN= Home Integration

Models 5 and 6 have 6-month social integration as the dependent variable and models 7 and 8 have 12-month social integration as the dependent variable (See Table 10). In model 5 and 6, injury severity and age entered the model first, in model 7& 8, injury severity, age, and sex entered the model first and then changes in emotional preoccupation coping from baseline to 6 months was entered next respectively. In model 5, age and injury severity accounted for 14% of the variance in social integration at 6 months; model 6 included the change in emotional preoccupation coping strategies from baseline to 6 months score was accounting for an additional 11% of the variance in social integration at 6 months. Model 7, age, sex and injury severity accounted for 14% of the variance in social integration at 12 months; in model 8, the
change in emotional preoccupation coping strategies from baseline to 6 months score was accounting for an additional 8% of the variance in social integration at 12 months.

Table 10. Multivariable regression model of independent variables on Social Integration at 6 and 12 months (n=71)

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Model 5</th>
<th>Model 6</th>
<th>Model 7</th>
<th>Model 8</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIN 6 month</td>
<td>F=5.30 (p=.01)</td>
<td>F=7.23 (p&lt;.000)</td>
<td>F=3.59 (p=.02)</td>
<td>F=4.46 (p&lt;.000)</td>
</tr>
<tr>
<td>R-squared= 0.14</td>
<td>R-squared= 0.25</td>
<td>R-squared= 0.14</td>
<td>R-squared=0.22</td>
<td></td>
</tr>
<tr>
<td>Injury Severity</td>
<td>0.10 (p= 0.21)</td>
<td>0.05 (p= 0.48)</td>
<td>0.11 (p= 0.23)</td>
<td>0.07 (p= 0.45)</td>
</tr>
<tr>
<td>Age</td>
<td>-0.06 (p&lt;.000)</td>
<td>-0.04 (p= 0.03)</td>
<td>-0.05 (p= 0.02)</td>
<td>-0.04 (p= 0.12)</td>
</tr>
<tr>
<td>Sex</td>
<td>-1.69 (p= 0.03)</td>
<td>-1.55 (p= 0.04)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping (EP)</td>
<td>-0.10 (p&lt;.000)</td>
<td></td>
<td></td>
<td>-0.10 (p= 0.02)</td>
</tr>
</tbody>
</table>

Note. EP= changes in emotional preoccupation coping strategies from baseline to 6 months
SIN= Social Integration

Models 9 and 10 have 6-month productive activities as the dependent variable and models 11 and 12 have 12-month productive activities as the dependent variable (See Table 11). In model 9-12, injury severity and age entered the model first and then changes in emotional preoccupation coping from baseline to 6 months entered next. Model 9, age and injury severity accounted for 19% of the variance in productive activities at 6 months; model 10, the change in emotional preoccupation coping strategies from baseline to 6 months score and was accounting for an additional 5% of the variance in productive activities at 6 months. Model 11, age and injury severity accounted for 20% of the variance in productive activities at 12 months; in model 12, the change in emotional preoccupation coping strategies from baseline to 6 months accounted for no additional variance in productive activities at 12 months.
Table 11. Multivariable regression model of independent variables on Productive Activities at 6 and 12 months (n=71)

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Model 9</th>
<th>Model 10</th>
<th>Model 11</th>
<th>Model 12</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PRO 6 month</td>
<td>PRO 6 month</td>
<td>PRO 12 month</td>
<td>PRO 12 month</td>
</tr>
<tr>
<td></td>
<td>F=7.78 (p&lt;.000)</td>
<td>F=6.88 (p&lt;.000)</td>
<td>F=8.11 (p&lt;.000)</td>
<td>F=6.48 (p&lt;.000)</td>
</tr>
<tr>
<td></td>
<td>R-squared= 0.19</td>
<td>R-squared= 0.24</td>
<td>R-squared= 0.20</td>
<td>R-squared= 0.23</td>
</tr>
<tr>
<td>Injury Severity</td>
<td>Variable</td>
<td>Variable</td>
<td>Variable</td>
<td>Variable</td>
</tr>
<tr>
<td></td>
<td>(p-value)</td>
<td>(p-value)</td>
<td>(p-value)</td>
<td>(p-value)</td>
</tr>
<tr>
<td></td>
<td>0.13 (p= 0.04)</td>
<td>0.11 (p= 0.08)</td>
<td>0.08 (p= 0.19)</td>
<td>0.06 (p= 0.33)</td>
</tr>
<tr>
<td>Age</td>
<td>-0.05 (p&lt;.000)</td>
<td>-0.04 (p&lt;.000)</td>
<td>-0.06 (p&lt;.000)</td>
<td>-0.05 (p&lt;.000)</td>
</tr>
<tr>
<td>Coping (EP)</td>
<td>-0.06 (p= 0.04)</td>
<td>-0.05 (p= 0.10)</td>
<td>-0.06 (p= 0.04)</td>
<td>-0.05 (p= 0.10)</td>
</tr>
</tbody>
</table>

