

“THERE’S NOHING MILD ABOUT IT:” THE LIVED EXPERIENCE OF MILD TRAUMATIC BRAIN  
INJURY (MTBI) FROM AN OCCUPATIONAL PERSEPCTIVE

by

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Submitted in partial fulfilment of the requirements  
for the degree of Master of Science

at

Dalhousie University  
Halifax, Nova Scotia  
August 2016

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## **Abstract**

This study explored everyday life for six individuals diagnosed with mild traumatic brain injury (MTBI) at least one year earlier. Using a phenomenological design, two in-depth interviews with each person explored occupations such as self-care, leisure, and productivity, as well as occupational identity, transition, and adaptation, and issues surrounding legitimacy, passing, and stigma. Analysis revealed that everyday occupations such as shopping, preparing food, driving, and managing finances, posed tremendous challenges for participants. Participants passed through denial, guilt, and grief before transitioning toward rebuilt occupational identities, and eventual occupational competency. Seeking social support and community involvement were key. Finally, participants spent considerable time seeking legitimacy within legal and medical communities, and often altered their everyday lives in order to be viewed as less brain injured. Increased knowledge about the everyday occupational lives of MTBI survivors holds valuable, practical implications for occupational therapy, and other health professions.

## LIST OF ABBREVIATIONS USED

ABI	Acquired Brain Injury
ACRM	American Congress of Rehabilitation Medicine
ADL	Activities of Daily Living
BIANS	Brain Injury Association of Nova Scotia
CAOT	Canadian Association of Occupational Therapists
CDC	Centre for Disease Control
CMOP-E	Canadian Model of Occupational Performance and Engagement
DAI	Diffuse Axonal Injury
MOHO	Model of Human Occupation
MTBI	Mild Traumatic Brain Injury
MVA	Motor Vehicle Accident
OPH	Occupational Performance of Health
OT	Occupational Therapy
PCS	Post Concussion Syndrome
PTH	Post Traumatic Headache
PTSD	Post Traumatic Stress Disorder
RTW	Return to Work
TBI	Traumatic Brain Injury
WHO	World Health Organization

## **Acknowledgements**

This study owes a great deal of appreciation to the men and women who participated in this study. By opening up about your personal, and often painful, experiences with MTBI, you helped shed light on crucial issues within our MTBI community. Your stories will undoubtedly help other survivors, health professionals, and members of the public strive toward learning more about and implementing potential key services for this population.

With heartfelt gratitude, I acknowledge the continuous community support and encouragement of the Brain Injury Association of Nova Scotia (BIANS) - especially from Shelley, Chriss, and Patrick. I would have likely continued to fumble my way through the darkness had it not been for your patience and accommodation which enabled me to see this project through.

This project would not have been possible without the unfailing support of my thesis supervisor, Dr. Brenda Beagan, who over the years provided ongoing guidance, encouragement, and scholarly reflection, especially during times that I didn't think I could go on. I also wish to thank my committee members, Dr. Heidi Lauckner and Dr. Brenda Merritt, for providing timely guidance and scholarship – it has been an honour and privilege to work with you. I wish to acknowledge the financial support of the Nova Scotia Health Research Foundation (NSHRF). The generosity of your financial assistance (and patience) made this project, which started so many years ago, a reality.

Finally, I wish to sincerely thank my family and friends for your understanding, patience, and support throughout a journey which would have been otherwise overwhelming and isolating. To my best friend (Amy Bethune), Scott, my sisters, parents, and grandparents, and countless others who stood by me throughout this endeavour - thank you for being there when I needed you the most.



## CHAPTER 1

### INTRODUCTION

*“Some days you feel as though you’re stuck in a cognitive straitjacket. Imagine having the worst head cold of your life, waking up groggy after sleeping in too long, and adding a hangover to the equation. It’s like my mind and thoughts are hidden behind a veil, obscuring clarity, barely within reach at times.”* (Butler, 2014).

Concussions, or mild head injuries, are a popular topic right now within athletic and academic research circles. In fact, over the last decade there has been increased public awareness about the consequences of Mild Traumatic Brain Injury (MTBI), particularly through concussion-in-sport prevention initiatives as well as through media attention to military blast injuries (Bryan, Clemans, Hernandez, Marie, & Rudd, 2013). This is especially evident within the National Hockey League (NHL) since ten former players filed a class-action lawsuit against the league, alleging that it has not done enough to protect its players from mild traumatic brain injuries - specifically concussions (Peters, 2014). Learning about the ongoing concussive struggles of famous hockey players, including international celebrity Sidney Crosby, has helped raise the profile of this previously silent and unknown injury. Concussions and other mild head injuries are now more widely recognized and acknowledged in the media than ever.

Most people would be hard pressed to not know someone, directly or indirectly, affected by head injury. Recent media coverage and subsequent public awareness have contributed to evolving knowledge base about head injuries. There has been a strong shift in public thinking about this topic (which was often previously regarded as “just a concussion”). It is now part of a larger discussion, thanks to the media, which

acknowledges the longer term impacts of trauma to the head. However, advances in both qualitative and quantitative research, focusing on the potential persistent, long-term physical and psychological effects of MTBI, have also greatly contributed to knowledge about this phenomenon.

Although increased public awareness regarding sports-related head injuries has been advantageous in highlighting the necessity to learn more about and effectively manage this neurological condition, it is important to note that sports injuries are merely one of several ways in which a person may experience head trauma. Motor vehicle traffic accidents, home and work accidents, assaults, and falls are also common causes, and they too should garner public awareness and recognition (Bazarian et al., 2005). Moreover, despite public exposure to snippets of information about the persistent struggles of athletes living with MTBI, we are rarely privy to information about what it is actually like for head injury survivors on *an everyday level*. This thesis explored exactly that: the effects of MTBI on the everyday occupational lives of MTBI survivors.

### 1.1 Significance of MTBI

Differentiation between terms and diagnosis of TBI (e.g. concussion, MBTI, post-concussion syndrome), are diverse and vary within academic and clinical populations. Generally speaking this study focuses on *mild* traumatic brain injury, which can be loosely defined as a person who has had a traumatically induced physiological disruption of brain function (Dikmen, McLean, & Temkin, 1986). A more in-depth definition and discussion will be provided in later sections. MTBI is a significant problem

in Canadian society, and in most industrialized countries, in terms of both prevalence and cost. MTBI (also often referred to as Post Concussive Syndrome) is one of the most common, serious, and disabling neurological disorders in Canada - affecting approximately 200,000 Canadians each year, with approximately 500 per 100,000 population requiring hospitalization (Brain Injury Society of Toronto, 2014). Traumatic brain injury is a spectrum diagnosis and may range from mild to more severe forms of head trauma. In fact, milder forms of TBI account for at least 75 percent of all traumatic brain injuries in Canada, yielding an annual cost of nearly \$17 billion to our healthcare system (Northern Brain Injury Association of BC, 2016). Alarming, the annual incidence of TBI is greater than that of multiple sclerosis, spinal cord injury, HIV/AIDS and breast cancer combined, taking the lives of approximately 11,000 Canadians each year (452 people are brain injured each day). It represents Canada's leading killer and disabler of Canadians under the age of 40 (Brain Injury Association of Waterloo, 2014). Despite the general trend that the vast majority of individuals diagnosed with MTBI fully recover and return to pre-injury levels of function, many (approximately 10-20%) continue to report ongoing symptoms associated with their head trauma years later (Northern Brain Injury Association of BC, 2016). This study is about them; the relatively small, but significant percentage of individuals who navigate through life and negotiate the long-term effects of MTBI each and every day.

## 1.2 An Occupational Perspective

The consequences of traumatic brain injury can be mild, moderate, or severe (Foy, 2009). The numerous consequences of traumatic brain injury have been well

documented. Individuals who have sustained moderate to severe head injuries face common physical (e.g., headache, dizziness, fatigue, muscular injuries), cognitive (e.g., memory, attention, concentration, processing, planning, organizing), social, and psychosocial (e.g., anxiety, depression, irritability, impulsivity, self-esteem, suicidal thoughts) limitations and consequences (Guervin & Le Guet, 2012). Such outcomes affect, to some degree, nearly every aspect of an individual's life, including the ability to take care of oneself, engage in paid or volunteer work, participate in fun/leisure activities, express oneself, and experience balanced, fulfilling interpersonal relationships. Although each brain injury is unique and highly personalized, with outcomes dependent upon the mechanism of injury and the precise area of the brain affected, researchers *have* reached consensus that individuals with moderate to severe brain injuries typically experience irreversible effects on their everyday lives and occupations (Guinto & Guinto-Nishimura, 2013). For those diagnosed with milder levels of TBI, however, the symptoms and their effects may not be as obvious, but may still represent catastrophic, disabling forces in their everyday lives. There is a paucity of research about the impact of mild traumatic brain injury on the everyday lives of individuals, and an even greater gap exploring MTBI from an occupational perspective.

As will be discussed in Chapter 2, psychologists have examined the emotional and psychological impacts of MTBI, sociologists have explored the social consequences, neuroscience and medicine have studied the neurological effects of head trauma, and countless other allied health professions (nursing, physiotherapy, social work) have contributed to literature by unveiling important information about the ways in which individuals with MTBI can improve the quality and sustainability of their post-injury

lives. Significant contributions to the literature on MTBI have also been made within occupational science and occupational therapy. For example, occupational therapists have developed effective cognitive aids for increasing short-term memory; useful community participation strategies for increasing social involvement; and proven environmental modifications to help facilitate better learning (Blackwood, 2009). However, despite the plethora of studies providing general knowledge about MTBI, and effective therapeutic management and rehabilitation approaches, there is surprisingly little written about MTBI from the MTBI survivor's occupational perspective. This study explored the effects of MTBI on daily roles and routines, identity and sense of self, and processes of occupational transition and adaptation (which will be defined and discussed in detail in ensuing sections).

Occupational science generates knowledge through research and clinical practice about occupations, or the things that people *do* within their everyday lives.

Occupational science was developed by occupational therapists in the late 1980s in order to strengthen the knowledge and theoretical base of the practice of occupational therapy. An occupational perspective highlights the relationship between occupations (or meaningful daily activities) and health (including the examination of unhealthy occupations). An occupational perspective of health is based on evidence that individuals require meaningful and purposeful occupations in order to help preserve and/or enhance overall health and wellbeing. An occupational perspective of health is unique in that it focuses on the relationship between daily occupations and the physical and social environments in which they take place, rather than solely focusing on

individual abilities, skills, and symptoms. Therefore, an occupational perspective of health is derived from the study of occupational science (Wilcock, 2006).

Existing evidence concerning MTBI provides very little information about the everyday effects of MTBI, or the effects of MTBI from an occupational perspective, which focuses on a way of looking at or thinking about the things that humans do in their everyday lives. Few anecdotal accounts or personal narratives from an occupational perspective exist. What exactly is it like to have an MTBI? What does a typical day look like? What are the obstacles and challenges to having an MTBI while navigating through life at work, home, school, or in the community? How does having an MTBI affect ones daily occupational participation and engagement? Do individuals with MTBI alter their occupational lives in some way, or the things that they do, in order to get by? Do individuals try to hide the residual effects of MTBI? Does having an MTBI affect an individual's identity and sense of self, and if so, how? As suggested, while there has been extensive research about the effects of moderate to severe TBI, less has been explored about mild TBI from an occupational perspective. An occupational perspective involves the ways in which people think, the things that they do, and how they change over time, combined with the importance of examining what we do, why we do it, how we do it, and the effects of those behaviors on our lives and the lives of others (Dawson & Trueman, 2010). This in-depth occupational approach to MTBI provides rich insight into both the personal experiences of MTBI, and the meanings and perceptions of occupation and occupational transition and adaptation after head injury.

The Canadian Model of Occupational Performance and Engagement (CMOP-E) identifies self-care, leisure and productivity as central to the occupational therapy domain of concern, with spirituality at the centre, and attention to how person, environment and occupation fit together (Townsend & Polatajko, 2007, p. 23). Those aspects of doing were central to the current analysis. The Model of Human Occupation (MOHO) adds some additional dimensions that seem essential to this exploration: occupational transition, adaptation, and identity (Kielhofner, 2002; 2008). Occupational transition involves exploring and experimenting, developing skills and habits for new roles, new situations, and new occupations. Occupational adaptation is the process of establishing a new identity through acquiring occupational competence. The goal is “to identify and enact a self and a way of living that is experienced as good... and allows one to realize one’s unique potentials, limitations and desires” (Kielhofner, 2008, p. 129). Occupational transitions are accompanied by potential loss, particularly when socially valued identities are disrupted or discontinued (Vrkljan & Miller Polgar, 2007; Wiseman & Whiteford, 2009). According to Kielhofner (2008), occupational identity concerns the constellation of doing, volition, habits, routines, competences and experiences in relation to an evolving sense of self. Vrkljan and Miller Polgar (2007) further define occupational identity as “the interdependence that exists between what humans do in their environment (occupation) and their perceived sense of self over time (identity)” (p. 31).

Ann Wilcock’s theoretical approach Occupational Perspective of Health (OPH) adds the important dimensions of doing, being, becoming and belonging (2006; see also Hitch, 2014). *Doing* refers to meaningful engagement in occupations, employing skills

and abilities. *Being* is a sense of self as an occupational being, related to meanings, skills and capacities. *Becoming* has a forward-looking aspect, and relates to goals and aspirations, growth and development through occupation. Finally, *belonging* concerns the ways humans connect to others through occupations and the contexts of occupations, forging relationships. Doing, being, becoming and belonging provide a way of thinking about occupation that cross-cut the CMOP-E dimensions, as individual occupations – for example, paid employment – may be defined as productivity, and may simultaneously be an aspect of being (related to sense of self), becoming (through job aspirations) and belonging (through workplace relationships). The analysis employed here will begin from the more descriptive examination of what people do (drawing on CMOP-E, framed as everyday occupations), to analysis of more abstract processes (MOHO's transition, adaptation and identity), to analysis in the final chapter of how the occupational impacts of MTBI affect doing, being, becoming and belonging. Together these comprise an occupational perspective.

### 1.3 What We Know About MTBI From an Occupational Perspective

Several useful studies, stemming from a variety of academic disciplines have been conducted using qualitative designs with individuals who have suffered traumatic brain injuries – with the goal of exploring, analyzing, and describing personal experiences with MTBI. At the same time, several studies in the occupational science literature have examined the personal narratives of persons living with various disabilities, exploring concepts related to disability and occupational identity, occupational transition, and occupational adaptation. With regards to TBI however,



most have focused on more severe injuries. Information gleaned from studying occupational concepts of identity, transition, and adaptation, while not directly related to MTBI, provide a basis from which to further explore in-depth experiences of MTBI-beyond simply examining the occupations that people engage with and the difficulties and challenges that might arise while doing so. It is important to examine MTBI from an in-depth occupational approach because survivors tend to face a 'new normal' which may involve the renegotiation of an occupational identity (gained through processes of occupational transition and adaptation). Therefore, we need to dig under the layers of occupational engagement and learn more about the deeper effects of MTBI at the everyday level. Occupational science has examined the impacts of events such as the onset of multiple sclerosis, moderate and severe traumatic brain injury, stroke, retirement, and homelessness on occupational identity, and processes of occupational transition and adaptation. These indicate the importance of examining the everyday implications of major transitions and how these are impacted by disability and changes in ability.

The next chapter will examine disparate fields of evidence relevant to this research study including: general knowledge about TBI (including definitions, mechanism of injury, symptomology, and recovery trajectories); a focus on MTBI from clinical and psychological literatures; personal accounts of first-hand lived experiences of MTBI; and occupational science analyses of occupational transitions that may shed light on processes involved in changes to everyday life that occur with a traumatic onset of disabilities, such as MTBI.

## 1.4 Statement of the Problem

While many studies have examined the lived experience of persons diagnosed with various cognitive and physical disabilities, along with numerous studies exploring the impacts of MTBI, virtually none have examined the lived experience of MTBI from a detailed occupational perspective. This study explored the effects of MTBI on self-care, leisure, and productivity at an everyday level, along with information about how MTBI affected processes of occupational identity, transition, and adaptation, including occupational changes (additions and deletions). In the discussion, these results are analyzed using the framework of doing, being, becoming, and belonging (Wilcock, 2006).

Few studies have specifically explored changes within daily lives, including trying to “pass” as non-injured, or “hide” the residual effects of MTBI, as well as potential new occupations in which individuals engage, including peer support and/or advocacy. The purpose of this study was to address these gaps in the literature by developing thick description of the everyday experience of living with a MTBI and its outcomes for a select group of individuals living with MTBI - providing a rich, qualitative analysis from an occupational perspective. It is important to gather this type of information and level of detail because MTBI is outwardly not visible to society, and although it has shown to create drastic effects on the lives of survivors, it is still considered “mild.” It is important to know more about what it was like to live with MTBI, every day, in order to outline just how serious and debilitating the disability can be; subsequently reeducating (and possibly helping to reshape practices and policies within) the academic, clinical, and legal circles involved in the assessment, management, advocacy, and treatment of

MTBI. Finally, I am also an MTBI survivor as a result of a motor vehicle accident, which was largely beneficial to the investigative process. This will be discussed in greater detail in the methodology section.

### 1.5 Method and Research Questions

A phenomenological, descriptive inquiry was used in order to develop deeper understanding of the “lived experience” of mild TBI for individuals. For the purpose of this study, *lived experience* was defined as people’s experiences with the everyday occupations, activities, and tasks with which individuals with MTBI engage, as well as their experiences of adding, changing or abandoning occupations, and finally, their perceptions about the effects of MTBI on their doing, being, becoming, and belonging (Wilcox, 2006).

The main question was: what is the lived experience of mild traumatic brain injury from an occupational perspective? This methodology in particular was used in order to explore the lived, everyday experience of MTBI from the perspectives of six, purposively selected individuals who engaged in two audio-recorded interviews. The guiding sub-questions were:

1. What are the daily effects of MTBI on an individual’s self-care, leisure, and work/productivity?
2. How does MTBI affect processes of occupational engagement, occupational identity, transition, and adaptation, as well as everyday roles and routine?
3. What occupational adjustments (adding or taking away) do people engage with after MTBI (e.g., passing, advocacy)?

## 1.6 Significance to Occupational Therapy

In qualitative research, biases such as personal experience with a topic are seen as valuable to a study because it allowed the researcher to bring in-depth insights to the topic at hand, though they were explored, questioned and directed appropriately. I have worked as an occupational therapist for the last ten years in various clinical settings including community outreach, Veterans Affairs Canada (with individuals diagnosed with MTBI and Post Traumatic Stress Disorder (PTSD), and workplace safety (providing cognitive and vocational rehabilitation services to individuals with MTBI). These clinical experiences enabled me to learn about MTBI, and witness issues surrounding secondary effects (e.g. negative mental health outcomes, vocational interruption, etc.) and transitional and adaptation implications (e.g. social isolation, struggling for legitimacy, and decreased occupational engagement).

Several years ago, I sustained head trauma as a result of a head-on motor vehicle accident. Being an MTBI survivor provided me with a unique insight into the lived world of MTBI and its challenges and limitations – which ultimately helped me better identify with occupational therapy MTBI clients. Finally, because I am involved with the Brain Injury Association of Nova Scotia (BIANS) and sit on the board of directors, I have interacted with numerous MTBI survivors which also helped shed light on the specific challenges and needs within the local MTBI community – especially the existing gap in provincially funded community services for this population. These combined experiences helped highlight my professional and personal interest in the MTBI community – and provided the basis for my interest and involvement in learning more

about and researching this topic. Several quotes, written in my personal journals, are provided in this study and were drawn from my personal experiences and writing.

Occupational therapists more often work with clients diagnosed with moderate to severe traumatic brain injuries within rehabilitation facilities. Because MTBI is a common condition, as mentioned above, therapists are likely to come across clients with MTBI – though an MTBI diagnosis may not be the primary reason for the referral. People with MTBI often face secondary conditions and residual psychological effects including anxiety, depression, substance abuse, social isolation, and suicidal ideation (Bryan et al., 2013). Clinicians may not always know why such secondary conditions are present, or if/when these secondary conditions are the result of MTBI. With increased understanding about the lived experience of MTBI, a new research and clinical direction in occupational therapy may be sparked. Increased awareness about the lived experience of MTBI could help prompt clearer and more effective assessment and intervention guidelines. Therefore, occupational therapy is an important profession in working with MTBI survivors. This research contributes to the interdisciplinary treatment of MTBI because it enables occupational therapists to become more attuned to noticing issues in the everyday lives of their clients, whereas standardized assessments may miss important details. Further, occupational therapists may help translate the learned strategies from this study into their client’s daily lives, which might be strengthened by truly understanding clients lived experience.

Finally, this study has the potential to make a theoretical contribution to existing occupational science literature about the concepts of occupational identity,

occupational transition, and occupational adaptation, building on experiences of people with MTBI. Not only will persons associated with brain injury benefit from this study, information from this study might also benefit a breadth of other physical and mental health groups, as survivors may experience similar themes and daily occupational challenges and outcomes. It may help increase our understanding about occupational adjustments or changes, post-diagnosis, as well as potential new occupations necessitated by living with chronic health conditions. Much can be learned through the exploration of the specific research question for this study: what is the lived experience of mild traumatic brain injury from an occupational perspective?

## CHAPTER 2

### BACKGROUND AND LITERATURE REVIEW

In this chapter, background information about the challenges associated with defining and diagnosing MTBI will be presented. Issues surrounding the potential long-term effects of MTBI, including the diagnosis of post-concussion syndrome, will be explored. A review of the literature will begin with details of the more concrete components related to MTBI including cognitive, sensory, physical, and vocational effects. Next it will examine the social, emotional, and psychological impacts of MTBI, as well as emotional and social considerations including anxiety, depression, PTSD, substance use, and suicidal ideation. Chapter 3 will present the theoretical and conceptual foundations for the study, exploring occupational identity, transition and adaptation.

#### 2.1 Defining Mild Traumatic Brain Injury

Currently, there are no universal standard diagnostic criteria defining MTBI (Guinto & Guinto-Nishimura, 2013). Diagnosis is primarily based on the characteristics of the immediate symptom sequelae following an accident or event (McCrea, 2008). It is universally recognized that one of the greatest challenges researchers and clinicians face is properly defining and diagnosing MTBI, especially when classifying acute symptoms along the mild, moderate, to severe continuum (McCrea, 2008). This is due to the fact that MTBI has been characterized by unclear definitions for more than three decades and there is a continued struggle toward the development of a definite diagnostic identity (Silver, McAllister, & Arciniegas, 2009). Therefore, it comes as no surprise that

the absence of a singular, universal definition has made it challenging to effectively diagnose and subsequently work with or research individuals with MTBI. Survivors face the potential effects of this unclear terminology, first hand. For example, insurance providers may use different definitions of MTBI, each with different eligibility criteria for a diagnosis, which may exclude some survivors from benefits (with differing subsequent return-to-work outcomes). Individuals may spend a great deal of time trying to convince their providers of their validity as MTBI survivors. The point is that unclear definitions within research and clinical circles may have negative implications for survivors, yet we do not know exactly how. It is important to delve deeper into exactly how these terminology ambiguities affect every day occupational experiences.

Terms such as mild traumatic brain injury, mild brain injury, mild head injury, minor head injury, closed head injury, and concussion are often used interchangeably by health professionals (Hou et al., 2012). In fact, finding information about MTBI is challenging because of the ambiguous terminology often found in the literature (McKinlay, Bishop, & McLellan, (2011). Additionally, an individual with an acute concussion may, for example, receive a mild or moderate brain injury diagnosis, crossing over two (mild and moderate) of the three major diagnosis (mild, moderate, and severe) categories of severity along the TBI continuum (Chamelian and Feinstein, 2004). In response to this ongoing diagnostic confusion, experts have suggested that concussion occurring immediately after a variety of traumas be graded according to the criteria established by the American Academy of Neurology (2014). It has been argued, in fact, that concussions and MTBI are essentially the same thing (Foy, 2009); yet others have claimed vast differences between the two (Bergman, Fabiano, & Blostein, 2013), while



some have speculated that the two terms may be differentiated by recovery times (Larrabee & Rohling, 2013). The term concussion has become increasingly absent within clinical, theoretical, and expert definitions of MTBI (Petchprapai & Winkelman, 2007).

To highlight the complexity in this arena, different definitions of MTBI used by various health and governmental agencies are compared in the table below:

<p><b>American Congress of Rehabilitation Medicine (ACRM):</b></p> <p>A patient with mild traumatic brain injury has had a traumatically induced physiologic disruption of brain function, as manifested by at least 1 or more of the following:</p> <ol style="list-style-type: none"><li>1. any period of loss of consciousness</li><li>2. any loss of memory for events immediately before or after the accident</li><li>3. any alteration of mental state at the time of the accident (e.g., dazed, disoriented, or confused), or</li><li>4. focal neurologic deficits that might or might not be transient, but where the severity of the injury does not exceed the following:<ol style="list-style-type: none"><li>a. loss of consciousness of approximately 30 minutes or less</li><li>b. after 30 minutes, an initial Glasgow Coma Scale (GCS) of 13-15, and</li><li>c. post traumatic amnesia (PTA) not greater than 24 hours</li></ol></li></ol>
<p><b>Center for Disease Control (CDC):</b></p> <p>The occurrence of injury to the head arising from blunt trauma or acceleration or deceleration forces with one or more of the following conditions attributable to the head injury during the surveillance period:</p> <ol style="list-style-type: none"><li>1. any period of observed or self-reported transient confusion, disorientation, or impaired consciousness;</li><li>2. any period of observed or self-reported dysfunction of memory around the time of the injury; or</li><li>3. observed signs of other neurological or neuropsychological dysfunction such as:<ol style="list-style-type: none"><li>a. seizures acutely following head injury;</li><li>b. among infants and very young children: irritability, lethargy, or vomiting following head injury;</li><li>c. symptoms among older children and adults such as headache, dizziness, irritability, fatigue, or poor concentration, when identified soon after injury, can be used to support the diagnosis of MTBI, but cannot be used to make the diagnosis in the absence of loss of consciousness or altered consciousness.</li></ol></li></ol>

<p>4. Any period or observed or self-reported loss of consciousness lasting 30 minutes or less. (CDC "Report to congress," 2003, p. 10).</p>
<p><b>World Health Organization (WHO):</b></p> <p>MTBI is an acute brain injury resulting from mechanical energy to the head from external forces. Operational criteria for clinical identification include:</p> <ol style="list-style-type: none"> <li>1. One or more of the following: <ol style="list-style-type: none"> <li>a. confusion or disorientation</li> <li>b. loss of consciousness for 30 minutes or less</li> <li>c. post-traumatic amnesia for less than 24 hours</li> <li>d. other transient neurological abnormalities such as focal signs, seizure, intracranial lesion not requiring surgery</li> </ol> </li> <li>2. Glasgow Coma Scale score of 13-15 after 30 minutes post injury or later upon presentation for health care;</li> <li>3. These manifestations of MTBI must not be: <ol style="list-style-type: none"> <li>a. due to drugs, alcohol, or medication,</li> <li>b. caused by other injuries or treatment for other injuries</li> <li>c. caused by other problems (e.g., psychological trauma, language barrier)</li> <li>d. caused by penetrating craniocerebral injury (Holm, 2005, p. 137-141).</li> </ol> </li> </ol>

**Table 1: Definitions of mild traumatic brain injury**

The challenge with the ACRM definition is timing and documentation. Due to the often tragic nature of, for example, motor vehicle accidents and the typical ensuing flurry of activities post-accident, individuals may not have had the above criteria documented (Ruffolo, Friedland, Dawson, Colantonio, & Lindsay 1999). Interestingly, this definition requires just a single criterion of unconsciousness, amnesia, or any alteration of mental status for a diagnosis of MTBI to be made; hence there is considerable discretion for professionals diagnosing MTBI. In comparison with other definitions, the ACRM is the most comprehensive because of its proposed clinical criteria (e.g., length of coma, duration of post traumatic amnesia, and the Glasgow Coma Scale scores), widespread current usage, and wide acceptance among health

professionals (Baggerly, 2009) – which is why it will be employed as the primary definition for this study.

Alternatively, a strength of the definition used by the National Center for Injury Prevention and Control, lies in the acknowledgment of acceleration and deceleration forces as a mechanism of injury; older definitions required a direct physical blow to the head in order for a diagnosis to be made (Baggerly, 2009). However, unlike the ACRM, it does not specify duration of post-traumatic amnesia (which is important, Baggerly, 2009), so it will not be used in this study. Finally, the world health organization's (WHO) Collaborating Centre Task Force on Mild Traumatic Brain Injury Operational Definition specifies length of loss of unconsciousness (less than 30 minutes) and considers confusion and disorientation at the time of injury. It also specifies length of post-traumatic amnesia (less than 24 hours), which is important because length of post-traumatic amnesia has shown to adequately predict future functional outcomes (Marshall et al., 2012).

However, with narrower definitional criteria there is less room for interpretation which means that individuals with various presentations of MTBI may be excluded from diagnosis, including those seen as “too mild” or “too severe” (Baggerly, 2009). In the end, none of the above definitions are universally used or accepted, and clinicians/researchers are free to employ whichever one they feel most appropriate (Theeler, Lucas, Riechers, & Ruff, 2013). This clearly contributes to ongoing clinical and research confusion that exists today with regard to diagnosis and treatment, which subsequently has implications for individuals experiencing long-term effects of MTBI (discussed later in this chapter). This study embraces the definition/criteria outlined by

the ACRM. Detailed discussion of the complexities of the Glasgow Coma Scale, the neuropathology of MTBI, and the concerns and complications of 'post-concussion syndrome' are presented in Appendix A.

## 2.2 The Expected Course of MTBI

The most common causes of TBI in Canada are falls (45% of hospital admissions for TBI); motor vehicle accidents (36% of hospital admissions for TBI); violence (22-49% of hospital admissions for TBI for those under 60) and sports (28% of children and youth and 8% of adult admissions for TBI are related to sports accidents) ([www.cihi.ca](http://www.cihi.ca)). The most common sports-related injuries are from boxing, football, field/ice hockey, lacrosse, martial arts, rugby, soccer, wrestling, auto racing, cycling, horseback riding, roller blading, skateboarding, skiing, and snowboarding (Brain Injury Association of Waterloo, 2014). The mechanisms of injury in mild, moderate, and severe brain injuries are essentially all the same (Brain Injury Association of Waterloo, 2014). The major difference is the degree of applied force.

The diagnosis of MTBI is largely based on the subjective acute symptoms reported by patients (McCrea, 2008). In most paediatric and adult cases, symptoms of MTBI are transient in nature, with rapid or gradual resolution within days to weeks post-injury (Giza & Hovda, 2001; McCrea, 2008). According to a summary of the results of several studies on self-reported symptoms MTBI, the most commonly experienced acute symptoms of MTBI are: headache, blurred vision, dizziness, subjective memory problems, and other cognitive difficulties and sleep problems (WHO Task Force, May 2014). Importantly, symptoms in approximately 75-80% of individuals with MTBI

gradually resolve within one to two weeks, and sometimes within several weeks (Carroll et al., 2004; Dean & Sterr, 2013; Rohling, 2009; Stulemeijer et al., 2005).

While permanent cognitive, psychological, and psychosocial problems due to MTBI are uncommon (Guinto & Guinto-Nishimura, 2013), there are individuals (approximately 10-20%) who continue to exhibit persistent symptoms related to MTBI twelve months after the original injury (Makdissi, Cantu, Johnston, McCrory, & Meeuwisse, 2013). These individuals do not return to their pre-accident levels of occupational, social, and independent function; a concerning finding for health care providers assisting in their MTBI treatment. These cases often prompts subsequent further investigation into a potential diagnosis of Post-Concussion Syndrome (PCS) (Makdissi et al., 2013).

To date, the cause of persistent PCS has not been agreed upon in research, and physicians and researchers continue to question the validity of it as an actual condition (Meares et al., 2011). Some have speculated that the true cause of PCS may lie outside the biological realm and into psychological and social facets (Lange, Iverson, & Rose, 2011). Specifically, the majority of skeptics about PCS have proposed that it may be merely a result of numerous setbacks in an individual's life: physical, emotional, cognitive, psychosocial, vocational, financial, and recreational disruptions which contribute to what appear to look like MTBI symptoms (King & Kirwilliam, 2011). They postulate that such cumulative stressors interact with personality and pre-existing physical and mental health factors, resulting in an apparent syndrome - post-concussion symptoms are deemed psychosocial in origin, rather than neurological (Dischinger, Ryb, Kufera, & Auman, 2009). This is complicated by common co-morbidities, including post-

traumatic stress disorder, chronic pain, anxiety, and substance use/abuse (Bryant et al., 2012). All of the controversy surrounding diagnoses, plus contestation regarding the origins of symptoms leads to ongoing struggles for legitimacy among survivors of MTBI.

### 2.3 Review of the Literature on MTBI Effects

In the literature, there is a paucity of information from the perspective of the MTBI survivor. Many phenomenological studies have aimed to gain insight into the personal experiences of TBI survivors, however participants have normally fallen along the moderate to severe end of the TBI continuum. In fact, few studies have specifically focused on mild TBI as the neurological condition under review, in spite of the fact that research has clearly and consistently shown distinction among the various severities of TBI. Gaps persist in knowledge about the circumstances surrounding slower and/or incomplete recovery, or post-concussion syndrome. The limited information about mild TBI outcomes tends to explore broad, persistent impacts of MTBI on major life roles and functions, rather than on the personal, everyday experiences of head trauma. This is important because the everyday experiences of MTBI, in addition to changes within daily roles and routines, may help highlight nuanced themes previously undiscovered. Thus, more detailed information is needed concerning the everyday effects of MTBI from the perspective of the survivor. The current study wishes to uncover novel, detailed accounts from the direct perspective of survivors. It also attempts to increase understanding about the ongoing effects of MTBI on everyday life specifically interpreted within an occupational science theoretical framework.

It is also important to highlight the link between the below described person components (e.g., cognitive, affective, and physical body functions) and occupational engagement and performance. Occupational therapy explores the relationship between the components of a person, the things they do (occupations which include activities and tasks), and the environment (Townsend & Polatajko, 2013). All three of these facets (person, occupation, and environment) are interrelated and overlap and affect one another. Therefore, before discussing concepts of occupational transition, adaptation, and identity, it is important to first highlight the effects of MTBI on the person, as well as occupation, in order to paint a clearer picture about how the components affect these occupational processes and alternatively, how the process of transition, adaptation, and identity affect the components of a person.

#### 2.4 Cognitive Effects of MTBI

MTBI has repeatedly been shown to create an adverse effect on cognition. This has been well established in studies with athletes, military, and civilian trauma survivors (Bryant, Vasterling, & Keane, 2012). The significant effects of injury on cognition are normally identified in the initial days after the injury and according to the literature, typically resolve themselves within 3 months (Bergman et al., 2013). Therefore, the vast majority of individuals do not exhibit lingering cognitive symptoms beyond 12 months. However, this does not mean that all MTBI patients recover fully within such a time frame. A small, though significant percentage (approximately 10-20%) of individuals with MTBI (typically co-morbidly diagnosed with post-concussion syndrome) continue to experience negative neuropsychological effects years later, and sometimes throughout their lives. These individuals, sometimes classified as 'complicated' cases, who present

symptoms at least 12 months after their original injury, comprise of the participant base for this study. This diagnostic group is understudied and overlooked within clinical and research facets, but as suggested, the outcomes which have been reported, including severe psychological, social, and vocational consequences, are devastating and are important to explore further.

Cognitive and sensory impairments commonly associated with MTBI include effects on memory, attention, concentration, problem solving, planning, processing, organization, fatigue, vertigo, dizziness, vision, language, and self-awareness (Nolin, 2006; Stulemeijer et al., 2006; Erez et al., 2009; Norrie et al., 2010; Barwood & Murdoch, 2013). The diagnosis of MTBI is based largely upon the subjective complaints and symptoms reported by individuals with suspected cases (Gosselin & Tellier, 2010). Similarly, the word “recovery” normally implies that the self-reported symptoms of MTBI have reached a point of resolution (meaning that symptoms no longer exist). As stated in the previous chapter, the diagnosis of Post-Concussion Syndrome (PCS) is typically attached to individuals who report continued, persistent symptoms at least three months after an MTBI.

The most severe cognitive (and physical) symptoms are normally reported and evident within minutes of the injury itself and tend to gradually improve within hours of the injury. Total delayed symptom onset is rare. While certain symptoms may be delayed until the person attempts usual occupations involving, for example, concentration, a total delay of symptoms (not experiencing or reporting anything until days or weeks after the injury) is rare and often viewed as questionable within clinical



and legal settings (Bergman et al., 2013). Typically, gradual symptom recovery occurs over a period of 7-10 days in an overwhelming majority of cases (approximately 80%) (Cantor, Gordon, & Gumber, 2013). In general, individuals with more severe forms of complicated MTBI (e.g., structural visual damage or seizures) have been shown to recover at much slower rates (if at all) and they may continue to exhibit prolonged cognitive symptoms years later (Dean & Sterr, 2013).

Post-traumatic headache (PTH) is perhaps the most commonly reported persistent, post-traumatic somatic symptom of MTBI (Theeler, Lucas, Riechers, & Ruff, 2013). It has also shown, both clinically and in research, to linger the longest (Bosco, Murphy, & Clark, 2013). PTH has been described by clinicians as the most problematic in terms of clinical management due to the fact that the majority of treatments for headaches do not always work for this population (Packard, 2002). Often presenting in the form of severe migraine, PTH can be found across the TBI spectrum, however evidence suggests it is more prominent within the mild, as opposed to moderate/severe TBI populations (Bosco, Murphy, & Clark, 2013). One explanation could be that, according to the research, PTH may be strongly linked to sleep disturbances (Gosselin & Tellier, 2010). Hypersomnia (inability to stay awake) and insomnia (inability to fall asleep), combined with impaired vigilance (often due to fatigue) are among the most severe and disabling symptoms for individuals, affecting about 50% of the MTBI population (Gosselin & Tellier, 2010). Sleep deprivation has been consistently shown to negatively affect a breadth of outcomes following an MTBI, including low energy, extreme fatigue, and poor cognitive and social functioning (Gosselin & Tellier, 2010), as

well as increased frequency and intensity of PTH (Theeler, Lucas, Riechers, & Ruff, 2013).

Similarly, in relation to sleep, research has found a conclusive connection between sleep disturbances and depression as a co-morbidity (Gosselin & Tellier, 2010). Despite the fact that the pathology of sleep-wake disturbances remains somewhat unclear, studies have shown that poor sleep quality consistently reduces cognitive test performance scores within MTBI populations – particularly on information processing speed and short-term memory (Dean & Sterr, 2013). PTH has also consistently been correlated with the diagnosis of mood disorders including persistent anxiety (Theeler, Lucas, Riechers, & Ruff, 2013), which will be discussed in greater detail later in this chapter. While such co-morbidities have been well-documented, a paucity of information exists about how these actual outcomes affect an individual's everyday life.

Research has repeatedly shown that decreased attention is the primary neurological effect of MTBI (Baggerly, 2009). Several outcomes associated with compromised attention include: mental slowness, inattentiveness, difficulty concentrating, distractibility, memory difficulties, and forgetfulness (Nolin, 2006; Blanchet, 2009; Erez et al., 2009; Wong, 2010; Bergman et al., 2013). Similar to other MTBI outcome timeframes, inattention normally dissipates and resolves itself within several weeks after the injury. Importantly, several useful studies have attempted to explore personal experiences with inattention. For example, individuals with MTBI described their impaired attention as feeling “like I’m in a fog,” “being in a dream,” and “hazy” when Wrightson and Gronwall (1981) interviewed participants (90 days post-

injury) using open-ended questions in a survey format in order to gain knowledge about their personal experiences with various cognitive limitations. When asked about feeling different than usual, participants reported feeling strangeness, unreality, being in a dream, detached, and not one-hundred percent (Wrightson and Gronwall, 1981).

When asked about impaired performance, participants in Wrightson and Gronwall's (1981) study reported feeling slow, possessing a bad memory, poor concentration, and the inability to properly solve a problem. These descriptions of the cognitive effects of MTBI have provided rich information about the personal, subjective viewpoint of participants, however they do not describe exactly *how* these experiences with inattention affect individuals on an everyday level. For example, *how* exactly does feeling hazy or like being in a dream affect one's ability to take care of oneself or others, work productively, effectively interact with family or friends, or experience leisure/fun?

In addition to inattention, another cardinal feature of MTBI is fatigue. Although traditionally difficult to quantify (and subsequently treat), research has proven that mental fatigue can be long lasting, ranging from weeks to a lifetime (Johansson, Berglund, & Rönnbäck, 2009). When asked about fatigue, Wrightson and Gronwall's (1981) participants reported being tired, irritable, and sensitive to noise. Not only does fatigue decrease physical levels of energy, but it also negatively impacts other cognitive functions including information processing speed (most significantly), short-term memory, and divided attention (Konrad et al., 2011). Fatigue reduces activity levels both at home and work, and within leisure and social pursuits (Stulemeijer et al., 2006) and may contribute to a reduced quality of life (Cantor, Gordon, & Gumber, 2013). Fatigue

has also been strongly linked with co-morbid depression, often precipitating a vicious cycle – low energy levels dissuade individuals from participating in meaningful activities, which, over time, creates feelings of depression (Cantor, Gordon, & Gumber, 2013). Conversely, a depressed mood often leads to decreased energy levels, which in turn, contributes to the inhibition of participation in meaningful activities (Norrie et al., 2010). One MTBI survivor described needing to perform everyday tasks more carefully post-accident, due to fatigue, saying “everything takes a lot of effort and can be quite draining” (Nochi, 1998, p. 872).

Research has also found a strong association between all degrees of TBI (mild, moderate, and severe) and balance dysfunction and dizziness (Chandrasekhar, 2013). Specifically, dizziness (and frequently co-morbid nausea), vertigo, imbalance, and gait ataxia (found in more severe forms of TBI). One MTBI survivor once wrote, “I felt uneasy going up and down the stairs, and always made sure a handrail was nearby– I was afraid of tumbling down” and “I often banged into bed posts, walls, and people, and found myself frequently misjudging the distances between objects” (Butler, 2014). Shortly after being diagnosed with MTBI, the same survivor wrote “I was fearful about going out in public because I was afraid I’d get dizzy and queasy, so I tended to avoid community activities altogether” (Butler, 2014). Such descriptions are helpful in shedding light about how dizziness may affect engagement in certain everyday activities. The current study will explore in depth such everyday nuances in order to gain rich, detailed information about just how MTBI affects the life and occupations of survivors (in everyday life).

Memory is another cardinal impairment of MTBI, and its effects on cognition have been well-documented in the literature, albeit not typically from perspective of the mild TBI survivor. Sternberg (1999) defines memory as “the means by which we draw on our past experiences in order to use this information in the present” (Sternberg, 1999, p. 112). Memory is the term given to the structures and processes involved in the storage and subsequent retrieval of information (Nolin, 2006). The hallmark feature of Diffuse Axonal Injury (DAI) in MTBI is Retrograde Amnesia (not remembering events just prior to a blow to the head). However, due to limitations with post-MTBI encoding (the process of being able to take in new information and keep it stored), post-event amnesia, or anterograde amnesia, is often more prevalent in MTBI populations where recovery is slow (Rees, 2003).