Note. EP= changes in emotional preoccupation coping strategies from baseline to 6 months  
PRO= Productive Activities

Thus, changes in emotional preoccupation coping strategies from baseline to 6 months contributed unique variance to 6 and 12 months social integration and 6 months productive activities.
5.0 Discussion

There are very few published, longitudinal studies of changes in psychosocial characteristics after TBI. This appears to be the first prospective cohort study to explore changes in coping strategies from pre-injury to 6 and 12 months following TBI and to determine the relationships between changes in coping strategies and community integration at 6 months and 12 months after TBI. SOs of people with TBI were interviewed post-injury and at 6 and 12 months using the Coping with Health Injuries and Problems (CHIP) and the Community Integration Questionnaire (CIQ). As hypothesized, coping strategies do change following TBI. Relationships between changes in coping strategies and community integration and between demographic factors and community integration exist. Further, use of emotional preoccupation coping strategies explains unique variance in 6 and 12 months social integration and 6 months productive activities.

5.1 Changes in Coping Strategies

Changes in coping strategies do occur following TBI. This study investigated the changes (between different time points) in coping strategies as, the ICF model led to the hypothesis that changes in coping (personal factors) in a maladaptive direction would influence community integration negatively. Changes in coping were not consistent across the four scales. As there were no significant changes in palliative coping, the discussion focuses on the other three areas of coping. However, the fact that there were significant changes in coping in these three areas supports the theoretical definition of coping provided by Lazarus and Folkman (1984) of coping strategies representing “constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person” (page 445). Many survivors of brain injury experience cognitive and behavioural changes, especially, when they are aware the new situation (after injury) are unable to control, thus it is not surprising to see that choices of coping strategies changed post-TBI.

Distraction coping strategies increased significantly from baseline (pre-injury) to 6 months and returned to baseline status from 6 months to 12 months. It may be adaptive to use more distraction coping after acquired TBI. If TBI patients were to continuously think about their
illness instead of thinking of other pleasant things, this may contribute to higher levels of depression and anxiety (Wallace & Bogner, 2000). There may be a number of reasons for the increases in distraction coping strategies from baseline to 6 months and decreases from 6 months to 12 months. For example, people with TBI often are less mobile initially and thus may spend more time doing sedentary activities (such as listening to music, thinking about good times). However, as their mobility increases they may be able to participate in more active pastimes. A second possibility is that TBI survivors may get more visitors at the beginning of injury but as they recover and they receive fewer visitors, this aspect of distraction coping is reduced. In fact, of the 8 items on the CHIP that represent distraction coping, 3 pertain to being with other people (Endler, & Parker, 2000).

Instrumental coping strategies did not change significantly from baseline to 6 months but decreased significantly from 6 months to 12 months. Five of the 8 items in this scale pertain directly to learning about and following medical advice. Thus, this decrease may have occurred because by this point in the recovery process, individuals with TBI have learned enough about their illness and have stopped seeking help or trying to learn more. Also, by 6 months post TBI, individuals would probably either be returned to work or be in some type of stable follow-up. One study reported that the highest rates of returning to work following TBI occurred after the first 6 months post-injury (Dikmen et al., 1994). This may be the reason that instrumental coping strategies decreased significantly from 6 months to 12 months post TBI. Also, one study reported that instrumental coping continues to decrease from 2.3 to 5.7 years after TBI (Tomberg et al, 2007).

Emotional preoccupation coping strategies increased significantly from baseline to 6 months and decreased significantly from 6 months to 12 months. All eight items in this scale pertain directly to negative emotional reactions. TBIs can result in reduced anger control, impulsiveness, increased frustration, and anxiety (items on CHIP) (Arlinghaus et al., 2005), but as individuals adapt, their emotional preoccupation coping strategies return to pre-morbid levels. These changes in emotion preoccupation coping may be related to the emotional and cognitive changes after TBI. Common cognitive and emotional changes following a TBI include frustration, anxiety, a reduced ability to adapt to new situation, and impaired judgment. These negative changes may cause TBI patients to rely more on emotional preoccupation coping strategies that might make them feel better (e.g., Fantasize about all the things they could do if they were better).
instead of using problem-focused coping strategies such as making efforts to deal directly with their health issues. The findings in this study confirm and extend reports by others. Tomberg et al. (2007) also found that people with TBI had increased use of emotional pre-occupation coping strategies. They studied 31 people and measured self-reported coping an average of 2.3 years after injury of baseline and then followed them prospectively to on average 5.7 years post-TBI (Tomberg et al, 2007). Also, the study reported that emotion-focused coping increased from 2.3 to 5.7 years after injury; however, the current study found a decrease from 6 months to 12 months. This is possibly because more severely injured people with TBI were not back at work or were unable to participate in home and social activities.

Similarly Wolters et al (2010) reported that passive emotion-focused coping styles increased between the start of rehabilitation and at least 5 months later via self-report in 110 participants (Wolters, Stapert, Brands, & Van Heugten, 2010). Thus, it may be common for people with TBI to exhibit the increased use of emotional preoccupation coping strategies within the first 6 months after injury. However, few studies that found similar results to the current work which is that emotional preoccupation coping strategies decrease from 6 to 12 months. This may be because the longer time since injury, TBI patients emotionally becoming more adaptive in both physical and emotional situation and able to go back to work/school which resulting in these strategies returned to baseline status between 6 and 12 months post-TBI.

In this study, coping strategies at 12 months was not significantly different than at baseline in any of the four scales. According to the coping strategies mean score, TBI patients’ coping strategies at 12 months went back to almost pre-injury status. One possible explanation for that between 6 and 12 months is that people are less likely to be coping with their injury as opposed to coping with the results of the injury.

A further point of discussion relates to viewing the distraction and emotional preoccupation subscales of the CHIP as two facets of emotion-focused coping (whereas the instrumental coping scale reflects the construct problem-focused coping). The emotion-focused coping scales behaved in the same way: increasing from baseline to 6 months and then returning to baseline.

A final point of discussion relates to the longitudinal validity of the CHIP. Longitudinal validity of the CHIP is established by these data as changes in coping were found to be associated with
community integration status. This study represents an initial investigation of longitudinal validity.

5.2 Relationship of Changes in Coping to Community Integration Status

In addition, the relationship between changes in coping strategies and community integration was explored. The reason to explore these relationships is that according to the ICF model (World Health Organization, 2001), the relationships between impairments, activities and participation (community integration status) are influenced by environmental and personal factors. Coping strategy is the personal factor focused on in this thesis. One other study found a relationship between coping and community reintegration (Karlovits & McColl, 1999). Karlovits and McColl reported that persons with TBI using more problem-focused coping strategies had more awareness of the problems they faced lead to better community reintegration (Karlovits & McColl, 1999).

In general the data in this study showed that increased use of emotional preoccupation coping strategies at 6-months post-injury (relative to baseline coping) was associated with less successful community integration at six and 12 months post-TBI. This may be because people with TBI involuntarily use emotional coping strategies (such as wishful thinking, denial etc) rather than the other types of coping strategies. Because of their cognitive problems, people with TBI, may have less ability to plan, or think through solutions to problems (problem-focused coping strategies). Thus, TBI survivors select emotional coping strategies to deal with the specific events instead of problem-focused coping. This view is supported by work by Krpan and colleagues who found that people with TBI who used more emotion-focused coping strategies had lower levels of executive performance (unable to make plan, or providing proper solution to problems). Conversely, those using more problem-focused coping had higher levels of executive performance (Krpan et al., 2007). In this study, it may be that people with TBI using more emotional coping also had lower executive function, which in turn led to poorer community integration status.

Unexpectedly, there were no changes in instrumental coping from baseline to 6 months and hence no statistically significant relationship to community integration at 6 months. It was
hypothesized that people who used more instrumental coping (getting information about their injury, following health care professionals’ advice) would have better community integration. In contrast to findings in this study, Karlovits and McColl found people with TBI used more problem-focused coping and they had better community reintegration (Karlovits & McColl, 1999). Thus, further investigation of this relationship is still required.