Previous studies of memory dysfunction following MTBI have investigated basic components of memory such as types of memory loss (e.g., retrograde or anterograde amnesia), limitations in short-term memory, and treatment strategies within a clinical population (Nolin, 2006). However, Erikson, Karlsson, Borell and Tham (2007) produced a useful, novel study using 4 in-depth participant interviews in order to examine the lived experience of memory impairment (on an everyday level) following brain injury. Specifically, the findings revealed four main themes that described participants’ experiences during the first year of rehabilitation. In the *Chaotic-Life World* theme participants described their lives as confusing, frightening, and full of chaos. Importantly, performance in their daily activities felt “fragmented” (e.g., having to force one’s self to think about putting the dishes away after washing, whereas pre-injury it would have come automatically). Here, procedural memory (remembering the order or

procedure for activities and tasks) was prominently affected, as was getting lost in conversations (attentional) and remembering what was said, plus loss of control over memory ability. In the *Struggling for Coherent Doing in New Contexts* theme participants described challenges with mastering new activities that were not previously integrated into their habit-body, and therefore automatic. Participants discussed the role of interruption (e.g., divided attention) and personal strategies used to regain cognitive order and remember things. In the *Conscious Strategies in New Contexts* theme participants created strategies to establish new habits in new contexts, such as enhancing memory structure (for example, environmental reorganization of items around the house to cue memory). Finally, in the *Achieving New Habits* theme participants re-engaged with familiar activities, which gave them a link to their former life and created increased automaticity in their lives again, as ways to enhance memory and gain confidence within themselves (Erikson, Karlsson, Borell, & Tham (2007).

Overall, the study showed, through lived experience, how participants' life-worlds (including memory) had suddenly changed following brain injury. However, the study did not distinguish the MTBI sub-population from the moderate to severe TBIs, and participants also included survivors of other forms of brain injury, including stroke, as opposed to trauma. Although symptoms may be similar between traumatic and acquired brain injured groups, it must not be assumed – outcomes likely differ greatly.

Qualitative studies and personal accounts can be valuable in learning about specific impairments (e.g., memory) related to MTBI because they suggest occupational effects. In a qualitative study with TBI survivors, one MTBI participant reported, in

relation to memory impairment, “I cannot understand myself” and “this is not like me: “I can’t remember clearly, you know. I remember driving to a throughway, but that’s all I can recall. It’s like a void, a black hole. My memory is like a chalkboard where some part is erased” (Nochi, 1998, p. 871). She also reported “my brain is short-circuited” and “my brain shuts down (Nochi, 1998, p. 872).” Another female survivor reported not being able to remember salad dressings on a restaurant menu but she could understand an in-depth professional lecture on linguistics (Nochi, 1998). In another study with TBI survivors by the same author, one graduate student described concrete coping strategies to address memory impairment:

I suffered a concussion not long after winning a \$30,000 academic scholarship, and began to find answering multiple-part questions to be a problem due to short-term memory limitations. Now, each time someone asks me a two-part question, I subtly touch a finger-tip to the table and leave it there as a signal to myself (Nochi, 2000, p. 1798).

In summation, there is ample evidence from neuropsychological studies about the presence of persistent, debilitating lifelong difficulties among some MTBI survivors (Ponsford et al., 2012). Headache, depression, sleep disturbances, dizziness, attention impairment, fatigue, and problems with memory are all common factors that affect daily living. Like Nochi’s (1998, 2000) previous qualitative research with TBI survivors, this study will move beyond the exploration of component impairments and into the investigation of in-depth, personal accounts of occupation-focused MTBI life.

## 2.5 Physical and Sensory Effects of MTBI

In addition to known cognitive outcomes, MTBI is also associated with physical and sensory outcomes which can include: balance and coordination dysfunction, hyperacusis (difficulty tolerating sounds), photosensitivity, nausea, pain, and soft tissue damage (Sherman, Goldberg, & Bell, 2006). Physical pain is a subjective experience, and can be transient in nature (Gallagher, Drance, & Higginbotham, 2006). However, the literature has established a clear link between chronic pain and MTBI. Consistent with the biopsychosocial model of illness, which states that biological, psychological, and social factors are involved in the causes and manifestation of health and disease, individuals with MTBI report that chronic pain often interferes with their everyday occupational, social, vocational, and recreational activities (Weyer, Schroeder, & Ruff, 2013). Similarly, we know that decreased occupational participation in meaningful activities can create subsequent feelings of social isolation for individuals limited by pain, as well as physical deconditioning, and consequences with mood, including anxiety and depression (discussed later in this chapter). In turn, each of these negative outcomes may exacerbate experiences of pain, like so many other vicious cycles associated with chronic conditions.

Physical outcomes associated with the MTBI have implications for everyday functioning. For example, neck injury is theorized as the most common cause of post-traumatic headache (Bosco, Murphy, & Clark, 2013). Possible mechanisms may include structural damage from acceleration or extension of the neck, development of myofascial pain and trigger points, interaction of the trigeminal and upper cervical



(occipital) nerves (Packard, 2002). Equally importantly, Dikmen, McLean, and Temkin (1986) found that pain associated with orthopedic and soft tissue injuries contributed to ongoing difficulties associated with vocational and leisure pursuit. Researchers have also explored the diagnosis of the popular term 'whiplash' and its effects on everyday life, and have shown a strong association between a number of musculoskeletal and neurological symptoms, including headache, neck pain on palpation, muscle pain, and pain or numbness radiating from the neck to the hands or shoulders (Suissa, Harder, Veilleux, 2001). In reference to physical outcomes related to an MTBI, one university athlete reported, "After hitting my head during the game, I could not regain my balance....I could not see straight when I tried to shoot foul shots, and could not even sit up without falling over" (Lyons, Brain Injury Association of America, 2014). Another survivor reported, "I can't brush my hair over the impact site because it still hurts years later" and "my ankle, head, shoulder, and low back ache from time to time, randomly, unprovoked....by noon I usually feel like a zombie" (Butler, 2014).

While the basic physical and cognitive effects of MTBI have become more established and somewhat clearer in the literature within recent years, little information is known about the effects of MTBI, for example, on occupational identity, adaptation, and transitions post-injury, as well as on quality of life and occupational balance, and potential occupational alternations (adding new occupations or taking away previous occupations). More detailed, in-depth information is required, both theoretically and clinically. What exactly is it *like* to have an MTBI and live with the symptoms outlined above? How do cognitive and physical sequelae of MTBI affect a typical day in the life of a survivor? What are the specific obstacles and challenges faced by MTBI survivors while

navigating life at work, home, school, or out in the community? Gaining more descriptive information about the day to day experiences of people with MTBI is analogous to plotting new, little communities along a roadmap to a recently discovered place. It is uncharted territory and needs to be explored in-depth.

## 2.6 Vocational, Educational, and Volunteer Impacts

Subsequent to cognitive and physical outcomes, vocational and educational pursuits are often impacted by MTBI. Employment and employment status are highly valued in Western society and as a result, most adults are expected to work within paid employment as a major contribution to society (Benedictus, Spikman & Van der Naalt, 2010). Brain injuries have repeatedly been shown to cause catastrophic changes to an individual's vocational life (Guerin, Kennepohl, Léveillé, Dominique, & McKerral, 2006). The vast majority of individuals who have sustained an MTBI are in fact, young adults who, prior to their head trauma, worked full-time jobs outside of the home (Guerin et al., 2006). However, within the MTBI population, rates of full return to work are consistently poor. The literature has shown that failure to successfully return to work (RTW) following an MTBI can lower motivation towards engagement in one's rehabilitation. Vocational involvement (in any capacity) is an important contributor to an individual's sense of accomplishment, meaning, and feelings of self-esteem and self-worth (Hooson, Coetzer, Stew, & Moore, 2013). Vocational outcomes post-MTBI have been shown to affect nearly every domain of an individual's life. Becoming re-engaged with a meaningful, societal contribution (such as work) may act protectively for an individual's healing and health – yet for so many survivors of MTBI, returning to

employment after a head injury is often frustrating and unsuccessful in terms of quality and quantity of work (Johansson & Tham, 2006).

One study, which examined vocational outcomes in MTBI survivors who had apparently recovered from the majority of their symptoms and had been cleared for return to work, found that 92% of participants endured chronic employment problems due to absentmindedness, poor planning and anticipation, indecisiveness or faulty decision making, erratic quality of work output, unreliability in work attendance, inability to learn from errors, and an inability to get along socially with coworkers and supervisors (Varney & Roberts, 1988). Although MTBI patients have been shown to have consistently higher return to work rates than those with moderate to severe TBI (Guerin, 2006), not all individuals with MTBI return to work at the same rate, or with the same pre-accident capacity or quality.

Researchers have attempted to explore the personal experiences of return to work from the direct viewpoint of the survivor, following traumatic brain injury (Johansson, 2006; Mealings, Douglas, & Olver, 2012; Hooson, Coetzer, Stew, & Moore, 2013). For example, Hooson, Coetzer, Stew, and Moore (2013) explored the experience of return to work (RTW) with 10 participants with TBI using semi-structured interviews in a phenomenological study. The experience of returning to work was found to be both painful and difficult. The majority of participants experienced a distinct grief reaction in the process of exploring re-engagement in occupations following their head injuries. Specifically, 4 major themes emerged from the results including: *personal costs of*

*lifestyle losses; impact of TBI on my work now; factors impacting the rehabilitation period; and what helped in return to work rehabilitation.*

In the *personal costs of lifestyle losses* theme, participants described a loss of self, and a loss of feeling part of the work gang, along with amended future occupational dreams, and re-defined wellbeing in the vocational sense. One participant reported, “The laughter, the camaraderie of it all . . . supervising lads, telling people what to do . . . I miss that” (Hooson, Coetzer, Stew, & Moore, 2013, p. 27), while another stated, “My promotion prospects within my current employment are probably diminished” (Hooson, Coetzer, Stew, & Moore, 2013, p. 27). In the *impact of TBI on my work now* theme, participants reported volunteering, re-training, and returning to previous employment opportunities, post-injury. With reference to volunteering, one participant candidly reported, “It was decided [by the clinicians] that I couldn’t work on a full-time basis and I couldn’t go back to my previous remit” (Hooson, Coetzer, Stew, & Moore, 2013, p. 27). In the *factors impacting the rehabilitation period* theme, participants experienced, for example, a change in their physical abilities and a rollercoaster of emotions after returning to work. One participant reported, “It absolutely knocked me sideways. I was so angry. . . ummm. . . It wasn’t my fault” (Hooson, Coetzer, Stew, & Moore, 2013, p. 27). Finally, in discussing *what helped in return to work rehabilitation*, participants reported having faith in clinicians’ knowledge and guidance, and family involvement as supportive factors for RTW. One participant stated, “All three, occupational therapy, speech and language and physio so...they all tie in hand in hand I think...without one I wouldn’t be the person I am now” (Hooson, Coetzer, Stew, & Moore, 2013, p. 27).

Another study (Rubenson, Svensson, Linddahl, & Björklund, 2007) collected data from 8 acquired brain injury survivors. Through the use of open ended questions in interview format, investigators gained insight about participants' personal experiences with returning to work, post-injury. The analysis of the data uncovered four major themes including: *a new person, stimulants and fellowship, understanding and support, and to reach insight*. One participant described profound emotion and feeling like a new person in returning to work, stating, "I felt it the first week already and then, when I went home, after two hours I needed to stop, and tears just ran down my cheeks" (Rubenson, Svensson, Linddahl, & Björklund, 2007, p. 208). In returning to work, participants described feeling a greater sense of stimulation if 'meaning' was attached to their particular job, as well as increased value in general as a result of socialization with others while on the job. Increased personal satisfaction also occurred when participants returned to the work force. They described this sense of increased social support and stimulation as a 'fellowship' which helped increase participation in the workplace and overall productivity. Maintaining a job was seen as both important and meaningful to personal security, especially for male participants (Rubenson, Svensson, Linddahl, & Björklund, 2007). Conversely, for others, paid work was not regarded as crucial to happiness and meaning, as long as participants engaged in other meaningful pursuits, including volunteerism, which helped facilitate fellowship through shared occupations (Rubenson, Svensson, Linddahl, & Björklund, 2007). Others expressed profound frustration while returning to the workplace, sometimes due to unaccustomed limitations. One participant reported, "In my case it was frustrating that I had so few working hours. There was a lot to do, but I only managed to begin certain things. I could

not be there and follow up the things I had started” (Rubenson, Svensson, Linddahl, & Björklund, 2007, p. 209). In the *understanding and support* theme, participants experienced support and understanding from managers and colleagues after their return to work, stating that this in and of itself was a prerequisite to a successful return to work, albeit for many it was only through the securing of part-time status. Finally, in the *reaching insight* theme, participants described internal resources like feeling social, happy, and positive as useful in their vocational experiences. Other resources mentioned included carefulness, creativity, and flexibility. One woman stated, “I try to take it a little easier....take breaks and maybe stretch the working day instead” (Rubenson, Svensson, Linddahl, & Björklund, 2007, p. 209).

The results of the study by Rubenson and colleagues (2007) clearly show that returning to work after an ABI is a process in itself, which takes a great deal of patience and time. Participants described this process as having to get to know a whole new person/employee in themselves, as another new facet in their post-accident lives. Kielhofner (2008) perhaps best described how individuals think and feel about work by suggesting that if work is interesting, meaningful and valuable, and if individuals believe in their own ability, they will become motivated to engage in paid employment. However, Johansson and Bernspaang (2003) purported that it is equally as important to consider both the individual’s work ability *and* valuation of work, because both factors influence intrinsic motivation. In either case, individuals with MTBI clearly face enormous personal and vocational challenges associated with returning to work after head trauma (Rubenson, Svensson, Linddahl, & Björklund, 2007; Hooson Coetzer, Stew, & Moore, 2013). Although the literature has shown similar trends in the difficulties

faced by those with TBI and ABI, few studies have specifically examined MTBI in relation to work. It has already been well established that MTBI, in comparison to more severe forms of TBI, carries distinct differences in both presentation and outcome, which may affect work outcomes, including job type, duties, and relationships with bosses and coworkers. More information is needed in order to determine how everyday life, including vocational pursuits, are affected by MTBI from an occupational perspective.

## 2.7 Emotional and Social Effects of MTBI

While the literature extensively outlines the sequela of cognitive and physical outcomes related to MTBI, it has been less inclusive in exploring social and psychological impacts. The cognitive, behavioral, and social outcomes may represent the most disabling forces in the lives of MTBI survivors (Ponsford et al., 2012). This notion was demonstrated when Ponsford et al., (2012) found that at two years post injury, 97% of a group of 175 moderate to severe TBI survivors were able to walk independently, whereas more than 70% reported ongoing cognitive and social/behavioral difficulties. However, this study did not include mild TBI as part of the evaluation; current MTBI statistics about these comparisons are needed. While the literature suggests that the psychosocial and emotional consequences for individuals with TBI represent a complex interplay of changes in cognition, behavior, and personality resulting directly from the brain injury and secondary problems (e.g., social isolation, anxiety, depression, substance use, low self-esteem and motivation), it is not known exactly how this interplay affects people with MTBI on an everyday level, and from an occupational perspective. Finally, there has been relatively less documentation about the

emotional/behavioral and social consequences of MTBI from the view of the survivor, which deserves greater academic attention (Ponsford et al., 2012).

Emotional and psychological symptoms are, in fact, often difficult to recognize and describe (Stoler, 1998). While individuals with MTBI may realize that something is not right emotionally (e.g., slight feelings of depression or anxiety), they may be less likely than non-brain injured populations to recognize and subsequently report the severity of their emotional symptoms. Embarrassment about emotional and behavioral issues is common after head injury and the literature suggests that individuals with suspected MTBI tend to be more comfortable discussing physical, as opposed to emotional, complaints with care providers (Gallagher, Drance, & Higginbotham, 2006). This scenario is complicated by the fact that many emotional and psychological symptoms typically have more than one underlying cause (Bay & Donders, 2008); some may be directly related to the area of the brain impacted (e.g., frontal lobe and subsequent deficits in emotional regulation), while others may result from secondary outcomes (e.g., depression and/or anxiety). Several emotional and psychological outcomes related to MTBI will be discussed below.

Post-Traumatic Stress Disorder, or PTSD, is also commonly co-morbid with TBI (and MTBI). PTSD may occur after exposure to a traumatic or life-threatening event, including motor vehicle accidents, physical or sexual assaults, natural disasters, serious accidents or injuries, or after exposure to other threats of death. Diagnosis can be made when individuals present with a set of symptoms including recurring flashbacks (e.g., day or night time nightmares), avoidance or numbing of memories of the event (e.g.,



not driving near the scene of the accident), and/or hyperarousal (e.g., intermittent high levels of anxiety) which must be present for more than a month preceding the traumatic event (CMHA, 2014).

Bryant and Harvey (1999) compared survivors of MVA's with and without MTBI's. Results revealed that despite the fact that both groups of participants exhibited high levels of stress associated with recalling their car crashes, participants in the MTBI group, who were also diagnosed with post-concussive disorder, were more often diagnosed with co-morbid PTSD. However, some have argued that because MTBI survivors are often diagnosed with amnesia (anterograde and retrograde), they are incapable of "reliving" a traumatic event which they are unable to recall in the first place (Bryant, Vasterling, & Keane, 2012). In either case, little information about personal experiences related to PTSD, from the perspective of the MTBI survivor, is available. How does experiencing symptoms of PTSD along with the other symptoms of MTBI, for example, affect an individual's ability to work, take care of one's self, interact with others, and experience fun? More information about everyday experiences is needed.

Experiencing MTBI is often viewed by survivors as a personal disaster (Baggerly, 2004). More often than not, individuals report experiencing feelings of defeat, frustration, and inadequacy, combined with anxiety over the sudden lack of control over their changing post-accident lives (e.g., changed relationship or employment status) (Chamberlain, 2006). Emotional elements after MTBI include denial, avoidance, emotional numbness, anxiety, grief, and guilt (Johansen, 2002). Other psychological responses include aggression, anger, social withdrawal, lack of control, and

overwhelming sadness (e.g., clinical depression) (Bay & Covassin, 2012). Studies have identified a substantially higher risk of anxiety and depression following MTBI than non-injured populations (Moore, Terryberry-Spohr, & Hope, 2006). In 2011, Meares et al. investigated the association between post-concussion syndrome and psychological outcomes in 122 trauma patients compared with a control group diagnosed with orthopedic injuries only and found that the MTBI group reported significantly higher psychological symptoms overall – concerning findings. While depression and anxiety may be more prevalent within the MTBI population, their precise effects on an individual’s everyday life and functioning is less known. Study participants likened having MTBI to experiencing an imbalance of harmony between the mind and body, causing subsequent intense emotional pain. The pain was debilitating. One participant claimed, “It (MTBI) has affected every aspect of my life, from life with my husband and children, while at work, and while with friends. The effects have been profound” (Meares et al., 2011, p. 945).

The literature clearly shows strong social effects of MTBI. For example, individuals with MTBI involved in romantic partnerships have reported drastic changes within their relationship responsibilities and roles as a result of their head trauma (Alston, Jones, & Curtin, 2012). This may be affected in part, by changes in coping and communication styles and alterations to personality and behavior including increased agitation and irritability, and/or depression (Van der Horn, Spikman, Jacobs, & van der Naalt, 2013). MTBI survivors have reported surprise concerning the severity of the effects on their relationships (Arnold, 2004). Conversely, spouses have also reported life-altering changes within partnerships and marriages. One spouse stated, “It was like

living with a stranger” and another claimed, “I missed that old person. That fun, loving, sweet woman I fell in love with. Life was just different. She was different” (Godwin & Kreutzer, 2013, p. 5). The literature also suggests that survivors often change (or in some cases give up) previous domestic responsibilities including household chores (e.g., cleaning or cooking) and daily tasks (e.g., getting groceries and doing errands, independently) as a result of headaches, low energy, and fatigue, leaving their partners with increased domestic burden (Peters, 2014). These role reversals have been shown to increase levels of stress within even the closest relationships and deeply alter life at home for survivors and their families (Bay & Covassin, 2012). Partners assuming such new tasks find themselves with less time available for previously enjoyed activities and pursuits, which can lead to long standing resentment at home (Johansen, 2002).

Sadly, many intimate relationships, including successful long-term marriages and partnerships, do not survive MTBI. Divorce rates for TBI are surprisingly high (estimated at 70%), and although MTBI relationship statistics are not clear to date, the literature show evidence of failure in both romantic partnerships as well as friendships (Andersson, Elgmark, Bedics, Kärrdahl, & Falkmer, 2011 ). In my own journaling, post-accident, I described changes within my long term romantic partnership: “I slowly went inward. The further I delved within, surrounded by my own grief, trauma, and subsequent bad choices, the further I removed myself from him....over time, I felt like I became another person and eventually, I lost him - he was the love of my life” (Butler, 2014). More information from an occupational perspective is needed concerning how relationships function on a daily basis, post MTBI. How exactly are they affected? What factors contribute to interpersonal and relationship changes and decline?

Other relationships may be affected as a result of personality changes and emotional consequences of MTBI. In her book on coping with MTBI, survivor and psychologist Diane Stoler (1998) includes the stories of multiple survivors describing post-injury effects on mood - subsequently affecting their interpersonal relationships. In reference to mood changes post-accident, one survivor reported, "I was a calm, patient person who could cope with stress and handle many situations at once. But one year after my accident.....I was in a conversation with my teenage daughter and I suddenly flew into a rage" (Stoler, 1998, p. 271). Another survivor reported frequent crying spells, irritability, and mood swings post-MTBI diagnosis (Stoler, 1998, p. 271). One young woman diagnosed with MTBI reported, "I rarely cried prior to my accident but I now find myself weeping and becoming extremely irritable for no reason," whereas someone else described their post-MTBI emotional state as, "I'm always worried about things.....always thinking negative thoughts about my situation and my life." Another described post-accident depression as "debilitating.....lurking just beneath the surface at every moment" (Stoler, 1998, p. 271). The impact on friendships and familial relationships is understandably profound, and often negative.

Not surprisingly, social isolation following MTBI is common and can deeply affect the lives of survivors (Alston, Jones, & Curtin, 2012). Due to changes in employment status (e.g., loss of a job or reduction in work abilities), cognitive capabilities, and overall psychological health and wellbeing, emotional and social lives are almost always affected among people with traumatic brain injuries (Arnold, 2004). However, as previously stated, MTBI is distinct from moderate to severe forms of TBI and needs to be explored if researchers and clinicians are to better understand it and better help

survivors. With increased understanding about the everyday effects of MTBI on social relationships, for example, clinicians might better prepare clients and their loved ones for post-injury social expectations and provide social connections and supports (Blackwood & Wilson, 2009). Increased knowledge about the effects of MTBI on everyday lives and occupations might also help prevent some of the common, predictable social outcomes related to MTBI, or at least help lessen their impact.

There is evidence that individuals with TBI are at an increased risk for suicide (Wasserman et al., 2008). A study by Simpson and Tate (2007) assessing suicidality in outpatients found that 17% of individuals with TBI had attempted suicide after head injury. In essence, individuals with a history of TBI reported a higher frequency of suicide attempts than those without TBI (8.1% vs. 1.9%). Even patients with non-complicated concussion have been found to be at an increased risk of suicide, which is startling (Simpson and Tate, 2007). Less is known about these associations within the MTBI community. In examining the everyday effects of MTBI on the lives of survivors, it would be important to know about the direct risk factors for suicide as well as the impact of occupations on these risk factors, from both an academic and clinical perspective. The literature has shown that a significant portion of MTBI survivors experience depression and anxiety so it is important to know if suicidal thinking commonly ensues these secondary (to TBI) conditions (Brenner, Homaifar, Adler, Wolfman, & Kemp, 2009).

In another study, Simpson and Tate (2005) found that survey respondents with a comorbid post-injury history of psychiatric/emotional disturbance and substance abuse were 21 times more likely to have made a suicide attempt, post-TBI, compared with

respondents without a history. Participants identified various contributing factors to their suicidal ideation including: *depression/hopelessness*: “I was sick of being the way I was” and “I wish my life had ended at the accident;” *relationship breakdown, relationship conflict, social isolation* (e.g., loss of friends since the TBI); *pressure of multiple stressors, instrumental difficulties* (e.g., lack of finances, work difficulties); and more generally, the *global impact* of the injury. These findings suggest that exploring suicidality is an important aspect of an occupational exploration of MTBI, especially in individuals with co-morbid conditions.

## 2.8 Substance Use

There is widespread recognition that a strong relationship exists between traumatic brain injury and substance use disorders (SUD) exists. In many cases, use of drugs and/or alcohol has been shown to steadily increase after a MTBI (Miller et al., 2013). Even compared with more severe forms of TBI, MTBI has shown to result in “weakened self-control among individuals which can lead to excessive alcohol use, and even eventual dependency” (West, 2011). Further, individuals who have suffered head trauma are more vulnerable to alcohol, with greater physiologic effects after consumption, because of neurological changes in the brain as a result of the head injury, combined with increased sensitization to the impact of the substance use over time (Vasterline, Bryant, & Keane, 2012). Corrigan and Cole (2008), cited in Vasterline, Bryant, and Keane (2012), showed that up to 50-65% of individuals with a TBI (80% of their sample were diagnosed with MTBI) reported frequent alcohol consumption, post-head injury. This statistic calls for alarm. In other words, over half of all MTBI survivors struggled at some point with drug or alcohol use/abuse following their head trauma.

These implications are profound, especially given the fact that substance use has been suggested to negatively permeate nearly every major facet of an individual's life, health, and wellbeing (West, 2011).

According to the literature, there are several key reasons for an increased risk of substance related disorders within the MTBI population: 1) Substance use may be a coping response to the psychosocial stressors of disability, 2) Substance use may be a consequence of damage to brain circuits known to mediate addiction (disrupting incentive-motivation neurocircuitry or causing persistent executive cognitive deficits), and 3) Substance use may represent self-medication for chronic pain or attentional/cognitive dysfunction (Heuchemer & Josephsson, 2006; and West, 2011).

The point is, substance use is a substantial concern within MTBI populations which will require respectful consideration within this study. It is more than possible that themes concerning substance use may surface in an occupational analysis of MTBI. In reference to alcohol consumption post-accident, in my own post-MTBI journal I wrote, "I turned to drinking because it took my mind off the trauma of the accident and the ensuing behaviors which eventually became my downward spiral." Further "drinking (and smoking) was the ultimate escape, until it eventually caught up with me when I realized that I had changed as a person. Underneath it all, I really just needed to come to terms with the fact that I was damaged. The very thing that I constantly relied on, as an OT, musician, and writer, was broken. I was broken. I needed to face my new reality, head-on, and actually grieve the lost grace of my old brain."(Butler, 2014).

Research has also shown a relationship between alcohol dependency and social isolation. According to the literature, as a rule the more dependent an individual becomes on a particular substance, the less likely they are to engage socially (Miller et al., 2013). In turn, social engagement decreases (at times to the point of withdrawal) which usually leads to increased rates of alcohol consumption (Bryan et al., 2013). This cyclical relationship is cause for concern, given that individuals with MTBI consistently report social isolation following an injury (Arnold, 2004). Survivors of TBI have also reported that excessive alcohol intake often creates feelings of anxiety, anger, and inadequacy; difficulty initiating and maintaining social relationships, problems with authority, communication problems; and ineffective social skills (Miller et al., 2013). Substance use and possible addictive behaviors are important to explore with MTBI survivors. Little is known about the effects of substance use on the everyday lives of individuals with MTBI, although several known outcomes are associated with substance use, including decreased functional independence, sickness, medical consequences, lack of community integration, disability, and lowered life satisfaction (West, 2011). More information is needed about exactly how substance use affects the processes of occupational transition, adaptation, and identity, for people with MTBI.

## 2.9 Summary

In summary, it is apparent that the cognitive, physical, emotional, and behavioral consequences of MTBI may create substantial effects on everyday occupation. This is clear in the literature. First hand perspectives from survivors can help enlighten clinicians and researchers about the lived experience on an everyday level, which is the issue at the heart of the matter. Even the most savvy medical practitioners and



researchers may be left in the dark when compared with those who have experienced a life changing event, including MTBI, personally. In this section, several of the cognitive, social and emotional, and psychological outcomes associated with MTBI were presented in order to help pave the road to deeper themes regarding occupation at a more theoretical level. The next chapter will examine theoretical concepts related to the direct questions posed in this study, including occupational transition, adaptation, and identity following MTBI, situating the research in the context of occupational science.

## CHAPTER 3

### CONCEPTUAL AND THEORETICAL FRAMEWORK

#### 3.1 Occupational Transition, Adaptation, & Identity

*“How strange that the nature of life is change, yet the nature of human beings is to resist change. And how ironic that the difficult times we fear might ruin us are the very ones that can break us open and help us blossom into who we were meant to be” (Elizabeth Lesser, Broken Open: How Difficult Times Can Help Us Grow, 2013).*

Traumatic brain injury has been described by survivors as a catastrophic, life-changing event. It often results in severe daily occupational disruption and creates enormous impact on the daily roles and routines of survivors, negatively affecting occupational engagement, performance, and balance (Blackwood, 2009). TBI poses significant challenges to an individual’s sense of well-being and autonomy, and has shown to decrease quality of life (Hoogerdijk, Runge, & Haugboelle, 2011) and impact occupational identity (Alsaker & Josephsson, 2003). Given these potential outcomes, it should come as no surprise that TBI represents one of the greatest causes of occupational dysfunction and disability for survivors, and hence, rebuilding a life post-injury is no easy feat. Changes in cognition and memory, endurance, motor function, regulation of emotions, behaviors, and the ability to take care of oneself, work, and socialize with others are but a few facets affected by head trauma – each becoming entangled in an intricate, interwoven web of life-long transitions and adaptations in the things that people do to take care of themselves and others. Such processes become part of life’s reconstruction, post-injury, and are inextricably linked to TBI survivors, albeit to different degrees and along multiple dimensions for individuals.

In-depth definitions of occupational transition, occupational adaptation, and occupational identity will be explored in greater detail in this chapter, however it is useful to briefly outline them here. Occupational *transitions* are changes in occupational expectations or demands (changes can be by choice or circumstance) and are central to occupational therapy because they involve taking risks and making adjustments to the activities, events, and changes we experience in our lives (Crider, Caldwell, Bunting and Forwell, 2015). Occupational *adaptation* is changing how we engage in occupations to overcome challenges and barriers and meet occupational goals, and requires shifts in our behaviours, roles, and self-concept or *identity* (Parsons, & Stanley, 2008). It is important to point out that there seems to be ambiguity within the literature about these terms: some claim that transition comes before adaptation (a linear process), while others posit that both occur simultaneously and are interrelated to and affect one another (Cotton, 2012). Due to the fact that these concepts overlap, it's probably safe to assume that the processes of occupational transition and adaptation affect individuals differently and at different times (especially because all three terms, including occupational transition, adaptation, and identity are constantly interrelated and fluctuations within any one of these facets affect the other components). This study aims to tease out distinctions among these processes/terms with our own participants.

The literature shows that following TBI, an individual's daily occupational roles, routines, and habits, each contributing to a life structure, become disrupted and more often than not, lost as a result of head trauma (Christiansen, 1999; Charmaz, 2002; Cotton, 2012). An individual's sense of meaning, purpose, and accomplishment, and overall identity, become altered because head injury often affects an individuals' ability

to evaluate and recognize their actual potential, which, depending on the severity and location of the injury, may be affected by neurological damage to centers of the brain that control insight and judgement (Hoogerdijk, Runge, & Haugboelle, 2011). Being required to complete a familiar, previously effortless activity or task (following MTBI), with decreased occupational ability, may create a disjunction between the old and new self (Bryson-Campbell, Shaw, O'Brien, Holmes, & Magalhaes, 2013). The incongruence between new and old ways of doing things can lead to an overwhelming sense of frustration and helplessness within survivors (Bryson-Campbell, Shaw, O'Brien, Holmes, & Magalhaes, 2013).

Most survivors initially report longing for their pre-accident selves and lives, and the vast majority experience a deep sense of emotional and occupational loss following head trauma (Hoogerdijk, Runge, & Haugboelle, 2011). It can take years to rebuild the pieces of a life destroyed by TBI, and a lengthy process in order to address subsequent occupational alterations (e.g., adding or taking away occupations), including the ways in which individuals participate in occupations (Boehm, 1998). While some individuals successfully rebuild their occupational roles, routines, and sense of identity following head trauma, others continue to struggle throughout their lives (Hoogerdijk, Runge, & Haugboelle, 2011). Despite these differences in outcomes, one thing is certain: an overwhelming majority of TBI survivors report undergoing some degree of occupational transition, adaptation, and identity transformation (Boehm, 1998). Such processes are rarely linear and tend to play out differently for individuals, highlighting the need to further investigate and understand the everyday occupational experiences of TBI, and especially MTBI survivors.

According to the literature, three major overall themes pertaining to TBI survivors' experiences with occupational transition and adaptation exist. In order to regain lost or forgotten feelings of mastery, autonomy, independence, and self-accomplishment, individuals who do the following 'adapt' better than those who do not: 1. Recognize their post-injury deficits; 2. Learn to truly accept them; and 3. Incorporate them into their new occupational lives (Boehm, 1998). These steps can be frustrating and lengthy, but if survivors honestly evaluate old and new abilities, roles, and routines, and develop effective subsequent occupational *adaptations* in order to cope with the transition, new meaningful lives may be forged (Hoogerdijk, Runge, & Haugboelle, 2011).

Although most TBI survivors experience some form of emotional and occupational transformation following injury, little is known in the literature about how these processes are experienced on an everyday level by the MTBI population. Are there similarities and/or differences in occupational outcomes between mild, moderate, and severe survivor populations? It seems reasonable to speculate that differences in functional levels might at least in part be as a result of level of injury, among other factors. In other words, individuals diagnosed with moderate to severe brain injuries likely experience different occupational outcomes than those diagnosed with MTBI living independently within their communities. However, is this always the case? We do know that survivors of MTBI report experiencing occupational disruptions and changes post injury. It is important to know more about what exactly these disruptions look like and how they are experienced on an everyday level. To what degree and how do survivors deal with them and navigate through their new occupations lives? Are there

factors which buffer or hinder the transition and adaptation processes? Although most transformations are often initially painful, positive transitional outcomes have been reported (Shaw & Rudman, 2009). For example, survivors have reported feeling as though they were given a second chance at life, reborn (Cahill, Rotter, Lyons, & Marrone, 2014), stronger, more refined in their occupational identity, possessed greater hope and optimism about their new lives, and more knowledgeable about what was truly important in life, including family and friends (Wiseman & Whiteford, 2009) proceeding head trauma.

For others, life represents a never-ending struggle perpetuated by an endless state of hopelessness, depression, and despair (Barker-Collo, Starkey, & Theadom, 2013). It may be within these vast occupational outcome differences, through the exploration of the everyday experiences of MTBI survivors, that answers to some of the questions posed in this study may be found. Insight into how and why the processes of transition and adaptation occur differently might help shed light on how occupational therapy may better prepare itself for preventative MTBI intervention, along with how it might act as a buffer in quelling anticipated negative, post-injury outcomes (Blackwood & Wilson, 2009). Given the potential gravity of these transitional/adaptive processes on health and wellbeing, further exploration is needed.

### 3.2 Occupational Transition

*“Perhaps one of the most incredible transformations participants seems to undergo pertained to their sense of self. Imagine if you will, a metamorphosis which is regressive rather than progressive - a butterfly transforming into a caterpillar. Add to this scenario one peculiarity, the caterpillar remembers it was butterfly, believes it still is and is motivated by this remembrance to once again be a butterfly.” (Author unknown)*

Navigating through life at any turning point can be both risky, and painful (Inkman, 2001). However, the transition from one phase to the next might be underestimated. There is a tendency to look at where others “end up” (e.g., situated in a new career, stable following an illness, officially retired, etc.) as opposed to how they actually got there, or the transitional processes experienced in order to achieve new beginnings. This may arise from, and certainly contributes to, the view that transitions are relatively easy to deal with or negotiate; after all, we have all experienced transition in our lives. Transition may be defined as movement, passage, or change from one position, state, stage, subject, concept, to another (Bridges, 2003). Shaw and Rudman (2009) summarized occupational transition by claiming, “Transitions are changes in what people do, are expected to do, or need to do...They involve taking on new sets of occupations and fitting these new occupations into other ongoing occupations, while relinquishing other occupations” (p. 362). The concept of occupational transition focuses on how such changes are negotiated by individuals, how the environment shapes them, and how the person and social context influence them (Shaw & Rudman, 2009).

The most common transitions in our culture include transitioning from one grade level to the next in school, post-secondary training, beginning a career/job, purchasing a home, marriage, having children, changing relationships, and retiring (Butler, 2015). However, like fingerprints, no two transitions are alike. Some create greater effects on our occupational lives than others. Kimmel (1980) first enquired about the occupational aspects of transition when he argued that, “rather than passive adjustments, transitions may be viewed as active adaptations involving complex processes having implications

for population-based patterns of occupational participation” meaning that individuals don’t just necessarily ride along a transition wave passively, rather actively participate in the process of adjusting to new life events or situations (Kimmel, 1980, p. 246). Bridges (2003) suggested that, “transition is a three stage psychological process that people go through as they internalize and come to terms with the details of a new situation, caused by a change in life circumstances (Dodds and Herkt, 2013, P. 5). Lastly, Blair (2000) purported that occupational transition involves risk, adjustment, and adaptation, resulting in shifts in behavior, roles, and self-concept.

Occupational scientists bring a unique perspective to the concept of transition, compared with other professionals. Historically, social scientists have paid more attention to life stages than to the transitions between them, which tended to simplify the progression between these stages. Occupational scientists delve a bit deeper into transition by dissecting it into the things that people *do*, including changes within roles, routines, and habits, as well as how changes within the self/identity occur, both during and after the transition (Blair, 2000). In terms of occupation, transition requires adaptation in terms of these changes in roles, balance of occupations, and occupational performance (Jonsson, Josephsson, & Kielhofner, 2001). This has been nicely illustrated in the literature by a plethora of studies examining transitional processes associated with disability, as well as research involving changes around vocation (e.g., retirement, job loss and change, and other career changes), smoking cessation, immigration, and homelessness – all from an occupational transition standpoint.



These studies have examined the process of transition, in-depth, focusing specifically on how individuals have transitioned from one life stage to the next, including how alterations were made to the things that they *did* every day, as well as how they felt about their evolving selves and lives throughout and after the process- all of which impact occupational identity. The doing (engagement with activity) seemed to symbolize and parallel changes with the being (e.g. the self). The connection between the two could more easily be analysed, which became central to developing patterns or themes related to transition in general, from an occupational perspective. However, despite the breadth of information pertaining to the aforementioned studies on transition, little is known about occupational transition of MTBI. There are merely a handful of articles outlining occupational transition post-TBI in general, and even fewer specifically related to MTBI. By drawing upon the unique presentation of MTBI, understanding transitions for this population may help yield information that could help benefit the lives of survivors, as well as impact interventions they typically receive. Considering the ongoing nature of symptoms following MTBI (e.g. post-concussion syndrome), transitions within work, family, and social environments may be challenging and occur long after structured supports are available. Therefore, a deeper understanding of such transitions, the unique challenges faced, and ways in which people with MTBI overcome them, can assist others in preparing for such transitions.

Transitions may be planned and expected (e.g., purposefully re-scripting vocation, including career directional change, retirement, or a career break) or unplanned and unexpected (e.g., being fired from work, coping with a life altering medical diagnosis or traumatic event, including TBI). There are transitional phases

common to both planned and unplanned life events, including: loss, an in-between period, and a new beginning. The literature suggests that in the loss phase, individuals identify a “gap” or something missing within their current situation (e.g., dissatisfaction with work, a hobby, medical issue, social life, etc.) and subsequently experience dissatisfaction with a particular component of their life (Boehm, 1998; Dodds & Herkt, 2013). This is followed by the largest chunk, the transition period, which involves transformation or changes within an individual’s physical, emotional, environmental, social, familial, financial, and vocational environments – consequently influencing one’s sense of identity in some way (Dodds & Herkt, 2013; Hallqvist & Hydén, 2012). The transition phase, the phase in which the greatest transformation occurs, is often the painful part of adaptation regardless of the type of transition or where it might be heading (Jonsson, Josephsson, & Kielhofner, 2001 ). In this stage, individuals may resist change within themselves or their lives and may experience a mismatch between their goals and abilities, leading, in many cases, to anxiety, depression, frustration, mismanaged time, activity imbalance, disorder, chaos, loss, and grief. Finally, as the dust settles, a new beginning or period of adaptation to the transition occurs, and ideally individuals eventually reach acceptance of their new ways of living and being (Walker & McNamara, 2013). Subsequent new roles, routines, and habits are incorporated into daily life again and individuals are able to re-establish successful occupational engagement, competence, performance, and balance (Buning, Angelo, & Schmeler, 2000). Whether one sees this as light at the end of the tunnel, or the beginning of a new journey, the processes associated with occupational transition and adaptation might

hold the key to the creation of new, meaningful occupational lives and enhanced occupational well-being.

The literature shows, through consensus about the typical/common steps involved with transition, that the above mentioned common transition phases may co-exist with several important component processes which are also part of planned occupational transitions, including: 1. A life changing experience or event (e.g., MTBI or job loss); 2. A pondering or reflection about the way things are or are not – which includes some degree of dissatisfaction with an aspect of life; acknowledgement of deficits and/or limitations, or the inability to do something; 3. Looking for change, or making a conscious decision to work toward recreating an identity and sense of being or new life activity or role; 4. Motivation to become independent and autonomous; 5. Active participation in restructuring one's occupational life and identity; and 6. Accessing social supports in order to sustainably move forward (Cahill, Rotter, Lyons, & Marrone, 2014; Dodds & Herkt, 2013; Wiseman & Whiteford, 2009). Aspects of these processes have been shown to be common in studies of the occupational transitions such as retirement (Wiseman and Whiteford, 2009), immigration (Hon, Sunm, Suto and Forwell, 2011), and driving cessation (Anstey, Windsor, Luszcz, & Andrews, 2006).

Transitional processes have been shown to be rather different when the occupational transition is occasioned by injury, health condition, or disability (Felix et al., 2013; Hallqvist & Hydén, 2012; Myers, 2006; Pettican & Prior, 2011; & Walker & McNamara, 2013). Such transitions are generally unwanted and unexpected. According to the literature, occupational transitions which occur as a result an unexpected change

in health or ability typically involve the following processes within various health groups or diagnoses: 1. Life changing illness/event; 2. Realization that things are different in life post illness/injury and that the self and occupations have changed (things cannot be performed the way they used to be); 3. Feelings of loss and longing for the old self and life, including previous roles, routines, meanings, habits; 4. Engagement with the occupational adaptation process, either knowingly or inadvertently; 5. Occupational disruption and/or dysfunction which can include social withdrawal, substance use, anxiety, depression, etc.; and ideally 6. Occupational transition, which entails acceptance and potential for a transformed occupational identity.