5.3 Relationship of Demographic Factors to Community Integration Status

Most previous studies that have explored the relationships between demographic factors and community integration did so with people with severe TBI (Truelle, Fayol, Montreuil & Chevignard, 2010; Winkler & Sloan, 2006; Karlovits & McColl, 1999) after their rehabilitation programs had ended (Goranson et al., 2003; Cicerone et al., 2004) and investigated only longer term outcomes (2-5 years) (Fleming et al., 1999; Stalnacke, 2007; Wood & Rutterford, 2006; Winkler & Sloan, 2006). In contrast, data for this study included people with all ranges of TBI severity and community integration outcomes in the medium and long term (6 months and 12 months).

Younger patients reported higher levels of social integration and productive activities at 6 months and 12 months after TBI. These findings confirm those in previous studies (Fleming et al, 1999; Corrigan, Smith-Knapp, Granger, 1998; Schmidt, Garvin, Heinemann & Kelly, 1995). In contrast to findings in this study that education was not statistically significantly related to community integration (home, social and productivity), Wood & Rutterford (2006) found that years of education made a significant contribution to community integration status (higher levels of education related to greater community integration) but was not significantly related to employment status.

Similar to other studies, female patients in this study were reported as having greater home integration at 6 months and greater home and social integration at 12 months (Schmidt et al., 1995). Like this study, Schmidt also reported no sex differences in productive activities. In relation to injury severity level, previous studies showed that there is no relationship between injury severity and productive activities (Wood & Rutterford, 2006). However, in this study only post-traumatic amnesia (PTA) was used to indicate injury severity (mild or moderate to
severe TBI) (Wood & Rutterford, 2006). Other studies using PTA, GCS, and incidence of neurosurgery to indicate the severity of injury found more severe TBI patients reported lower productive activities and community integration (Fleming et al., 1999). In this study, no relationship was found between injury severity and productive activities. However, patients with more severe TBI had lower levels of home integration at 6 months post TBI. In general, this study and others found the more severe the injury, the poorer the community integration.

5.4 Multivariable regression Analyses

Changes in emotional preoccupation coping strategies contributed unique variance to social integration at 6 and 12 months in multivariate regression models that included demographic factors and injury severity and to productivity integration at 6 months. In other words, using less emotional preoccupation coping strategies at 6 months relative to baseline predicted better social and productivity integration even considering other variables (demographic factors and injury severity).

The changes in emotional preoccupation coping did not contribute uniquely to productive activities at 12 months. This indicated that at 12 months after injury, age is the major factor which contributed to productive activities instead of emotional preoccupation coping (see table 11) which means younger patients will have better productive activities at 12 months after injury, whether they use more or less emotional preoccupation coping strategies.

5.5 Implications for rehabilitation

One of the outstanding questions regarding addressing coping in rehabilitation is whether health care professionals receive education about coping and changes in coping following TBI. If therapists do not understand that coping strategies can change, they will not be able to address this in rehabilitation. Previous literature showed that although only a small percentage (5%) of occupational therapists can not explain the construct of coping, more than 20% of them are addressing coping in their practice in an implicit manner, that is, they are not addressing it explicitly (Dawson & Trueman, 2010). This study has shown that the use of improper coping strategies is a significant predictor of poor community integration outcomes. Thus, if occupational therapists are unable to address coping explicitly, patients may choose coping
strategies involuntarily which may contribute to worse community integration outcomes and in turn may increase the risk of additional stressors and depression (Turner et al., 2000) and greater levels of disability (Woby et al., 2004). Thus, this strengthens the argument that research and education are needed in this area such as, what coping is, and how to adjust coping outcomes.

The implications for rehabilitation of current study are that knowing that emotional preoccupation coping strategies increase (from pre-injury to 6 months after TBI) and that these changes are related to lower productive activities and less social integration at 6 and 12 months suggests a path to explore through rehabilitation. For example, rehabilitation specialists could create a rehabilitation program to help TBI patients’ to limit their emotional preoccupation coping that could help them to enhance social reintegration and opportunities to return to work/school. To our knowledge, very little work has been done in this area (Anson & Ponsford, 2006b; Backhaus et al., 2010). The results in both studies are promising making this an exciting avenue for future research. Addressing coping strategies early in rehabilitation may assist in improving longer-term home and social integration as well as rates of return to productive activities and overall quality of life.

5.6 Limitations and Suggestions for Future Study

There are three primary limitations to this study which lead to areas for future research. First, all data were collected from TBI patients’ family members or friends and may not fully reflect TBI patients’ psychological conditions. Previous studies showed that participants and their proxies’ reports are not fully congruent, especially in relation to social activities (Hart et al., 2010). This may be because many proxies (family members or friends) may not be directly involved in patients’ social activities and thus may be less aware of patients’ social events. This may cause bias in the reporting of TBI patients’ social activities (Hart et al., 2010). It is also possible that SOs at baseline may provide a better picture about patients’ pre-injury status which also could cause bias.

There are various relationships between TBI patients and SOs in this research (such as family members or friends) which may affect the reliability of the responses. But according to Hart et al. (2010), congruence was not affected by participants and SOs relationships nor by the injury severity (Hart et al., 2010). In this study, SO data were used as this was the only way to collect
TBI patients’ pre-injury information. This would not have been feasible from TBI patients as many may have been in PTA, suffering pain, had cognitive impairments and so on.

The second limitation is that the data did not include TBI patients with prior significant neurological or systemic disease or prior significant substance abuse and psychiatric disease which may lead to a biased TBI sample (Macmillan, Hart, Martelli, Zasler, 2002). Future studies should include this subset of people with TBI and address related complexities.

A third limitation is that there were just 20 female TBI participants in this study. Although the male TBI population is much larger than the female (Guerrero et al., 2000), this may limit the generalization of the findings about sex and community integration to the larger female TBI population. Future work should make an effort to balance the ratio of males to females for addressing results that involve a sex issues.

5.7 Conclusion

The findings in this study confirm and extend what is known about coping strategies after TBI. As was hypothesized, coping strategies change after TBI in a maladaptive direction particularly in the first six months post-injury. Unfortunately these changes have a negative impact on community integration that extends to at least one year post-injury. On the positive side, the maladaptive changes in coping seen at 6 months post-injury seem to resolve by one-year post injury. These data also show relationships between changes in coping strategies, demographic factors, injury severity and community integration. The findings in this study suggest that these factors influence and interact with each other. The results of the current study also indicate that a proportion of individuals with TBI experience both psychosocial difficulties, especially regarding changes in coping strategies, and lower community integration after the injury. These aspects should be taken into consideration in the management of patients with TBI.
6.0 References or Bibliography


7.0 Appendices

7.1 Ethic Approval

CERTIFICATE OF RESEARCH APPROVAL

The Joint Baycrest Centre/University of Toronto Research Ethics and Scientific Review Committee has reviewed the following research proposal and considers the experimental procedures, as described by the investigator(s), to be acceptable on scientific and ethical grounds for research involving human subjects. Any amendments requested by the Committee have been received.

Investigator(s): Dawson, Stuss, Winocur, Schwartz

Title of Project: The investigation of psychological predictors of functional outcome following TBI

Date Reviewed by Committee: July 16, 2001

Composition of Committee by Discipline:

- Client Representative
- Community Representative
- Epidemiologist
- Psychologist
- Research Administrator
- Nurse

Sylvia Teaves, MHSc
Deputy Chair
Joint Baycrest Centre/University of Toronto
Research Ethics & Scientific Review Committee

RESPONSIBILITIES OF PRINCIPAL INVESTIGATORS

1. Any changes to the original protocol must be submitted to the Committee for approval.

2. All adverse events, whether encountered directly by the investigators or identified at other sites involved in a multi-centre study, must be reported immediately to the Committee.

3. Annual reports on the status of projects must be returned by the requested deadlines.

Failure to comply with any of these requirements may result in approval being suspended.

Baycrest Hospital, The Ben and Hilda Katz Building • The Jewish Home for the Aged, The Abe and Eileen Puschert Building
Baycrest Day Care Services for Seniors • Baycrest Terrace • The Joseph E. and Minnie Vagman Centre
Elm Ridge Group Living Residence • The Rotman Research Institute • The Kamin-Lamport Applied Research Unit

An academic centre affiliated with University of Toronto

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7.2 Six example items from CHIP

Item from Distraction Subscale:

Surround myself with nice things (e.g., flowers);

Items from Palliative Subscale:

Get plenty of sleep;

Items from Instrumental Subscale:

Learn more about the most effective treatments available;

Items from Emotional preoccupation Subscale:

Become angry because it happened to me;

Feel anxious about the things I can't do;

Wish that the problem had never happened.
7.3 Descriptive data

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Note. Descriptive data: GCS 6 hours
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Note. Descriptive data: AGE

![Histogram](image)

Note. Descriptive data: AGE
7.4 The relationships between changes in coping strategies (from 6 months to 12 months) and community integration at 12 months

<table>
<thead>
<tr>
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<th>Productive activities (P value)</th>
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Note. Correlation coefficient is Pearson’s correlation coefficient