When transitions are the result of injury or illness, occupational disruption can be profound, as individuals experience limitations in everyday life because of the disjuncture between old and new abilities. This can create considerable discomfort as individuals attempt to accomplish tasks/activities the way they used to. For change to occur, moving beyond occupational disruption appears to rest on motivation to change something within existing occupational roles, routines, and social lives, and within the sense of identity (Dodds & Herkt, 2013). It appears that individuals also need increased social support while coping with lost abilities (e.g., support from family, friends, or professionals). This can raise complex responses, including anger and denial (Bay & Donders, 2008). Moving forward involves two crucial steps: 1) acknowledging losses, followed by acceptance of the losses, letting go of resistance, and 2) finally embracing change. Ultimately, the hope is adjustment to the outcomes related to transition (and eventual adaptation) including an altered social, physical, cognitive, financial,

environmental, and educational life, along with transformations in identity, well-being, and quality of life.

There are important differences between injury/illness-related occupational transitions and planned, anticipated transitions. Resistance, grief, and a sense of loss are predominately found when transitions are related to medical disability. Unlike individuals who have time to ponder immigration or retirement, for example, individuals who have experienced trauma have had little to no time to plan or prepare and are forced to adapt the best they can (Bay & Covassin, 2012). Traumatic events tend to be swift in nature, and survivors are left in the wake with a potential mismatch between their old and new capacities and identities (Charmaz, 2002). While intrinsic motivation may contribute to successful transitions for both groups (Scornaiencki, 2013), individuals experiencing medically-related transitions such as TBI may be disadvantaged in relation to successfully navigating through their transition. For example, in addition to decreased motivation secondary to neurological damage and acute neurological stress' associated with the traumatic event itself, motivation may be affected by a litany of secondary factors including denial, anger, stress, disbelief, and other psychological, financial, social, and vocational issues (Bryant et al., 2010).

Individuals who experience trauma often resist change (Scornaiencki, 2013) because it is forced upon them. Although individuals who have not experienced trauma may too feel stuck or rooted in their previous abilities, the biggest difference is that trauma survivors do not initially have a choice about transitioning to a new life...they are forced to somehow manage to catch up, despite the fact that they weren't ready. We

know from occupational therapy literature that one of the key features of sustainable change is personal choice and control over our lives and destinies (Scornaiencki, 2013). Eventually, after a long and often painful road of transition, or recovery, many find their place within themselves and the community again, however, initially, survivors may resist new ways of being and doing.

Survivors may reject the idea that they are no longer the person they used to be, and hold on to self-perceptions rooted in their previous occupational abilities (Williams & Murray, 2013). Following head injury, for example, an individual's occupational skill set may become mismatched with current abilities and experiences of occupational environments. A TBI survivor required to shop for groceries while under the glare of bright lights in a crowded environment might experience occupational performance challenges including: taking longer to complete the activity, forgetting items on the shopping list, fatigue or headache secondary to the activity, or possibly avoiding the activity altogether. Yet, prior to their injury, they were able to perform this occupation with ease. Such a disjuncture may lead to overwhelming feelings of failure, hopelessness, depression, and despair (Blackwood & Wilson, 2009). This merely represents one example about how an individual, amidst transition (learning of their new ability set), makes sense of the world and environment around them. Eventually, they may find an optimal time of the day to shop, stick with a certain store or location, or recruit a family member or friend to perform the activity altogether. The point is, that these seemingly insignificant daily activities help highlight the broader processes and themes related to the discussion of transition and identity in this study.

### *Factors found in successful transitions*

Three key factors contributing to successful transitions appear to include: 1. Motivation to change (e.g., a willingness to participate in planning one's future); 2. The influence of social support; and 3. Personal reflection/honesty (e.g., moving past denial and honestly evaluating abilities/deficits and accepting the new self and life) (Bryson-Campbell, Shaw, O'Brien, Holmes, & Magalhaes, 2013). Buning, Angelo, and Schmeler (2001) interviewed two individuals who had switched over to power mobility (from independent ambulation) and identified two key themes related to transition: participants were intrinsically motivated to become more independent and autonomous within their lives, and experienced subsequent greater feelings of competence, adaptability, and self-esteem when transitioning because of their initial choice in changing their mobility habits. From her examination of employment transitions Scornaiencki (2013) suggests making a conscious decision to recreate and restructure one's life, including components of identity and sense of being, contributes to a smooth and successful transition. Self-knowledge (e.g., about strengths and abilities) and honesty (e.g., realistically evaluating abilities, which requires a level of insight) were essential characteristics. When they conducted in-depth interviews with occupational therapists who had decided to return to work following a lengthy career break, Dodds and Herkt (2013) found that participants had to individually navigate their own path to return to practice in order to optimize satisfaction and outcomes. The key was that individuals were required to navigate their *own* path to return to practice by acting *self-directed* and *autonomous*. Participants directly faced the transition (described as initially daunting), adjusted their outlook, and adapted to new circumstances, which resulted in

shifts in their behaviour (Dodds & Herkt, 2013). Evidently, intrinsic motivation acted as a catalyst toward creating sustainable, lifelong adaptation.

The link between social support and transition is paramount. Thompson and Fraser (2011) found that despite the apprehension experienced by participants transitioning from students to registered occupational therapists, peer mentorship, peer support, and shared wisdom (from both therapists and clients) enabled the students to successfully transition into their new roles. In Dodds and Herkt' (2013) study exploring professional re-entry, those who did not 'fit in' right away experienced inadequate social support, poor sense of professional identity, and limited or inadequate on-site reorientation. Most relevant to this study, when interviewing eight TBI survivors, Rubenson, Svensson, Linddahl, and Björklund (2007) found that returning to work following severe head injury was a long, painful process that required motivated individuals, workplace flexibility and accommodation, and long standing social support in the workplace. Each factor contributed to sustainable return to work.

Lack of social relationships – but also poor quality social relationships – can hinder successful transitioning. In a study with homeless women, Heuchemer and Josephsson (2006) found that although social support helped bind participants together and strengthen parts of their identities (and daily occupational regimes), some social relationships hindered their ability to live independently. Participants wishing to transition from homelessness to independent living found themselves unsupported while in abusive relationships, thus perpetuating cycles of abuse and prolonging goal attainment and sustainable, successful transition.



One of the central themes in the literature pertaining to successful transitions was the importance of self-reflection and honesty. Hammell (1999) discovered that individuals stricken by a catastrophic event could only move forward (and transition successfully) once their feelings of loss, anger, and frustration about new abilities had been acknowledged and dealt with honestly, including reflections about how their post-accident deficits affected their everyday occupational lives and futures. Scornaiencki's (2013) analysis of two employment transition narratives notes that self-knowledge and honesty, a need for individual growth, necessity, and courage and dedication were all essential factors for successful occupational transition.

#### *Unsuccessful transitions*

According to the literature, not all transitions are successful, initially. Luck and Beagan (2014) explored the occupational transition of smoking to non-smoking when they conducted in-depth interviews with seven female participants who identified as smokers. They found that despite the fact that smoking was considered an unhealthy behavior, it represented an occupation which held meaning, structure, and therapeutic benefit to smokers. When participants described quitting smoking, they reported feeling a deep sense of loss (because they no longer participated in a previously enjoyed occupation), which occasionally contributed to smoking relapse. Adapting to a non-smoking lifestyle meant that participant's daily roles, routines, habits, and relationships were altered and that competence to quit (and to remain quit) required practice and eventually developed over time.

Suto (2009) demonstrated that not all transitions are successful initially, when in-depth interviews were conducted with 14 highly educated women who had well-defined, notable careers and then immigrated to Canada. All of the women found themselves working below capacity (or not working at all), post-settlement. In particular, their new Canadian lives became filled with endless domestic responsibilities, and many of the women experienced downward vocational mobility (Suto, 2009). All women had initially experienced drastic occupational alterations post-settlement including: difficulty balancing work, parenting, employment, and leisure activities; decreased family support due to geographic relocation; occupational imbalance; and increased parenting and domestic stresses. Since each participant worked below capacity once living in Canada (e.g., part versus full time, decreased pay, and less than desirable jobs), they reported feeling unsuccessful compared with their pre-immigration lives. Overall, they personally viewed their transitions as unsuccessful.

Finally, when attempting to understand occupational transition related to older rural men's retirement experiences, farmers who remained part of the farming community post-retirement, experienced greater emotional, vocational, and economic success with transition than those who didn't. During this transition process, new and pre-existing identities were respectively created and preserved, which helped individuals successfully transition and achieve competence over time (Wiseman & Whiteford, 2009). Specifically, those who possessed a sense of control, acted as their own boss, and maintained a state of semi-retirement living, reported increased autonomy and happiness as semi-retirees. Maintaining strong connections with other farmers helped influence positive, sustainable, and successful transitions overall.

Conversely, those who retired “cold turkey” (full to no time status), and who were no longer connected to the farming community reported experiencing greater occupational imbalance and deprivation (e.g., sense of loss in their previous occupational roles and routines), along with subsequent depression. In essence, farming seemed to contribute to a valued occupational identity and enduring sense of self which could not be severed immediately. These findings seem to prompt larger, more philosophical questions including what exactly is a successful versus unsuccessful transition amongst individuals with MTBI? How do they define a successful transition? What role does achieving a state of peace and/or happiness following a major life event play, particularly following an unexpected change in abilities (such as MTBI)?

#### *Barriers to transitions*

It is important to describe potential barriers to occupational transitions because the relative ease and success of occupational transitioning is affected not only by personal factors (such as motivation, social support, and honesty) but also by cultural, economic, institutional, physical, social and environmental factors. Although barriers to transition are not the primary focus of this study, they are worthy of briefly exploring due to their potential adverse effect on the lives of MTBI survivors. Also, uncovering barriers to transition within our participant population, it might also help better prepare health professionals in their treatment approaches. According to the literature, policy and institutional barriers affect transition. For example, occupational therapists returning to work following a long-term career break reported decreased professional engagement and professional identity when institutional re-entry policies (e.g., access

to information and job reorientation) were not properly implemented in the workplace (Dodds & Herkt, 2013). Chinese immigrant women (new to Canada) from low economic backgrounds reported decreased occupational choice and engagement as a result of prolonged language barriers, along with acculturation and decreased access to community resources (Hon, Sun, Suto, & Forwell, 2011).

TBI survivors returning to work after prolonged absences faced decreased vocational success when their employers did not provide adequate workplace accommodation, including modifications to the hours worked and type of duties required (Rubenson, Svensson, Linddahl, & Björklund, 2007). Further, immigrants worked below capacity post-immigration, in less-than-meaningful occupations, as a result of strict, costly, and time consuming systemic educational barriers which imposed stringent professional regulations involving re-certification (Suto, 2009). For example, physicians reported strict re-entry guidelines to practicing medicine (e.g. upwards of 2 years in order to gain recertification), which negatively impacted community integration, financial stability, familial engagement, and the overall immigration transition.

The literature highlights the impact of less visible barriers on occupational transition including the effect of social stigma. Using a phenomenological analysis to explore the occupational transition of quitting smoking, Luck and Beagan (2014) found that participants engaged in time consuming occupational behaviors associated with 'hiding' their smoking (e.g., from family, friends, and co-workers). One participant reported "a lot of shame.....I did a lot of sneaking" (Luck & Beagan, 2014, p. 6) and many experienced guilt over their smoking behaviours. Stigma also affected participants'

sense of identity (e.g., feeling like a failure for relapsing) and social engagement opportunities. Since occupational transition, like occupational performance, is a result of the dynamic relationship between people, their occupations, roles, and the environments in which they live, work and play (Baptiste et al., 1993), it is important to examine potential barriers to transition within the MTBI population, especially because so little information about barriers was found within the literature on MTBI (as opposed to TBI). What barriers might MTBI survivors face? Since we already know that the daily roles, routines, and habits of moderate to severe TBI survivors are drastically altered post-injury, it would be valuable to explore potential barriers associated with self-care, leisure, and productivity in our participant group.

### *Summary*

Survivors of MTBI may experience drastic changes within their daily occupational roles, routines, and habits, and identities, and may subsequently spend years cognitively, emotionally, and socially “stuck” within occupational transition (never really adapting successfully to their new life and self). They may or may not need assistance in identifying gaps, or something missing, from their post-injury lives, and while many possess the insight required to change their lives and desire a different future – many, due to the nature of neurological damage, do not (as described in the aforementioned sections on negative personal and occupational outcomes). While other transitions may be simultaneously occurring in their lives, naturally, (e.g., marriage, having children, retirement, etc.), the major “full-life” transition to life post MTBI, may be delayed/stuck; causing a disjunction between what someone believes they can do and what they can actually do (creating resistance). Little is known about the MTBI population and how

they negotiate life on an everyday level following head trauma. While we know that survivors are required to individually navigate their own sustainable path to return to life, less is known about their everyday occupational experiences as MTBI survivors in transition.

### 3.3 Occupational Adaptation

Occupational adaptation and transition are inextricably related; as individuals transition from one event, circumstance, or stage to the next, they are required to find ways to cope with and eventually adapt to their new state of being and living (Bontje, Kinébanian, Josephsson, & Tamura, 2004). Originally defined by Fidler and Fidler in 1978, occupational adaptation was described as the extent to which persons are able to develop and change in response to challenges, or otherwise achieve a state of well-being through the things that they do. Kielhofner proposed that *adaptation* “is the construction of a positive occupational *identity* and achieving occupational *competence*, over time, in the context of one’s environment” (Kielhofner, 2008, p. 107). Schkade and Schultz (1992, p. 831) used the term *adaptation* while referring to “a state of competency in occupational functioning towards which human beings aspire,” and Spencer, Cole, Davidson, and White (1996, p. 189) summarized occupational adaptation as being “a cumulative process emanating from one’s life history.” Through a large-scale, qualitative study based on life history interviews with individuals who had experienced major life illnesses, Mallinson, Mahaffey, and Kielhofner (1998) discovered that adaptation consisted of two distinct elements: *identity* and *competence* (which will be discussed in greater detail below).

Adaptation is a key concept to the profession of occupational therapy (Bontje, Kinébanian, Josephsson, & Tamura, 2004). As a health profession aimed at promoting meaningful occupations as interventions in order to assist individuals with adapting to life after illness/disability (Kielhofner, 2002), occupational therapy asserts that adaptation can be described in 2 forms: the state itself and the process. The state is defined as having reached competence in occupational functioning (Schkade & Schultz, 1992), while the process being one “through which the person and the occupational environment interact when the person is faced with an occupational challenge calling for an occupational response reflecting an experience of relative mastery” (Schkade & Schultz, 1992, p. 831). This means that the adaptation process is both individual and internal in nature, and normally evolves through the engagement of actively “doing things” (occupations) which give people purpose, meaning, and structure (Nelson, 1996). This philosophy is central to the theoretical underpinnings of occupational therapy.

Similar to occupational transition, individuals adapting to life following disability almost always report a loss of their former self. Soeker and Shaheed (2011) interviewed ten participants diagnosed with MTBI in a qualitative South African study, through the use of in-depth interviewing, and found 4 common elements in the adaptation process, including: loss of former self, uncertainty about the future, the road to self-acceptance, and participation in occupations that enabled growth. Following injury, participants experienced loss of self, decreased social, cognitive, and physical functioning, as well as decline in confidence, family involvement, and future aspirations and goals. Concerning the future, participants reported fear of the unknown, uncertainty about continued

family support following discharge from in-patient rehabilitation, fear of being a burden on society, and fear of social stigma and judgement. On the road to acceptance people described rebuilding self-beliefs and abilities, strengthening social supports, and reflections about factors that enabled recovery. Finally, in order to enable growth, participants emphasized the importance of actively engaging in occupations that made them feel independent, competent, and physically healthy and socially involved.

For the participants in this study, occupational adaptation was a part of adjusting nearly all of life's major facets involved with occupational functioning. The results highlight the fact that in order to successfully adapt to life after head trauma, individuals had to eventually accept their new identities. To do so required personal reflection (which was still possible despite the cognitive and emotional challenges associated with neurological damage to the brain) and acceptance of loss, which forced individuals to strategize and find new, effective strategies for successful engagement in everyday occupations – occupational adaptation to renew competence in self-care, leisure, and productivity (Soeker & Shaheed, 2011). Further, engagement in familiar occupations enabled participants to form a base from which to develop a new occupational set (e.g., engaging in new activities and finding new ways of performing old activities).

Participants who did not adapt successfully were afraid to try new occupations, usually fearing social stigmas associated with being seen as different or a failure (Soeker & Shaheed, 2011). Such fears can lead to social isolation and occupational alienation. The authors concluded that individuals with brain injuries undergo a process of reflection and self-acceptance before they are ready to readapt to the worker role. They also concluded that self-efficacy beliefs are instrumental to successful occupational



adaptation. New occupational patterns, roles, and routines were formed during the transition phase of adaptation, based on the functional capacity of the individual with the brain injury. These results are very relevant to this study because they provide insight into the process of occupational adaptation and its link to individual's sense of competence and identity.

According to the occupational adaptation framework of reference, adaptation is a normal developmental process which leads to competency in occupational functioning following injury or disability (Schkade & Schultz, 1994). Therefore, occupational competency is an aspect of achieving occupational adaptation. Aligned with critical core concepts in occupational therapy, the frame of reference describes adaptation as a process of developing the skills necessary to perform occupations within the context of specific environments (Gilfoyle, Grady, & Moore, 1981). Adaptation occurs both internally (how we feel) and externally (what we do) as the result of occupational engagement (Nelson, 1996). Adaptation is a lifelong process and not merely an end result; for survivors of head injuries, like all people, it is not an overnight process nor an endpoint. However, the process of adapting to a new life, post head injury, might be different for individuals with MTBI in that they might experience a unique process of reflection and self-acceptance before they are able to authentically and sustainably adapt to new occupational competencies in their post-injury lives.

According to the theory of occupational adaptation outlined by Schultz (2009), occupational dysfunction occurs when the demands of an occupation do not match an individual's ability to successfully complete them. In fact, adaptive capacity can be

overwhelmed by disability. In other words, greater dysfunction normally requires a greater necessity to adapt (Schultz, 2009). This is interesting because one might think that since MTBI doesn't outwardly appear as severe (even structurally neurologically) as moderate to severe TBI, that individuals with MTBI might require less adaptation. This might be somewhat true, especially since MTBI survivors are typically still able to live, work, and function independently (although not always), as opposed to more severe forms of TBI where survivors often reside in assisted living situations and may never work again. However, perhaps some of the environmental factors (e.g. expectations, invisible disability, stigma, etc.) require greater adaptation than one would initially expect. This idea lends credit to Schultz (2009), who posited that occupational adaptation interventions should focus on improving adaptiveness, not just functional skills and abilities.

Theories of adaptation suggest that another primary goal of occupational adaptation is mastery over the environment. Internal factors that make up the person (e.g., cognitive, sensorimotor, and psychosocial) interact with the occupational environment or external factors (e.g., social, cultural, institutional, and physical), influencing one another; the individual is affected by limitations and/or deficits found within both facets. These interactions, between internal and external factors, affect mastery, which in essence, poses the greatest occupational challenge within in the adaptation process because so many factors are at play (Schultz, 2009). The role of the environment in occupational adaptation is pivotal, both shaped by and shaping adaptation (Nelson, 1988). Specifically, the environment includes physical objects, geographic locations, social groups, and culture, each affecting level of functioning.

More importantly, adaptation processes are specific to the individual, taking environmental components into consideration, thus there is no cookie cutter approach to successful adaptation.

### *Importance of occupations in adaptation*

Occupational adaptation not only involves who we are or who we evolve to become as a result of disability, but it also requires purposeful, active engagement in the things that we do, our occupations (Bontje, Kinébanian, Josephsson, & Tamura, 2004). While striving to find satisfaction within occupations, individuals may try to maintain pre-existing roles and routines as well as developing new ones. Bontje, Kinébanian, Josephsson, and Tamura (2004) found that in order for older persons with physical disabilities to successfully adapt to life with physical and emotional limitations, they were required to assume active roles in their post-disability lives. They weighed and secured options for occupational engagement, experimented, practiced and exercised new ways to complete occupations perceived as challenging, utilised social supports, and identified potential solutions to help overcome constraints within their occupational environments.

Lexell, Iwarsson, and Lund (2011) examined occupational adaptation in people with muscular sclerosis and found that, despite adaptation being non-linear and a constant struggle, familiar occupations increased engagement and competency overall, contributing to successful adaptation. This is an important concept: people change, environments change, occupations change, and we must evolve to meet those demands. Their findings appear to align closely with occupational therapy theory that

people can enhance competency in the things that they do if a sense of accomplishment and achievement in active occupational engagement is achieved. Competency is both internally defined (as a state) and may also be achieved when successfully participating in necessary or chosen occupations. According to the literature, the key is that adaptation is holistic overall and must incorporate cognitive, physical, social, and environmental components to well-being.

Following a TBI, loss of self and the road to self-acceptance are overarching themes found in occupational transition and adaptation literature. Williams and Murray (2013) highlighted the internal processes involved in adaptation when they examined the lived experience of occupational adaptation following stroke. They found that true adaptation required emotional persistence and resilience, internal motivation to change (adapting to the new self and living with deficits), and strong individual efforts to make changes. Several important coping strategies were employed by stroke survivors, including: using humor in everyday life, expressive anger, positive self-talk, maintaining hope, feeling fortunate, and accessing social supports (Williams & Murray, 2013). Despite the initial shock to the system and a whole new way of living following stroke, acceptance of the new self has been reported frequently in the literature as key to successful adaptation. Not only are individuals required to change the way that they do things, but also the way in which they feel about themselves and their new occupational lives. It seems that post-injury or disability, people are forced to reframe their identities in order to successfully adapt. Therefore, adaptation requires both a new way of being and establishing new ways of doing (Kielhofner, 2008). Therefore, it is anticipated that several of these emotional/personal themes related to self-identity might be present

within the lives of MTBI survivors and revealed in this study as contributing factors to new lives post head trauma.

#### *Adaptation after brain injury*

*“I found myself pulling away from the people and activities I loved and over time I felt stripped of myself like paint thinner smeared across a wooden surface. Then one day I woke up and realized that I’d become a different person with a new (unwanted) life in the process. In the end, I crashed, grieved my old self and life like a death, and then, when there was no steam left I forced myself to start over, alone (Butler, 2014).*

The few studies explicitly examining adaptation after brain injury are worth discussing in some detail. In a qualitative study with rural people with acquired brain injury (ABI), Parsons and Stanley (2008) found that adaptation only occurred once participants came to terms with actually having a brain injury. Participants needed to accept how different they were, accept their new personalities and lives, learn how to live with permanent deficits, and learn new methods of doing things in order to re-gain independence and meaning. The process of adaptation included self-acceptance, identity transformation, and environmental influences on occupation. Chamberlain’s (2006) study with TBI survivors identified important barriers to adaptation post-injury. These included struggling for legitimacy (e.g., wanting people to believe the severity of injuries), clinicians not supporting and understanding their adaptation process (e.g., pushing for a faster recovery), and emotional challenges such as regret and grief, invisibility and a stranded sense of self, and entrenchment in the past.

Erikson, Karlsson, Borell and Tham (2007) found for their study participants’ lives following head injury were chaotic, filled with confusion, apprehension, and fear (anxiety). They struggled for success performing occupations in new contexts; new activities were difficult to master and unplanned events were challenging. Though they

needed conscious strategies, achieving new habits was possible and occupational adaptation became a reality. In their study, Alston, Jones and Curtin (2012) found women who had survived TBI tried harder than men to 'pass' as non-disabled, in an attempt to be viewed as still "normal." Women disproportionately faced violence and abuse and were frequently taken advantage of, including financially. Women participants experienced greater difficulty transitioning to their new lives and selves, suggesting social inequities - which further complicated adaptation after injury (Alston, Jones and Curtin, 2012). Finally, both Klinger (2005) and Hoogerdijk, Runge, and Haugboelle, (2011) note that adaptation after brain injury is inextricably intertwined with changes in occupational identity.

### 3.4 Occupational Identity

*"The best way out is always through." (Robert Frost)*

Kielhofner (2002) linked occupation with identity in coining the term *occupational identity*, which he subsequently defined as "a composite sense of who one is and wishes to become as an occupational being generated from one's history of occupational participation. One's volition, habituation, and experience as a lived body are all integrated into occupational identity" (Kielhofner, 2008, p. 106). Further, Christensen posed four propositions about occupation and identity including: identity shapes and is shaped by our relationships; identities are closely tied with what we do; identities provide a central figure in a self-narrative that provides coherence and meaning to everyday life; and because life meaning is derived in the context of identity, it is an essential element in promoting wellbeing and life satisfaction (Christensen,

1999). Research has consistently shown a strong connection between occupation and identity, particularly notable in connecting occupational transition and adaptation processes. Restructuring lives means discovering who people really are and the things that are most important to them (Phelan & Kinsella, 2009).

Restructuring the self, following a life-changing event or disability, is no easy feat. Chronic illness often disrupts the taken for granted notions of the self, including the ways people think about themselves and the world around them (Charmaz, 2002). Often, individuals with chronic illness resist seeing themselves as disabled or different than others, and while this has been shown to be a protective factor in psychology, it may also delay the successful formation of new identities during the adaptation process (Alaskar & Josephsson, 2003). Reflections and reassessments about one's self may need to precede positive occupational changes (Charmaz, 2002).

Both preserving aspects of former identity and the development of new aspects of identity may be important. For one stroke survivor, preserving identity meant benefitting from using existing strengths and abilities, and building on past occupational successes (Price, Kinghorn, Patrick, & Cardell, 2012). On the other hand, Howie, Coulter, and Feldman, (2004) found that older individuals with serious illness used crafts as a means to shape new identity. While in the company of other participants they explored new outlets for inward expression, aligned themselves with valued occupations with which they were familiar, and learned from others (Howie, Coulter, & Feldman, 2004). Self-awareness was shown to increase through shared experiences with disability, and social support groups encouraged the development of new skills and abilities. In a

qualitative study examining the negotiation of identities in individuals with chronic rheumatoid arthritis, Alaskar and Josephsson (2013) found occupational histories were interwoven with everyday occupations. Occupations mediated personal meaning, providing experiences of performance capacity and feelings of mastery. Their findings suggest that redeveloping and managing identities, post illness, was an occupation in itself (Alaskar & Josephsson, 2013).

There are a few studies on TBI and identity which illuminate the lived experience. Nochi (1998) qualitatively examined “loss of the self” in TBI, finding that survivors found it difficult to develop clear self-knowledge about how they actually got to where they ended up (e.g., brain injured). This was demonstrated in their realistic expectations about what they could and could not do, occupationally. The loss of the self only became conscious once participants compared their past and present selves and abilities, identifying a relative deprivation within their new occupational lives. These types of revelations are especially difficult for TBI survivors because processes involved with insight and judgement can be affected neurologically. Due to memory loss, participants found it difficult to remember who they were before their injuries. Therefore, rebuilding new identities (based on components of the past) was especially trying. Subsequently, survivors were forced to fill in these blanks in order to bridge their new identities with their old – leading to confusion, frustration and at times, despair throughout the identity reformation process (Nochi, 1998).

Stigma negatively affects successful identity formation. Participants in Nochi’s (1998) study felt as though society judged and viewed them as different and invalid



because of their brain injury status. Many participants disliked the word “disability” because of the negative stigma often attached to it. To combat this participants used specific strategies in order to pass as uninjured or normal, including using certain language (TBI versus disability, or head injury versus brain injury), selectively choosing with whom to spend time, rearranging their occupational time so that busy shopping spaces could be avoided, and fulfilling advocacy roles within the community. Though not specific to mild TBI, this study identifies important processes including experiences with loss and grief, personal reflection about identity, and the creation of new occupational roles and routines, as well as habits following head trauma. In conclusion, the sense of self is complicated, even for non-disabled populations, and requires constant refinement and modification over the life time (Nochi, 1998).

In a further analysis, Nochi’s 2000 study suggests multiple self-narratives may evolve post-injury. The ‘self as better than others’ narrative included language like “it could be worse” and “I’m not as bad as.” The ‘recovering self’ narrative highlighted the road to rediscovering parts of the old self, and involved upholding and embracing positive aspects of the new self. Finally, in the ‘self living here and now’ narrative, survivors worked toward restoring feelings of self-worth by mustering bravery toward their new challenges, and by not adhering to labels imposed on them by society (stigma). They opted to focus on the here and now (present) and reported that this stage involved doing whatever it took to address barriers (Nochi, 2000). The findings of this study suggest occupational identity may evolve in complex and shifting ways after brain injury.

Looking more specifically at mild TBI, Hoogerdijk, Runge, and Haugboelle and (2011) explored how four individuals made sense of the occupational adaptation process post-injury, as well as their specific occupational performance. Using repeated interviews, the analysis indicated that adaptation is centrally about *a necessary struggle to gain a new identity*. Though occupational adaptation involved a protracted learning process, it was facilitated by engagement in familiar occupations within familiar environments. Though each person's process was individual and situated, it was clear that adaptation was necessary in order to gain a new sense of self.

Finally, in a recently published meta-analysis of 16 studies pertaining to changes within identity in TBI populations, Bryson-Campbell, Shaw, O'Brien, Holmes, and Magalhaes (2013) found three common themes: The loss of identity, social stigmatized identity, and structuring rehabilitation practices. In the *loss of identity* theme, participants described damaged or lost identities as a result of TBI which affected occupational engagement and performance. Identity, defined as a missing component to post-TBI life, was something that was once valued to all participants – which made them work more diligently in order to re-establish a new self. The void or emptiness described by survivors was impacted by the occupations in which they chose to engage, and conversely, the occupations in which they engaged shaped their identity by either reinforcing (successful occupational completion) or hindering it (unsuccessful occupational engagement) (Bryson-Campbell et al., 2013).

The authors of this study used “acquired brain injury” as the main search string for the meta-analysis, which means that all levels of severity (e.g., mild, moderate, and

severe) were included in their review. This is important to note because we already know that individuals with MTBI experience identity loss and reformation differently. All ABI survivors cannot and should not be grouped together for this reason, and it is important to view MTBI as a distinct population for a number of important reasons: information is missing about survivors' experiences with daily occupational roles and routines, self-care, and leisure post-injury; little is known about survivor's experiences with occupational transitional, adaptation, and identity; and few studies in occupational therapy have examined the impact of barriers and stigmas on survivors' occupational engagement, participation, and competency.

Most participants experienced shame and confusion as a result of social stigma (theme 2) because they felt society viewed them as stupid or powerless (Bryson-Campbell et al., 2013). These negative social labels attached to their new TBI social identity, which in turn affected occupational engagement, impacted occupational competency overall. Despite many participants struggling for legitimacy and societal acceptance, the review found most professional rehabilitation practices are not structured to address issues of identity (theme 3). It would be beneficial for studies to further explore ways of restructuring rehabilitation in order to support survivors with ongoing identity struggles, including for example, encouraging individuals to take time to grieve and cope with their identity losses, or participate in available cognitive therapy programs in order to assist them with accepting their changing identities. When this was possible, survivors were able to move forward and re-develop who they wanted to become during rehabilitation (Bryson-Campbell et al., 2013). Further, re-establishing community roles by not pulling away but contributing to society, resulted in individuals

finding solace and meaning again (e.g., advocacy for others). This scoping review is pivotal in highlighting the common themes present within a large number of studies. Individuals with TBI who maintained hope and who demonstrated personal choice, intrinsic motivation, growth, freedom, and stimulation within their occupational worlds, were able to combat loss, grief, disempowerment, and social stigma, and develop new self-worth and esteem, personal goals, and create a new life plan – which helped form the foundation for a sometimes stronger, more defined identity as a survivor (Bryson-Campbell et al., 2013).

MTBI negatively affects individuals cognition, social, psychological, and emotional well-being, and negatively affects occupational engagement which eventually requires occupational transition and adaptation. Those processes appear to be accompanied by a necessary shift in identity. Though there has been little research on occupational identity and TBI, there has been important work on broad identity changes after brain injury – some of which has focused on occupational identity within other contexts. Little is known about the MTBI population and how they negotiate life on an everyday level following head trauma. While we know that survivors are required to individually navigate their own sustainable path to return to life, less is known about their everyday occupational experiences as MTBI survivors while transiting and adapting to their new lives and selves. Sadly, often MTBI survivors outwardly appear normal or fine, yet the literature tells us that nearly every facet of their emotional, social, psychological, vocational, educational, and financial lives are disrupted as a result of head trauma. Perhaps this population of people may best represent a “lost” or

“forgotten” group of disability survivors – begging the question, how can we best help them if we know so little about their everyday lives and challenges?

The next chapter details the methodology and research design for this study, followed by two chapters presenting study results.

## CHAPTER 4

### METHODOLOGY

The research question that guided this study was: What is the lived experience from an occupational perspective of individuals diagnosed with mild traumatic brain injury? The sub-questions that guided the research were:

1. What are the daily effects of MTBI on an individual's self-care, leisure, and work/productivity?
2. How does MTBI affect processes of occupational engagement (including roles and routines), identity, transition, and adaptation?
3. What occupational adjustments (adding or taking away) do people make after MTBI (e.g., passing, advocacy)?

#### 4.1 Objective of the Study

The primary goal of this qualitative study was to describe the lived experience of mild traumatic brain injury. In particular, the study gained increased understanding, using in-depth interviewing methods, about the everyday occupational experiences of MTBI from the perspective of the survivor. This included the examination of how MTBI affected the ability to take care of oneself and others; engage in leisure activities/pursuits; and participate in paid and/or volunteer work. I also explored how MTBI impacted processes of occupational transition and adaptation, as well as transformations in occupational identity. Finally, alterations to daily occupations were explored, including adjustments made in response to socially constructed barriers of MTBI (e.g. social stigma and behaviours associated with trying to pass, or hide MTBI).

Participants revealed information about how MTBI affected their everyday life including cognitive and physical abilities, psychological well-being, social interaction, vocational pursuits, and the occupations which affected and were influenced by the aforementioned facets. The detailed, focused results were interpreted and analysed within an occupational science framework. Phenomenology was used in order to develop a descriptive base from which I was able to learn about the lived experience of MTBI. The population sample comprised six adults diagnosed with MTBI, who ranged in ages from 35-60 years of age. The intention was to interview individuals at least one year after an MTBI diagnosis, a time frame which accounted for a natural progression of recovery but still allowed for reasonable descriptive recall of events prior to and following MTBI. All of the participants represented the 10-20% of people who do not recover from the effects of MTBI within the traditional one year healing period. Although individuals with MTBI experience limitations in short-term memory, long term memory was typically unaffected by MTBI in this study.

#### 4.2 Overview of Methodology

This phenomenological study attempted to make sense of and interpret the “phenomenon” of the everyday life of people living with MTBI by uncovering and interpreting meanings that participants attached to the experience (Denzin & Lincoln, 1994). I moved beyond the examination of symptoms and was able to gain rich, in-depth descriptions about the everyday occupational lives of MTBI survivors. This included exploring the implications of MTBI on daily occupations affecting and affected by occupational transition, adaptation, and identity. I was able to break down everyday life

and microscopically explore exactly what survivors felt and did, every day, in order to have been able to carry on with and live their new lives following injury.

The cardinal aim of this study was to learn more about the unique world of MTBI from the perspective of the survivor, including the subjective realities survivors created in their everyday lives. In-depth, personal stories were relayed through in-depth interviewing, and shared understandings were developed about what MTBI was like on an everyday basis. In addition to unearthing stories related to individual experiences, themes common to participants were identified within an occupational science framework (Cook, 2001). Broad and specific domains of MTBI were explored and included self-care, leisure, and productivity; as well as themes associated with transition, adaptation, and identity transformation, and personal and occupational adjustments associated with occupational meaning, balance, control, and choice. Each were explored within the 2 interviews and themes were teased out in the data analysis.

#### 4.3 Methodology

Qualitative research “begins with assumptions and then uses theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem” (Creswell, 2013, p. 247). As discussed in the literature review, gaps exist in the literature pertaining to the lived experience of MTBI. Qualitative research enabled me to explore MTBI using an open and flexible style of participant inquiry in order to listen to and understand stories about what it was like to live with MTBI from the perspective of the person who lived with it.



Qualitative inquiry was useful for this particular study because it enabled me to develop theories and themes based on the detailed, personal descriptions of participants (Creswell, 2013). The information currently available in the literature does not adequately explain or capture the ‘complexity’ of MTBI because it tends to describe, at the surface level, everyday components of MTBI (e.g. cognitive, physical, social, vocational, and psychological), as opposed to everyday theoretical, social, and emotional meanings attached to MTBI, including for example, barriers to occupational transition, social stigma, adapting to life with deficits, changes within occupational roles and routines, etc. Qualitative methods best aligned with the research question (and sub-questions) posed in this study.

Phenomenology is “the descriptive study of lived experience in an attempt to enrich the lived experience of something by mining its underlying meaning” (Van Manen, 1997, p. 90). Phenomenology has been long described as both a way of *doing* research (as a method) and questioning or conceptualising it (at the philosophical level). The goal of phenomenology is to transform a lived experience into a written expression of the essence of the experience - in this case living with MTBI, which enables the reader to become powerfully *animated* in the experience. What exactly is a “lived experience?” Dilthey (1985) claimed that “in its most basic form, a lived experience involves our immediate, pre-reflective consciousness of life: a reflexive awareness which is unaware of itself (Dilthey, 1985, p. 114).” The goal of this study was to describe commonalities among all participants and then reduce these individual experiences into a universal “essence” of what MTBI is like - both in general, and with a narrowed focus on daily occupations and changes in occupational roles and routines (Moustakas, 1994, p. 53). By

developing a composite description of daily life with MTBI, the reader had the opportunity to learn what it is like to live with the diagnosis, and how exactly life was affected by the personal experience of MTBI.

According to Luborsky and Lysack (2008), phenomenology focuses on “the everyday life-world and gives attention to the careful description of how the ordinary is experienced and expressed in the consciousness of individuals (p. 229).” This approach recognizes the value of exploring personal, subjective life views and experiences of MTBI. Differentiated from other forms of qualitative research, and aligned with the values of this study, phenomenology respects and upholds the sense of the *lived experience* because the meanings identified by individuals with MTBI actually become the *knowing* and *knowledge*, and over time, with analysis, common themes identified helped address the question and sub-questions in this study (Van Manen, 1997).

Although it can be realistically quite difficult to fully comprehend a phenomenon unless someone has personally experienced it, it is not impossible. Phenomenology attempts to flesh out these meanings in such a way that the reader feels part of the group (Moustakas, 1994, p. 87). However, merely asking someone to recall an experience is not enough. Participants with MTBI were urged to recall their experiences associated with MTBI in such a way that essential stories and themes, including the meaning structures of the experience, were richly uncovered and described (Van Manen, 1997, p. 45). Qualitative life experiences can be brought to life in such a way that descriptions of the experiences are recognised by readers, which are highlighted through the interpretation of these experiences (Van Manen, 1997). This approach attempts to delve beyond simply unraveling something – it wishes to truly recapture,

and then share the experience of MTBI so that the reader feels as though they are there or that the experience could have been theirs (Hammell & Carpenter, 2000). Finally, I aimed to pull the reader into the main questions of the qualitative study in such a way that the reader cannot help but wonder about the nature of the phenomenon (MTBI under investigation (Hammell & Carpenter, 2000)).

In-depth interviewing used in phenomenology was important for this study. The goal of in-depth interviewing was to have participants reconstruct their experiences of the topic under study. In-depth Interviews can be broadly defined as “a relatively unstructured interview that is utilized to capture participant’s perspectives and experiences on topics or issues of relevance in their lives” (Kaufman, 1994, p. 76). It aimed to discover what was important to participants including their own personal meanings and perspectives, and how they viewed, categorized and experienced the world of MTBI (Hammell & Carpenter, 2000). On their own terms and in their own language, participants were encouraged to openly discuss their experiences with me by freely expressing their views and personal everyday experiences with MTBI. Subsequently, the reader can gain insight into how MTBI was experienced at the everyday occupational level and how occupations contributed to the processes of transition and adaptation, and identity reformation (Laliberte-Rudman & Moll, 2001).

Specifically, the study explored, in detail, how participants made sense of their personal and social worlds. The main currency for phenomenology is the meanings that particular experiences and events held for participants. My approach is phenomenological in that it involved detailed examination of the participant’s life world; attempting to explore personal experiences concerned with an individual’s personal

perception or account of an event - as opposed to simply attempting to produce an objective statement of the event itself (Smith & Osborn, 2003). Overall, the participants tried to make sense of their world, while I tried to make sense of participants trying to make sense of their world. Overall, this study was concerned with trying to understand what MTBI was like from the participant's direct point of view.

#### 4.4 Recruitment and Data Collection

The "word of mouth" technique was used to recruit six participants who were members of a local brain injury association in my home city. I sit on the board of directors for the Brain Injury Association of Nova Scotia (BIANS), and as such, information about the study was spread to members of the association's local chapter through my connections (see poster, Appendix B). Those who responded by contacting me to show initial interest were provided with a basic overview of the study, including study criteria (e.g., who was permitted to participate in the study and the types of information the study was looking for). Individuals met the following inclusion/exclusion criteria: diagnosed with MTBI within the last 5 years (but after at least 1-year of receiving the diagnosis); self-identified as experiencing ongoing symptoms related to MTBI; no pre-existing mental health or psychiatric diagnosis (prior to head injury); were between the ages 35-60 years old (defined for the purposes of this study as middle adulthood); and were either biological sex (male/female differences were not of focus).

Since participants were diagnosed with MTBI for at least 1 year post-injury, they were almost all diagnosed with co-morbid post-concussion syndrome. As discussed in the literature review, post-concussion syndrome is defined as experiencing lingering

symptoms related to MTBI at least one year after the initial injury. This timeframe was important because it gave participants adequate time to naturally progress in their healing, such that they achieved medical stability. Psychological and cognitive co-morbidities, including anxiety, depression, and PTSD were not considered exclusion criteria because they are often typical outcomes of MTBI. English as a first language was required because I do not speak a second language, and dialogue in alternate languages could affect the interpretation of analysis. I verified with participants their comfort level with being contacted via telephone in order to discuss the overview of the study and expectations about participation. I introduced myself to participants, explained my role as the investigator, reviewed the reasons for participant selection, explained exactly how the interviews were conducted, time requirements (e.g., number and length of interviews), and the process of informed consent, including potential emotional discomfort/distress associated with recall of painful, traumatic memories (Moustakas, 1994). See Appendix C (consent form). I also disclosed my own MTBI to participants.

Interviews took place at a time and place which were convenient to participants. Two interviews (each 2 hours in duration, 2 weeks apart) were conducted in-person and close to participant's home environment in order to reduce travel time and potential fatigue. I felt that two, two hour interviews was more than enough time to gather information necessary about MTBI on an everyday level, while also aiming to prevent participant fatigue and exhaustion. A semi-structured interview format began with open ended questions, and probes were only used once participants presented their own views about their personal experiences with MTBI (see Appendix D for the interview guide). This allowed for a broad exploration of the lived experience without leading

influences. A semi-structured interview guide acted as a researcher memory aid. In particular, the guide was developed based on the fact that I previously worked as an OT with MTBI clients; met and counseled MTBI survivors through my volunteer position with the brain injury association of Nova Scotia; and personally experience MTBI on an everyday basis – all of which helped motivate and guide the particular questions in the interview guide. The 2<sup>nd</sup> interview took place within two weeks. Transcribing was possible within this time frame because I had the audio tapes transcribed professionally within several days. Second interviews were more probing in nature and were based on analysis of the previous interview (Hammell & Carpenter, 2000). All interviews were recorded digitally with participant's permission.

#### 4.5 Data Analysis

Following each interview, I made detailed notes about my impressions stemming from the interviews through the use of a reflexive journal, as suggested by Schatzman and Strauss (1973). These notes consisted of my thoughts on the content presented by participants, as well as reflections on how the interview went and emotional reactions. I submitted the interview audiotape to a transcriber once each interview was complete, and transcription occurred within several (e.g., 4-7) days of the interview. Throughout the research process, I constantly referred to my reflexive journal – where I wrote about myself, including my experiences, choices, and actions during the research process.

Once transcribed, the document was reviewed several times. Initially, I checked for accuracy (Hammell & Carpenter, 2000) and corrections were made when necessary. Both the recording and transcript were reviewed again without interruption in order to

try to gain a sense of flow, or the overall nature of the participants' experience (Baggerly, 1994). Subsequently, the written transcription document was re-read in order to try to obtain a detailed, accurate picture about what MTBI was like for a particular participant on an everyday level. Then, it was reviewed (read and coded) again, and more theoretical themes associated with occupational transition, adaptation, and identity, were developed. In other words, after each interview, the data was analyzed and common themes were found. This occurred after interview 1 and interview 2, for all participants. Finally, the written document was reviewed again in order to flesh out descriptions about how MTBI might create occupational alternations, including potential behaviours associated with stigma and trying to hide elements of living with MTBI. A systematic procedure, moving from narrow units of analysis (phrases, sentences, paragraphs) to broader themes/units, was used (Hammell & Carpenter, 2000). The overall goal in this study's analysis was to take these themes and form a detailed description or summary about what it was "like" to live with MTBI, and "how" exactly it was experienced (Moustakas, 1994).

Once a general sense of the lived experience was gained, I reorganized and restructured the content (Bromley, 1986). In essence, I developed a description of the lived experience for each participant and then looked across them all in order to find common themes. Events described by participants which emerged during the interview were written up in sequential order. Every attempt was made to ensure that the content reflected the view of the participant, as opposed to those of myself/the investigator (Bromley, 1986). Sequencing the content helped solidify the occurrences associated with the individual experiences. This also helped tease out other descriptions

of events that may not have been obvious otherwise. Sequencing also helped connect thoughts/experiences and content presented by MTBI participants. For example, comments by participants about how MTBI affected self-care, leisure, and productivity, and experiences with occupational transition, adaptation, and identity helped paint a clearer, more complete picture (Hammell & Carpenter, 2000).

Once the sequencing was completed, I again restructured and organized the content. However, in this case it was done following each research sub-question. Specifically, content reflecting self-care, leisure, and productivity, occupational identity, transition, and adaptation, and occupational adjustments and modifications (e.g., behaviours associated with trying to pass as less brain injured in order to combat stigma) were catalogued under the sub-questions. A table listing events in temporal order and a figure depicting attached time-frames, was constructed in order to stay organized (Hammell & Carpenter, 2000). A summary of each person's narrative was provided to participants for their review. In order to deepen the discussion in this thesis, I employed analytic categories (e.g. doing, being, belonging, and becoming) (Wilcock, 2006). These categories were useful because they helped weave the major themes/findings together in order to create a more complete and realistic picture of the everyday occupational experiences of MTBI within an occupational science framework. They also helped bridge chapters 5 and 6 together because they enabled me to connect the daily 'occupations' (found in chapter 4's results) with more theoretical themes discussed in chapters 5 and 6, which created an overall interconnectedness of the data.

#### 4.6 Trustworthiness and Reflexivity



It is important in qualitative research to reflect critically on the relationship between the research and the researcher, and explore how the study may be affected by the researcher herself. In this study, I have both insider and outsider status - as an MTBI survivor and health professional (occupational therapist). I realize that both of these experiences affect and impact my worldviews. Also as a head injury survivor, I was at an advantage because I entered the process better informed about what it was like to live with an MTBI and the common struggles/challenges typically experienced (over most investigators) which helped establish better rapport overall with participants – especially because participants were aware that I was also a head injury survivor. Alternatively, due to my position as a survivor, I was also at risk of potentially missing concepts/themes found within participants’ stories because they may have seemed obvious to me as a result of shared experiences. However, being a registered occupational therapist with ample academic and clinical training/experience was helpful in navigating these potential barriers and biases. Also, my supervisor served as a peer in that she was able to provide ongoing feedback regarding critical questions.

Phenomenology is congruent with the principles of occupational therapy, which believes that *enabling* occupation means collaborating with people in choosing, organizing, and performing meaningful occupations in a given environment (CAOT, 1997). Meanings attached to occupations, or the things that we *do* in our daily lives, become central to human behavior, and our desire to do things or engage in activities transcends professional, geographic, social, and cultural differences among people – we may ascribe different meanings to the things that we do, but the things that we do, regardless of our life differences, have meaning to us all (Kielhofner, 1998). Therefore, in

order to make sense of participants' behaviours, close interaction between the participant and myself (investigator) was pivotal to a study using this methodology (Cook, 2001, p. 110). According to Kielhofner, occupational therapy holds that it is important to know and respect the unique perspective of the client (Kielhofner, 1998). Such value includes recognition that disability, including MTBI, is deeply personal and experienced uniquely by individuals. As such, survivor's stories were uncovered, analysed, and disseminated to readers.

Being a head injury survivor was quite beneficial to the investigative process, and I took steps to ensure that potential conflicts/biases were dealt with consistently throughout the process in order to ensure accurate and representative participant data. One way to accomplish this was by having someone ask me the same questions that were asked to participants. This way, I was able to experience the questions first-hand in order to check their relevance/merit in the study. More importantly, it gave me the opportunity to (re)examine my own assumptions and expectations about participants' experiences by diligently ensuring that I was open to experiences that were quite different than my own – by giving me time to reflect about potential differences prior to asking participants. A notebook with my personal questions, comments, and observations was kept during the interviewing process.

Trustworthiness in qualitative research is ensured partly through making certain participants see themselves reflected accurately in the study. Following each set of interviews, an overview was prepared for each individual participant including an overall description of the nature of the experience, which outlined what life with MTBI was like

on an everyday level, and matters related to adaptation, transition and identity (Moustakas, 1994). Throughout the process, I diligently referred to my reflexive journal in order to help combat personal biases. I also used my supervisor and committee members to enhance trustworthiness by engaging in group discussions (during the analysis stage) focused on being questioned (by the aforementioned members) about the analysis and being required to support/justify the data and themes.

Throughout the entire process, participants communicated with me either through phone conversation or the internet - participants knew the potential risks of using the latter (e.g., internet). In other words, due to the nature of the internet, there was always a chance that confidentiality could be compromised and I was clear with participants that correspondence between them may not be %100 secure.

Once I read through the transcripts, I drafted a summary of each person's story/narrative (as opposed to participants being required to read their entire transcript) in order to help decrease the burden of participants reading the entire document. Participants only saw their own summary, not those of others. This summary was disseminated to each participant in order to uphold adequate member checking; enhancing trustworthiness (Hammell & Carpenter, 2000). In particular, participants received a summary of their narrative after both the 1<sup>st</sup> and 2<sup>nd</sup> interviews so that they had opportunities to review their statements and check for inconsistencies and/or mistakes twice during the interviewing process. Providing participants with opportunities to clarify their descriptions (especially since concentration, memory, and sometimes judgement are problematic for MTBI survivors) was essential when working

with this population. Participants were asked to review the document for accuracy in the representation of their individual experiences. This also helped identify gaps in the development of the complete case, which also increased trustworthiness (Moustakas, 1994). Participants did not have access to other participant's narratives/information, as confidentiality issues could have arisen, especially in smaller geographic areas where participants could figure out who other participants were.

I was unable to provide summary narratives for individual participants in the thesis due to confidentiality concerns. Although it may have been helpful to have individually identified participants, including attaching details about participants to each quote, confidentiality would have been compromised. BIANs is a relatively small community in the city of Halifax, NS and it would have been fairly easy to identify participants based on their age, gender, job description, relationship and parenting status, and hobbies and leisure pursuits (even if pseudonyms were used). Therefore, I decided to keep participant information minimal in order to protect participants' rights and confidentiality, and uphold my responsibilities as an investigator. Finally, my supervisor had opportunities to offer feedback throughout the study, which according to Moustakas (1994) enhances trustworthiness.

#### 4.7 Ethical Issues

Several important issues pertaining to ethics were addressed in this study in order to effectively examine the lived experience of MTBI. Key ethical considerations were managed, including the minimization of physical, emotional, and psychological damage (Seale & Barnard, 1999). Survivors of MTBI often experience persistent issues related to pain, typically secondary to trauma (e.g., motor vehicle crashes). Physical

components including prolonged sitting, standing, flexion at the neck and waist, visual disturbances, bright lights, dizziness, and migraine headaches are but a few. In order to help accommodate these issues, I took measures in order to help prevent or quell the onset or severity of these symptoms including: ensuring accommodative public transportation; adequate room space; adjustable lighting; large, distinguishable written print; proper seating (e.g., back and neck support); breaks; study information material was read slowly and audibly; and positional changes were encouraged (e.g., sitting to standing and standing to sitting).

In addition to physical symptoms associated with MTBI, it was anticipated that participants might experience emotional or psychological discomfort. Being asked to recall a traumatic event (e.g., car accident) had the potential to elicit or intensify previous feelings of anger, sadness, grief, shame, loss, or a breadth of other emotional responses to trauma/head injury. Some participants cried while discussing the primary cause of their head injury or become distant, understandably. There was also the risk that participants might discontinue participation from the study, or that certain pieces of their information would be omitted from the transcription (neither scenario actually occurred). In order to prevent or help minimize these potential emotional outcomes, I tried to ensure participants were fully debriefed on their rights as participants including their right to take a break, stop, or withdraw from the interview or study at any time without pressure or penalty (e.g., withholding compensation); psychological assistance (free of charge) was available for debriefing (a well-informed, psychologist was available to speak with participants however no one required this service); and participants knew

that they were able to share their thoughts/feelings with me, especially if psychological help was not necessary.

Confidentiality was upheld at all times. In order to help protect participants' private data/information, I ensured that all transcriptions and audio-recordings were not displayed in public (e.g., at the medical library), and that they were stored in a locked cabinet at my home, accessible only to me. Following review and analysis, the recordings were destroyed and discarded properly. Records linking real names with participant information were stored separately from data, and pseudonyms were used throughout the study. Contact information was also destroyed after the interviews and final editing. Computer files were password-protected and stored on a password-protected computer. They were erased and raw data will be destroyed five years post thesis-completion (Van Manen, 1997).

Despite the fact that individuals with MTBI may possess decreased judgment and insight, informed consent was still possible. Typically such cognition is more compromised in survivors diagnosed with moderate to severe forms of TBI, however at times, MTBI survivors may experience them, which potentially posed a challenge. Therefore, a legible, plain English concise information form was given to participants in order to ensure complete understanding of the objectives of the study, as well as their role. Although this type of form is typical for any study, the form for survivors of head trauma form was written in a clear, easy to read, easy to understand way (key points were highlighted, decreasing the need for long, detailed sentences). Further, I ensured that the consent forms were fully understood by asking participants to reiterate, in their

own words, the content of the form. Where possible, consent information was sent to potential participants in advance. I ensured that I was readily available for questions/comments after the forms were viewed. Further, ongoing consent (throughout the process) was requested, which is especially necessary in a population who may experience short-term memory loss. In addition to verbal consent, participants were asked to sign a consent form; the study did not proceed until signed consent forms were obtained. Again, participants were reminded throughout the research study, about their right to withdraw at any time, without consequence.

While there was potential for coercion or undue influence, as I was likely to know potential participants through BIANs, it was important to understand these are passing acquaintances, rather than friendships. Issues of power between myself and participants were acknowledged: participants were able to choose where the interview took place (giving them a measure of control); and in order to help decrease the more obvious aspects of any socioeconomic differences, I dressed casually. Again, participants had several opportunities to review their transcriptions and offer interpretations of their data, when necessary. Further, participants felt somewhat empowered by sharing their personal experiences and insights with MTBI – their voices were heard. Compensation was offered in the form of a \$25 gift card as a token of appreciation for participation in the study (after completing both interviews). This initiative helped participants feel valued for their contributions.

#### 4.8 Strengths and Challenges of the Method

As mentioned, several challenges to conducting qualitative research with this type of methodology existed. Individuals with MTBI experienced limitations to attention, concentration, memory, judgment, and insight, however these symptoms did not create confusion in understanding the purpose of the study, their roles as participants, including their rights, or the consent process (Van Manen, 1997). Although not all MTBI survivors experience these symptoms, it was anticipated that they would possess some, which forced me to be aware of (and vigilant about) my responsibilities. I am a registered occupational therapist of 10 years and anticipated that my clinical judgment and reasoning, along with experience working with survivors, and especially my own experience as a survivor, enabled me to acknowledge and appreciate the common challenges that this population faced while participating in this study. The purpose of this study was to learn about the personal, everyday experiences with MTBI, not to predict future behavior or measure outcomes which is a benefit to using this methodology. Meaningful descriptions of occupational challenges associated with MTBI, including themes surrounding transition, adaptation, and identity was gained through the interpretive analysis, as opposed to performance measurement or the development of treatment strategies or interventions. Therefore, a well laid out, understandable interview guide (consisting of several probes) was used in order to help guide participants' recall, especially while describing their everyday experiences – experiences that they may not have seen as meaningful or particularly significant.

In spite of the limitations to this methodology, phenomenological in-depth interviewing was an excellent approach to explore the everyday occupational experiences of MTBI. It helped provide greater understanding, from an occupational



perspective, of the cognitive, physical, social, financial, vocational, environmental, and emotional lives of survivors, and made a valid contribution to this literature in occupational science. Although the ultimate goal of this study was not to use survivors' information in order to find ways to better "treat" MTBI, there was no question that the profession might benefit from deeper understanding of lived experience of MTBI from an occupational perspective. Even program planners, legal advocates, and medical personnel working with this clientele might benefit from gaining an increased understanding about the everyday experiences of MTBI – which in turn, may positively benefit survivors in the long run (Baggerly, 1994).

The next two chapters present the results of the research, followed by a chapter further interpreting those results in the Discussion and Conclusions.

## CHAPTER 5

### RESULTS: OCCUPATIONAL LIVES

Participants' everyday experiences with MTBI are explored in Chapters 5 and 6. Chapter 5 offers findings related to three key themes including: Everyday Occupations, Interpersonal and Relational Occupations, and Intrapersonal Occupations and Concerns. Chapter 6 provides a more detailed analysis of occupational processes, including legitimacy; passing and stigma; occupational identity, transition and adaptation; occupational failure; and future outlook. Chapter 5 disseminates results related to everyday activities of daily living and instrumental activities of daily living, whereas chapter 6 builds upon the results of chapter 5 and outlines, in greater depth, results pertaining to occupational processes.

Five females and one male participated in this study. Ages ranged from 35 to 60 years of age. Four participants received an MTBI diagnosis as a result of motor vehicle accidents; one was a result of a workplace assault; and one was a result of a sports accident. All six participants were diagnosed with MTBI and were interviewed at least one year after their diagnosis. Time since injury varied, ranging from 15 months to 8 years, with most participants 2-5 years post-diagnosis. Three participants were partnered (with children) and three were single (of the single participants, two were not involved with romantic partnerships, and one reported experiencing a new partnership). At the time of the interviews, five out of six participants had returned to work in some capacity (3 worked part-time, and two returned to full-time hours), and one never returned to paid employment (but was heavily involved with community volunteerism).

## 5.1 Everyday Occupations

The first theme focuses on the everyday occupations of maintaining self and others, which includes some instrumental activities of daily living, as well as productivity. Five sub-themes are explored below: transportation, shopping and groceries, food, finances and employment.

### *Transportation*

Most participants identified occupational changes associated with transportation, including driving and routines and schedules, fear and driving, alternate forms of transportation, alterations to driving patterns and schedules, and positive aspects of driving. Five participants identified experiencing changes to the act of driving itself, four of whom ceased driving completely for at least a year following their accident. Once driving activity resumed for these individuals, driving skills and feelings of competency changed: participants exhibited greater caution overall. Specifically, participants reported driving more slowly than they had previously, feeling a delay in their reaction times to stop signs, traffic lights, and/or other vehicles. These changes created feelings of decreased confidence and security, and increased feelings of risk during the occupation.

Driving also impacted daily routines and/or schedules. Two participants, in the group of four individuals who ceased driving for at least one year after their accident, reported changing routes and driving routines. All of these changes highlighted the importance of keeping things the same, or familiar, for participants engaged in the activity of driving. Changes involved spending more time mentally preparing to leave the house and carefully planning alternate routes of travel in order to make the occupation

of driving safer and more efficient. For example, some participants left home extra early to avoid peak traffic times, decreasing the possibility of cognitive overstimulation and fatigue. Other strategies included taking “backroads” or purposely taking the “long way” in order to drive at more comfortable speeds. Some participants reported only travelling routes that they were familiar with, where any deviations caused anxiety and panic (e.g., road detours or bridge closures). Here, a need for routine was described as central to resuming this occupation following MTBI. Other participants reported changed driving habits altogether: “I avoid the city of Halifax 100% now and always stay close to home”; “I don’t go as far now as I used to and I definitely don’t go out as long.”

Fear was also a common theme identified by most participants, such as getting into another car accident; fear of hitting another driver (or pedestrian), and fear of slow cognitive processing and decreased reaction times (e.g. stopping for other cars or pedestrians at stop signs or lights). All participants had been medically cleared to drive again; however, participants described lingering feelings of uneasiness about their driving abilities. They felt that because they were not the same person they had been prior to their head injury, they posed a realistic threat to others on the road. Constant apprehension about arriving and departing safely overall negatively impacts the occupation of driving.

Alternate forms of transportation were an option. Participants who abandoned the occupation of driving often resorted to public transportation, an ultimately safer but more exhausting option. Two participants routinely took the bus. One participant was forced to sell her car after her head injury for financial reasons, but claimed she would

have taken the bus anyway to avoid potential accidents. Participants weighed pros and cons associated with travel by bus: it helped eliminate stress associated with driving independently, but increased travel duration (e.g. waiting for the bus or transfers), which exacerbated cognitive symptoms of fatigue and headaches:

The bus is less stressful than driving myself but I'm actually exhausted by the time I get to work because it takes me an hour and a half just to get there...it would have taken me 25 minutes to drive on my own.

Alternations to driving patterns and schedules also impacted meaningful occupations. Prior to her car accident, one participant drove herself to visit her late husband's grave; following her head injury, she abandoned the tradition:

It's not like I'm going to get my current husband to drive me there....it would be strange considering I'm visiting my late husband, even though he says he supports it. I used to like going alone but now I don't go at all.

Other participants adjusted their occupations to ensure additional support and reassurance while driving (family and friends would accompany them and act as a second set of eyes). If companions were unavailable, participants often delayed or cancelled their commitments altogether. Alternatively, while some participants needed to be alone in the car while driving, in order to help decrease multiple stimulation and noise in the cabin, others preferred company. Driving turned into a source of constant frustration and shame for participants who described not being able to share the driving responsibilities, post-injury.

Not all aspects of driving and transportation were negative. Participants capable of resuming the occupation of driving described a sense of mastery and accomplishment: “driving is the one thing I do where I don’t feel brain injured....I can drive for hours and hours, and when I do, I feel normal again.” Another participant, no longer owner of a vehicle, refers to driving as feeling “like heaven” when driving to weekly out-of-town physician appointments:

The sense of relaxation while driving, and reprieve from the city keeps me going.....because on the way home I stop and get groceries because I actually have a car again and feel free...thanks to the insurance company who pays for it.

### *Shopping and Groceries*

Occupations associated with general shopping activities changed. For example, rather than risking subsequent frustration and fatigue in busy malls during the Christmas holiday season, participants resorted to purchasing “quick fix” presents such as gift cards and magazine subscriptions. Some avoided shopping altogether or only did so online. Some participant’s minimized drugstore shopping by buying shampoo and body wash in bulk during sales events. Visually scanning personal items at drugstores was exhausting, and exacerbated symptoms of dizziness and nausea. One participant who used to love clothes shopping stopped the activity altogether, due to symptoms of headaches and dizziness, and would only do so when absolutely necessary (e.g. when clothes became ripped or tattered).

Shopping also negatively affected family activities. Two female participants who are mothers of daughters had previously enjoyed clothes shopping with their daughters, but were unable to do so since their head injury:

My daughter asked me the other day while we were in the mall if we could go to a certain store but at that point I was already exhausted. I went anyway and just sat there like a zombie. Then I told her we needed to leave and she looked so disappointed. I felt like an awful mom.

Grocery shopping represented one of the biggest challenges to activities of daily living for nearly all participants, specifically highlighting the impact of the physical environment and the cognitive demands of grocery shopping, food choices, and shopping strategies. The physical environment posed the greatest challenge, and participants described 'dreading' shopping for food. Grocery store shopping was seen as an activity to overcome based on the proximity to participants' homes (e.g., requiring driving or transportation); store layout (e.g., too many similar items and expansive store sizes and layouts); bright lights (e.g., inducing light sensitivity); and crowded spaces (e.g., increasing confusion and frustration). Most participants became overwhelmed after only a few minutes inside grocery stores, often prompting the abandonment of the occupation altogether for participants' partners to assume. Single participants and those who lived alone were forced to shop for food with little or no assistance, and identified feeling resentment about doing so. Grocery stores became so stressful for single individuals, they avoided large chain stores in favour of small, nearby stores charging higher prices for items.

Shopping pursuits produced effects of cognitive symptoms. Decreased short-term memory (forgetting) and inattention posed the greatest challenges for the majority of participants:

I make a list and then I forget to look at it, or I forget to bring my list totally and when I get there, I'm like, oh my God, I don't know why I'm here or remember what I'm supposed to get!

Other participants identified scanning their lists for what seemed like hours in order to stay focused on the task at hand. In-store distractions were debilitating, as were altered store layouts. Other participants reported limiting shopping to the outer aisles to avoid the extensive visual scanning for items in long, busy aisles; this strategy impacted food choices. The location of fruits, vegetables and breads in the outer aisles often meant basic grocery needs were met, but meal selection became static, predictable, and "boring." Lacking the ingredients for certain meals, including casseroles, several participants who were mothers reported feeling like an inadequate family cook, when children would remark at mealtimes "not that again" or "can't we have something different?"

Food choices were also affected by MTBI, with participants' new focus on convenience and preparation. Participants (single and with families) often resorted to quick, pre-processed meals such as soup, Kraft Dinner, and instant rice packages. Salads, stir-fry's, casseroles, and stews were seen as the most difficult and exhausting meals because of ingredient preparation and planning. One participant, who lived alone, found grocery shopping daunting: "I don't shop for food anymore. I can't do it and I hate it. I usually just go buy a big bag of potatoes and throw one in the microwave every night for



supper.” Some participants welcomed help during grocery shopping from those who could help find items, while others preferred shopping alone to decrease distractions.

Other shopping strategies included: buying items closest to the main door and check-outs; immediately asking clerks for assistance; only visiting smaller and older stores with basic designs; using a specific grocery store chain (e.g., Sobeys’s as opposed to the Superstore) and/or using a specific store location (avoiding new locations); maintaining ongoing grocery lists in order to avoid purchasing large orders; and omitting some grocery habits altogether (e.g., no longer visiting Costco because of its busy, large layout). Participants who were able to shop for food often experienced debilitating fatigue and dizziness afterwards, which resulted in groceries being left in the car or on the kitchen floor. During one incident, a participant discovered she had left groceries in the car several days prior, which had rotted and thus forced her to shop for food again.

#### *Food Preparation and Consumption*

All six participants identified occupational changes associated with food: preparation, cooking and baking tasks, body/weight, and socialization. Food preparation was regarded as exhausting, and represented a source of constant stress and frustration, especially for those participants required to cook regularly for their families. For families, daily meals became dishes that were quick, pre-packaged, or in bulk for ease of reheating; meals that required several ingredients were avoided. One participant stated “on a good week, I spend a half a day, usually my day off if you can believe it, going crazy making tons of casseroles that I can reheat and use as leftovers for the next week.” Participants bought pre-cut meats and pre-assembled fruit and

vegetable trays. Executive functions in making complex meals require goal-setting, planning, organization, and monitoring, which are all impacted by MTBI.

Four out of six participants described cooking as the “worst part of the day” because of daily fatigue that was normally heightened by supper time. By the time participants arrived home from work they described feeling “exhausted.....totally spent, and I literally have nothing left in me.” Despite finding food preparation frustrating and exhausting, participants with children also expressed embarrassment about asking friends and families for help. Two mothers felt that by asking for help, they would be avoiding their responsibilities as mothers and nurturers, and expressed shame that impacted their willingness to reach out and seek social support. Each mother experienced a unique sense of loss associated with cooking and meal time ‘failures’, and preferred fatigue and irritability over asking for help with the occupation.

In addition to fatigue, occupations associated with cooking and baking were negatively impacted by cognitive deficits including inattention, concentration, and limitations with short-term memory:

I valued my kitchen and culinary skills above all else. I was known as a great cook. I thrived from cooking interesting, new recipes for my hubby and the kids. Since my head injury, I’ve stopped trying new receipts because they never turn out. I can’t follow new recipes anymore and I forget to check the ingredients or I put the wrong ones in....I just lose track. Just last week I literally blew up my cake. I must have cried for an hour.

Another participant reported “one morning the kids just sat at the breakfast table and started laughing. I wondered why until I looked down and saw that I was pouring milk in their sippy cups instead of cereal bowls.” Despite numerous mistakes and dread associated with meal preparation, participants described forcing themselves to do so out of obligation and necessity. One described “you can skip the gym, walking the dog, folding clothes even, but you can’t skip feeding your kids. It’s necessary but unbearable most days. I used to love cooking and eating but now I secretly hate it.”

Single participants fared a bit better in this sense because they weren’t responsible for others and had the option to skip meals or eat ‘crap’ if they so chose. One participant described the difficulty of making macaroni and cheese: “actually Mac and Cheese isn’t that easy because you still need to remember to take the noodles off the stove and add the milk, butter, and cheese.” Soup, sandwiches, instant mashed potatoes, pre-packaged rice, and microwaved potatoes, along with snacks such as peanut butter and crackers, were common food choices identified by single participants. Socio-economic status similarly impacted food choices: lower income participants could not afford pre-cut fruit and vegetable trays, nor dining out. Alternatively, participants with higher incomes ate meals out more regularly, especially during times described as “being too tired to give a damn.” One participant described eating out as a “lifesaver.....if I’m having a bad brain day, I just whisk my family off to the nearest restaurant.”

Weight and body image was impacted by occupations surrounding food choices. Four of six participants described changes in body weight: three participants stated that

they gained weight as a result of eating quick foods high in carbohydrates including potatoes, bread, and pasta. These body type changes were described as frustrating and depressing:

I've gained almost 60 lbs since my car accident and it really bothers me. I feel like I just don't have the energy to cook anymore, and even if I did, I don't have the money or energy to get a gym pass or work out. I used to go to the gym 5 days a week. It's awful.

Another participant described gaining almost 100 lbs since her accident but couldn't pinpoint the exact cause "most days I forget to eat. I literally have no appetite. Yet, I've gained so much weight.....I starve and then I must just gorge on really crappy food." One participant who lost 40 lbs attributed the change to emotional factors and mood:

I am stressed out all the time. Not only do I never feel like eating, but the thought of making food is more exhausting than getting through the day itself. I feel like I'm starving to death but don't really care!

Food practices affected occupations associated with socialization and bonding.

One mother of two school-aged children reported,

My kids and I would bake all the time but it's just too exhausting now. If I have all the ingredients I'm in luck. If not, I dread the evil monster grocery store and usually make up an excuse about why we can't make cookies or bread. It's hard. Sometimes I feel like I should be the mother who bakes all the time, but I just can't bring myself to do it with the kids. Occasionally, I buy cookies in a tin and put them on a nice plate and pass them off as my own – especially when the kids need to bring cookies to school.

Another participant described how his brain injury affected his ability for social connection:

I used to love grabbing a few beers and sitting with the guys to listen to live music but I just get too dizzy nowadays from all the noise and crowds and stuff so I don't go much there anymore.

Below the elements of socializing will be explored more fully. Overall, food preparation and eating, which were once viewed as creative, rewarding, relaxing, and social for participants, became occupations to overcome.

### *Finances*

Nearly every participant experienced occupational changes associated with financial management, including: financial role changes; money management post-MTBI; changes in money habits (including the role of irregular bill payments); effects of financial stress and panic; online banking; effects of cognitive symptoms on financial wellbeing; the negatives outcomes of mismanagement; and occupational scaling down.

Managing finances was noted by nearly all participants as a constant source of stress, disorganization, embarrassment, and failure. Two participants experienced so many negative outcomes (high anxiety) associated with managing money that they eventually bequeathed the role to their significant other. As a result of decreased short-term memory and elevated stress, participants described feeling overwhelmed by paying bills because they made so many banking errors. What was once a source of pride for one participant who had been the sole money manager became a difficult feat marked by missed bill payments, overpayments, or incorrect payments. One participant reported

I was great with money growing up. When I got married, it was only natural that I manage our money. But after my brain injury, I kept messing up, you know, making big mistakes like completely forgetting to pay bills that weren't regular. One year I realized I owed over \$10k in property taxes because I kept losing the statements. It was horrible. So I handed the torch over to my husband, who is terrible with money, but compared to me, he's a lot better.

Other changes in money habits and spending left three participants in a state of constant stress and panic. Irregular bill payments (e.g. bi-monthly power bills, and annual water and property taxes) were identified as the biggest contributors to banking mistakes because they were difficult to incorporate into predictable banking routines. In fact, predictability in financial management was described by five of the six participants as essential to maintaining financial routines. Online banking was viewed as both a benefit and disadvantage: it enabled participants to do personal banking at home, which helped conserve time and energy, but it also caused frustration because participants described frequently forgetting their electronic passwords which subsequently locked them out of their online system.

Participants who had once successfully managed their finances were forced to acknowledge their post-injury cognitive deficits in short-term memory, organisation, planning, and multi-tasking:

I get a call one day from someone at the power company. He said I hadn't made an online payment in over 7 months and warned me that they were going to cut off my service. Thank God I had a good payment history before that or I would have

been cut off long ago. Anyway, I said I pay you each month, faithfully. It turns out I had added them as the wrong payee and ended up sending all of my money to my phone company instead of the power people. It was embarrassing. I mean, it's not like I could tell them I had a brain injury.

This revelation was prevalent among the majority of participants, and several identified these post-injury financial changes as a form of failure.

While pre-authorized payments were favoured by some, as it reduced monthly checking, these posed a barrier for others who were often heavily penalized for overdrawn accounts. When insufficient funds occurred, participants were charged fees of \$45 each, charges that added up over time and proved embarrassing for participants because it reminded them of their ongoing deficits and limitations.

Mismanagement of money had long-term implications for some participants. While some participants received phone call reminders from financial representatives, others were not so lucky and found themselves in arrears with financial institutions. One participant learned about her financial arrears situation when a collection agency reached her at home; she described her shock that her financial situation had become so mismanaged and overwhelming. Digging herself out (e.g. repaying debts) was nearly impossible because this participant was unable to work due to her injury and had little income. For others, negative financial situations involved maxed out or unpaid credit cards, both resulting in poor credit scores that negatively affected their financial status and reputation (described by some as completely ruined).

The financial strain of working less than full-time also contributed to financial stress, and affected participants' ability to engage in favoured leisure pursuits. Participants described having to decline joining certain clubs or activities/sports, meeting with friends for drinks or a meal out, gyms memberships, going to the theatre or cinema, and traveling – all forms of occupational scaling down. One participant who didn't return to work was forced to sell her car and purchase a less expensive model. Another participant described how handing over her weekly paycheck to her husband was demeaning, but necessary. Losing track of spending was common for those who had returned to work, and in fact nearly everyone described being unaware of their bank balances. Participants remained financially strained because they attempted to repay large debts incurred while they were off work. Participants described feeling baffled about where their money was going:

Before my head injury, I always knew how much I had to spend. I just kept a mental note of everything. Now, I get hit with huge bills, which I can't afford to pay, and literally have no idea how I got there. I'm broke right now. I'm always broke.

Other participants were required to cover some medication costs associated with their head injuries because they stopped receiving benefits once they returned to work.

### *Employment*

All six participants identified occupational changes associated with paid employment, including: the return to work process; returning to work as a source of pain, frustration, and humiliation; part-time work as a sense of accomplishment; factors



essential to a successful return to work; the role of modifications to the physical work place; and the benefits of flexibility in work hours.

Three major categories emerged during the return to work process: changes in work status, changes in job type, and modifications to the workplace. Though all six participants attempted to return to work shortly after their injuries, each of them ultimately left work again (for some it was a period of weeks before they were able to return again, and for others it was a period of several months). By the third year post-injury, five out of six participants were back to work; two to full-time employment, two to a part-time basis, and one to three days a week. One participant never returned to paid employment despite several unsuccessful attempts (she is currently on year seven, post-accident). However, she is involved with regular volunteer work for her provincial brain injury association:

It's still like work, I just don't get paid to do it. My clientele changed from ministering people in a church to helping people in the community with brain injury – I just replaced my traditional work role....it's almost the same.

Of the six participants, one returned full-time to their pre-accident employer after having been off work for approximately nine months. The other individual who returned to full-time work changed her vocation/employer twice as a result of three failed return to work programs, which eventually led to dismissal from her pre-accident job. The three participants who returned to part-time employment had previously worked full-time, and all three were also married with children. These participants described being forced to reduce their work hours due to cognitive overload including

fatigue, stress, anxiety, and depression, decreased energy and an inability to recharge and reenergize; decreased coping strategies, less time for themselves and their families; occupational imbalance; and decreased happiness.

All six participants described the return to work process as painful, frustrating, and at times, humiliating. Most participants experienced failed attempts at returning to work before they were able to achieve vocational success. Five out of six people were unable to return to work in the capacity that they had prior to their injury, and all described a subsequent sense of shame associated with 'failing' to fulfill their pre-accident roles and routines. The return to work process was viewed as time-consuming and lengthy; each participant experienced several instances of returning to work and missing days of work before finally finding a match between their post-injury abilities and job requirements. These participants felt they had let themselves and their families down with their reduced income, especially those who were the sole or greater breadwinners. One participant described her work hour reduction as

failed hopes and dreams. With less money from working part-time, I just see less stuff for everyone - there goes that family trip to Disney or a cottage we always wanted. My income now just helps pay the mortgage and some bills....yet I went to school for 9 years in order to do what I did, career-wise.

Not everyone viewed part-time work with a sense of failure. When successful, participants experienced pride in overcoming so many vocational challenges. Three participants described their return to work, in general, as an accomplishment at being able to work outside the home, particularly after having been off work for so long. One

participant described being back at her pre-accident job as “the biggest accomplishment of my life, next to getting married and having kids,” while another celebrated having any kind of work:

I couldn't go back to the job I had before my head injury. I tried too many times and in the end it was determined by my insurance provider that the job was no longer a good fit for me. I like what I do now. The pay is really good and I feel safe there. I love my boss and coworkers.

One participant, who had worked at her pre-accident job for over 15 years, boasted that despite severe short-term memory limitations, she was able to fulfill the requirements of her previous job because of her engrained skills and abilities:

It's just second nature to me. When I'm at home I can't even get a new recipe right but at work, I just go into robot mode, you know, it's automatic. And I've been told I'm pretty good at it.

Participants described several factors essential to their successful return to work: supportive bosses, environmental modifications, and flexible work schedules. Some attributed their success or failure to their boss's support; bosses who were warm, approachable, and non-judgemental were viewed as safe persons with whom participants could openly discuss their vocational woes and fears. Conversely, bosses who seemed curt, impatient, or judgemental were viewed as unsafe and unapproachable, often causing feelings of isolation for participants:

I knew when I got back I had messed up. You know, little things that I had never done before. I was so vulnerable. One harsh, jerkish word probably would have sent me over the edge, or at least sent me home permanently.

Another described her employer as,

the nicest person I know. I guess his sister had a TBI so he understands some of the things I'm going through. He told me straight up 'take a break when you need to, or leave early if you feel you need to.' It has made all the difference. That's why I'm still there today.

Still another participant viewed her employer as "awful, sneaky, watchful, and super judgemental" and believed she was unable to return to her pre-accident job after two unsuccessful return-to-work programs because of constant feelings of inadequacy: "it's just wasn't worth the stress and emotional anguish."

Modifications to the physical work environment were also described as essential supportive factors in the return-to-work process. Participants experienced constant limitations with attention, memory, and concentration, headaches, fatigue, and stress while at work. Supportive employers altered workplaces by dimming the lights near a workstation or relocating a workstation to quieter, lower traffic areas of the building. Other environmental alterations included turning off background noise (e.g. fans and radios) and the designation of "quiet" rooms for employees needing reprieve. Some employers permitted participants to work from home when possible, and others encouraged them to take additional breaks or leave work early when needed. One participant described these supportive workplace practices as "the reason for my success. The head stuff was going to happen no matter where I worked so I was just glad that the place I loved helped accommodate me."

The three participants who returned to work part-time each described how they would not have been able to do so without a reduction in work hours. Since they were also all married with children, this schedule compromise was the most significant factor in enabling them to manage a home/work balance. Having a mid-week reprieve (e.g. Wednesdays off) provided them with the opportunity to recharge cognitively in order to get through the rest of the week. Although returning to work in any capacity was described by all participants as all-consuming, a supportive employer, changed work status, and environmental modifications were key – they all enabled participants to reach some vocational goals, maintain a sense of pride and accomplishment, and contribute to a work/home life balance.

## 5.2 Interpersonal and Relational Occupations

The next four sub-themes will explore results pertaining to the theme of interpersonal and relational occupations, including leisure, parenting, friendships and relationships.

### *Leisure*

All six participants experienced marked occupational changes associated with leisure, including: lost activities; the impact of fatigue on activity; the relationship between paid work and having fun; and engagement with new activities. Engagement in leisure occupations significantly declined for all six participants. However, for some, new, purposeful hobbies were experienced by three of six participants, albeit they were performed differently than they had been prior to injury. Reasons for overall declines in leisure pursuits included increased levels of stress and fatigue, demotivation and anxiety

and depression; diminished cognitive capacity including challenges associated with planning and organisation; limited finances; an unbalanced daily life; and stigma.

All six participants experience a limited leisure life following head injury. Activities such as hockey, running, skiing, knitting, cooking and baking, shopping, canoeing and kayaking, and swimming, were lost as a result of challenges associated with head injury. These losses were compared to losing friendships, which resulted in feelings of guilt and shame, especially because participants sometimes could not find ways to pick up the pieces or carry on. One participant described her loss in the ability to run as “devastating”:

I ran three to four days a week just to clear my mind. I was good at it. I needed it. Although there are more quiet things I can do now for relaxation like baking a cake here and there, I just don't get the same release that I did from running. It was so quiet and peaceful and really my only alone time. Now even when I bake, the kids are right there so it's more about them than me....because you know, Mommy is supposed to bake for her kids and all.

Another participant felt that his fear of re-injury prevented him from playing hockey, though his ability to do so remained intact:

I haven't picked up a hockey stick since my concussion and I don't think I ever will again. I was told by my doctor that another blow to the head could really do a number on me. So I just don't play anymore. Though I have to say, I really miss it.

Fatigue represented one of the biggest challenges to participating in leisure occupations. All six participants identified chronic fatigue as negatively impacting

physical activities and hobbies. Most described feeling stuck in constant survival mode, and any remaining energy was devoted to their families. Days or weekends off were normally spent trying to catch up on sleep or housework, and attempts at recreation produced decreased abilities and skills that left participants feeling discouraged and even more drained. In general, participants experienced a mismatch between how they were required to perform an activity, and how they were actually able to do it:

I stepped into the skis and felt great. Like I can do this. Then when I started actually going down the hill, it was awful. People were zooming by me and I immediately got so dizzy, I wanted to throw up. It was worse than scanning the aisles at the grocery store. I haven't gone back since. It wasn't worth it.

The most significant barrier to engagement with leisure activities – aside from fatigue and other cognitive deficits, ability level, and motivation – was paid employment, which robbed participants of the energy necessary for having fun. Five out of six participants resumed work in some capacity following head injury and described the resumption of work as all-consuming and exhausting; those who worked part-time used their mid-week (Wednesday) reprieve to catch up on sleep and housework; and, those who worked full-time did similar things with their weekends. Therefore, cognitive and physical demands of the workforce contributed to cancelling out opportunities for participation in meaningful leisure activities. Participants described this as being caught between a rock and hard place because returning to work was viewed as a source of pride and accomplishment, and financially necessary in most cases, but leisure activities almost always suffered as a result.

Though many leisure activities were abandoned, not all were lost. Participants learned to adapt to their new abilities, and occupations associated with leisure or having fun became centered on timing (e.g. during good days). Some participants changed the frequency of activities, altered the methods required to complete them, or explored new activities altogether. Some participants changed how often they participated in hiking or swimming, for example, attempting the hobby during good days and during times of peak energy. Participants were unable to commit to regular recreation classes but avoided the disappointment and guilt associated with having to cancel. One participant who had previously gone to the gym three to four days a week still managed to attend the gym once every two weeks. Another could no longer attend her usual weekly yoga class, but was able to hold informal yoga classes in her basement with close friends. Methods of performing activities also changed: the participant who loved yoga could no longer do a “downward dog” pose because it increased dizziness and headaches, so she ultimately avoided the position. Another participant changed the way in which she baked: rather than make several batches of cupcakes at once, and in order to avoid fatigue and burn out, she kept a bowl of mix in her fridge and made muffins during high energy times.

Changes in the types of leisure activities, following head injury, were experienced by nearly everyone. This was primarily experienced as a shift from physically active and demanding hobbies, to quieter, more sedentary pursuits. Physically demanding activities that usually required significant energy, skill, and motivation were replaced with less intense activities that aligned with participants’ post-injury capabilities. One participant who gave up running used mowing her lawn with a ride-on



lawn mower as a form of exercise; another replaced kayaking (due to a shoulder injury) with quiet canoe rides with her husband; and the participant who abandoned hockey replaced it with soccer and weightlifting.

### *Parenting*

Three of six participants had children: two had school-aged children living at home and one had grown children living on their own (and was a grandparent). Participants with children at home identified challenges with parenting related to their physical home environment, their symptoms, discipline, routine and structure, guilt, shifted burden, and MTBI as a family issue.

Participants with children described the impact of the physical home environment on their ability to fulfill occupations associated with successful parenting. All three participants with children were female and identified feeling responsible for the overall running and order of the home. Achieving neat, organized, and predictable home environments was described as manageable and helped facilitate peaceful home lives for participants and their families. Conversely, homes described as disorganized, messy, and cluttered hindered participants' ability to successfully fulfill domestic roles and routines related to shopping, cleaning, cooking, and laundry, as well as morning, meal, homework, extracurricular, and bedtime routines. Keeping up with their homes (e.g. organization) was described as a never-ending task that seemed impossible some days. Mothers with MTBI experienced a distinct need for sameness within the home, especially because of the challenges associated with short-term memory loss and forgetfulness, fatigue, frustration, irritability, and domestic burn out.

Following MTBI, participants with children were required to exercise additional, and often exhausting, pacing practices in order to get by as parents. One participant reiterated several times that,

before my car accident I was organized and had oodles of energy. I felt like supermom. Now by suppertime I can barely keep my eyes open... my head is pounding, I'm dizzy, and I literally can't talk anymore....and this is like 5pm and I still have the nighttime routines to get through. It's the hardest thing I've ever done.

Another said,

I'm always tired, always. I spend what little energy I save throughout the day, pacing myself with naps and whatnot...it's all gone after school because I spend so much time picking up after my kids. I'm so hard on them sometimes. I just want them to be as neat and organized as I used to be, you know, to get by, but they're just kids!

Maintaining the home required household organization and cleaning. All three participants with children found organization easier to manage than the occupation of cleaning. One participant hired a housekeeper who helped with domestic activities that were described as too stressful and exhausting to complete independently (e.g. washing floors, dusting, cleaning bathrooms, dry cleaning, and doing laundry); this additional assistance was essential to successfully fulfilling her everyday domestic occupations. Household stress associated with cleaning increased fatigue, anxiety, and irritability. Participants with less money were not able to afford housekeeping assistance but wished that they could because the task represented such a source of angst and stress.

However, not all occupations associated with cleaning and maintenance were viewed as negative. One participant (with grandchildren) described the occupation of cleaning as a stress reliever and way in which to relax and unwind at the end of the day. She described experiencing a sense of pride and accomplishment because she could still successfully complete the activity; she also used the activity to recharge herself emotionally and cognitively so that she could spend quality time with her two sons and grandchildren.

Occupations surrounding parenting, often seen as a loss of spontaneity towards everyday occupations, were also impacted by MTBI. Participants with children experienced a plethora of negative symptoms related to MTBI including stress, anxiety, depression, irritability, and fatigue, and described how these symptoms affected their ability to parent effectively. Since participants were diagnosed with MTBI after their children were born, comparisons were made between their pre- and post-accident lives. As a result of constant fatigue, participants frequently declined certain occupations with their kids, including playing house or dress-up, baking, riding bikes, going for walks or shopping or to the movies, and completing arts and crafts. Spontaneous occupations associated with sleepovers suffered because participants were required to spend so much time to prepare for and plan them. Or if they were permitted, participants' children were only allowed to have 1-2 friends stay the night (in order to reduce noise and fatigue). Birthday parties were viewed as stressful for similar reason - two participants subsequently resorted to holding parties at fast food restaurants because they offered party packages.

Participants with children described taking daily naps in order to recharge before their evening routines, but also expressed guilt about doing this instead of helping their children with homework before supper. One participant (with grandchildren) described how fatigue affected her patience with her grown son:

One day, my son and his wife were all excited and went to look at a new house so they dropped the grandkids off. When they took an extra hour to get back I was so burnt out I felt awful. I couldn't wait until the moment they walked in the door. Of course I didn't say anything when they did...because they talked for another hour about how nice the house was. My head was spinning and I was going to throw up. I spent the next day in bed, recovering.

Overall, cognitive symptoms impacted participants' ability to get through their daily roles and routines without assistance, reprieve, or some kind of modification to their daily lives.

Disciplining children, another component of parenting, was also affected by MTBI – often characterized by memory lapses that impaired their ability to discipline their children, and negatively impacted promises that were made. Participants described limitations with short-term memory which made it difficult to remember conversations with their children during arguments:

I can't even fight properly anymore....well not actually fight...but parent. My kids say things like 'well, you said' and I honestly can't even remember what I said. I actually resorted to taking notes during arguments sometimes. Notes!

Raising teenage children can be stressful for most; however, mothers with MTBI experienced additional stress and frustration because of their compromised ability to

discipline effectively, which often forced the other parent to step in and play that part. Participants with grown children faced equal frustration with discipline, albeit differently. In addition to arguing, participants with teenaged children described difficulty remembering things like whether or not they gave permission for their kids to go somewhere, whether they gave permission for friends to visit, or whether they had agreed to drive their children somewhere or pick them up. These participants doubted themselves often and subsequently experienced shame as a result of not being able to remember important details or events related to child-rearing.

In addition to issues surrounding discipline, irritability also affected parenting. Participants described frequently experiencing frustration, lack of sleep, and issues surrounding anxiety and depression, and felt that due to their post-injury demeanour, they were somehow cheating their kids out of the mother that they deserved. Participants described themselves as curt or short, quick to respond or defend themselves. One participant described how her children were probably 'safer' going to their father with concerns or problems about school or friends because he wouldn't be as likely to snap at them. Overall, parents in the study felt as though they were no longer able to provide diplomatic solutions to problems associated with parenting.

Shifts of burden occurred in the homes of all three participants with children. In addition to the increased burden of negotiating family disputes and arguments, non-brain injured partners of participants were required to 'pick up the slack' and fulfill increased domestic roles including cooking, cleaning, arranging home maintenance, managing finances, and holding the family together overall. Participants felt that this

shift in burden may have negatively affected their children because their partners were so busy managing the household, as opposed to doing things like having fun or playing games and sports. Only one partner was interviewed during this study (because a participant requested his presence); however, it would have been interesting to learn more MTBI from their unique perspective. As mentioned, guilt became a central theme in this study, especially in relation to parenting. Participants described going back and forth between “I’m better than I was” to “I’m still not the parent I used to or want to be.” Participant’s envied non-brain injured parents because they had so much more time, energy, and patience with their children, and were not forced to battle constantly with symptoms and mental health issues.

MTBI was described as a family issue, and children often helped accommodate participants’ inabilities and shortcomings. This meant that participants were required to negotiate the negative effects of head injury with both themselves and their families on a daily basis. Participants’ children became fully aware of their mother’s symptoms (e.g. irritability, fatigue, anxiety, and depression), as well as the common triggers. One participant identified a cluttered, messy house, arguing children, unpredictability, and fatigue as exacerbations of her chronic symptoms:

My kids both know the types of things that set me off. They just know that we have a different rhythm than most of their friends. When I’m tired they say things like ‘are you having a concussion day?’ and they try to work around me.

Some specific strategies for negotiating everyday symptoms included: asking their children to wear headphones in the car to decrease cabin noise; encouraging their children to take an hour of time alone in their bedrooms; seeking additional support

from their partners with occupations surrounding supper, homework, and bedtime routines; and limiting the company of their children's friends to every couple of weeks. Participants managed their everyday roles and routines better as a group/family. Their children often helped accommodate their everyday needs and these negotiations were described as crucial to the survival of the family unit. Daily routines and predictability were viewed as essential to the fluidity of the home, and deviations from these needs were described as disastrous. When asked, participants without children stated that they didn't know how people with MTBI managed to parent, and described the idea of parenting as "daunting, I actually don't think I could do it. I can barely take care of myself."

### *Friendships*

All six participants experienced occupational changes associated with friendships, including: volunteerism and shared experiences; lost friendships; changes in socialization; changes to the nature of friendships; and strategies for maintaining friendships.

Occupations affected the nature of friendships for most participants. Individuals who became involved with new volunteer opportunities and/or peer support groups (e.g. other brain injury survivors) developed new, cherished friendships with other brain-injured individuals, often leading to a stronger sense of identity. This shared experience and peer support was described as meaningful and pivotal to participants' sense of support and personal growth. Three of the six participants were involved with BIANs, and one person became involved with mentoring other brain injury survivors outside of the organization; all described as forms of social growth and forward

movement. Participants emphasized the importance of being part of like-minded organizations, with like-minded people, and how they positively contributed to feelings of validation, support, and hope for the future. This shared experience of community engagement also seemed to help buffer the effects of stereotypes and judgement against people with brain injuries: participants felt that they had a shoulder to lean on. One participant stated “even my own family doesn’t quite get me like my brain injury friends. They just get it. They get me. I don’t know what I’d do without them.”

However, not all friendships could be salvaged following head injury. While some participants gained new friendships following head injury, others lost friends primarily as a result of time and energy constraints, memory issues, and lack of focus. Three participants described no longer having the time or energy for old friends, especially because they were forced to eventually adjust and adapt to their new occupational lives and selves:

I’m lucky to take care of myself and my family. I have nothing left at the end of the day. Weekends are generally spent catching up on sleep and doing household stuff, like cooking and cleaning, so over time my friends and I just sort of drifted apart.

Others described how old friends seemed uncomfortable about speaking about brain injuries. Two participants described losing some friends completely immediately following brain injury, for no apparent reason. However, in general, participants experienced an overall decrease in the quality of friendships; several identified feeling responsible for these losses due to their cognitive limitations (e.g. decreased short-term



memory, irritability, and lack of planning and motivation). One participant summed up her relationship with an old friend:

She told me she'd had the baby but I forgot because was going through so much at the time. I was in another world. After the baby was born, I actually once asked her when the baby was due. She was hurt, obviously. I had to ask her twice what her son's name was...she had already told me a few times. I know I must have come across as not caring but I really did. I genuinely couldn't remember his name. We just drifted apart. It still bugs me to this day. I really loved her.

Overall participants experienced less social activity because they were too drained to be an effective friendship partner. Due to constant fatigue, participants became less socially active than they had been prior to their head injuries. Offers for attending events such as baby showers, sports teams, and dinner/movies were frequently turned down because participants were either too stressed out or tired. Naps were described as essential components to getting through daily life and if they were not taken, participants could not carry out the rest of their day's events, making it difficult to fulfill occupational commitments. Not only were social invitations declined, but participants were also forced to cancel plans frequently as a result of unforeseen occupational challenges and struggles. Participants described becoming the 'unreliable friend' and experienced subsequent guilt and shame over their diminished capacity to be trusted, faithful friends. Five out of six participants described a decline in participation in leisure occupations (with friends):

I barely go out anymore. Most of my life is spent with my family and if I do have a little bit of energy left at the end of the week, I usually spend it cleaning or getting caught up on sleep.

Daily occupational changes to the nature of friendships also occurred.

Participants were forced to spend a considerable amount of time and energy extensively planning and preparing meetings with friends. Three participants described how due to their constant fatigue and anxiety, extra caution about who they could be with was warranted. For example, one participant described how she could only be around calm people due to the fact that people with high energy or anxiety increased her stress and anxiety. Fast-talking, high strung friends were avoided because participants described not being able to 'keep up' with the pace or language used. Occupations involved with making changes to the physical environment were also identified. Changes to the types of establishments visited (in order to avoid long drives getting there), and places frequented (e.g. places that didn't contain bright lights, or noisy, crowded environments) were made following head injury. Other strategies used by participants at restaurants included: avoiding visiting during peak busy times, sitting with their back to the other patrons to minimize distractions, and ordering items on the menu that wouldn't take long to prepare and arrive. These strategies were described as carefully thought out by participants, and were identified as essential to being able to socialize with friends in public. Some participants avoided public places altogether and resorted to taking walks in the woods or visiting friends in a more relaxed environment such as someone's home. One participant, who used to love spending time in pubs, described how he stopped going altogether because of the noise, crowds, and bright lights.

Occupations associated with these pre-planned strategies were described by participants as an integral aspect of maintaining friendships. Participants had to weigh social contact against symptoms of fatigue and anxiety, and examine the 'costs' of social interaction. Spontaneity within friendships diminished because participants were unable to take certain risks: the potential negative outcomes associated with cognitive, emotional, and physical fatigue did not out-weigh the benefits of maintaining certain friendships. Yet not all friendships were strained. One participant's relationship with her best friend was strengthened by her brain injury because she could better identify with her friend's longstanding struggle with anxiety and depression. Another participant described how spending time with her non-brain injured girlfriends kept her "sane" because it was refreshing to be around people from "the real world who didn't eat, breathe, and sleep head stuff."

### *Relationships*

Both coupled and single participants identified occupational changes associated with their relationship status/situation, including: positive and negative aspects of being single versus attached; experiences of freedom; negative aspects of being single; and occupational imbalance and breakdown.

Participants who were married with children experienced freedom differently than those who were single. Overall, being partnered meant more obligations but also adequate support and assistance from immediate family members. Responsibility for their children and partners meant that participants were obligated to plough through difficult occupations and complete childcare, household chores, shopping, managing finances, etc., despite the onset of symptoms or needing a break. As a result of fulfilling

everyday, familiar responsibilities, married participants appeared to experience greater stress and anxiety because often they were unable to take time to unwind, recharge, rest, or regroup. However, having a family was also noted as a great asset and source of encouragement and motivation for participants. Specifically, participants with families felt that they could not negotiate the effects of their brain injuries on their own, and described being thankful for the additional family support:

I don't know what I'd do without my husband. He's our rock and holds the whole family together ever since my head injury. If I were single, I think I'd be an absolute wreck. I would probably never leave my house again. My husband and kids really encourage me to get out.

Though comparisons are risky in qualitative research, it did appear that single participants experienced brain injury differently than those who were married with children: being single meant fewer obligations but less support overall. Single participants identified experiencing more occupational choices in their activities of daily living, including activities associated with cooking and baking (e.g. the option of making quick meals or skipping eating altogether), shopping (e.g. the option of giving gift cards for Christmas), and maintaining sleep (e.g. napping when they wanted). Single participants expressed relief that they were not required to negotiate the effects of their head injury in order to accommodate others. However, this was not necessarily a choice; one single participant commented "I don't think I could be in a relationship right now....maybe ever. I mean, I can barely take care of myself." When small victories were accomplished, like attending a doctor's appointment or buying food, single participants proudly celebrated their small successes and accomplishments on their own.

However, not all occupational aspects of being single were positive. Single participants identified engaging in less self-care activities, were less physically active than attached participants, spent more time alone in their homes, and reported feeling lonelier and more isolated overall. Dietary needs were negatively affected – all three single participants described times where they barely ate, forgot to eat, overate, and consumed quick, unhealthy meals in order to survive. Single participants seemed less engaged socially, possibly because they did not have the motivation from family members. Despite the fact that single participants intentionally chose a more reclusive life, they appeared to be lonelier overall. Although these statements were only based on differences seen between six individuals, themes between the attached and single participants were apparent. While attached participants described spending less time recuperating from overload and fatigue, single participants had the option of pacing themselves better and napping when necessary. Overall, being required to get up, take care of others, and go the extra mile represented an occupational buffer to some negative health outcomes.

Single participants described experiencing occupational imbalance and breakdown; they seemed to fare better cognitively, but poorer emotionally. Although relieved to have responsibility only for themselves, they also described spending so much time alone it became unhealthy. Excessive periods of time alone seemed nearly synonymous with poor emotional coping strategies (e.g. over- or under-eating), and more negative experiences with mental health (e.g. anxiety and depression). Being alone so often meant fewer opportunities for positive self-talk or positive feedback from others, whereas attached participants had people living in their vicinity who provided

regular feedback, encouragement, and the sharing of occupational responsibilities. Single participants appeared to ruminate more frequently about their losses, and at times seemed lost in reflections about their selves and lives. Overall, it seemed that although cognitive symptoms were better managed by single participants, emotional health was jeopardized.

### 5.3 Intrapersonal Occupations and Concerns

The next five sub-themes will explore the study results pertaining to the broad theme of intrapersonal occupations and issues/concerns. They include spirituality, fear, spontaneity, staying positive, and positive outcomes of MTBI.

#### *Spirituality*

All participants identified occupational changes associated with spirituality: lost meanings, spirituality and recovery timelines, new meanings, and spirituality redefined in everyday activities. Spirituality is a central concept to the profession of occupational therapy, and aligns with the profession's core value of treating people in a holistic manner through the use of meaningful activity. Participants remarked on gaining and losing elements of what they considered to be spiritual (in both a religious and non-religious sense). Most participants, however, experienced a sharp decline in occupational engagement with meaningful activities for the following reasons: more time was spent negotiating the everyday effects of MTBI and "surviving;" the ability to successfully complete previously enjoyed occupations changed or declined; and the desire to resume previously enjoyed or new activities diminished (as a result of both motivations factors as well as neurological damage to areas of the brain that control

planning and organizing). Finally, two participants described adopting new, post-injury occupations that better aligned with their post-injury capabilities and provided them with a sense of peace, meaning, and flow to their daily lives.

Several participants described losing an overall sense of meaning in their everyday lives, including participating in occupations once identified as important facets to achieving a life balance. In fact, occupational balance shifted for all six participants. As a result of aforementioned deficits in cognition, memory, planning, organization, and motivation, as well as increases in fatigue, irritability, anxiety, and depression, participants described having little time or energy for meaningful, fun pursuits. Participants spent so much time trying to complete their everyday roles and routines, identified by several as a form of survival, pursuits described as spiritual were eliminated. One participant described this loss as

depressing. I feel like a zombie most days. It's an accomplishment if I can actually remember to wash my hair or make muffins for my kids. I normally do something wrong and mess it up. It happens with supper meals, laundry, and everything. I'm just always exhausted. I barely see friends anymore and to be honest, I just can't. I've stopped running and swimming. My life is made up of constant stress and fatigue, mixed with a lot of worry and guilt. There is no real *flow*, as you call it.

Since most participants defined spirituality outside the scope of traditional religion practice, spirituality was often replaced with prolonged periods of occupational angst and unrest. However, a connection between achieving spirituality and injury time frames were significant: participants who were injured several years ago seemed more

connected to themselves and their new occupational lives, which increased feelings of peace and contentment, compared with those who had recently been diagnosed. Those recently diagnosed described spending more time surviving and trying to figure things out (e.g. how to get through the day, accomplish a goal or task, or incorporate MTBI into a work day).

Participants in the earlier stages of brain injury seemed to spend more time and energy resisting change, leading to feelings of loss and emptiness. Conversely, those further along in processes of transition and adaptation seemed more motivated to try new occupations or make adjustments to their overall occupational lives. One participant, who was injured a year ago described her new life as

desolate. Like the Norah Jones song says, I feel empty as a drum! My old life was made up of my husband and children, working full time, knitting, yoga, cooking, baking, and skiing, and doing some volunteer work. Now I barely see my friends and only really walk down my own little street. My life balance is gone and some days it's just going through the motions to get by. The things I used to love are far, far away. I try not to think about it too much because it's depressing. I'm just so empty.

Despite decreased engagement in activities formerly considered fun, special, or meaningful, not all participants described losing every aspect of spirituality. Participants found meaning in new and old occupations, causing feelings of accomplishment, pride, and joy:



I can still clean. Before I just cleaned to get it over with but now I have a little process – I light my candles, put on nice music, and clean my heart out. I feel normal when I do it because I can work at my own pace and I get to see my good work in the end. I say to myself, you're not completely bonkers.

Another participant described returning to playing soccer:

I never, ever thought I'd play it again. I used to play it a lot when I was little. I was so proud day the day I stepped out onto the field. Even getting there was a huge deal for me.

Other participants experienced purpose, relaxation, and success while engaging in occupations associated with baking, and another participant who took up drawing following her head injury, described it as

pretty cool. I couldn't draw for shit before my brain injury. Now I do it all the time. I love it and although I'm not the best person in the world at it, I'm not that bad either. It calms me inside.

Although new activities were not defined as spiritual, small victories and overcoming deficits and barriers were experienced as pivotal, strong moments to participants' sense of self and accomplishment. Feelings of pride, joy, and meaning were used to describe occupational changes, and are important considerations for exploring spirituality. For most participants, spirituality became parallel to experiences of achievement, pride, and accomplishment. Therefore, spirituality seemed redefined by experiences with MTBI and was an important component of recovery.

*Fear*

Participants experienced occupational adjustments related to fear: specific fears post-MTBI; fear preventing forward movement; fear of poor parenting; fear of driving; fear of not regaining old identities; fear of job loss due to poor performance; fear of poverty; and fear of new settings and unplanned situations.

The most common examples of fear were fear of loud, crowded spaces; being involved in another car accident; not being believed by care providers; not being able to drive again or participate in certain leisure activities; the possibility of lifelong cognitive symptoms; not being able to return to work full-time; not being able to provide for their families or maintain an adequate livelihood; not measuring up to pre-accident ways of thinking and being; being a bad partner/mother; and not being able to return to the person they were prior to their accident. Some fears were stronger than others (e.g. fear of driving or crowds versus not returning to the person they once were). However, underlying hesitations about moving forward and accepting life as a brain injury survivor were described as scary and painful.

One participant described her fear of driving as “deep rooted”:

I used to love driving but because I was hit by a car, cars really scare me now.

Driving isn't fun anymore and actually cars seem more like a deadly weapon to me.

I have this little radius that I travel in with my car and almost never venture

outside of it. If I have to, I take the bus over the bridge into the city!

Another participant described her fear of being unable to provide for her family in the future (she is the sole bread winner):

After a few years, I finally found something I could do, work-wise. It's part-time which now means that our income is reduced by half. I'm afraid if I get another concussion I'll be done for. I wouldn't be able to work ever again. I could barely get to where I am now. If that happens, I might as well say goodbye to a good life for my children.

Participants described longing for their former selves, as well as their pre-accident skills and abilities, attributes which they feared would never come back. Two participants felt that their brain injuries impacted their ability to parent effectively, especially during arguments or debates with their children/partners. Participants experienced shame and guilt over being unable to participate in certain family outings and activities due to ongoing negative cognitive symptoms, including irritability, anxiety, and fatigue. Participants feared that the limitations associated with their brain injury might create negative, lasting effects on their children or partners (e.g. anger or resentment). They also described being fearful about the possibility of family members not forgiving them for being absent during important family events or school concerts. Other fears described were not being able to travel abroad, play certain sports or activities, or meet new friends or even become a parent.

Two participants felt that they were 'failures' professionally: they described feeling tremendous pride and accomplishment over their educational and professional achievements, but feared they would never measure up in the workplace. One participant described her grief at realizing she could not meet the requirements of her pre-accident job:

Yes, they've been good to me and I really appreciate that but if I keep messing up, there's nothing saying that they won't put me in another area or replace me with someone else. I mean, I might even do that to me if I were my boss.

Fear of job performance and job loss paled in comparison to single participants who described a sense of foreboding and tension about meeting their everyday financial obligations. One participant, cut off from insurance benefits after failing two gradual return-to-work programs, expressed fears about eviction and homelessness as "torture":

I couldn't even get my resume together on my own because of my head stuff. I kept messing up or forgetting to add things. I worked on it for weeks, in between massive migraines, numerous trips to my family doctor and the ER, and severe bouts of anxiety and depression.

As a result of cognitive symptoms associated with head injury, participants also feared to venture too far from their homes. One participant described this as a type of social agoraphobia; she would lie awake in bed and imagine getting a sudden migraine while in a crowded bar, which caused nightmarish panic. Participants devoted so much time to planning daily routines, pacing activities, and simplifying tasks that the thought of unfamiliar and unplanned aspects of the day created fear. Participants were also fearful of the physical environment, especially not being able to escape a stressful situation or scenario. Somewhere between coping with realistic (and unrealistic) fears, and accepting that so many cognitive, physical, and emotional symptoms might be permanent, participants fought to hold on: "I will endure whatever storm comes my

way, just as long as I am able to rest, from time to time, before I get back up, and fight again.”

### *Spontaneity*

Nearly everyone described experiencing occupational adjustments related to spontaneity: lost spontaneity; daily life as rigid and inflexible; the need for sameness; experiences with travel; and pre-planned everyday life.

Spontaneity, previously seen as fun, interesting and essential to a meaningful everyday life, declined significantly for participants following head injury. Participants identified needing predictability and rhythm in their occupational lives following MTBI, and noted that daily life had become rigid and inflexible. As a result of limitations with short-term memory, concentration, attention, and fatigue, participants had to devise new, predictable ways of completing occupations, doing whatever was necessary to find a workable, everyday rhythm:

After my accident, I couldn't do stuff the same way anymore – from paying bills to making meals. After years of disappointment and failure, I eventually had to figure out new ways to cope with the new me and my new life. My days now revolve around making sure I get enough sleep and trying not to spend too much energy on things that I'll pay for later. Everything is a negotiation. Things are so bad I can't even change the way I make the kids lunches every day. If I try to change it up and make it interesting, I'll really mess up.

Tight schedules and regimented occupational regimes were essential for both single and attached participants, and represented one of the key ingredients to

symptom management, energy conservation, and completing ADLs. This 'need for sameness' was experienced by nearly every participant in some way. While some participants performed specific activities a certain way (e.g. making school lunches, driving routes, or preparing meals), others were intent on maintaining predictable weekly schedules, albeit with some flexibility in daily activities. This need for sameness helped buffer the negative effects of head injury, so much so the idea of spontaneity made some participants anxious when it was mentioned:

Ugh, that's pretty much zero! I used to love jumping in the car on weekends and going for long drives. It was peaceful and therapeutic to me. Now when I do it, I either get lost or panic about which route to take or how tired the drive will make me. I haven't actually done those drives in over 5 years now – it's just too much! Things are finally doable but most days I feel like I'm barely hanging on. One interruption would tip me right over and I just can't be caught off guard like that.

In other words, predictability represented a common thread that wove throughout and cemented participants' daily occupational lives. When daily schedules were interrupted, the balance that participants had fought vigorously to secure was lost.

Occupations associated with fun and leisure pursuits were also negatively impacted by participants' fear of spontaneity, including travel. One participant, who used to love to travel south each year, abandoned the occupation following her head injury: "I just dream about travel now. We used to travel a lot because we loved exploring new places." When asked about her greatest fears associated with international travel, she replied,

I can't imagine moving around loud, busy airports. The lights would kill me. Or doing things like planning our ride to the hotel, what to have for supper, or what to do during the days. There are too many choices, it's daunting and not really fun anymore. I can barely plan what I'm going to make for supper most days, let alone which country I'd like to see.

Life following head injury became a negotiation of life on a daily basis, not an exploration of it. Participants found the process of finding a new life rhythm as draining and consuming, and the little energy that they managed to conserve was devoted to ADLs for themselves and their families, working, or trying to participate in leisure activities. Dreaming 'big' became less of an option.

Daily occupational life became pre-planned down to the letter, and nearly all activities were over-scripted. Lack of spontaneity affected social outings and activities with friends and family. Participants described devoting a significant portion of time to pre-planning events, as opposed to relaxing and enjoying the natural flow of conversation. For example, when scheduled to meet a friend for a meal at a restaurant, one participant described ruminating over about how she would get there, whether there would be traffic, where she would sit, how long she would stay, and worry whether a large group might show up. Regarding restaurant dining, another participant commented,

Oh, we never go anywhere new. It's the same every time because I know and trust it. I actually know it like clockwork – busy times, menu items, wait staff, lighting, even where I'm going to park, for gosh sake. I wouldn't dare try somewhere new.

Yet this inflexibility also caused embarrassment and regret:

It pisses me off. I feel like I'm 80 years old and I'm only 38. I can't do off-the-cuff stuff anymore but I want to. I feel stuck. I've always been a pretty adventurous and kinda reckless but these days, my life is sadly over-scripted.

Since pre-planning became part of so many everyday occupations, participants described a subsequent shift in internal priorities. Although several participants described an imbalance in daily life following head injury, not everyone experienced a total collapse of balance. Rather, life changed in that it became more about negotiating the daily effects of head injury within customary occupations. One participant longed for the pre-accident spontaneity of experimenting with recipes:

I would bake for hours. Sometimes new recipes, sometimes I'd just experiment and throw things together. Now I literally have to stick to things I've made since I was little or recipes that a 7-year old could follow. I need structure or I forget to add ingredients or add too much. Either way, I'm still baking for the kids. I just have less to choose from.

Although she described her baking activity as rigid and somewhat robotic, she noted, "I want to try new recipes, desperately, but I'm lost somewhere between knowing that I'm different now, and still battling the fact that maybe someday I'll actually get back to making yummy things again."

#### *How People Stayed Positive*

Participants identified occupational changes associated with staying positive: strategies for maintaining positivity; drawing on relative comparisons; focusing on remaining abilities; connections with peers; volunteerism; engaging in cherished occupations; and learning about MTBI.



Despite the struggles and limitations experienced during the renegotiation of everyday life, participants still stayed positive. Relativity was a coping mechanism in many cases; statements such as “it was much, much harder right after the accident,” or “I’m not where I want to be but I’m further along than I was” show the optimism participants were able to maintain. Using a relative point of comparison to an earlier point helped quell the constant struggle with adapting to life after brain injury because it eased the pang of occupational pain and loss. This quality was present in nearly everyone. One participant used relativity as a “check-in” to hope their brain would heal further, facilitating a form of personal resolution toward peace.

Acknowledging remaining strengths and abilities was also a strategy used by participants. Similarly, relativist viewpoints were expressed, including “I’m not as good at soccer as I used to be but I can still kick the ball around,” or “even though I can’t work full-time anymore, I’m glad that I can hold down a part-time job.” Other participants identified feeling grateful that they could continue to fulfill pre-injury roles (e.g. mother, daughter, friend, and partner), despite changes to the way these were performed. However, it is important to note that not all pre-injury abilities were completely lost: participants were forced to tap back into things they thought were lost, or alter the ways in which things could be done. Learning to draw, for example, became a point of pride for one participant who had not done so before: “I didn’t draw before my brain injury. Period! I couldn’t. Now I’ve been drawing a lot of comic characters and mapping out my frustrations and feelings in picture form. It’s amazing!” In addition to acquiring new abilities (or reconnecting with old ones), participants also felt thankful for remaining relationships with friends, children, and partners; the ability to work part-

time; and the fortitude to continue battling MTBI - all supportive factors which helped shape positivity.

Connections with peers who also experienced MTBI helped provide participants with new perspectives, support, and hope, especially during difficult times. They also reassured participants that challenges associated with MTBI were not unique to their situations. Shared experiences enabled participants to receive support with everyday occupations (e.g. grocery shopping together) and acted as a gentle vehicle for emotional growth and healing. All six participants, in some way, became involved with other people, groups, or organizations associated with head injury. Four participants became involved with their local Brain Injury Association of Nova Scotia (BIANS), while others pursued active mentoring roles.

One participant who did not return to paid employment described her volunteerism as

A privilege. I get to be the survivor rep for BIANS and help a lot of people. I also help out a lot with BIANS events and I'm on the board of directors. It feels good and I think people respond well to me because of my former life and job as a minister!

Every day supportive connections, ranging from coffee dates and walks in the park, to attending community seminars, provided participants with a non-judgemental environment where they could give and receive information: "no one really gets me like my brain injured friends. Not friends or family, my minister, or even therapist. It means

everything!” Overall, these interactions gave participants additional strength to carry on with their daily lives and uphold positivity.

Level of social support appeared somewhat synonymous with outlook. Those with adequate social supportive networks, including friends, family, partners, other survivors, or co-workers, appeared to be more positive about their futures than those who described being isolated. Living with other people seemed to buffer the effects of negative thinking and helped thwart rumination. Most participants described seeking and benefiting from some form of support from others. Whether through conversation or company, participants utilizing social supports had opportunities to get out of the home and emotionally reenergize, regroup, and essentially plan or dream together.

Alternatively, some participants disliked constant talk about their injury:

I don't always want to talk about the accident, or how I always forget to add milk in my coffee, or how shitty my memory is, or how I'm terrified to drive. Sometimes I just want to be around people without brain injury because it makes me feel normal.

Cherished, meaningful activities brought a sense of peace, mastery, and accomplishment to participants' lives, but participation in meaningful leisure activities were described as few and far between due to reduced energy and motivation. Still, participants who managed to engage with meaningful activities described a sense of pride in their ability to do so. One participant described the occupation of driving as peaceful because she was able to successfully and effectively perform the activity which made her feel free (not brain-injured) and hopeful. Another participant described how

baking cupcakes helped her remain positive because, although she was required to pace herself and perform the activity over a long period of time, the outcome made her feel grateful for her remaining ability to do something for her children.

Finally, participants who sought out additional resources about brain injury, along with those who participated in ongoing research projects and other treatment and learning pursuits, described feeling optimistic about their future. Two participants described how volunteering to participate in a neuropsychological study that focused on biofeedback, exercise, and mental energy conservation, contributed to hope that neuropathways might regenerate over time. Another participant volunteered to partake in a study about the effects of diet on brain health, and two participants involved with the same study took vitamin supplements aimed at helping improve energy and cognitive function. One participant described the study as

hopeful. I feel like I'm looking for a lost child. I'll never stop trying to search for answers about what happened to me. Being in this study means that I'm still trying and that there's still hope that I might get back some of the things that I loved and lost.

Others felt proud of attending free educational seminars offered by local universities and organizations. Participants described how being part of these learning opportunities made them feel informed and knowledgeable, thus enhancing their ability to comprehend information about their own brains and deficits. They also described this involvement as beneficial for interpreting and articulating findings from studies to other brain injury survivors:

I sit there and I don't really understand most of the stuff they're talking about. But I'm there. Sometimes I lose track of what people are talking about, and I drift away into my own little world but I just keep saying to myself, even if you just hear one thing that makes sense, it might help you. It was worth it.

Another participant described how searching for online information about brain injury enabled her to achieve academic goals. Regardless of the environment, participants described feeling a sense of enthusiasm and optimism while engaged with learning pursuits; the quest in learning more about what happened to them, neurologically, was described as never-ending:

I just dig and dig and dig around for information. Stuff I already know. Stuff I don't. As soon as something promising comes up, I usually tell my brain injured friends and we check it out together. I guess I'm hoping one day I'll find something that really helps me. I'd like to get back to who I was. I'm forever searching for the answers. Until then I'll just keep digging.

#### *Positive Outcomes of MTBI*

Most participants identified experiencing various positive outcomes associated with MTBI: strength and resolve; resilience; insight and empathy for others; compassion and connection; stronger relations with family and friends; and redefined successes and roles.

In addition to positivity and optimism about the future, participants identified some positive outcomes associated with head injury. Many described stronger personal character and resolve when trying to overcome daily limitations and barriers. Others described finding new compassion, connection, and empathy toward individuals who

experienced significant disease or strife, and three participants described experiencing closer, stronger interpersonal relationships with family and friends. Finally, several participants discussed ways in which their successes, post-injury, had been redefined.

Becoming both resilient and mentally stronger were acquired traits described by most participants. Some described their experiences as having been to hell and back or as an epic ongoing battle. Others likened living with a brain injury to new personal awakenings and evolution:

I won the war. I've gone to hell and back and nearly died because of it, but you know what? I'm still here. I walk around most days like a zombie with an invisible shield around me now – it might be bitterness or resentment, I'm not sure!

Though once you've been to battle, you're never really the same. You break open in some way and nothing scares you anymore. I could actually take on the world right now.

Participants described feeling as though they had grown wiser and stronger as individuals, and despite the continuation of symptoms present in daily life, had evolved into higher quality people overall.

Changes in personality and character traits equipped participants with increased insight and empathy for others, brain injury survivors as well as individuals facing other life-changing illness or circumstance. Participants described experiencing greater depth and insight into others' pain and suffering, and subsequently felt more empathetic, understanding, and loving toward those who were struggling. They also experienced increased compassion and connection with people in need:

It's weird because I walk a little slower now around people on the streets. I used to kind of blame them deep down for their bad choices and how they ended up there. I'm different now. I usually dig into my purse and drop change into their buckets. I want to say I know where you are. I've been there. You can make it. You're not the only one who had seen hell.

Another participant described her understanding and compassion toward others as a new mission in life: "you can't go back once you've changed. I will spend the rest of my life helping people. It's as important as the air in my lungs."

Two participants identified stronger bonds with loved ones as the result of head injury. One participant, who was married with children, moved back home with her parents to receive continuous care and felt thankful for the chance to become closer to her parents. Another participant, also married with children, described moving in with her dying grandfather to take care of him as the best emotional decision she had ever made; without a brain injury diagnosis and subsequent time off work, she would have been unable to provide him this support and care. Other participants experienced stronger relationships with friends who stuck by them after their injury. One participant felt her relationship with her teenage daughter had been strengthened by her brain injury because she could better identify with some of her daughter's emotional and learning difficulties.

Participants expressed gratitude for their remaining abilities, described by one as a form of awakening:

I can't run anymore but I can still walk. I can't cook for hours on end but I can still make a simple meal and feed my family. I can't stay awake from morning until night anymore, but I can take a nap and recharge myself so I can do more when I wake up.

Some described experiencing greater appreciation for life in general, and for having survived their injury/accident. Positive outcomes of "seeing the forest for the trees" were identified by participants who took on advocacy roles.

Participants described being better listeners and more supportive within their roles as mothers, daughters, sons, brothers, sisters, partners, co-workers, and friends: "these days, I try to treat everyone with kindness and compassion because people who are angry or struggling need it the most." They also described being less judgemental toward others and prided themselves on trying to put themselves in other people's shoes. One participant described her new perspective as

profound! It's just I just didn't get it before. I was so busy with trying to climb the corporate ladder. There was no stopping me really. Then after my head injury, I was forced to pause and really think about life – for the first time in 37 years. It changed my life.

Regardless of the type of positive outcome, participants all identified new inner processes as they tried to re-examine their new lives, post-injury.

The next chapter explores how participants struggled to establish the legitimacy of their status as brain injured, even while navigating pervasive social stigma concerning the condition, which sometimes meant attempting to 'pass' as unaffected. It examines



issues of occupational identity and how identities shifted over time for participants. It investigates occupational transitions, and processes of occupational adaptation.

## CHAPTER 6

### RESULTS: IDENTITY, TRANSITION, AND ADAPTATION

This chapter goes beyond the occupational effects of MTBI to explore deeper processes. Chapter 6 provides a more detailed analysis of occupational processes, including legitimacy; passing and stigma; occupational identity, identity reconstruction, new life as a brain injury survivor, and celebrating recovery; occupational transition; occupational adaptation and redefining successes, adaptations to identity; occupational failure; and future outlook. While chapter 5 explored results related to everyday occupations of daily living, interpersonal occupations, and intrapersonal occupations and concerns, chapter 6 builds on those results and details results pertaining to occupational processes. Struggles with proving legitimacy of diagnoses were coupled with passing as non-injured and managing or avoiding stigma. Both of those connect with shifts in identity, processes of occupational transition, and occupational adaptation.

#### 6.1 Legitimacy

Participants describe legitimacy as being ‘believed’ by others for having a head injury. Five out of six participants discussed their personal experiences with legitimacy, including struggling to be believed at both the individual and institutional level. Several themes were identified regarding legitimacy: language use; insecurity and doubt; and legitimacy as an occupational battle.

Nearly all participants described being negatively impacted by the use of everyday language. One participant hated the term ‘*mild* traumatic brain injury’ because

of its implications about severity: “mild means not bad. Like you’re using ‘mild’ laundry detergent or ‘mild’ hot sauce – like it doesn’t cause some sort of burn. It’s absurd.”

Another participant felt compelled to justify her mild brain injury to co-workers and acquaintances:

It’s a mild brain injury but it’s not really mild. I haven’t called you in months because I have migraines and throw up all week. I have a hard time reading and sending emails and I’m tired constantly. Actually, my life has become a living hell.

Other participants described how hearing certain terms used interchangeably in everyday conversation impacted their ability to be understood or taken seriously. Terms such as ‘mild traumatic brain injury,’ ‘post concussive syndrome’ and ‘concussion’ were used loosely by individuals within and outside of medical and legal communities, creating confusion and misunderstanding about the diagnosis and subsequent treatment. One participant described being annoyed and confused about the contradictory language of the literature and medical communities: “they can’t even agree on the same term. When I first started researching MTBI online I could barely get anywhere because everyone used different words to describe it. It was more than frustrating.” Further, another participant described taking offense at the use of “concussion” to describe an MTBI because

everyone knows someone who’s had a concussion, and for the most part concussions get better. Legitimate MTBIs don’t. These terms are degrading and devalue my experience as someone with permanent injuries.

Finally, participants expressed frustration on hearing 'migraine' used to describe an ordinary headache, and 'concussion' used to describe any type of head impact, regardless of symptom severity.

Several participants described how well-intended words of support and comfort were personally experienced as hurtful, painful, and humiliating. Everyday phrases such as "oh, you'll get over it," or "keep your chin up and try to be positive" were found to be insensitive. Participants made efforts to portray the severity of their brain injuries to legitimize their everyday experiences with MTBI, but unsuccessful attempts left participants feeling angry, damaged, and further victimized. Some individuals' expressions of condolences or support were viewed by participants as competitive ("I know how you feel" or "once I had a bad headache"). One participant's friend asked, "how are you enjoying your time off work?"; the participant felt demeaned and that there was an implication of defrauding the insurance system and possibly malingering. Another participant was told by a co-worker, "Oh, I know someone who had a much worse injury because they were in the hospital for weeks after their car accident." The participant made an excuse to leave the room to avoid further discussion about her own car accident because she had not spent any time in the hospital.

Several participants described the relationship between the hidden effects of head injury and legitimacy. Comments such as "you look fine to me" or "you're not as bad as my cousin" and "you look like you're getting better" devalued participants' experiences with battling an invisible injury. Consequently, participants described these statements as catalysts for becoming defensive or being selective in their choice of

conversation partner; they also represented an interruption to the grieving process because of efforts to defend authenticity, as opposed to seeking out proper supports.

Experiences with legitimacy also represented an occupational battle with respect to professional and educational backgrounds. Participants with a professional background felt they could better relate to other professionals because they shared a similar 'pay grade' and could talk on the same level. One participant, a social service professional prior to her head injury, felt validated as a brain injury survivor because of that work: "I had automatic legitimacy because I was like the professionals I was interacting with." Another participant, who worked for 30 years as a registered nurse in the ER department, felt automatically validated by her co-workers once she received an MTBI diagnosis:

They knew the type of person I was. I was respected. People would always come to me for advice and support at work so I guess it just automatically followed me from the work environment to my life on disability.

## 6.2 Passing and Stigma

Participants identified stigma associated with having a brain injury as a significant element of their experience of living with an MTBI. They argued that discrimination is a challenge for people with brain injuries because MTBI-associated symptoms are frequently invisible and survivors are perceived as dramatic, faking it, or exaggerating their symptoms. In cases when symptoms are more apparent to others, participants argued that they are often seen as defective, a little off, moody, or unintelligent. In response to this stigma, participants identified engaging in occupations and activities that enabled them to "pass" as non-brain injured, including attempts to

minimize the severity of their symptoms in order to fit in, get by, or avoid judgement by others. These occupational adjustments and efforts consisted of fear of being judged; avoiding ruining things for others; and avoiding vulnerability or appearing weak. Other strategies for passing included avoidance, avoiding revealing the need for assistance, tricks to hide things, avoiding certain tasks, abandoning the notion of appearing 'normal' and assuming roles in advocacy, and using humor.

Most participants identified being afraid of being judged as central to hiding the effects of their brain injury. Rather than continue to fight for validation, one participant described emotionally retreating from people by pretending she felt fine, which stopped the constant barrage of questions about her car accident. Others felt that only certain people had earned the right or privilege to hear about the specific effects of brain injury on their lives, so some participants were selective about those with whom they would discuss the topic.

Verbal judgements such as "you're too bad to work but not bad enough to go for a walk or to the movies" were experienced by participants as painful and humiliating, as were non-verbal judgements such as the tone of someone's voice or non-verbal cues (e.g. shoulder shrugging or rolled eyes). Fear of being judged by family and friends was less common but still present. One participant refrained from discussing her symptoms with her sister following comments about not working (e.g. "you have so much time on your hands" or "you could do that – you're not working anymore"). One participant related remaining silent when a contractor visited her home and commented about her poor housekeeping ("it looks like a hoarder lives here"). She described feeling too

ashamed and embarrassed about the state of her home to defend herself against the accusations, though the disarray was a result of the decreased motivation and disorganization from her brain injury.

Avoiding relentless questions about the severity of their brain injury, combined with wishes not to be seen as responsible for ruining other people's fun, forced participants to hide their symptoms from family and friends. One participant described the cognitive overload whenever she looked after her grandchildren (to the point of dizziness and vomiting), but would avoid complaining about her symptoms or taking breaks because she did not want to cut short the visit. Another participant went shopping with her daughter despite having exceeded her fatigue levels, because she did not want to spoil their plans. Participants described keeping their suffering to themselves despite symptoms of fatigue, stress, and irritability. For example, instead of worrying family members who noticed she was slurring one night, one participant pretended that she had had too much to drink because it was easier to explain being tipsy than suffering from symptoms related to her brain injury. Another participant pretended a family emergency caused her to leave a social event early, rather than explaining her double vision and nausea to colleagues at the party.

Fear of vulnerability or appearing weak were other reasons for hiding the effects of brain injury, in attempts to preserve dignity and character. This was especially true for participants who prided themselves on their independence prior to their brain injury. Participants who identified as well-adjusted, assured, and successful described fears of being viewed by others as damaged, insecure, or dependent following head injury. They

took extra measures in order to minimize the effects of brain injury, especially while liaising with the general public. One participant had missed three consecutive years of paying property taxes, but pretended she had paid them due to embarrassment.

Another participant, who accumulated numerous parking tickets, was too humiliated to tell the municipality that her negligence was a result of short-term memory limitations and instead paid the sum. Both participants managed their money independently and successfully prior to their car accidents, but felt the truth would leave them exposed or lead to possible judgement, shame, and mockery.

Participants used multiple strategies for hiding the effects of their brain injury in the workplace, including avoidance. For most, being vulnerable and revealing their symptoms was easier to do with trusted family members and friends than co-workers. One participant described hiding in the stretcher room during breaks at the hospital where she worked to hide her headaches, dizziness and fatigue from colleagues. By removing herself from the work environment, she was able to rest and recharge her brain in private without notice or questions. Another participant pretended to use the washroom and sat on the toilet in order to close his eyes and prevent fatigue and dizziness at work, which helped avoid questioning or judgement from others. Although some participants described these strategies as coping strategies as opposed to hiding the effects of their brain injury, others described them as not wanting to appear 'less than' or not 'up to snuff.'

Learning to ask for assistance or accommodation in the workplace was viewed by participants as a strategy and process, but was difficult for participants in leadership



roles. One participant oversaw several employees in her workplace and felt pressure to uphold her professional identity by appearing capable at any cost, even if it meant hiding her MTBI symptoms. Another participant described not wanting her healthcare clients to see her as brain injured because she feared that it might negatively impact or taint their perception of her as a capable health care provider. Strategies for hiding her symptoms included taking secret breaks in the bathroom to regroup and collect her thoughts, taking extensive notes during discussions with clients, and using her days off to complete paperwork that may produce fatigue or mistakes during workdays - all of which helped maintain clients' trust in her and their perception of her as a sound clinical practitioner.

Using tricks to minimize or hide the effects of brain injury also had an impact on participants' self-esteem. One participant described paying for inexpensive items like coffee or snacks with a \$20 bill to avoid counting out change. Another participant at a work party, who did not want work colleagues to know her symptoms had worsened and therefore she had to leave early, secretly asked wait staff to dim the lights to make it seem like the party was naturally dying down. Some strategies for minimizing the effects of brain injury became deeply engrained in everyday occupations (automaticity), while others continued to be thought out and more deliberate.

In order to help fight stigma, participants described using several strategies in order to try to 'pass' as non-brain injured. For example, while socializing with non-brain injured friends one night, one participant noticed her fatigue and slurred speech, so she decided to become

really quiet. I figured if I didn't say much they wouldn't notice. The other option was to order a drink - but no one was drinking - and pretend that it went straight to my head. I liked being out with normal people because I didn't really want to talk about my brain injury. For just one night I wanted to be the old me.

Another participant avoided picking up her water glass when her hands started to tremble while out with new friends; she described this as necessary to feel normal and non-brain injured. Both participants reported wanting to feel "normal" around non-brain injured acquaintances.

Finally, though some participants struggled to minimize or hide the effects of brain injury, others identified being proud of their gains compared to the time of their initial diagnosis, so they abandoned occupations associated with trying to appear 'normal' and instead took on MTBI advocacy roles. Taking opportunities to provide people with information about MTBI was also viewed as a form of legitimacy, sharing their lives experiences in addition to the literature: "I don't care anymore. I resisted my label for years and I'm just so sick of giving a damn what others think. I've made peace with where I'm at now and I want the world to know." Another described using humor to quell harsh judgements about people with brain injuries, making her feel like she was "on top":

I just laugh at myself and make jokes about being extra careful crossing the street in order to avoid another head injury. Or I'll say things like 'gee, I'll just blame my brain injury for asking you that 3 times', even if it had nothing to do with it.

### 6.3 Occupational Identity

Occupational identity has been defined by Christiansen (1999) as a form of personal identity or “who we think we are.” His definition of the self includes roles and relationships, possibility or potential (e.g. who we might become), and a value aspect that provides a basis for choices and decisions. Individuals also have a social identity, or a sense of who they are in relation to how others view them; therefore, social interaction is also an essential element of identity.

In this study, all six participants experienced disruptions to their identity, including a loss of their sense of self. Several themes emerged in relation to occupational identity, or “who we think we are”:

1. the *initial shock* (including identity disruption, the damaged self and lack of awareness, occupational cessation, and loss of self with loss of occupations);
2. *grief, constant battle, and an eventual decline in mental health* (including longing for the former self, anger and resentment, denial, lost skills and abilities, anxiety and depression, and loss of hopes and dreams);
3. *reconstruction* (including creating new meanings and purposes, rejecting interim identities, accepting change, changed personalities and hobbies, connecting with the old self, and abandoning, adapting, or resuming occupations);
4. *new life as a brain injury survivor* (including returning to old occupations, new occupational pursuits, new parenting roles, freedom from judgement, intelligence considerations, and remaining gaps); and
5. *celebrating recovery* (including stopping the search for more recovery).

### *Initial shock*

Alterations to sense of self, including diminished feelings of personal security, self-awareness, and self-concept, were experienced by all participants. Despite the severity or type of injury, nearly everyone described the weeks and months following head injury as rife with physical, cognitive, emotional, and psychological suffering, including symptoms of nausea, dizziness, and migraine headaches, emotional lability, and musculoskeletal pain. Participants described being overwhelmed and overloaded by their plethora of symptoms, and confused about how to view themselves or their post-injury occupational lives. The majority of participants referred to this initial period as being “frozen in time” and stagnant because to them, life became immediately static as opposed to fluid and evolving. Following their injury, participants described entering into a survival mode because most of their time and energy was spent trying to get through each day by minimizing symptoms. Immediately following the injury, five out of six participants stopped working, volunteering, and/or socializing, and four described becoming either bed-ridden or house-bound in order to be cared for by family members or friends. One participant described this period in time as:

... a 180. I went from someone who was highly active and healthy, working full-time, and a wife and mother of two small children, to someone who laid on the couch all day with a cold cloth on my forehead, running to the bathroom to throw up from pain and nausea.

Neurological effects of brain injury impacted participants’ sense of self-awareness, which created subsequent disruptions to identity. Self-awareness is often

key in order to recognize disruptions, adapt to change, or rebuild identity, and participants described being 'robbed' of the ability to truly grasp the breadth of their injury/situation. Also, as a result of physical damage to the brain, some participants described lacking the insight and awareness necessary to understand the factors that contributed to the changes in their identity, creating prolonged emotional distress. An inability to use positive self-talk or self-sooth to quell the emotional and psychological effects of cognitive interruption were also identified, leading to feelings of disconnection and helplessness. One participant described the initial phase of her recovery as

foggy. It was like I was living a nightmare. Like I was watching my life from a TV screen, looking down on myself. I was on lockdown like someone hit a switch on a conveyer belt and it just stopped. My thoughts were so scrambled. My life just stopped. I was frozen in time.

As a result of experiencing ongoing symptoms, most participants stopped participating in meaningful occupations, especially activities that involved fun and leisure and socializing with friends and family. These occupational cessations, especially for non-essential occupations, created an overwhelmingly paralyzing occupational imbalance. In fact, throughout the interviews, the majority of participants focused on their first year of life post-brain injury and used phrases like "right after my car accident" or "in the beginning" in order to highlight the magnitude of the initial shock/impact on their occupational lives. Disruptions to emotional and occupational aspects of identity were constantly used as a point of reference for most participants.

For example, one participant repeatedly described her everyday life following brain injury as

hellish! I couldn't think, I couldn't do anything, I couldn't be me. I had no time to say goodbye to myself, it just happened in the blink of an eye. Yet, I had a body and was walking around like I was still alive but I was actually dead inside.

As a result of decreased occupational participation, participants described slowly losing themselves because so many meanings attached to various occupations were lost. Lives that were once meaningful, busy, and balanced became replaced with periods of prolonged inactivity, boredom, and a sense of bleakness and loss, contributing to an erosion of self over time. Therefore, loss of self was often a result of loss of occupations. These changes also contributed to a sharp decline in participants' sense of occupational mastery, achievement, and purpose, and eventually led to what was described as an occupational crisis, or the sudden cessation of participation in meaningful everyday activities.

#### *Grief, constant battle, and eventual decline in mental health*

Participants all described their sense of self as damaged. In fact, all six participants described longing for their pre-injury lives, and four described desperately wishing to return to pre-injury ways of thinking, feeling, and living. Identity was further impacted by processes of grief: participants grieved aspects of cognition including memory, concentration, and attention, as well as higher forms of thinking (e.g. hope and dreaming). One participant felt that "aspects of composure and rationality were gone": "I entered into a deep state of unrest. I couldn't collect my thoughts and I never felt free. I was in fight mode, constantly. Irritated by everyone and everything. I hated

the world. I was so incredibly angry.” Other phrases like “I miss my old brain” or “I desperately wanted the old me back” outlined the constant turmoil between participants’ past and present selves. Longing to get back to some prior place was commonly identified as part of the typical grief trajectory, though different in experience and duration.

Although relativity (me then *versus* me now) was used to hang onto aspects of the former self and life, those who resisted change seemed to experience greater difficulty with making adaptations to themselves and their occupational lives. Participants missed the peaceful, relaxing, and calm or reflective aspects of their old selves and reported being stuck in a prolonged state of hypervigilance, regret, and denial. This stage lasted for different amounts of time for participants and was influenced by factors such as type and severity of symptoms, personality, and level of social support. Four of six participants experienced immense anger about their MTBI diagnosis and subsequent symptoms, and identified resentment that their lives would be forced to change. Participants spent years resisting changes before considering that their lives might not return to the way they were before their injury. Although resistance was experienced by nearly everyone and represented part of the typical grieving process, it was described as a painful, constant battle against inner demons. One participant compared resistance to fighting a “monster”

It was like something was always chasing me. I was running away from my future, and running toward my past. But the monster was always gaining on me, catching up. Then it just caught me. I’m not sure if it was actually my conscience or some

sort of surrender but once it caught me, I realized that I might not ever be the same. It was worse than dealing with a death in the family.

Denial, described in psychology literature as common during the initial stages of grief, was experienced by all participants. Phrases like “I can’t be like this forever” or “I refuse to accept this is the new me” highlighted persistent feelings of resistance, loss, and failure. One participant described her battle with accepting change as an

...ever-burning ember in the fire of resistance. I vowed I’d get back to who I was. If I just did exactly what my doctor told me to do, and allowed my brain to heal, I would eventually return to who I was. I compared it with recovering from a nasty chest cold or infection. Eventually it would get better, like all things in my life had before. It wasn’t until I realized after a long time, that there was a chance my life might always be different, I crashed, burned, and eventually wanted to die. How do I rebuild a whole new person? Who knows how to do that?

In addition to longing for the old self, participants’ lost skills and abilities impacted grieving. Participants described being humiliated and frustrated by their inability to adequately perform certain occupations, especially those involved with leisure and hobby pursuits. Skills needed to perform ADLs effectively (e.g. grocery shopping, paying finances, or doing laundry) were largely impacted by cognitive and physical symptoms, pain, decreased motivation, and other mental health issues (e.g. anxiety and depression), and were described by participants as compromised, defective, or inadequate. This ultimately led to a ‘defective’ sense of self. Participants identified feeling constantly disappointed and discouraged that their ongoing symptoms



prevented them from adequately participating in activities associated with returning to work, having fun, and socializing with friends. One participant described longing for the ability to play soccer again, and felt constantly belittled (internally) by her inability to run on the field, kick the ball, or score goals. Overall, although grief was experienced differently, those who continued to hang onto and compare their pre/post-accident selves (and lives) described facing the greatest resistance to re-establishing their identities post-injury.

All six participants experienced negative mental health effects including severe anxiety and depression. In addition to experiencing a decreased sense of personal security and well-being, participants described uncertainty about their past, present and future selves. This perpetuated motivational challenges in order to combat declining mental health. As part of their damaged sense of self, participants constantly focused on mistakes and inadequacies:

I tried to bake cookies without burning them, drive around my neighborhood without getting scared, or clean the house without forgetting to dust but it felt like everything I did was defective. It was all wrong. I couldn't do anything right.

As a result of over-focusing on their failures and occupational inadequacies, participants became stuck in a perpetual state of hypervigilance and anxiety that negatively impacted their ability to internally rest or relax. At different points throughout the grieving process, and in response to feeling overwhelmed and over-burdened with mental health issues, some participants described eventually giving up, crashing, or succumbing to defeat. Several participants described this as losing hope, which had the

most profound impact on their identity; others attributed their inability to dream about the future as the most significant factor in the decline of their identity.

Two out of six participants described entertaining thoughts of suicide following their head injury; one participant twice attempted to take her own life. Resisting change, severe anxiety and depression, and feelings of hopelessness were described as contributing factors to her suicidal ideation. While trying to pinpoint a more exact cause of these negative mental health outcomes, three participants identified a strong connection between feeling a loss of control over their lives and the idea of giving up. Because their post-injury occupational lives were in constant flux and upheaval, participants eventually accepted defeat and completely fell apart before they were able to learn ways of adapting to their new reality. Participants had yet to resume old occupations or modify them in some way; these adaptations came at a much later time. Overall, the grieving aspect of recovery was described by three participants as the darkest days of their lives.

### *Reconstruction of identity*

The last major stage of the grieving process was described as the reconstruction of the self. As time passed, by eventually accepting change and loss, participants were able to begin the process of adapting to and rebuilding a new identity by finding new meanings and purposes. Some attempted to redefine themselves as a result of their experiences with MTBI (including setting new goals for the future and pursuing new life roles), while others experienced continued tension about moving forward. Most participants used terms such as 'warrior' or 'fighter' to describe their attitude toward

identity reconstruction. Participants gradually adopted a more active, motivated role in overcoming barriers and challenges associated with MTBI, and identified a strong desire to move past denial and resistance. One participant emphasised the thought, time, and energy she dedicated to battling and eventually overcoming her old demons (e.g. old vs. new self) by rejecting her interim identity and the idea that she was still a victim. Another participant described how stopping the search for validation and empathy enabled her to tackle and conquer severe depression, anxiety, and defeat.

Three out of six participants described how accepting change (including their new selves and occupational lives) only occurred once they learned to stop hiding the effects of their brain injury. One participant identified this progression as

freedom! I spent years denying that there was anything actually wrong with me. I invested so much time and energy into hiding problems associated with my migraines, inattention, and short-term memory, it just wasn't worth it anymore. I lived in constant state of unhappiness. Just when I thought that life was too unbearable to live anymore, I decided to stop giving a damn. I had to let go. I wouldn't have made it otherwise.

Participants also described how learning to accept change/letting go of resistance helped legitimize their experience as brain injury survivors. Prolonged feelings of loss and disconnection to their former selves was exhausting and impacted meaningful occupational choices, which in turn impacted occupational identity. Participants described becoming sick of feeling stupid or inadequate about their participation in certain occupations, and missed feeling personally secure and accomplished in everyday life. They learned to disregard others' judgements once they recognized the negative

impact of these judgements on their ability to accept change and move forward. At different periods throughout the grieving process, all six participants described reaching a point where they finally accepted what had happened to them, grieved their tremendous losses, and assumed a more purposeful, active role in rebuilding identity.

One major theme that developed during the reconstruction stage of recovery was a change in the balance of internally- and externally-oriented activities. Some described this as becoming more introverted after living extroverted lives, while others likened it to changes in internal processes required to achieve a state of peace and relaxation. For example, one participant described her former hobbies requiring extensive physical skill and energy, including running, yoga, sailing, working out at the gym, and playing team sports. However, she eventually decided to move forward and try more sedentary occupations including knitting, mowing the lawn on her ride on mower, and yoga. Once she was able to recognize and accept the value of a different occupational set-up, she was able to better work with her post-injury abilities and accommodate her ongoing cognitive limitations. Given that her post-injury abilities were better aligned with her post-injury sense of self, she let go of her old leisure life and found a sense of peace and mastery again. Another participant took up reading, writing, walking, drawing, and painting, after many years participating in marathons and intense impact sports. She experienced newfound pride and accomplishment at mapping out her inner feelings through drawings caricatures. Phrases such as “I loved reconnecting with my artistic side” and “I couldn’t draw before the accident, so I was pretty amazed with myself” or “I really learned to embrace silence in my life” exemplified the

importance between the state of letting go, resuming meaningful activities, and attaining a stronger identity.

Participants also described the importance of maintaining some aspects of the old self. One participant discovered new ways to perform old activities, either through pacing, task simplification, or other methods of adaptation. Other participants identified the importance of not completely losing all facets of their former selves, but did need to find different ways to incorporate their old sense of self into their new occupational lives. This was difficult for many because participants were required to gauge whether holding onto various activities was worth the risk of aggravating symptoms and becoming defeated. For example, playing hockey would not be worth frustration, anxiety or fatigue if MTBI symptoms were exacerbated, so it was a choice to abandon hockey altogether and attempt a lower-impact sport to benefit their identity and sense of achievement. Participants had to decide which activities to resume and which to abandon based on how important the activity was to them, how good they were at it, and how much the activity was missed.

Activities that were not as cherished were easier to let go. This was done mostly by trial and error because after several starts, misses, and stops, combined with periods of occupational frustration and failure, participants were able to slowly replace old activities with new ones, building a new sense of self/identity. This balance was difficult to achieve initially, but participants became skilled at it and were eventually able to feel satisfied knowing that they were working toward change. Resuming old activities or modifying them in some way made participants feel close to remnants of their old self. One participant described how “laughing, driving, and editing peoples’ reports all made

me feel like the old me”, while another described her newfound love of baking as central to feelings of mastery and accomplishment:

I used to bake almost every day but now I just do it a couple of times a week. I’m just happy to be back in the kitchen with my kids. There’s nothing like the smell of fresh cookies – it brings me so much joy!

Overall, the use of old skills was described as important in maintaining an ongoing relationship between the old and new identity.

#### *New life as a brain injury survivor*

Once participants were able to accept their identity as someone with an MTBI, they embraced their new lives. While some resisted using terms like ‘survivor’ or ‘victim of a car accident’ or ‘brain injured,’ others described the terms as a source of pride and accomplishment because they overcame something profound and life-changing, heard in interviews in phrases like “I survived” or “I overcame.” Participants were different than they once were: they described knowing that their sense of self and their lives had changed, and most subsequently and proactively took steps necessary to reorganizing and rebuilding their self-concept, occupational meanings, accomplishment, and sense of occupational adequacy over time.

Old meanings attached to various pre-injury occupations and roles changed as well. For example, aspects of her old identity remained for one participant worked as a social service professional prior to her car accident: she was still able to provide hands-on support and encouragement to members of her local brain injury community, and she achieved a board position with her provincial brain injury association. Although her previous identity was largely shaped by her role as a social service provider, she was still

able to connect with her 'spirit' and 'think deeply' about herself and life, post-accident, by helping others. Feelings of mastery and achievement still emerged, albeit differently. Despite her continued struggle with symptoms and some mental health issues, she described continuing to perform some aspects of her old self (in the new form of advocacy) as "life-changing."

Academic pursuits also shaped and were shaped by identity changes. One participant with an MTBI returned to school after having been absent from the academic world for over two decades. Despite ongoing symptoms and challenges associated with new learning styles, he was able to successfully complete his coursework and achieve new academic pursuits. He described himself as a 'brain-injured student' and proudly proclaimed his academic accomplishments under this title. He also identified optimism and hope about his future prospects because he was able to achieve a sense of self-control and power in his new identity. Although participants described a strong link between their vocational career and identity, new meaningful occupations associated with working as a brain injured person enabled them to look past labels and embrace new ways of thinking and feeling about themselves.

The link between parenting and identity, especially during the reconstruction phase, was described by three participants as challenging but rewarding. Participants identified challenges with parenting as an MTBI survivor, including engaging in leisure occupations with their children, arguing with their children, and disciplining their children. Participants who were parents described how relationships with their children were strengthened when they learned to better understand and embrace their new

identity. As participants continued to move past their damaged self into recovery and rebuilding modes, they became more organized and conscientious parents due to increased self-esteem and confidence. Further, as participants established greater meanings associated with increased occupational engagement and self-discovery, parenting styles and methods also changed. One participant, who once cherished the activity of baking with her young children, learned to schedule time for baking based on her energy levels, enabling her to resume aspects of previous meaningful occupations and aspects of her old self. Although she was unable to bake as often or make intricate recipes, she was still able to provide fresh baked goods occasionally for her children's classmates at school. Another participant with grown children living outside of the home described how ongoing struggles associated with headaches and fatigue affected her ability to babysit her grandchildren. However, once she learned to agree to babysit only babysit on her days off, she became a less stressed, more energetic grandparent. Regardless of how the changes were made, parents who learned to modify or adapt their meaningful occupations described becoming better parents.

Social support also represented a strong factor in the restoration of personal and occupational identity. Traditionally, self-worth has been in part defined by what others think about us, and how we interact with the world, including family and friends, co-workers, acquaintances, and the public. Participants experienced changes to their sense of self once they learned to stop worrying about what other people thought about them, or once they stopped comparing themselves to their old selves and others. When this occurred, participants were freed from fear of judgement and able to rebuild a social identity successfully and positively. Individual differences and strengths were



slowly embraced again. Participating in social activities helped increase feelings of self-esteem and worth, and in turn, participants re-engaged with the social world and derived new social meanings and support from others. Some participants abandoned terms like 'normal people,' which also helped them re-establish a healthy social identity. Participants learned to accept their new identity relative to others, which also included admitting they found some things they used to do difficult. This admittance helped ease the pressure of constantly trying to keep up, and helped bring a sense of purpose and pride about the new skills and abilities that they brought to evolving friendships.

Intelligence and identity were strongly correlated with reconstruction of the self. Three out of six participants identified coming to terms with the fact they were unable to read, write, or learn as they had previously. This realisation and acceptance was a form of grieving because intelligence, including academic achievement, self-learning, increased education, and other types of learning pursuits had changed following head injury. For individuals who identified as being smart prior to their accidents, grieving the loss of intelligence (cognitive ability) was essential to identity growth. Phrases like "I'm not as smart as I used to be" or "I read and write like an 8<sup>th</sup> grader now" helped outline some of these challenges and perspectives:

One of the things I prided myself on before my car accident was my brain. Yeah, I felt that I was pretty smart and people told me I was way above average. After the accident, when my neuropsychologist told me that I was only 'average' now, I pretty much fell apart. My sense of identity was basically wrapped around my intelligence.

However, over time, participants described learning to accept changes in their learning styles/cognitive ability and recognized themselves as intelligent even though their learning styles had changed

Participants found new ways to compensate for their cognitive deficits. Two out of the three participants who highly valued intelligence took part in new academic ventures associated with their brain injury association, enabling them to make adaptations or modifications to their new cognitive selves. For example, one participant admitted she made peace with her inability to pursue graduate studies, so instead took an active role in public speaking and advocacy for her local brain injury chapter. Another participant who once self-identified as a voracious reader replaced that occupation with writing poetry, a skill that aligned better with her post-injury abilities (e.g. it was easier to write shorter sentences and for shorter periods of time). However, when asked, all three participants revealed hoping they would continue to make neurological progress and thus become smarter in time.

However, despite progress, participants identified remaining gaps and uncertainties in their identity. One participant returned to full-time work after two years away following her accident, but described continually battling her old sense of self because

it never really goes away. I'm back to work because I'd be living on the streets if I didn't but I literally have no steam left by the end of the work week. I live to work. I still don't really know who I am and I'm constantly wondering if I'll ever be happy again.

Another participant described her current sense of self as “a wanderer” lacking a strong identity: “I’m never really sure who I am and I usually forget the best parts of who I used to be.” These participants described their new identity as more static than progressive, meaning some aspects of identity were seen as an end point rather than a process. Although most participants resumed occupational engagement and found new meanings and purpose in the latter stages of identity reformation and growth, underlying insecurities, including longing for peace and self-assurance were present.

Dreaming about the future and identity were also described as related. Although some personal values and occupational goals were slowly being met over time, some participants pondered shifts in their ability to dream about the future:

I used to be a big dreamer but now I’m a small dreamer. They’re more basic and local. It’s hard to see a big picture. They’re probably more realistic now I guess at the end of the day. But those big dreams kept me going...you know, those dreams that know deep down will probably never come true but its hopeful and fun to think about them anyway. Well, they’re gone now.

Some described their diminished ability to dream as depressing and sad, while others embraced the fact that they had learned to dream more realistically and be part of the real world. While some described their new sense of dreaming as “haunting! I tell it to back off because I don’t have time for it,” others accepted smaller, everyday victories like getting the right groceries or remembering to wash their hair. Either way, participants described desperately wanting to achieve a happy, balanced, and fulfilling life. Overall, participants worked hard at reforming their identity through occupational

engagement and mastery, despite lingering identity confusions about who they were or where they would end up.

### *Celebrating recovery*

Some participants identified value in learning to stop actively seeking recovery from their injuries; this included finding a place of acceptance about their new sense of self. Although the majority of participants felt as though they had given up on themselves and life initially, especially during the initial stages of grief, resistance, and denial, many described later becoming determined to seek out additional supports and 'get better.' These steps in identity reformation represented an internal process for finding peace, which provided them with a greater sense of self and balance. In other words, identity was primarily reembraced and re-established once participants recognized and accepted they could not resume all aspects of their former self and life. Some participants claimed to know when to stop searching for additional recovery: one participant described a sense of peace and accomplishment in realizing the time and energy she had put into clinging to her old sense of self, and how channeling her time and energy into new meaningful occupations was beneficial. Another participant described how she stopped actively trying to recover once she was able to accept (and grieve) her failures, and recognize the impact that her lost skills had on her ability to move forward. These steps fashion an 'ability awareness,' because once participants accepted they were no longer able to do certain things, they could move forward in making new occupational and social connections.

One participant described how the positive aspects of her new life were recognized and embraced when she stopped searching for more recovery:

Life is more than returning to my old self. After a few long, painful years I realized that life can actually be pretty rich after a severe injury. It was a mindset.

Something that I needed to be conscious of in order to see the forest for the trees.

I needed to accept the gains I'd made in the years since my car accident and try to live life to the fullest again which meant stopping the search for more answers or the idea that I'd get better. I consciously chose to let my old self go.

Another participant described how when she emotionally took off her concussion hat, she was able to experience greater meaning and peace than she had, even prior to her injury. A third participant described how actively celebrating her new life, post-injury, helped her reengage with the community by participating in community events and fulfilling advocacy roles with her local brain injury organization; she found new levels of spiritual awareness and acceptance in activities that brought on peace, calmness, and relaxation. For her, like most others, the process of rebuilding their identity was achieved at internal (emotional) and occupational (engagement in daily activities) levels.

One participant described going so far as to holding a specific "recovery day" with her husband and children. She described how one day her family bought a celebration cake and celebrated her new self and life after recovery. She likened it to a christening. Her family made a pact to celebrate the event annually:

I was just me because I chose to no longer recover. I chose to stop and let go of all the things I'd been hanging onto. Once I let go of those old demons, I was free!

The weight of the world came off my shoulders. It was a magical day.

Transitioning from someone who had had a severe concussion to someone who was no longer recovering from a severe concussion enabled her to reconnect with herself and achieve a stronger sense of personal security, self-worth, and happiness overall.

#### 6.4 Occupation and Transition

Participants described aspects of their transition to life following head injury as “frustrating, painful, and brutal,” as well as “humiliating, humbling, and complex.” However, not all participants experienced negative effects as a result of moving from one phase to another (transition). Despite ongoing struggles associated with developing a positive self-concept and resuming participation in meaningful occupations, some participants found transitioning from their pre- to post-injury lives as a form of personal and emotional freedom and a chance to learn and grow as individuals. Transitioning is central to occupational therapy because it involves taking risks, making adjustments to sense of self, and creating adaptations to occupations in everyday life. These elements of change resulted in shifts in behaviours and habits, roles, routines, as well as self-concept and self-acceptance. Overall, for most participants, the process of transitioning from life before injury to life after injury was experienced as unique and individual.

For all participants, transitioning to a life following head injury created significant impact on self-esteem and self-worth. As a result of prolonged and heightened stress and frustration associated with trying to figure out how to live life effectively again after injury, participants experienced a chronic mismatch between what they wanted to be able to do and what they were actually able to do. Finding the right person-occupation fit, or degree to which individual skills and abilities matched employment requires, was

described as complicated by nearly everyone, especially during the initial and middle phases of recovery. Individual factors that were part of the person-occupation fit included: psychological limitations (e.g. severe anxiety and depression), pressure to make changes before participants were ready, setting unrealistic goals (e.g. returning to work too soon or attempting activities that were not aligned with skill level), ineffective skills and abilities, and personality characteristics (e.g. confident and strong versus lacking confidence, low self-esteem, or resisting change). Environmental factors included: demands of the home and family life (e.g. unable to meet familial demands due to symptoms, guilt, grief, and decreased motivation), demands of the job (e.g. symptoms while at work, lack of workplace accommodation, and poor support from bosses and coworkers), and cultural implications (e.g. feeling pressured to return to work because they were 'professionals,' attempting to fulfill roles at the wrong time/place or feeling pressure to become a better wife, mother, brother, sister, or friend, and feeling a sense of obligation to contribute financially, despite not being ready to work).

Participants, at varying times throughout the recovery process, described experiencing a poor person-occupation fit in nearly all facets of everyday life, resulting in feelings of confusion, helplessness, and hopelessness. As a result, participants described the initial and middle stages of transitioning to life post-injury as the most stressful, negatively impacting occupational performance, satisfaction, and overall health and well-being. A poor person-environment fit also created feelings of failure and defeat for participants who attempted activities that were too difficult or outside of the scope of their abilities. Therefore, initially participants withdrew from participating in

meaningful occupations, which perpetuated feelings of failure and inefficiency. This, in turn affected feelings of self-worth and self-esteem because participants were unable to achieve goals they had set for themselves. Interrupted occupational engagement and participation, commonly experienced by all participants during transition, impacted the occupational flow of daily life and left participants, especially during the initial stages of transition, feeling lost and without purpose.

During the transition from pre- to post-injury life, those who described feeling more restricted in their everyday occupational choices transitioned slower and more painfully than those who exercised greater choice. These facilitators of transition varied and were experienced differently by everyone in the study. For example, participants with adequate familial and financial support were more easily able to modify their work schedules (e.g. full to part-time) compared to single participants, who had fewer options. Additionally, participants who made choices on their own terms experienced a more fluid and sustainable transition to occupational participation, compared with those who attempted to participate in activities to appease family and friends. Other factors associated with moving forward included growing 'sick of feeling bad' or becoming 'tired of being miserable,' prompting participants to try new activities, or modify the ways in which old ones had been carried out. In other words, only when participants made self-directed, conscious efforts to pursue activities of their choosing, including embracing new and old occupations, could they effectively transition to a better occupational fit.



Timing and emotional motivation also played a significant role in transition. Participants who allowed natural healing (one to two years) following their injuries were more successful than those who attempted to make big changes to their occupational lives within the first two years after injury. Timing also affected participants' outlook about the possibility of creating a better life for themselves. As more time passed, and participants continued to experience emotional setbacks (e.g. stress, frustration, and feelings of failure), they described eventually becoming sick of feeling unhappy and unhealthy, which helped spark change. All six participants found it was around year three after brain injury that they felt able to take steps toward adapting to everyday life. Participants who resisted change or hung onto aspects of their old identity were less able to create successful transitions. Furthermore, participants made gains in their personal sense of self and occupational lives only once they moved past feelings of grief and loss. Overall, the element of timing following MTBI is an important consideration when examining the link between personal choice, occupational engagement, and successful transitions.

Nearly everyone experienced occupational disruption that eventually led to the creation of new routines, purposes, and meanings. Immediately after injury, participants' daily routines were negatively altered or lost. Routines associated with grocery shopping, performing other ADLs, going to work, spending time with friends and family, and engaging in leisure pursuits/hobbies literally ceased overnight. This occupational disruption seemed to last for at least two years before participants began to make adjustments to everyday routines. Initially, participants experienced 'occupational chaos' because they could no longer carry out daily routines; the routines

they could salvage were described as too stressful or ineffective. One participant compared her daily routines (or lack thereof) to living in a constant state of boredom and upheaval:

One of the worst times for me was about two years after my accident. I wasn't working anymore, barely saw my friends, and pretty much sat home alone all day. I had nothing to do and nothing to look forward to. It was like I had the TV turned on in my life and the only channel that was playing was static.

Certain aspects of transitioning to a new, post-injury identity and occupational life helped forge new occupational routines, giving participants a novel sense of purpose and meaning. For example, when one participant returned to part-time work instead of full-time, she described spending more leisure time with her children. Another participant described how disorganized she had been prior to her accident, but because of some post-injury limitations with short-term memory and inattention, she was forced to create strict routines for herself around the home in order to stay on track. For her, this was viewed as a source of strength because she described how for the first time in her life, she became organized and goal directed. Three participants credited maintaining a highly structured life to 'keeping their sanity' because without it, ongoing symptoms made everyday life too overwhelming and unbearable. All six participants described the positive benefits of re-establishing structure in their lives.

Most participants needed structure and routine in order to 'survive' their daily lives; however, as a trade-off, spontaneity in everyday life was forfeited. Nearly everyone described living an extremely regimented occupational life that had become

so structured, little room for movement or flux existed. Three participants described how even slight deviations from their new occupational routines resulted in confusion, stress, and internal or familial chaos. For example, one participant described making breakfast and lunch the exact same way every day; one described fulfilling work duties and obligations in an almost robotic manner, and several described living highly predictable home and family lives. High structure, or a need for sameness, was essential to negotiating cognitive limitations, so alterations to existing schedules were identified as simply not worth it. Most participants described this as 'good enough for now but not good enough forever,' because of longings for spontaneity and flexibility again.

As a result of leading highly structured lives, participants noted a lost ability to dream about the future. Although some adjustments and modifications were made to occupations and occupational routines during transition, which enabled participants to resume some of their old activities (and adopt new ones), dreaming about the future was described as restricted. Participants were so focused on maintaining a tight schedule to navigate everyday life that they felt unable to make big plans for the future. One participant described lack of dreaming as

depressing. I've always been a big dreamer. They kept me going. Now I only have little dreams like being able to see the symphony or making it to my daughters Christmas concert without having to leave early. It's just not the same. I miss dreaming. It represented hope for me. It kept me feeling alive.

Negative experiences with MTBI, including the impact of ongoing symptoms, combined with the energy required to readjust to everyday life, left participants with little time to think outside the scope of their daily lives. This affected participants' confidence to

make any big dreams a reality. Even when participants wished to make big plans for their future (e.g. career change), the experience of ongoing symptoms made it difficult.

Before participants were able to progress toward creating change, including a new occupational life, they were all required to acknowledge a gap between the lives they were living and their desired life. Until a gap, or recognizing that something was missing, was identified, participants felt stuck in a state of limbo and unhappiness. In other words, they could not change their lives until they actually realized something was wrong. Then they were able to work toward creating positive change through taking occupational action (participating in occupations again). One participant described the idea of finding the gap as “you can’t change what you don’t acknowledge,” while another identified it as “ignorance is bliss, except in the case of brain injury: ignorance is torture because you’re stuck in emotional purgatory.”

After identifying a gap phase, a contemplation phase followed before participants were able to take control of change. During this phase, participants described becoming sick of feeling anxious and depressed, inactive and sedentary, or without work and leisure activities, and subsequently contemplated change. Yet nearly all participants described how they needed to be emotionally ready to actually move forward in order to truly contemplate change. Many described this phase as terrifying because the future was unknown, and participants were afraid of experiencing further failure; the thought of ‘not making it’ was especially daunting because it threatened what little self-esteem and self-worth remained. Fear of failing also made participants question their competence to fulfill roles associated with being a mother, partner,

sister, brother, friend, or employee. Throughout the interviews, it became apparent that those who possessed stronger personalities (e.g. fighter, driven, headstrong) seemed to make quicker, more fluid transitions to finding a better occupational way to live. Conversely, those feeling greater guilt, grief, or resistance to change, seemed to transition slower.

Taking control involved proactively working toward finding new ways to cope with life, as opposed to reactively dealing with occupational setbacks and limitations. Things like acknowledging and dealing with their state of mind, including mental health issues; rebuilding their daily schedules; and becoming involved in work or the community, enabled participants to make positive adjustments to their overall occupational lives. Participants were required to navigate their own path proactively in order to reembrace life, post-injury. However, for some participants assuming control and power was found to be a tedious process in itself. One participant outlined challenges associated with resuming running following her injury. Despite taking steps to control and enhance her physical health, time constraints, fatigue, and physical limitations made it difficult for her to fulfill this occupation. Regardless of the numerous trial and error setbacks and challenges associated with transitioning, most participants eventually found a new life rhythm, especially once specific strategies to create change were identified.

Participants used numerous strategies to make sustainable changes to their occupational lives following head injury. Transition not only included taking steps toward achieving a new state of mind and thinking processes, but also hands-on

modifications or alterations to occupations associated with socializing, becoming involved in the community or workforce, and mastering the ways in which ADLs were performed. The strategies will be described in more detail in the adaptation section, but most of them centered on energy conservation, pacing, task simplification, managing symptoms with medications, seeking counselling, and taking active roles in rebuilding occupational identity. Finding a good occupational fit was described as laborious and tedious, but necessary, and the journey was sprinkled with numerous setbacks and failures; however, finding new strategies to successfully navigate everyday life was described as essential to embracing successful transition.

Social support, including teaming up with other MTBI survivors, was paramount to the transition process. In fact, all six participants described how support from others, including family, friends, co-workers and bosses, and the brain injury community enabled their personal and occupational gains. Five of six participants described becoming socially isolated, which was “empty, lonely, and depressing.” Most participants stopped working, volunteering, and socializing with friends (or family members) for several years, and identified feeling lost and alone most days. Decreased social support contributed to experiences of general and social anxiety, described by one participant as humiliating and devastating. Rebuilding social relationships during transition strengthened participants’ identities as brain injury survivors and provided them with the support needed to transition through the most difficult aspects of life. Social support also provided participants with opportunities to get out of the house and have fun, and helped enhance self-esteem and happiness overall. Shared experiences with other members of the brain injury community helped legitimize and validate

participants' experiences as MTBI survivors, and lead to emotional bonding and increased physical and psychological health.

Shared experiences played a crucial role in helping participants move forward. Phrases used to describe the connection with other MTBI survivors included comments like "they helped save my life" or "they made me feel alive again." Not only were participants able to seek comfort from those who understand the plight of battling symptoms, being socially isolated, and being absent from the workforce or social events, but they also helped participants reengage with community. Community involvement included educational and social events offered by participants' brain injury community, as well as participation in new occupations in the company of other survivors. Most participants described being too overwhelmed or not confident enough in resuming engagement with meaningful activities independently, so support from others motivated them to try new activities outside of the home. Transitioning forward was significantly eased by support from MTBI friends, who helped strengthen each other's occupational lives. Shared experiences, in fact, represented one of the biggest supportive factors in the transition to life following brain injury, and was identified by three participants as more powerful/influential than the support received from close family and friends.

Tangible and internal rewards also resulted from successfully transitioning forward. Participants described different levels of understanding through shared experiences:

Who better to understand me than someone else who's been there? I went inward for a long, long time and didn't think I'd ever climb out of hell again, but

once I started connecting with other people who were in car accidents, I felt like the weight of the world was taken off my shoulders. I could breathe again. No one gets me quite like my brain injury friends. They're even more important than my own best friends.

The formation of new social relationships influenced participation through shared meaning, representing one of the greatest catalysts for forward growth. Phrases like "if I'm having a bad day, the first person I text is a brain injury friend" or "when I need advice about whether to cancel something because I'm tired, I call a brain injury friend" shows the influence of new friendships on transitioning to a better life following brain injury.

Outcomes of transitions were psychological, cognitive, social, financial, and environmental in nature. For most participants, major transitions included: learning to fulfill ADLs effectively, maintaining the home environment, returning to work (for all but one participant), reengaging with social relationships, learning to parent or be a partner again, returning to the community including volunteering with the brain injury association, and participating in leisure activities. In addition to these active processes of change, internal concepts such as self-esteem and self-worth, peace, and happiness also transitioned over time. Internal processes changed or evolved in response to occupational engagement and participation, and in turn, occupational engagement and participation helped improve the health of these internal processes. State of mind and occupational engagement were symbiotic; each affected the other by inducing change. However, this relationship was not always positive. An unhealthy state of mind made it difficult to reengage with work or the community, and these internal processes



negatively affected occupational participation. While trying to pinpoint exactly which came first, moving confidently toward change or moving toward change to gain confidence, most participants found both aspects influenced one another, albeit differently for each person. One participant described forcing herself to attend a brain injury event as the greatest catalyst for her transition forward, another identified returning to work and making her own money again as the biggest influence on change, and a third participant identified seeking counselling for grief, anger, and suicidal ideation as the turning point for movement forward.

Regardless of the catalyst, and despite the fact that transition journeys were unique, common components of the transition process included the experience of a major accident/injury (four were car accident-related, one was a workplace assault, and one was sports related); realisation that things had changed, including the sense of self and occupational life; feelings of loss and longing for the pre-injury self and life; negative occupational patterns including failure and mismatches between what participants wanted to be able to do and what they were actually able to do; limitations to everyday life; identifying a gap, or something missing in life following head injury; becoming restless and contemplating change; taking steps to reclaim lost power and control; seeking and utilizing supports from family, friends, and the brain injury community; and the acceptance of new occupations and occupational routines.

Failures were part of every transition experienced by all participants. Successful transitions required internal elements like honesty and motivation, along with external elements like social support and workplace accommodations, combined with adequate

skills and abilities to reach occupational goals. Any one of these elements affected the matrix of finding a good life balance and occupational fit. For example, if participants were not ready to move forward emotionally, lacked social support, or used ineffective skills and abilities, they were unable to transition forward successfully.

Over time, participants described slowly adjusting the ways they did things, including making alterations to their state of being and sense of self. The participant whose poor workplace accommodations prevented her from returning successfully transitioned to another work site once her insurance provider realized the poor fit between her and her employer; the participant who was unable to reach her goal of walking around her neighbourhood found a way to stay active by using a stationary exercise bike; and the participant who experienced social isolation and anxiety eventually made new friendships while attending events sponsored by her local brain injury association. Despite the fact that during the time of the interviews, nearly all participants described ongoing transition struggles and many questioned some emotional and occupational decisions they had made, nearly everyone identified making positive changes to their occupational lives. Most identified their experience with transition as a fluid process as opposed to a static end point, and nearly everyone felt that further improvements to their sense of self and occupational lives were forthcoming with time and occupational adaptation.

### 6.5 Adaptation and Defining Successes

Occupational adaptation can be defined as the extent to which a person's perceived identity corresponds with their competency performing meaningful

occupations in a relevant environment (Kielhofner, 2008). For nearly everyone, occupational adaptation was an individual response to both intrinsic and extrinsic factors, and if successful, the response resulted in increased occupational performance (Schultz, 2009). However, successful occupational competency was only achieved if both intrinsic and extrinsic factors were modified or adapted in some way. Participants identified three major types of occupational adaptations: physical and cognitive modifications, changes to the sense of self and identity, and alternations to the environment. For participants, adapting to life after brain injury represented both a means to an end as well as an end state. Overall, adaptation was experienced as a dynamic, evolving process often littered with occupational shortcomings and failures before participants were able to reach a desired state of occupational health and wellness.

Occupational adaptations to overcome physical and cognitive deficits were widely discussed during our in-depth interviews. Throughout the interviewing process, participants spoke proudly about the physical and cognitive adaptations that they had made as a result of numerous trial-and-error experiences with occupations. Phrases like “it took years but I finally got it down” and “these strategies represent my new brain” or “I can’t live without this new system” highlighted the importance of creating effective cognitive adaptations in order to help maintain successful competency in daily occupational life. All six participants emphasized how maintaining sleep (which helped reduce fatigue) was the most important cognitive adaptation to life following brain injury. Strategies for ensuring adequate sleep varied from participant to participant, and while some included keeping set routines (need for sameness) or preventing fatigue,

others abandoned certain occupations. For example, three participants described sticking to predictable nightly bedtimes, and taking naps when needed (if possible), as well as avoiding sleeping in non-regular environments (e.g. hotels or with friends or family); other participants named occupational omissions as the most effective adaptive strategy in order to maintain energy levels and decrease fatigue (e.g. skipping yoga class or soccer).

Setting small goals, as opposed to making big plans, was identified by nearly everyone as a pivotal occupational adaptation, especially for participants who were married with children. Other cognitive strategies/adaptations included learning to repeat phrases in order to force their brain to encode the information, maintaining strict and repetitive personal and familial schedules, avoiding procrastination or last-minute plans, completing occupations one step at a time, avoiding performing occupations simultaneously (multi-tasking), and actively employing strategies aimed at maintaining existing cognitive ability. Numerous minor occupational adaptations to habits and physical environment adaptations to daily life were helpful – one participant reported washing her hair several times in order to ensure that it got done in case she later forgot whether she had done so. Another participant reported always leaving medicine caps open in order to signal that pills had been taken. She also ensured that her car was always filled with gas whenever she drove in order to ensure that if she forgot to do so, she wouldn't run out.

The process of occupational adaptation was described as two-fold: it involved making physical adaptations to the environment and adapting occupation by using compensatory strategies, including changing habits or routines. This included

incorporating assistive devices, and learning alternate ways to complete occupations in order to achieve a better state of occupational competency. One participant, who struggled with anxiety and depression immediately following her head injury, learned to meditate through the occupation of driving. She discovered how to channel her cognitive/emotional responses through more effective adaptations, replacing prior responses to stress with decompressing during a long car drive.

Adaptation was identified by all six participants as a state and a process, and primarily involved making changes to both elements of identity and occupational competency. The process aspect of occupational adaptation was described as internal in nature because it revolved around participants' self-concept and identity, whereas adaptation as an end point primarily focused on achieving occupational competency through participation in meaningful occupations. Therefore, one cannot underestimate the link between occupational identity as a component that interacts with occupational competence, or the sense of satisfaction with being able to engage successfully in valued occupations. Here, the ability to redefine one's identity was necessary for participants to develop occupational adaptations, and personal influences and the environment were equally necessary to achieve occupational competency.

Developing a positive self-concept was key in order for participants to move toward adapting occupations. As noted previously, identity and occupational engagement and participation are linked. Participants not only utilized new physical tools and adaptive aids in order to achieve occupational performance, but they were also required to adapt to their new sense of self and identity in order to find more

effective ways to complete occupations. All six participants described becoming a different person than they had been prior to their injuries. Following head injury, participants were required to find occupations that supported their feelings of capability, which in turn helped them come to terms with their changing sense of self. Alternatively, changing aspects of the self over time also led to new occupational engagement and participation; both processes affected and were dependent on the other in order to achieve occupational performance.

### *Adaptations to identity*

Adaptations to identity were experienced in several ways, but primarily involved modifying occupations. Participants who tried to engage in previous occupations often found those occupations too difficult following head injury. Attempts to re-engage with these old occupations, without making modifications to the self or ways in which occupations were performed, almost always resulted in failure. For true adaptation to occur, participants were required to find new occupations that made them feel more capable and successful. One participant realised she was no longer able to play in a competitive soccer league as a result of lost abilities, fatigue, and decreased energy; she chose to adapt by joining a non-competitive, lower level (ability) women's soccer league. Every participant shared stories like this, occupational setbacks from attempting to perform old occupations in previous ways. The majority of participants, through a process of trial and error, eventually learned to adapt components of themselves (identity) and their occupations.

Avoiding or abandoning occupations that resulted in failure was another way of adapting. Sometimes participants were unable to find better ways to perform formerly

meaningful occupations (substitution), or some occupations were abandoned altogether as a result of changed meanings (e.g. decreased meaning). Once participants were able to own their insecurities and inabilities, they could make peace with leaving certain occupations behind. For example, due to fear of re-injury/concurrent head trauma, one participant decided to stop playing hockey permanently and replaced the lost occupation with soccer. Another participant, who previously enjoyed downhill skiing, adapted the occupation by replacing it with the less intense activity of cross country skiing. A third participant decided to stop running as a result of both lost interest and physical limitations, but did not want to replace it with anything in particular; instead, she used that time to reorganize her home and catch up on professional paperwork. Avoiding or abandoning occupations came with emotional and psychological benefits. By admitting they were unable to do something, participants removed the negative effects of experiencing a poor occupational fit, including avoiding feelings of failure, defeat or anxiety and depression, thus preserving their dignity and paving a road to evolution and self-discovery.

Other forms of occupational abandonment yielded positive outcomes.

Participants who were unmarried or without children/families described leading an especially solitary life following head injury. Social life became greatly restricted, and in many cases, almost non-existent in the months and years following head trauma.

Although single participants described negative physical, cognitive, and emotional health outcomes initially associated with being alone and withdrawn from society and occupational engagement, two single participants identified achieving greater peace and solace as a result of leading quieter lives. Participants who had previously lived

busy, balanced occupational lives identified finding new forms of balance in their post-injury lives, which was described as a new pace of occupational “freedom! I learned to love the quiet. I wouldn’t have been comfortable with it before. I think it’s because I didn’t know myself well before” and

taking time alone was something new for me. For the first time in my life, and ironically during the hardest time in my life, I learned to just relax and enjoy the quiet. I learned to like my own company.

Single participants learned to live without a romantic relationship and described not feeling as though it were a void or loss in happiness. Time and energy that would have been spent with a romantic partner was devoted to symptom management, getting caught up on sleep, becoming involved with community work (e.g. BIANs), and nurturing new friendships. One participant remarked “I can barely take care of myself, let alone someone else,” to explain why she was not in a romantic relationship; yet she did not long for what was lost, and relished her newfound sense of identity because she looked forward to experiencing new meanings associated with taking on new occupations (e.g. volunteer work).

Participants who were married with children adapted various aspects of their occupational lives to uphold family goals and values. Two participants, who were also working mothers with young children living at home, described feeling responsible for the everyday workings of their domestic lives, and identified engaging in occupations aimed at preserving their former family life. For example, one participant, who experienced regular migraines, refused to let her children see her fatigued or in pain, so planned her naps around her children’s school schedule. Other examples of



occupational alterations maintaining family values included minimizing symptoms by lying about how participants really felt, making up non-brain injury excuses if an event had to be missed, avoiding having their children see them take medications or use assistive devices, and remaining silent during symptom flare-ups, which resulted in 'suffering in silence.' Most occupational adjustments were done to thwart worry, especially in young children, or to avoid their family's reactions/judgements. Overall, adapting by concealing problems with occupations or symptoms were strategies employed in order to protect former roles.

Adaptations in attitude were also a significant element of the adaptation process. Participants emphasised how 'who they were' was deeply connected with the things that they did, and how the things that they chose to do were deeply intertwined with who they were. Throughout the interview process participants spent a great deal of time discussing themselves in past tense, including their former occupational lives. They also focused on numerous losses that negatively impacted concepts of self-esteem and self-worth. However, as occupational competency changed over time, through adaptation, so did their identities. One participant identified attitude as a key factor in survival, and eventually adapted to and thrived in her occupational life:

My attitude affected my whole life. Everything got pretty negative after the accident and my whole way of thinking focused around the things that I couldn't do. I was defeated for a long time. My attitude was contributing to my own demise, and for the longest time I didn't even know it.

Attitude adaptations also contributed to identity transformation, because once participants were able to accept that life was not the same, they were able to weigh

occupational options and make pertinent occupational decisions; stay the same, which prolonged suffering, or adapt. Participants described the need for developing an attitude of acceptance about being brain injured in order to achieve occupational competency and wellness.

### *Environmental adaptations*

A third component of occupational adaptation was the environment (external factors), consisting of changes to the physical environment (e.g. home and work place), social influences (e.g. friendships), and cultural influences (e.g. values, norms, habits, and traditions). Once participants made changes to their outlook and attitude, which helped enhance self-esteem, they were able to focus on creating adaptations to their environments. The ultimate goal was to master their environments through adaptation to increase occupational competency. As previously stated, the relationship between the internal (identity) and external factors (environment) of the adaptation process was experienced as interactive, complex, and ongoing. Following head injury, participants experienced occupational and environmental chaos, characterised by disorder, which could be reorganized through adaptation. Participants unable to create effective adaptive responses as a result of ineffective environmental factors experienced dysfunction, described in the transition section as a mismatch between what participants wanted to be able to do and what they were actually able to do. Dysfunction also occurred when the challenges of an occupation exceeded participants' capacity to adapt, either as a result of poor timing (e.g. not being ready to change), lost skills, or the setting of unrealistic goals.

The relationship between adaptation and leisure pursuits were paramount. Participants who engaged in occupations associated with travel described adapting in several ways. One participant who feared loud, busy airports stopped travelling internationally, but adapted by taking frequent, shorter weekend trips around her province. Those who continued to travel internationally used compensatory strategies such as taking only direct flights, arriving at the departure gate as late as possible to avoid crowds and fatigue, and spending money on pre-purchased window seats furthest from busy aisles. One participant, who was more financially well-off than most, adapted her travel environment by hiring a cook and driver to help out with domestic responsibilities while vacationing with her family in Florida.

Since environmental surroundings affected adaptation, participants were forced to learn new ways of doing things by employing compensatory strategies in their environment. Many avoided certain environments, including loud, bright, and crowded places such as restaurants, movie theatres and large sporting events; used gift cards as Christmas presents in order to avoid shopping for Christmas presents in busy malls; and conserved energy by using gift bags instead of wrapping presents individually. More financially stable participants had their cars professionally detailed each year in order to avoid stress and fatigue, and some hired weekly housekeepers who helped maintain organization in the home – both strategies aimed at ensuring domestic organization.

Some participants adapted their social environments by selecting their preferred environments or companions. For the majority of participants, this involved avoiding people who were viewed as hyper or loud in order to decrease excessive cognitive

processing and stress. Participants who chose to spend time with old friends described as high strung or overbearing made several adaptations to create smoother social interactions: scheduling shorter visits together, choosing quiet, familiar home environments; and ensuring that other friends would be present to avoid one-on-one discussion. One participant described how she stopped participating in team sports because the constant movement, talking, and energy contributed to symptom flare-ups. She adapted with replacement activities such as walking in the woods or mowing her lawn with her ride-on mower – activities that helped her experience a sense of accomplishment and victory. Most participants made smaller but significant everyday adaptations to their physical environments, including leaving items in the same place; using alarms, beepers, or sticky notes as reminders; and ensuring strict daily domestic routines, all of which helped contribute to a better person-environment fit.

Regardless of whether adaptations were made at home, work, or during socializing or leisure pursuits, all six participants identified numerous trial-and-error attempts in order to figure out how to best perform occupations. Once they actively selected and participated in meaningful occupations, participants were able to learn new ways of doing things that eventually led to satisfaction and occupational competency. Sometimes just contemplating or thinking about how things could be done more efficiently was enough. Other times, participants needed to try occupations (and get them wrong), or utilize supports or assistance in order to figure out the best possible ways to adapt, especially during the initial adaptation stages. Even during the interview process, four out of six participants brought notes with them and checked their smart phones intermittently throughout the sessions in order to stay on track. Despite the fact

that participants were all in different stages of adaptation, five out of six described making adaptations just to meet with me. These included extensively planning how they were going to get to the meeting place (e.g. drive themselves or take the bus), how their daily and weekly schedules were rearranged in order to be present for the interviews, and how they would squeeze in a nap after the interviews in order to recharge and proceed with their day.

### *Occupational failure*

Occupational failures were another form of adaptation and often represented the key to learning and adapting. Since adaptation was viewed as an ongoing process as well as an end state, participants described not having fully adapted to their new sense of self and life. One participant described how being 'open' to failures and trying to understand them as part of the process of growth and learning enabled her to take occupational failures with a 'grain of salt.' Failures were experienced in different ways. Some participants, who learned to adapt to certain occupations on a trial-and-error basis, experienced failure once they started to feel well again. Similar to individuals who stop taking medication because they 'feel fine' due to the medications' effects, participants experienced intermittent occupational failures as a result of feeling good and subsequently overdoing it. For example, one participant stopped wearing her leg brace during hiking activities because it had helped prevent lower leg pain (yet the pain and difficulties with hiking returned at a later time); another participant stopped wearing her convergence prism eye glasses during reading activities because she felt that she was able to read well again (yet she experienced significant subsequent eye strain and dizziness).

Even occupational failures that were not intermittent had positive benefits. In fact, most failures were described by participants as a result of trial-and-error experiences that eventually led to success (finding the right occupational fit). Since adaptations differed depending on so many factors including different occupational goals, personality type, and where participants were in the adaptation process, the process was experienced as a constant, continuous struggle, featuring failures along the way. One participant described her failures in trying to perform the activity of baking as a good thing. For years I beat myself up over not being able to get recipes right after my brain injury. I felt like a total loser and failure. It wasn't until a friend reminded me that the whole art of cooking and baking is pretty much based on the idea of experimenting with new ingredients until you get it right, that I learned to accept failures as a part of the journey. They weren't failures at all. Just little detours.

## 6.6 Future Outlook

The majority of participants described the outlook about their futures as hopeful, positive, and having potential. Most expressed elements of optimism about their ability to continue to adapt and refine aspects of their identity and self-concept, and occupational roles and routines. Three out of six participants felt that they would continue to make gains in their vocational lives by increasing their work hours from part- to full-time, varying the types of duties that they were responsible for, or pursuing career advancements down the road. One participant identified looking forward to retirement in the near future, while two others expressed interest in eventually

resuming post-secondary educational goals; however, one participant did say that obtaining an executive Masters of Business Administration degree was a dream that would probably never come true because she knew deep down that she would never be able to achieve it cognitively. Most participants felt that their ability to participate in leisure activities, including cherished sports and physical pursuits, would continue to improve with time, physical therapy, training and increased exercise or further adaptations. The participant who did not return to work identified feeling hopeful about her ability to continue to assist her local brain injury community with educational and advocacy efforts, but was unsure whether she would be able to return to paid employment. Single participants did not mention seeking romantic relationships in the future, but both expressed feeling content devoting their time to volunteer pursuits. One participant talked about how nice it would be to get married and become a father one day, and the participant with grandchildren identified looking forward to spending more time with her grandchildren after retirement. The two mothers with small children described hope about their futures, but identified ongoing struggle with finding occupational balance in their busy lives with small children.

However, not everyone had a positive outlook. One participant described being unsure about whether she would be 'ok' down the road, and identified aspects of her future self and occupational life as bleak and depressing. Interestingly, for two participants, pessimism about the future centered on the concept of the self and identity, as opposed to occupational competency. Stress and loss associated with decreased intellectual ability and other forms of cognition were described by both participants as devastating and never-ending. They both described themselves as having

strong personalities that would not just let them 'be,' and how they would continue to resist forms of occupational change for as long as they could.

Everyone described being hopeful about continued improvements to memory, concentration, and attention, as well as their ability to continue to seek social support and interact with other MTBI survivors. When discussing the future, nearly everyone identified hanging onto aspects of their former sense of self and identity:

It never really goes away. It's like that one person you loved so much years ago, but for whatever reason, you lost them. You can barely speak their name because you loved them so much. It's like that. It's painful to think about the old me. I'm not sure I'll ever truly move on and let her go. She's always in the back of my mind, lingering like a ghost.



## CHAPTER 7

### DISCUSSION

This study aimed to gain rich, in-depth understandings about the effects of MTBI on everyday occupational lives; the effects of MTBI on occupational identity, transition, and adaptation; and occupational adjustments, including the addition, cessation, or modification of occupations. While numerous studies have examined the lived experience of people diagnosed with various cognitive and physical disabilities, few have examined the lived experience of MTBI from an occupational perspective. Most have explored moderate to severe forms of TBI, often from perspectives of nursing or medicine, and often with a focus on symptomatology and return to work. Few studies have examined the specific, daily occupational challenges associated with performing occupations, or for example, struggling for legitimacy, trying to pass as non-brain injured, or making attempts to hide the effects of MTBI.

This study allowed for the collection and detailed description of the daily experiences from a small sample of individuals with MTBI, providing detailed qualitative analysis, from a uniquely occupational perspective. It explored the impacts of MTBI on occupations like shopping for and preparing food, arranging transportation, managing money, maintaining friendships, parenting, and pursuing education, employment, or advocacy. It examined how occupations were abandoned or modified in order to meet the daily needs of life after MTBI, and the relationships of occupations with identity. An occupational perspective specifically examines the things that we do and do not do (doing), and the meanings of those engagements and lack of engagements; the ways in

which our doing connects to how we think, feel, identify and relate to ourselves (being); the ways we use doing in relationship with others (belonging); and the ways that we evolve or change over time through doing and becoming (Wilcock, 1999; Hitch et al. 2014). Each of these will be discussed below, followed by an examination of occupational adaptation, transition and identity. This chapter ends with exploring implications and limitations.

### 7.1 Doing After MTBI

For nearly everyone in this study, occupations associated with actively fulfilling, or 'doing,' occupations associated with self-care and home-making, leisure, and paid employment represented some of the greatest challenges following MTBI. Instrumental ADL's, including driving and transportation, financial management, and shopping were reported as difficult, overwhelming, and stressful. Memory loss, fatigue, decreased motivation, and stress and anxiety contributed to participants' need to either avoid or modify occupations in order to effectively fulfill their goals. Surprisingly, the occupation of grocery shopping represented the most daunting daily occupation because of the physical environment of grocery stores, which are typically overwhelming and overstimulating for those with light sensitivity, inattention, decreased motivation, confusion, and disorganization. Avoidance of grocery stores resulted in avoidance of shopping for food, which affected food choices and eventually issues surrounding body image and weight.

The process of returning to paid employment was typically painful, frustrating, and at times humiliating (see Hooson, Coetzer, Stew, & Moore, 2013). As found in previous work, some MTBI survivors never return to work in the same capacity and may

be forced to work on a casual or part-time basis (Guerin, 2006). Nearly all of the participants who worked full-time prior to their accidents, were only able to return to work on part-time, and three worked from home offices. Job flexibility and income level were the central to these adaptations. A supportive boss and co-workers, job duty modifications, and environmental workplace accommodations were pivotal for a successful and sustainable reentry into the workforce (Rubenson, Svensson, Linddahl, & Björklund, 2007). Unlike previous literature, in this study relationship status also affected return to work; single participants had fewer opportunities to modify work hours due to the financial constraints of only earning one income.

A novel finding was participants' ongoing struggles with successful money management. As a result of making repeated financial errors, successful management of finances was rarely achieved – most participants were either forced to pass the role of management to significant others, or continue to deal with negative financial consequences. The in-depth occupational challenges associated with financial management and MTBI has only been previously discussed in terms of financial vulnerability – with the vast majority of these focusing on low incomes, lack of employment, and disability costs. However, though there is evidence through previous research regarding the redistribution of domestic tasks within households (Johansson, 2002).

The importance of findings related to financial challenges cannot be underestimated. Nearly everyone in the study experienced immense challenges related to independent financial management, including profound long-standing negative outcomes of missed and incorrect bill payments and credit score decline. Experiences of

ongoing confusion, frustration, and stress and anxiety were common among participants, especially for those who lived alone and lacked familial and social support in the home. These findings are startling because since single participants had fewer options for assistance than their partnered peers, outcomes related to managing money differed greatly. With little to no community assistance with financial management for MTBI survivors, financial woes between participants with different relationship status and social support levels are not likely going to go away in the near future – unless financial management assistance is available to survivors and implemented at the community level.

In relation to transportation, while some continued to drive, others – especially those who had been in car accidents – ceased driving or severely altered their driving habits. Public transportation helped alleviate the fears and cognitive requirements of independent driving, but negotiating transit systems created additional fatigue with negative consequences on daily lives. Those who continued to drive reported that it allowed them to feel ‘normal’ and unaffected by brain injury, suggesting maintenance and mastery of meaningful pre-injury occupations play an important role in identity adaptation. As others have found, driving cessation can be a significant blow to identity (Anstey, Windsor, Luszcz, & Andrews, 2006).

For study participants, leisure was deeply compromised, often contributing to social isolation. However, while participation in leisure typically dwindled in the months and sometimes years following brain injury, participants eventually learned to resume some leisure-related occupations – especially after they grew increasingly frustrated with leading boring/inactive, imbalanced occupational lives. Although leisure

occupations were among the first to be abandoned following head injury, they were among the key steps participants took toward rebuilding aspects of their sense of self. This highlights the interconnected, dynamic relationship between doing and being.

## 7.2 Being After MTBI

Being in occupational therapy concerns our relationships with ourselves, who we understand ourselves to be. Following brain injury, participants experienced a state of internal and emotional emptiness and loss, especially in terms of spirituality. Fear, hopelessness, occupational cessation and imbalance, inactivity, and loss of spontaneity were factors that contributed to a devolving sense of security and happiness. Life following head injury was typically absent of work, fun, and socializing and became centered on periods of prolonged confusion and dissatisfaction – emphasizing the relationship between loss of meaningful activity and loss of spiritual self-connection. Activities that were once viewed by participants as spiritual (e.g. reading, yoga, or running) were replaced by less meaningful activities associated with surviving day to day life and managing symptoms. However, participants eventually learned to reintroduce meaningful occupations into their post-injury lives – including activities which were viewed as spiritual.

Over time, spirituality became redefined in two ways: activities that were once viewed as spiritual no longer held the same meaning (e.g. cooking became a means to survival as opposed to something that was fun and relaxing); and small victories linked to ADLs (e.g. cleaning the house) which were once performed in order to fulfill routine

obligations actually became defined as spiritual because they made participants feel proud, masterful, and accomplished, providing a new sense of occupational mastery. These achievements, however small, were celebrated as victories because they represented building blocks to a new identity and occupational wellness. This was an unexpected finding that highlights the relationships among spirit, occupation and health, and the fact that spirituality may be achieved in the most unexpected, mundane everyday activities.

Despite the fact that fear was prevalent for nearly everyone following head injury and somewhat temporarily ruled participants' lives by negatively impacting occupations associated with returning to independent driving, returning to work, parenting, socializing with friends, or getting back into everyday roles and routines, fear eventually subsided as participants more actively engaged with meaningful occupations. As participants grew increasingly frustrated by leading unfulfilled occupational lives, fears were pushed aside as participants took steps to return to work or socialize with family and friends. Despite numerous occupational mistakes along the way, reengaging with meaningful activities gave participants a sense of strength and accomplishment.

The loss of spontaneity following head injury was a major, unexpected result. Participants who ended up leading highly predictable, regimented occupational lives were often dissatisfied and unhappy about their lost opportunities for adventure, exploration, and excitement. On one hand, a highly structured life enabled participants to successfully fulfill occupational roles and obligations. On the other hand, it robbed participants of the stimulation (and reward) derived from making changes and/or trying

new things. Although participants who lead regimented lives appeared to fare better overall in that they were able to create a semblance of occupational balance following head injury, nearly everyone described longing for spontaneous occupations (e.g. road trips, travel, unexpected outings). Loss of spontaneity – though necessary for occupational accomplishment – left participants feeling confined. However, some occupations were absolutely necessary to engage with and left participants with little choice (resulting in an ensuing loss of spontaneity). For example, must-do occupations associated with mothering and caring for children, and working full-time (for single participants) were required and assumed primacy over other occupations that could more easily fall by the wayside.

### 7.3 Belonging After MTBI

Belonging concerns relationships with others, feeling part of something beyond oneself. For participants, lack of belonging was expressed through loss, anxiety, loneliness, and social isolation – factors which contributed to disrupted sense of positive self-concept and identity. In this study, disconnections in belonging were primarily found in areas of parenting, friendship, leisure, and relationships.

Prior studies have highlighted challenges associated with family life, including parenting, and MTBI (Erikson, Karlsson, Borell, & Tham, 2007). Often following brain injury, daily occupations associated with fulfilling parenting duties and obligations have been handed over to significant others, which may result in a shift of burden (Alston, Jones, & Curtin, 2012). Successfully accommodating the limitations and challenges associated with MTBI often becomes a family issue as opposed to an individual problem.

These findings were confirmed in this study. Memory loss, inattention, and irritability negatively impacted participants' ability to effectively fulfill family obligations and roles. Participants with families were often too overwhelmed and fatigued to independently fulfill so many pre-injury roles and routines, and were forced to pass responsibilities to their partners (see Johansson, 2002). However, unlike other studies, our study also found that children played a pivotal role in occupational life because they represented a source of strength in accommodating participants' needs, despite the fact that they were also viewed as a challenge because their care placed so many occupational demands on everyday life.

This study produced novel results concerning MTBI and the disciplining of children. Participants described specific strategies used to effectively 'argue' with their children (e.g. taking notes during fights), and the challenges of not remembering what they said their children could or could not do. Participants were only able to effectively fulfill parenting roles if they received adequate support from their significant others, if sleep was maintained, and if there were ongoing opportunities for pacing activities. Parents in this study experienced guilt and shame because their symptoms negatively impacted their families, and because they were not the parents they were prior to injury. Over time parents let go of their losses to some degree, redefining parenting efficacy and mastery.

Friendship is another key aspect of belonging, and friendships were either lost or changed. In fact, friendships suffered the greatest socially, more than romantic partnerships, especially during the first two years of recovery. Lack of time and energy, as well decreased focus and attention, organisation, and avoiding excess stimulation



harmed friendships. Reduced social involvement eventually lead to loneliness, anxiety, and social isolation. Withdrawal from social lives allowed participants to grieve losses, cope with symptoms, and renegotiate lost/changed occupations. When they were ready to renegotiate their social lives, efforts to increase social contact were initially stressful and discouraging (e.g. social engagements had to be extensively pre-planned) and were often weighed in a cost/benefit analysis (e.g. is this activity 'worth it?'). Friendships became more selectively chosen, and changes in friends were common, including new friendships within the brain injury community. Adapting environments and activities for social contact was also critical for some.

Social engagement can enable occupational engagement and participation, and a strengthened sense of self or identity (Thompson and Fraser, 2011). In this study social support was one of the most significant factors in occupational competency and re-establishing a sense of self. Meaningful social relationships facilitated a healthier sense of self-concept and worth; increased happiness and wellbeing; fewer negative mental health experiences; and less social isolation. It is noteworthy that nearly everyone experienced multiple benefits, including a strengthened sense of self, from peer support and becoming involved with a local brain injury community.

In terms of social support, there is little evidence regarding how being single or in a partnered relationship may affect recovery after MTBI. While we know that individuals with MTBI (and families) often experience a shift in burden related to stress and frustrations associated with juggling domestic and childcare responsibilities (Bay & Covassin, 2012; Johansen, 2002), less is known about how single participants navigate through daily life following head trauma. In this study, while single participants

experienced fewer domestic obligations (making it easier for them to care for themselves and maintain sleep), they experienced less familial, domestic, and financial support and were more socially isolated overall.

As a result of decreased familial support, single participants seemed to experience poorer emotional and mental health outcomes compared with attached participants who were often pushed (albeit sometimes beyond their capacity) to care for themselves and others simply because they had no choice. Therefore, attached participants seemed to fare better both emotionally and financially, despite their additional domestic obligations. These findings are important when considering how relationship status affects occupational change, including the removal or modification of occupations in the domestic environment; how relationship status impacts occupational engagement and reengagement during the transition process; and the benefits of a well-established social network following MTBI.

#### 7.4 Becoming After MTBI

Becoming, or making changes to one's self and life over time, involves self-actualization and transformation (Hitch et al., 2014). Being able to look forward to and sense the future are important components to becoming. In this study, aspects of becoming included staying positive, creating new hopes and dreams, and acknowledging the positive outcomes of MTBI. In their study, Alston, Jones, and Curtin (2012) outlined ways in which individuals created new, meaningful identities and occupational lives following head injury. Participants in this study stayed positive in similar ways, focusing on gains as opposed to previous abilities, embracing remaining strengths and abilities,

forming new friendships and engaging with peer support groups, and participating in learning and educational pursuits.

Successful occupational engagement was only possible when participants were able to move past stages of grief and loss (Chamberlain, 2006). This was primarily achieved when a significant amount of time had passed (over two years) and participants really took the required time to “become” in order to make their transition and adaptations (which helped form their new, post-injury identities). Here, a certain amount of healing and self-acceptance occurred for nearly everyone. Once participants successfully engaged with occupations that helped them feel proud and accomplished, they were more equipped with the motivation and confidence necessary to redefine their identity disruptions. Creating new hopes and dreams for the future was also only possible once participants were able to restore a sense of mastery over their environments and occupations, creating a beneficial occupation/environment fit. The transitional road to recovery was sprinkled with occupational set-backs and failure, which played an important role in helping participants figure out their post-injury abilities and limitations, ways to overcome obstacles and challenges, and methods for re-establishing occupational roles and routines.

Some saw a bright future, particularly those who had moved past the stages of grief and loss, no longer hiding the effects of brain injury. Accepting identity changes and taking active roles in MTBI advocacy and education seemed to contribute to the ability to envision a positive future. Nearly everyone had also come to see ways they had become better following head injury. These positive outcomes of MTBI included:

deeper insight into themselves; increased empathy for injury survivors; and increased understanding and compassion for anyone who has experienced life-changing events.

### *Struggling for legitimacy*

In terms of becoming, struggling for legitimacy, struggling to be believed, seemed to pose major barriers. Nearly everyone described negative experiences with everyday language that tends to trivialize the impact of MTBI, and with well-intended words of comfort that were experienced as hurtful and humiliating. Participants found themselves constantly having to re-legitimize their experiences, and defending themselves from the judgements of others became something of an occupation in itself. Chamberlain (2006) found that the adaptation process following TBI was actually significantly impeded by the time, energy, and adjustment required to legitimize experiences with TBI. In this study, the least obvious, or hidden effects of brain injury most significantly impeded adaptation and identity shift. Comments like “you look fine to me” or “you’re not as bad as my cousin” interrupted the process of rebuilding identity because they created barriers to acknowledging true inabilities and limitations; slowed down the process of self-acceptance; prevented seeking social support; and decreased self-concept and worth. They also interrupted the grieving process because so much time was spent defending authenticity, as opposed to moving forward.

Professional background, job type, and level of education were factors which helped enhance legitimacy, as those were advantageous in navigating healthcare, insurance, legal, and medical systems. Participants generally felt judged, belittled, and bullied into complying with rules, especially involving the return to work process.

Insensitivity, aggression, and judgement were among the more powerful experiences of interactions with caseworkers, supervisors, and employers. Even meetings with trusted health professionals left participants feeling vulnerable because they felt questioned and scrutinized because symptoms related to MTBI are not always visible, and diagnostic tests related to MTBI seldom show ‘proof.’

In their review of identity after brain injury, Bryson-Campbell et al. (2013) suggest that institutional supports should enable survivors to identify their occupational struggles, and take the time necessary to grieve their occupational and identity losses. In contrast, in this study participants typically felt invalidated and unsafe with health professionals. As a result, they became preoccupied legitimizing their diagnoses. Those who over-emphasized symptoms, striving for legitimacy, were read as not-credible. Being told there was nothing wrong with them took a significant toll on participants, hindering becoming – developing a post-injury authentic identity.

### *Passing and stigma*

Even as they felt forced to ‘prove’ they had ongoing symptoms from MTBI, nearly all of our participants also frequently strove to hide the effects of their brain injury. This was primarily due to: fear of being judged; fear of negatively impacting families; fear of being vulnerable; and fear of losing professional credibility. I also found that while most participants, at some point, attempted to appear less brain injured (and more normal) than they were, others became tired of adjusting their occupations in order to hide the effects of brain injury, and subsequently participated in occupations associated with advocating for other survivors and educating the public about MTBI.

Social stigma can deeply impact identity and occupations, causing people to 'sneak' or hide stigmatized occupations (see Luck & Beagan, 2014). In his study of the 'loss of self' in the narratives of people with TBI, Nochi (1998) found people felt judged socially because they were viewed as 'different' and 'invalid' and stereotyped as crazy or stupid. Participants in the current study initially experienced shame about having an MTBI, especially those who had viewed themselves as healthy and strong prior to injury. Some were also ashamed that they were no longer working in paid employment, that they weren't able to successfully complete occupations that were once viewed as easy, or that they were required to ask for assistance with basic ADL's. Participants disliked the word "disability" because of the negative stigma attached to it, and in order to try to combat stigma associated with MTBI, participants selectively choose who to spend time with, modified occupations in order to avoid busy, public places, and fulfilled advocacy roles within the community, especially so they could surround themselves with survivors who would be less likely to judge them.

As others have found (Soeker & Shaheed, 2011), people took explicit measures to evade stigma and ensure that they were not perceived as 'defective.' Some devised clever strategies for getting out of uncomfortable situations (e.g. asking wait staff to preliminarily lower lights to signify the end of a party), others simply engaged in occupations that made them feel non-brain injured (e.g. being around non-brain injured friends). Either way, finding strategies to be read as 'normal' helped uphold confidence, dignity, and self-concept.

A major strategy for coping with stigma was 'passing.' In their qualitative study with women with TBI, Alston, Jones, and Curtin (2012) found that individuals with low quality of life, or an inability to reframe a new, positive self-narrative were more likely to engage in 'passing,' or trying to appear 'normal,' attempting to hide the effects of brain injury. In the current study, passing was also a strategy used by participants who prided themselves on being independent and strong prior to their brain injury. Those who identified as being well-adjusted, independent, and successful took measures to not be seen by others as damaged, insecure, or dependent. Passing allowed some to maintain professional status and integrity. Participants who were in leadership or professional roles hid the effects of MTBI, including minimizing symptoms in order to be seen by others as confident and proficient. Being viewed as weak or incapable potentially had disastrous professional, vocational, and financial implications if clients (or employees) were to view them as incapable of effective leadership. In a healthcare setting, participants also used passing to convey impressions of trustworthiness and sound clinical judgement. For some participants, in unable to pass, participants risked losing their jobs, incomes, positions, and trust and respect from others.

All participants significantly adapted occupations in order to minimize or hide the effects of brain injury, including withdrawal from friendships, leisure activities, and public settings. Many avoided situations where they would be required to explain themselves (e.g. avoiding discussing MTBI mistakes with service people or contractors) and found social isolation preferable to being read as defective. Adjustments to daily occupations in order to be perceived as 'well' included lying about symptoms to family and friends; changing the meaning of symptoms (e.g. pretending symptoms were a

result of alcohol consumption as opposed to MTBI); and suffering in silence in order to avoid worry or judgement, or in order to avoid disrupting family occupations. A level of personal sacrifice (e.g. lost sleep, overload) was experienced by most participants in order to pass as less symptomatic.

Alston, Jones, and Curtin (2012) suggest ongoing attempts to pass as normal, or less brain-injured, can either enable or limit adjustment. This appeared to be echoed in the current study, though long term benefits of passing were scant. While participants who engaged in passing behaviours were initially able to divert attention from themselves and convince people that they were less affected by MTBI than they were, they were still eventually required to acknowledge their limitations and inabilities, accept changes within themselves and their lives, in order to develop and become anew.

Most participants reached a point where they stopped caring what others thought. They eventually grew sick of trying to appear 'normal' because it consumed so much time, energy, and thought. This outcome was a form of freedom and represented a place of true becoming, and identity development. They replacing hiding the effects of brain injury with occupations centered on advocacy and public education which equipped them with a sense of pride, accomplishment, and leadership. Some simply shrugged off improper or inaccurate labels used by others, while others deliberately took opportunities to correct hurtful labels and provide accurate information. Others used light-hearted humor to deflect harsh judgements, and some considered themselves spirited, fighters, driven to make positive changes in their community. In any



case, participants gained a sense of validity, mastery, and dignity as brain injury survivors, and minimized the loss of self, once they were able to effectively find ways to legitimize their everyday experiences – which positively impacted and strengthened identity and self-concept, motivation, and hope for the future.

## 7.5 Occupational Adaptation

The second major focus of this study was on how MTBI affects occupational adaptation, transition and identity. Each of these will be discussed below. For participants, occupational adaptation was characterized by disorder and loss, order, and then reorganization – all shaped by a pressing need for occupational mastery within accommodating occupational environments (Schultz, 2009). Adaptation was both a state (e.g. achieving occupational competency) and an internal process (e.g. adaptations to identity). These results highlight the interactive relationship between occupational identity and occupational competency, or how the things that we do directly influence the ways in which we relate to ourselves. Sustainable adaptation to life following brain injury only occurred once participants were able to successfully engage in meaningful occupations and make adjustments to their sense of self. Neither component of adaptation (e.g. state or process) were more important than the other – rather they worked symbiotically to help enhance and advance the other toward forward movement and recovery.

Confirming research by Erikson, Karlsson, Borell and Tham (2007), participants in our study first experienced occupational disorder and chaos (e.g. domestic disorganization and overall occupational imbalance) followed by order (Schultz, 2009),

achieved primarily through the reorganization of both internal and occupational processes. Those who were able to effectively adapt environmental factors experienced order, whereas those who were not able to match what they wanted to do with what they could do, experienced dysfunction. In other words, reorganization occurred when the challenges of an occupation matched the participant's capacity to adapt themselves, their occupations, and their surroundings.

Participants adapted everyday occupations through processes of trial and error. These included using memory aids, setting new routines, breaking occupations into smaller tasks, avoiding multi-tasking and procrastination. They also adapted the balance of occupations, such as ensuring adequate sleep to reduce fatigue. Although their adaptive capacity had been overwhelmed by disability (Schultz, 2009), participants eventually learned to replace, avoid or abandon occupations that resulted in failure. Once participants were able to 'own' their insecurities and inabilities, they could successfully leave certain occupations in the past. Avoiding or abandoning occupations yielded emotional and psychological benefits because it preserved time and energy, ensured a healthy person-occupation fit, and minimized failure, anxiety, and depression. This upheld dignity and paved a better road to self-discovery and evolution.

It is important to note positive aspects of abandoning certain occupations during the adaptation process. Despite the fact that single participants were often socially isolated and lead more solitary lives following head injury, they had more time alone and were able to know themselves better than they had prior to their accidents. This resulted in increased creativity, peace, and purpose. Further, some of our participants who replaced previously busy lives with slower-paced daily regimes described this a new

form of occupational freedom because they had created more time to embrace the quieter, more reflective, spiritual side of life. The absence of some occupations afforded spaciousness.

In contrast, some participants adjusted their daily occupations to specifically maintain 'sameness' and familiarity. These findings support work done by Hoogerdijk et al. (2011) who found that adaptation was most successful when participants engaged with familiar occupations within familiar environments. This was particularly true of participants who were partnered with children, who attempted to preserve their familiar family lives. They hid or minimized symptoms, reduced the complexity of some tasks (such as food preparation), relied on memory aids, and pushed through fatigue in order to participate in family events and roles, thwarting worry and avoiding negative reactions from family members.

There is no question that an internal process of adaptation was also key. In a previous qualitative study exploring adaptation following brain injury, Klinger (2005) highlighted the relationship between self-identity and occupational engagement. In the current study, effective occupational adaptations, allowed participants to enhance their own occupational performance and competency over time, in turn developing positive self-concept. Despite longing for aspects of their former lives, participants recognized the importance of engaging in occupations which helped increase feelings of competence. Similar to Klinger's (2005) findings, acceptance of a new self was paramount to successful occupational adaptation. Such acceptance required adaptations to their attitudes as well. Although aspects of their former selves were lost

following brain injury, participants who learned to embrace post-injury strengths and abilities were better equipped to lead positive and rewarding new occupational lives following brain injury.

In a South African study of the adaptive strategies used for return to work, Soeker and Shaheed (2011) also highlighted how individuals with mild to moderate brain injury formed new occupational patterns or routines based on new functional capacities. In the current study, too, participants were required to undergo a reflective process and reach a level of internal acceptance before they were able to develop the self-efficacy necessary for occupational adaptation. Initially following brain injury, participants made many unsuccessful attempts to engage in occupations which no longer matched their capabilities, almost always resulting in failure and defeat. However, over time as participants redefined their identities (Hoogerdijk et al., 2011; Klinger, 2005) they were eventually able to experience occupational efficacy again. Internal adaptations (e.g. letting go of grief and loss, accepting changes and inabilities, and possessing the desire to move forward) helped propel participants toward occupational adaptations which in turn strengthened sense of self and purpose. As Kielhofner suggested, occupational adaptation is the process of establishing a positive identity through achieving occupational competence. The challenge of occupational adaptation is “to identify and enact a self and a way of living that is experienced as good... and allows one to realize one’s unique potentials, limitations and desires” (2008, p. 129).

The importance of occupational failure emerged clearly in this analysis.

Occupational failures became part of everyone's journey and were actually necessary for participants to eventually recognize their abilities and limitations following brain injury. Schkade and Schultz (1992) suggest that occupational adaptation is a cyclical process wherein people faced with an occupational challenge interact with their environment aiming to develop competence and mastery. To adapt, with each experience the individual must evaluate the outcome and use feedback for subsequent experiences. Eventually, learnings are integrated and/or modified for use next time. In essence, occupations are adapted through practice, to maximize competence. Luck and Beagan (2014) note the importance of reframing 'failures' to quit smoking as 'practice, deriving new insights from repeated trial and failure as part of occupational adaptation. In the current study, 'failing' in occupational attempts enabled participants to recognize and accept their new capacities so that they could then make adaptations to their occupational lives and goals. In essence, intermittent failures created opportunities for acknowledging revised truths, which lead to strengthened identities and successful occupational adaptation.

## 7.6 Occupational Transition

In studies with numerous populations, it has become clear that occupational transitions – once occasioned through choice, development or dramatic disruption – require adaptation and elicit identity shifts (Hon et al., 2011; Klinger, 2005; Luck & Beagan, 2014; Wiseman & Whiteford, 2009). Occupational transition entails occupational exploration and experimentation, developing competence in new roles

and realities, and finally acquisition of the capacities and habits needed for renewed occupational participation (Kielhofner, 2008). In this process, people engage in self-reflection and reassessment in a “process of knowing themselves, exploring the worth and meaning of their lives, and seeking to control the circumstances and direction of their lives” (Kielhofner, 2008, p.135). Crider, Caldwell, Bunting and Forwell (2015) emphasize that occupational transition is inextricably intertwined with identity.

Though their study was focused on return to work, a chosen transition, Dodds and Herkt (2013) identify some important components of occupational transition, including positive, supportive, and encouraging initial conditions, a contemplation phase, and an action phase. They suggest success depends on individual’s personal motivation and strength, identity, and connectedness. These results somewhat parallel current results in that the role of identity, including motivation, strength, and self-concept deeply influenced participant occupational transitions. Emotional readiness also appeared to be key for participant. Both studies highlight the importance of social support during transition.

In this study, all six participants initially experienced a poor occupational fit during the initial stages of transition, which was repeatedly viewed as a mismatch between what participants wanted to do and what they were able to do. Finding the right person-environment fit, or degree to which individual skills and abilities matched the requirements of the environment, was key to transition through seeking out new occupational competences. Ineffective occupational performance often lead to low self-opinion, which in turn, lead participants to withdraw from meaningful occupations,

perpetuating feelings of loss, failure, and inadequacy. Personal factors, including psychological limitations, pressure to make changes before participants were ready, setting unrealistic goals, and personality characteristics held the power to either propel or prevent forward movement; while environmental factors, including demands of the home and family life, demands of the job, and cultural implications also played a significant role – the relationships between the two needed to be in synchrony before participants could create positive and sustainable occupational changes.

Bridges (2003) identifies transition as a three stage process that people experience when considering entering a new life phase: the 'ending' which involves letting go of certain roles and occupations (e.g. grief, loss, anger); the 'neutral' phase, or the bridge between the old and new, which involves slowly re-orientating and realigning with a particular goal (e.g. returning to work or re-socializing with friends); and the 'new beginning' which involves finding acceptance and motivation, and working toward embracing change. While these stages aligned with our participants' transition experiences, I found that the notion of 'choice' played an important role in creating smoother transitions; those who were more restricted in their occupational choices (e.g. single participants) transitioned more slowly and more painfully than those who exercised greater choice; those who made choices on their own terms, as opposed to as a result of pressure from others, experienced a more fluid and sustainable transition to occupational participation. In addition, growing tired of feeling inactive and unproductive and feeling sick of mistakes or failing occupationally, served as significant precursors to moving forward into occupational transition.

The study results emphasize the influence of timing; participants who were further in time from the MTBI were more likely to let go of their losses, make fewer occupational failures, were more healthy emotionally, maintained a more positive outlook about their occupational abilities, and made more significant changes to their daily occupations, compared to those who had been recently diagnosed. It also appeared that those who resisted change and tried to hang onto aspects of their former lives experienced the most emotional and occupational set-backs. Once participants let go of the past, they were better able to overcome occupational chaos, loss, and imbalance, and begin making adjustments to lost roles, adapting occupations, and creating new routines and structures.

Participants described successful transitions in terms of reaching a place of satisfaction, efficacy, competency, and happiness. For example, some people felt they had successfully transitioned once they were able to effectively fulfill certain ADLs, maintain organization in the home, return to work on any basis, meet with friends, parent effectively, or volunteer. These occupational competences were built on, and contributed to, increases in self-concept and esteem, self-efficacy, motivation, decreased mental health issues, and increased peace and meaning, as well as happiness. Overall, despite the fact that each transitional journey was unique for participants, common stages were found among participants, including: the experience of MTBI; realisation that aspects of the self and life were different; feelings of loss and longing for pre-injury selves and lives; negative occupational patterns including failure and mismatches between what participants wanted to do and what they could do; limitations to everyday life; identifying a gap or something missing in life; restlessness



and contemplating change; taking steps toward reclaiming occupational engagement; seeking social supports; and the acceptance of new occupations and occupational routines.

Interestingly, failure was experienced by everyone and was a common catalyst to making occupational alterations and eventually moving forward. In other words, no one got it 'right' at first. Because not all transitions were immediately successful, I also found that participants tended to repeat various steps along the way, until they were able to find an effective person-occupation fit. While most participants initially avoided certain occupations, everyone made attempts to modify certain aspects of occupation (adaptation) before they could attain occupational fluidity and competency. Overall, participants identified transition as a more fluid, as opposed to static, process, and nearly everyone felt that further improvements to their sense of self and occupational lives would be made as they progressed in their transitions.

### 7.7 Occupational Identity

The relationship between identity and occupation is dialectical: occupation is shaped by identity, just as identity is shaped by occupation. Identity shifts were key to both occupational adaptation and occupational transition. In previous studies of brain injury, survivors have been found to experience loss of self in various forms, despite the fact that they often use strategies to avoid or minimize the impact of loss. Nochi (1998), for example, found that losses of self were clearer when individuals compared themselves to who they were before injury, and the sense of self was threatened by labels society imposed upon them. In the current study participants each experienced a

loss of self-concept, esteem, and identity following brain injury. However, the results also suggest stages of identity shift, including: the initial shock of MTBI; identity disruption which included a damaged identity; loss and grief; self-acceptance; identity reconstruction; and eventually new ways to view the self and celebrate growth and recovery.

Alterations to identity following brain injury typically include grief, loss, resentment, anger, and diminished feelings of security and self-awareness (Nochi, 1998). Immediately following brain injury most participants entered a survival mode meaning that they became completely preoccupied with symptom management and coping with occupational failure; nearly all facets of occupational life, including work, leisure, and socializing, just stopped. As a result, participants withdrew from occupational engagement and participation, even while experiencing considerable occupational chaos and imbalance. Decreased occupational engagement lead to fewer opportunities for achieving occupational mastery, achievement, and purpose, which contributed to an erosion of the self, insecurity, and occupational disconnect.

Immediately following brain injury, participants experienced the greatest self-damage, especially because they spent so much time and energy stuck in the past, or longing for former ways of thinking, feeling, and living (e.g. lost cognition, emotional balance and health, and lost occupational abilities). A mismatch, between what participants wanted to be able to do, and what they could actually do, resulted in profound disruptions to identity (Boehm, 1998). Once participants were able to move past the initial stages of grief and loss, they were eventually able to create adaptations

to aspects of their self, as well as with occupations. This sense of a trajectory echoes earlier work by Nochi (2000).

Like others, (e.g. Kubler-Ross, 2009 & Alston, Jones, & Curtin, 2012), this study found that following brain injury people experienced similar stages of grief, including denial, anger, bargaining, and anxiety and depression, which negatively affected self-concept and occupational efficacy. Some study participants succumbed to hopelessness and despair at different points (e.g. suicidal ideation, severe anxiety, and clinical depression). However, eventually participants grew tired of focusing on symptoms, not working, having fun, or socializing, and made purposeful efforts to redefine themselves by finding new occupational meaning and purpose. This was an identity reconstruction phase, accomplished in conjunction with occupational adaptation. Over time, participants took steps to redefine their personal identities, primarily by attaching new symbolic meanings to themselves (e.g. warrior and fighter), rejecting the idea that they were victims, or stopping the search for validity from others; they were then able to adopt more purposeful and active roles in overcoming occupational barriers associated with MTBI.

In their study, Erikson, Karlsson, Borell and Tham (2007) found that during recovery participants with memory impairment were required to create new habits, make conscious strategies, and use familiar activities in order to reinstate routines and occupational patterns that had been disrupted by TBI. While this was also true for participants in the current study, in order to do this participants first had to accept that aspects of identity and occupational performance had changed and might not ever

become fully reinstated; let go of hanging onto the past; and learn to stop hiding or minimizing the effects of brain injury. Honestly accepting what had happened to them, how they had changed, how life might not ever be the same, and how they were required to restructure themselves in order to move forward, was key to assuming a more proactive role in rebuilding the self.

Once they accepted an identity as someone with an MTBI, participants experienced other profound identity shifts, highlighting the 'becoming' aspect of occupation. Significant changes in personality required parallel changes in occupations. For example, those who have been more extroverted became quieter and more introverted, replacing highly social, active occupations with more solitary or creative pursuits. These changes to align occupation and identity helped create participants feel accomplished and proud, masterful. Similarly, once participants stopped comparing themselves to their former selves, they were able to embrace their differences and strengths and successfully rebuild social identities. This included the formation of meaningful and trusted friendships, supporting identity shifts (Nochi, 2000).

Importantly, with greater identity acceptance, every participant became involved in advocacy roles, especially with their local brain injury community, and some participants became involved with learning and academic pursuits, along with public speaking engagements and awareness campaigns – strategies which allowed participants to look past labels and embrace new ways of thinking and feeling about themselves. In fact, becoming involved with the TBI community and making new friendships were major supports for restructuring and strengthening the self. As has

been found in other contexts, engagement with peer/social support had positive impact on personal identity development (e.g. Heuchemer & Josephsson, 2006; Rubenson, Svensson, Linddahl, & Björklund, 2007).

Stopping the search for additional 'recovery' was perhaps the most compelling result pertaining to identity. Once participants reached a level of acceptance about themselves and their occupational future, some were able to let go of the idea that they might continue to get better. This stage seemed to signify reaching a certain desired state of being. Participants who were able to say "this is the new me and I like her/him" appeared to experience a greater sense of self-concept, esteem, and efficacy, and increased emotional security, peace, and balance compared to those who clung to aspects of their former selves. One participant even developed a celebration to embrace her new life as someone with an MTBI commemorating a kind of 'rebirth' as someone who was no longer recovering from a concussion. This was a particularly strong description of identity shift.

Finally, some participants continued to grapple with gaps in their identity. This included battling old demons; feeling like a wanderer without an identifiable purpose; struggling with underlying, lingering emotional insecurities; facing uncertainty about their future identity; missing former dreams or the ability to dream; and secretly longing for aspects of the former self. These conflicts support the findings of Erikson et al. (2007) that even when occupational engagement and competency is enhanced, individuals may continue to struggle with a visible future horizon. It also supports findings by Hoogerdijk, Runge, Haugboelle (2011) that the process of developing a new

self-concept is a lifelong process that continues long after rehabilitation and recovery end.

## 7.8 Implications

Occupational therapists and other clinicians often work directly with clients who have been diagnosed with moderate to severe traumatic brain injuries, especially in rehabilitation settings. Others will encounter clients with MTBI even if that is not the primary reason for referral. It is critical that clinicians know more about the occupational lives of these clients, long after the initial injury. Therapists need to understand how daunting and stressful it can be for clients with MTBI to get ready for and travel to therapy appointments; how exhausted they may be afterwards; and how they might spend the entire ensuing day in bed recovering. Clinicians may not realize the amount of energy clients devote to hiding the effects of their brain injury from others, and may be able to help clients develop strategies to pass as less brain injured – or disclose, when they are ready.

There is an important role to play in helping validate the occupational effort required for clients to effectively engage in transition and adaptation processes. Clinicians may be in a position to help clients truthfully acknowledge their abilities and limitations, as well as helping people re-evaluate occupational fit, in order to move toward next stages of recovery. They also play a valuable role in encouraging clients to take time to heal and recover. Therapists would then be able to eventually help people identify just-right occupational challenges so that occupational successes are experienced at the right/appropriate time - but with the goal of incorporating them into

client's daily lives as soon as possible. Social support appears pivotal to successful adaptation and transition (including support from health care professionals) which suggests a potential role in helping link clients with other MTBI survivors.

This study also makes clear that processes of adaptation, transition, identity change and recovery go on long after MTBI rehabilitation is considered 'finished.' Participants emphasized a significant gap in community health support for individuals with brain injury. To date, the only supports in Nova Scotia are on an in-patient basis (e.g. rehabilitation center). Most individuals with brain injury get 'lost' and forgotten about once they've been discharged from the hospital. Virtually no support is available to the MTBI community other than local non-profit brain injury associations, which are extraordinary resources, resting on insecure funding.

The province may well need a provincial health strategy geared toward increased community supports for individuals diagnosed with head trauma. The brain injury community needs to learn more about other effective community based models so that provincially funded MTBI support systems may be considered. New mothers, for example, receive mandatory visits from community health practitioners following discharge from the hospital. Increased academic and professional knowledge, perhaps in part gained from this study, among countless others, is one way to provide policy makers with concrete information in order to identify key services needed. For example, knowing that grocery shopping and food preparation, general shopping, and financial management represent some of the greatest daily occupational challenges for individuals with MTBI, elements of programs similar to meals-on-wheels (for seniors),

volunteer chauffeur programs (for veterans), or financial advising services could provide templates from which to follow.

Knowing that peer support plays a significant role in MTBI recovery, provincial strategies aimed at linking MTBI survivors with their peers could be an important first step at the community level. Occupational therapists and occupational therapy students should specifically learn more about MTBI (rather than solely focusing on more severe forms of TBI) and recognize its distinct challenges and needs – especially surrounding the hidden effects of the disability and how they affect every day occupational life and recovery. However, before changes can be made, we must first acknowledge what it's really like to experience and be part of something so profound and life changing; an increasingly common diagnosis which has traditionally been under looked and unrecognizable by both survivors and the public. Thus recommendations for policy makers would include the implementation of:

- Support services such as home visits after traditional rehabilitation services cease
- Support services that assist with grocery shopping and other shopping
- Assistance with food preparation and/or food provisioning
- Assistance with financial management, especially for single people
- Assistance with driving and transportation
- Structured linkages with peer support communities

Finally, the results of this study have implications for theory in occupational therapy and occupational science. In this study, occupational adaptation differed for each person, and took place over differing time frames, but typically followed similar stages, from disorder and loss, to order, and then reorganization to accomplish occupational mastery (Schultz, 2009). Adaptation was both a state (e.g. achieving occupational competency) and an internal process (e.g. adaptations to identity).



Adaptations involved changes to the environment, social connections, and timing of occupations, as well as new physical and cognitive strategies to enhance capacity. Abandoning some occupations allowed space for novelty, while adapting some occupations also allowed retention of the familiar. Most importantly, effective occupational adaptations, allowed participants to enhance their own occupational performance and competency over time, contributing significantly to the development of a renewed occupational identity. At the same time, acceptance of a new – post-MTBI – identity appeared central to successful adaptation. The study highlights the interactive relationship between occupational identity and occupational competency.

There is also an intriguing theoretical insight in this study regarding occupational choice and balance (Townsend & Polatajko, 2007). Participants generally stripped down complex occupational lives post-MTBI, to retain only those focused on survival. Leisure, and occupations oriented to meaning and the spirit, to social connection, to pleasure, and to future orientation fell by the wayside. Occupational lives centered on the obligatory, the necessary. This hints that the notion of occupational choice may be rather a luxury for some individuals or populations, at least at certain times. At the same time, the concept of occupational balance is typically used to refer to varying types of occupation, varying occupational roles and responsibilities, and/or a balance in the use of time (Dür et al., 2015). It is intriguing to consider the potential value of attending to balances and imbalances in obligatory and chosen occupations.

## 7.9 Research Limitations

The individual nature of participants' experiences and the small sample size (six individuals) meant that the findings from this study are not generalizable to the experiences of everyone with MTBI. However, despite the (deliberate) small sample size, the findings revealed rich, in-depth data about the everyday experiences of MTBI. This information is valuable especially to other MTBI survivors, clinicians, community health initiatives, and as discussed, policy makers. Due to the fact that post-injury time frames varied (e.g. 1 year *versus* 8 years post-injury), some common elements to the occupational identity process were noticed: those more recently diagnosed with MTBI experienced daily occupational life differently than those who had lived with TBI for long periods of time. This might be seen as a drawback because the gap in injury time frames could have been narrowed. However, this is also an asset because the common stages of recovery helped highlight the trajectory of occupational participation and engagement, competency, and identity reformation.

All of the participants recruited for this study were somehow involved with the BIANs community, in some way. Although participation and involvement varied (e.g. length of time and degree of involvement), it should be noted that nearly everyone had connected with other survivors (peer support) through BIANs. It is possible that had I recruited individuals from outside the brain injury community, the personal experiences and challenges might have looked somewhat different. For example, participants might have been even more socially isolated or had even less social support than participants from BIANs. Since we know that the road to recovery often involves prolonged periods

of negative mental health experiences, social withdrawal, and loss of occupational engagement and competency in leisure activities, it is possible that recruits from outside of the BIANs community might have represented a different stage along the road to recovery trajectory. Although this is purely speculative, it is worthy of considering.

Also, since participants were also predominately working 'professionals' prior to their injuries, experiences surrounding vocational reengagement, struggling for legitimacy, and combating stigma might have looked different for non-professionals. While we know that one of the buffers for legitimizing experiences of MTBI included holding a professional designation, it's possible that individuals with less education from more working class backgrounds may have experienced MTBI differently – especially with occupations associated with liaising with healthcare, legal, and medical communities.

Participants who had been recently diagnosed with MTBI were less occupationally engaged than those who had had more time to grieve, make mistakes, or take steps to transition toward a more engaged, balanced occupational life. This difference was unanticipated prior to the start of the study, yet could also be considered advantageous because the disparity in injury time frames, and subsequent occupational implications, helped shed light on reasons and advantages for occupational abandonment, reengagement, and eventual recovery.

Differences between participants who were single and attached became apparent during data analysis, and in some ways split the participant population into two groups; occupational experiences were quite different for those who were married

with children versus those who were single. Implications for food practices, financial management, transportation, social support, and domestic life were identified.

However, these differences also served as a source of strength because they provided worthy insights into the importance of buffering or supportive factors of social and familial support. Age was also a substantial difference, in that those who were younger experienced occupational identity, transition, and adaptation differently than those who were older – primarily because occupational roles and responsibilities were different (e.g. caring for small children versus looking forward to retirement). These differences due to developmental life stage warrant further exploration.

Some participants tired more easily than others during the interviewing process and in two instances, interviews had to be cut short in order to accommodate symptoms of headaches, dizziness, and fatigue. Interviews were typically scheduled for between 1.5-2 hrs. On the other hand, two participants expressed a desire to keep talking and “get it out” extending their interviews.

#### 7.10 Future Research

Few, if any studies have explored the daily occupational experiences and challenges associated with MTBI and parenting. In this study, it became clear that parents of small children face unique challenges associated with ADL's, including the maintenance of domestic organization, grocery shopping, management of symptoms, and childcare, including discipline. Apart from these results, we know relatively little about how exactly parents with MTBI renegotiate their everyday occupational roles and routines. Even less is known about single parenthood and MTBI. Parents in this study all had partners, providing them with increased options and choices surrounding financial,

domestic, and vocational obligations. Since single participants were solely required to take care of themselves, maintain household organization, buy and prepare food, and secure transportation, they tended to fare worse economically, emotionally, and psychologically. Further research should examine how single parents with MTBI manage.

Future research involving occupational changes (e.g. abandonment or modification) associated with struggling for legitimacy, overcoming barriers of stigma, and trying to pass as less brain injured, is encouraged. While this study provided some important insights into these issues, more depth is warranted. Stigma and passing are typically explored outside of occupational therapy and occupational science, yet occupations are central to passing. More research is needed on how occupation is used in and affected by passing and stigma management. In addition, research on how passing affects client-therapist interactions would be valuable; clients may try to pass as less affected by MTIB than they really are, fearing judgement and stigma. They may knowingly or unknowingly try to fool therapists into thinking that they are stronger or more capable than they actually are – especially in order to thwart worry, be seen as less vulnerable, or uphold dignity.

Finally, at present there are no existing occupational therapy protocols for assessing and treating identity disruption (for TBI or MTBI), and there are no protocols for assessing the stages of transition following head injury. Occupational therapists typically focus on helping clients create adaptations to occupational dilemmas and challenges, however we are less equipped with knowledge (and expertise) about how to

effectively help individuals re-navigate their occupational lives and identities following life changing events like brain injury. Information from this study might help contribute to the formation of these protocols, especially because aspects of our results are novel (e.g. passing, stigma, and legitimacy surrounding MTBI). While we've generated explicit and rich information about everyday life following MTBI, further research about potential gender differences, relationship status (e.g. single versus partnered), and parenting and MTBI is necessary in order to further contribute to this evolving field.

### 7.11 Conclusions

This study set out to explore a deeper understanding of the lived experience of MTBI. It aimed to gain rich, in-depth information about the everyday effects of MTBI on taking care of one's self and others, engaging in paid employment, participating in leisure, and socializing. It also explored the effects of MTBI on occupational processes of occupational identity, transition, and adaptation; occupational changes associated with trying to be believed (legitimacy), facing societal judgement (stigma), and hiding or minimizing the effects of MTBI (passing), as well as occupational adaptation including the addition, abandonment, and modification of occupations.

The lived experience of MTBI was individual and unique. However common themes and experiences with occupational adjustment, modification, and adaptation were identified while I attempted to answer my main research and sub-questions. Occupations associated with *doing*, including shopping for and preparing food, independently managing finances, and returning to paid employment represented the greatest daily occupational challenges, especially during the initial stages of recovery.

Occupational adjustments included avoidance or abandonment of occupations that were perceived as too difficult. In particular, the activity of grocery shopping was experienced as most stressful and debilitating, and challenges associated with this occupation persisted well into recovery.

In addition to occupational deletions, other types of occupational adjustment strategies used by participants were experienced in the form of occupational modification and alteration. This included making purposeful adjustments to the ways in which occupations were completed; especially evident for those returning to work who were required to modify work hours, schedules, and duties. Successfully returning to paid employment was only possible with support networks in place, and those who were partnered experienced more options to modify work schedules in order to match their post-injury abilities.

With respect to *being*, all participants experienced a state of internal and emotional emptiness and loss, especially in terms of spirituality. Fear, hopelessness, occupational cessation, inactivity, and loss of spontaneity contributed to decreased security and happiness. Occupational meanings associated with spirituality became redefined and either changed or were replaced with new meanings. While some fears dissipated over time, with increased positive self-concept and occupational engagement, others continued to affect participants' ability to successfully and independently complete occupational goals (e.g. drive). Loss of spontaneity was often experienced as a necessary trade-off because leading structured, predictable

occupational lives enabled participants to fulfill occupational obligations, despite the fact that opportunities for change, adventure, and excitement had diminished.

With regard to *belonging*, participants all experienced significant occupational disruption to activities associated with fulfilling family obligations, maintaining friendships, socializing, and having fun. Occupational responsibilities and duties were often passed over to significant others, resulting in a shift of domestic burden. MTBI generally became a family issue and children's roles as supporters and negotiators were ingrained into the fabric of the home. Participants struggled to provide effective discipline to children, however through the use of creative adaptive strategies, they were able to find ways to more effectively parent. Most opportunities for friendships and socialization were initially lost following brain injury, however as participants adjusted internally, and increased involvement in meaningful occupation, friendships were either left behind or restored. Social support was perhaps the most significant factor in the development of the self and achieving occupational competency, and peer support was key feature of facilitating increased occupational participation and a strengthened self-concept. Participants who were single fared better cognitively because they had increased time to maintain sleep and pace their occupations, however they were less well emotionally because of decreased social, familial, and financial support – highlighting the impact of socialisation and support on recovery and well-being.

With regard to *Becoming*, participants held varying outlooks about the future. While some experienced decreased ability to create or fulfill dreams, others were able



to see the positive ways in which their selves and lives had changed since brain injury, which helped quell the sense of loss about things they might not be able to do again. As a result of experiences with MTBI, participants all described increased appreciation and empathy toward other individuals facing life-changing situations. While nearly everyone gained in-depth insight into themselves and embraced some positive aspects of their post-injury identities and occupational lives, others continued to hang onto aspects of their former selves and lives and were insecure about their personal and occupational futures – suggesting that recovery from brain injury continues throughout the lifespan.

The everyday use of language and professional uncertainty about MTBI created stress and confusion for participants. Societal judgement and insensitive health, legal, and medical representatives complicated and interrupted processes associated with self-discovery and occupational competency because so much time and energy was spent trying to legitimize or ‘prove’ MTBI. Altering occupations in order to struggle for legitimacy negatively impacted participants’ emotional and occupational health, and it wasn’t until they reached a place where they stopped caring about others judgements (and sought social support) were they able to create a stronger sense of self and occupational engagement.

Fear of being judged, vulnerability, and loss of professional credibility often forced participants to adjust their daily occupations in order to be perceived as less brain injured than they actually were. Numerous goal-directed, creative occupational strategies were used in order to hide or minimize symptoms associated with MTBI. However, trying to pass as someone more capable than they were yielded both positive

and negative benefits. Positive outcomes enabled participants to avoid stressful situations and humiliation, and uphold dignity and professional credibility, however they were also only temporary solutions in that participants were eventually forced to accept new identities as brain injury survivors before they could overcome fears and transition forward. Participants were especially able to overcome barriers associated with stigma once they engaged with advocacy, volunteer, and educational pursuits, which helped validate and legitimize their experiences with MTBI. It also helped strengthen their personal and occupational identities.

Adapting to life following brain injury was a complicated and long-term process characterized by occupational disorder and chaos, order, and then reorganization in order to achieve effective, independent, and successful occupational mastery again. Occupational adaptation was experienced as a process, moving through common stages to reaching a state where post-injury skills and abilities matched the occupational demands and environment. Numerous physical and cognitive adaptations were made in order to move past stages of denial/grief and occupational incompetency, however participants typically either abandoned or modified occupations that were too difficult or beyond their capabilities. Discovering post-injury occupational strengths and abilities was primarily achieved through a process of trial and error, or occupational failure, which played an important role in helping participants eventually find a good person-occupation/environment fit.

Like the transition processes associated with TBI and other major disabilities, participants were each required to move through common stages. This includes a

realization that things had changed; feelings of loss and longing for aspects of the former self; occupational adaptation, which somewhat paralleled the five stages of grief; negative mental health experiences and occupational failure; motivation to change; participating in new occupations and seeking social support; and engagement with advocacy, volunteer, and learning pursuits. Issues surrounding choice and timing significantly impacted the transition process, and while most participants experienced transition at and for different lengths of time, they were each required to take risks, make adjustments to themselves, and create effective adaptations to occupations in their daily lives in order to effectively move forward.

Finally, participants experienced common stages in their identity shifts. Repercussions from the initial shock of MTBI created significant disruption to self-concept, esteem, and efficacy which resulted in a damaged way of thinking about one's self and the future. Over time however, participants took steps toward rebuilding their sense of self and occupational efficacy, primarily through the use of a supportive social support network. By taking proactive roles to learn about MTBI, advocate for themselves and others, educate the public, and volunteer to be part of a wider brain injury community, participants were able to find ways to better view themselves, and eventually celebrate personal and occupational growth and recovery.

MTBI is more common than people think, and occupational therapists and members of the legal and medical communities are likely to come across individuals with head injuries. Clinicians are in a key position to provide sustainable support for clients, however in order to do this they need to become aware of the everyday effects

of MTBI, especially on therapeutic processes. Currently, the province of Nova Scotia does not provide financial assistance to survivors of brain injury beyond discharge from in-patient and rehabilitation facilities. Nearly 100% of support available to individuals with MTBI is offered through the local non-profit brain injury association. However, recently the provincial government has announced plans to develop a provincial health strategy aimed at providing community support for ABI survivors. By forming a task committee of members from the Departments of Community Services and the Department of Health, along with feedback from various health organizations and professionals, it hopes to finalize the strategy within the next two years. MTBI falls under ABI, and although ABI also includes individuals with stroke and more moderate to severe forms of TBI, information about the specific needs of the MTBI population is crucial in order to support the needs of this population. Even if the proposed strategy falls through, concrete and detailed information about the everyday struggles and barriers of MTBI will be needed for future projects. For example, specific information about the effects of brain injury on ADL's, including the continuous struggle to shop for and prepare food would be helpful for programs interested in implementing food support for survivors.

The road to recovery following MTBI is expensive, both in terms of financial impact on society, and on the health and well-being, happiness, and quality of life for survivors. MTBI (or post-concussive syndrome) is something which has gained considerable attention over the last five years due to sports injuries and subsequent media coverage about the long term effects of concussion. At the individual level, life immediately following brain injury is almost always fraught with occupational

imbalance, and confusion, hopelessness, and despair. But the ongoing effects are also innumerable. Unlike injuries to other parts of the body, brain injury affects nearly every component of the ways in which the mind and body work and interact, affecting an individual's ability to fully participate in society or experience a satisfying life. While recovery from brain injury is lifelong, with additional support, at both the provincial and community levels, individuals may lead enriched lives and find meaning and purpose again.

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## **Appendix A – Diagnosis and biomechanics of MTBI**

### **Classifying and Grading TBI: The Glasgow Coma Scale**

Accurately detecting and diagnosing TBI results in improved injury management and treatment for individuals, both of which ultimately help improve outcomes following a traumatic brain injury (Baggerly, 2009). The first step in this process is recognizing and accurately *classifying* TBI at all severity levels, which is challenging for healthcare providers (McCrea, 2008). There is no universal prescription for this undertaking, and controversy persists surrounding the effectiveness of using various systems for the diagnosis and classification of MTBI (Teasdale & Jennett, 1976). While a classification system may be useful and diagnostically accurate for individuals with moderate to severe TBI, it may be inaccurate when dealing with mild brain injuries (Costanti & Cardoso, 2012). However, despite the fact most classification systems grade severity based on acute injury symptoms, the Glasgow Coma Scale (GCS) continues to be the most widely recognized/used tool for grading TBI severity, and remains heavily weighted in classifying and diagnosing MTBI (Teasdale & Jennett, 1976). As such, it is worthy of consideration here. See the GCS chart below:

The Glasgow Coma Scale (GCS) is a quantitative neurological scale aimed at providing an objective way of recording the conscious state of a person which is used for initial and subsequent reassessment (McCrea, 2008, p. 150). A score of 13-15 indicates mild TBI, a score of 8-12 indicates moderate TBI, and a score of 3-9 indicates severe TBI (Teasdale & Jennett, 1976). It assesses gross neurologic status across three areas (using 3 subsections) including motor function, verbal responding, and the ability to open one's eyes voluntarily or in response to a command (Katz & Alexander, 1994). The most basic

approach to grading TBI severity is based solely on a GCS score, which ranges in score between 3 and 15 (Katz & Alexander, 1994). The GCS has gained international acceptance as a valid and reliable approach to identifying the severity of TBI (Katz & Alexander, 1994). However the confusion, and critique, lies in the higher scores; a GCS score of 13-15 is one of the earliest determinants of MTBI. A perfect score of 15 indicates full alertness and consciousness, however one still may receive a diagnosis of MTBI based on this seemingly perfect score. On the other hand, individuals who have scored 15 are often seen as perfectly normal to assessing health professionals (which may result in serious legal and medical ramifications). Overall, however, scores of 13-15 suggest an “altered” state of awareness, and have traditionally indicated “proof” of MTBI (Baggerly, 2009).

The GCS is not without further shortcomings. Although this classification system has proven to be predictive of accurate outcomes for individuals with moderate to severe brain injuries, it may not be as useful for those with MTBI (Marion & Carlier, 1994). The scale tends to have greater utility in classifying more severe TBI’s because it was originally designed as an in-patient tool in order to assess level of consciousness (LOC) for those with definite loss of consciousness within a critical care environment (Marion & Carlier, 1994). This is a limitation for the assessment of MTBI. Research has shown that the majority of patients diagnosed with MTBI yield a score of 15, which would appear to many healthcare providers as unaffected or normal, devoid of impairment (Katz & Alexander, 1994). The overlap at top of the scale (score of 15) between MTBI and no injury can cause a slew of subsequent problems for individuals with MTBI seeking diagnosis and treatment, and ultimately affects legitimacy within

medical and legal institutions. Legal processes and insurance companies often heavily rely on scores and numbers in order to legitimize claims. While scores below 13 on the GCS suggests an injury too severe to be considered MTBI, scoring “too high” (e.g., 15) suggests the person is uninjured - both scenarios potentially excluding individuals from timely and appropriate diagnosis and treatment.

Further, the GCS has shown insensitivity to the detection of cardinal MTBI symptoms including nausea, headaches, dizziness, sensitivity to light and noise, or to alterations in mental status including confusion, disorientation, amnesia, and poor concentration (McCrea, 2008). Therefore, in clinical settings it is important not to rely exclusively on this scale and its subsequent core criteria; healthcare providers need to minimize the risk of missing key characteristics of MTBI and contributing to inaccurate diagnoses (Katz & Alexander, 1994).

## **The Biomechanics of MTBI**

### **What exactly occurs when the brain is injured?**

Originally, it was thought that a ‘true’ MTBI existed only for a short period of time (concussion) and that any persistent or lingering symptoms (called Post-Concussion Syndrome today) were the result of psychological, or non-injury related factors (Stulemeijer et al., 2006). Specifically, it was thought that any disruption to axons in the brain, as a result of force through a direct blow to the head, would not cause any structural damage to the brain, thus would resolve itself acutely. However, due to technological advances in the last decade, the scientific community has gained increased understanding about the foundation of the biomechanics and neuropathophysiology of MTBI.

There are two major types of traumatic brain injury: penetrating and closed. In cases of *penetration*, a foreign object (e.g., bullet) enters the brain and causes subsequent damage to specific regions (usually the area directly impacted by the object). The majority of penetrating injuries are focal, (localized) in nature and the path in which the object travels is almost always affected (tearing through brain tissue along its way). Subsequent symptoms of penetrating brain injuries vary depending on factors such as the specific part of the brain damaged. Conversely, closed-head injuries may be caused from a *non-penetrating* direct blow to the head, acceleration, deceleration, or rotational forces, any of which may result in internal damage to the brain (Stulemeijer et al., 2006). Closed-head injuries may cause two direct types of brain damage: *focal* (confined to a specific area of the brain) or *diffuse* (distributed throughout), however it is common for both types to exist within a single case (Kolias, Guilfoyle, Helmy, Allanson, & Hutchinson, 2013). Specific consequences of closed head injury may include: skull fracture; cerebral contusions/bruises; cerebral hematomas/blood clots; cerebral lacerations; or nerve damage (arises from a cutting or shearing force which damages nerve cells in the brain's connecting nerve fibers) (Kolias et al., 2013).

Secondary brain damage, damage to the brain which develops after the trauma (over time), is common in many moderate to severe brain injury situations. It may arise from generalized edema (swelling), increased pressure inside the skull (intracranial pressure), epilepsy (seizures), intracranial infection, hematoma (blood collection), high blood pressure, anemia (low iron concentration), carbon dioxide deficiency, abnormal blood coagulation (clotting), and changes in cardiac and lung function (Murthy, Bhatia, Sandhu, Prabhakar, & Gogna, 2005).



The most common causes of TBI in Canada are falls (45% of hospital admissions for TBI); motor vehicle accidents (36% of hospital admissions for TBI); violence (22-49% of hospital admissions for TBI for those under 60) and sports (28% of children and youth and 8% of adult admissions for TBI are related to sports accidents) ([www.cihi.ca](http://www.cihi.ca)). The most common sports-related injuries are from boxing, football, field/ice hockey, lacrosse, martial arts, rugby, soccer, wrestling, auto racing, cycling, horseback riding, roller blading, skateboarding, skiing, or snowboarding (Brain Injury Association of Waterloo, 2014).

The mechanisms of injury in mild, moderate, and severe brain injuries are essentially all the same (Brain Injury Association of Waterloo, 2014). Slips, falls, sporting accidents, motor vehicle accidents, acts of violence, and many other known common causes of TBI may result in damage to the brain. The major difference is the degree of applied force. Moderate and severe injuries are produced by greater force and normally result in more structural damage to the brain, often yielding worse functional outcomes (Bazarian et al., 2005). In many cases of mild traumatic brain injury, a temporary disruption of neuroaxons may occur (concussion), whereas greater force applied can result in more permanent, scattered axonal damage throughout the brain, called Diffuse Axonal Injury (DAI). DAI is most often found in moderate to severe brain injury cases and is more easily detected in neuroimaging (but not always) (Larrabee & Rohling, 2013). In cases of DAI, when the brain (enclosed in a hard skull) is subjected to strong inertial forces, it acts by moving back and forth within the skull, twisting and rotating secondary to the force (Kolias et al., 2013). Consequently, neural axons become disrupted and rotational forces damage neuroaxons and small blood vessels which run along the axis

of the brain (Baggerly, 2009). Subcortical axons and deep structures within the brain are damaged which is why most cases of DAI are considered “diffuse” (throughout).

Traditionally, neurological changes associated with *milder* brain injuries were thought to be reversible. However, Adams and Victor (2001) have demonstrated damage and axonal swelling at the site of the injury, as well as damage to nearby blood vessels and depletion of mitochondrial ATP in animal studies. This means that despite the fact research has traditionally thought that MTBI could not cause permanent damage to the brain, the scientific community now recognises the potential structural effects of MTBI in humans, generated from animal models (Adams & Victor, 2001).

The terms MTBI and concussion are often used interchangeably. Traditionally, concussion has been defined as, “trauma-induced alteration in mental status that may or may not involve a loss of consciousness” (American Academy of Neurology, 2014). However, the most universally accepted and widely used definition of concussion is from Rutherford (1989) who defines it as an acceleration/deceleration injury to the head, almost always associated with a period of amnesia, followed by a characteristic group of symptoms such as headache, poor memory, and vertigo. The latter definition is most synonymous with current understanding of MTBI, although it does not specify severity of injury, only the mechanism. Modern research has now delineated a clearer pathophysiology of MTBI referred to as the “neurometabolic cascade,” which is characterized by a “process of ionic shifts, altered brain metabolism, impaired neuronal connectivity, and disruption of normal neurotransmitters” (Giza & Hovda, 2001). However, the time course of return to normal cerebral function after the metabolic

cascade is not clear and most of the evidence suggests a gradual reversal of physiologic abnormalities within days to weeks after an MTBI (Giza & Hovda, 2001).

### **The Anticipated Course of MTBI**

The diagnosis of MTBI is based largely on the subjective acute symptoms reported by patients (McCrea, 2008). In most paediatric and adult cases, symptoms of MTBI are transient in nature, with rapid or gradual resolution within days to weeks post-injury (McCrea, 2008). According to a summary of the results of several studies on self-reported symptoms MTBI, the most commonly experienced acute symptoms of MTBI are: headache, blurred vision, dizziness, subjective memory problems, and other cognitive difficulties and sleep problems (WHO Task Force, May 2014). Importantly, symptoms in approximately 75-80% of individuals with MTBI gradually resolve within one to two weeks, and sometimes within several weeks (Carroll et al., 2004). Individuals with symptoms that persist for more than three months may qualify for a diagnosis of post-concussion syndrome; a hotly debated current topic in MTBI research and clinical circles (discussed later in this chapter).

Because mild injuries to the brain tend not to be visible, evidence of primary or secondary effects on the brain is rarely detected by neuroimaging (e.g., MRI, CT scan). However, suspected cases of MTBI are often confirmed through various cognitive screening instruments, which attempt to quantitatively measure acute cognitive symptoms. With a purpose aimed at assisting clinicians in the diagnosis of MTBI, such assessments provide a baseline from which to measure an individual's current state and anticipated progress (Blokland & Orest, 2006).

*Time Frame post-injury:*

Immediately after an incident or accident affecting the brain, individuals with MTBI experience some form of an altered state including, for example, disorientation. In many cases, they report feeling “out of it” or unlike themselves. Conversely, others experience a total loss of consciousness lasting up to several minutes (Mooney, Speed, & Sheppard, 2005). A period of confusion and posttraumatic amnesia almost always ensues, and individuals may become agitated and/or hyper aroused (e.g., excessive talking) (Adams and Victor, 2001). Subsequently, during this time the formation of new, short-term memories is unlikely. In the days following the initial injury, the majority of individuals experience anxiety, lability, and irritability (Kolias et al., 2013). They may also experience dizziness, nausea, headaches/migraines, pain, and a multitude of related musculoskeletal injuries (Keow, Ng, & Ti, 2008). Typically, people report severe limitations with attention following a head injury (Blanchet, 2009).

During the days immediately following head injury, individuals may find it difficult to attend to written print (reading and writing) or conversations. They may also become hyper-distractible because they are not able to properly encode the various environmental stimuli with which they are surrounded (Erez et al., 2009). Forgetfulness is often simultaneous with distraction (also a result of the amnesia phase) because it is difficult for individuals to hold information in one space (short-term memory), while encoding (or letting in) new incoming stimuli/information in another space. Individuals have described feeling frustrated, simplified, or stunned during this phase (Butler, 2014). However, such attentional deficits are not always immediately apparent following an injury, often only becoming apparent when individuals are required to employ their executive functions. In other words, it is not until individuals are required

to actually concentrate, pay attention, remember things, and/or solve problems (Bergman, Fabiano, & Blostein, 2013), that the true limitations of mild head injuries become apparent. This is important for suspected cases of MTBI in a hospital setting (post-admission), where admitted individuals may appear uninjured while on-site because they are required to “do” little cognitively; however they may realize their deficits soon after discharge (Nolin, 2006).

### *Long-Term Effects*

The likelihood of neurological recovery for individuals with MTBI is excellent – approximately 75-80% of individuals fully return to pre-accident levels of function (Stulemeijer et al., 2005). Typically, there are no permanent lingering neurological or behavioral effects for the vast majority of people with MTBI, and recovery from mild brain injuries typically follows a predictable pattern (Rohling, 2009): Individuals pass through a dazed/disoriented phase, into a period of confusion and post-traumatic amnesia, lasting anywhere from hours or days to weeks (Adams and Victor, 2001; Katz, 1994; Tate, Pfaff, and Jurjevic, 2001), and then alter back into their former cognitive and functional selves. Some continue to experience difficulty with focusing, concentrating, and remembering things (short-term) several weeks after an injury, however the overwhelming majority of survivors follow a favourable course of recovery by returning to normal occupational performance and independent functioning within several weeks. Currently, as a rule of thumb, researchers have reached consensus that cognitive impairments normally last up to four to six weeks after a mild traumatic brain injury (Wong, Murdoch, & Whelan, 2010). Essentially, neurophysiologic effects of MTBI follow a course of recovery consistent with the natural course of symptom resolution and

cognitive restoration as the brain returns to a normal physiologic state within days to weeks of the injury (Dean & Sterr, 2013).

### **Post-Concussion Syndrome**

The majority of MTBI's are self-limiting and follow a predictable course of recovery. Permanent cognitive, psychological, and psychosocial problems due to the biological effects of MTBI are uncommon in trauma patients and athletes (Guinto & Guinto-Nishimura, 2013). However, there are individuals (approximately 10-20% one year post-accident) who continue to exhibit persistent symptoms related to MTBI twelve months after the original injury (Makdissi, Cantu, Johnston, McCrory, & Meeuwisse, 2013). These individuals have not returned to their pre-accident levels of occupational, social, and independent functions, which is concerning to health care providers assisting in their treatment, and may prompt subsequent further investigation into a potential diagnosis of Post-Concussion Syndrome (PCS).

Though controversial, post-concussion syndrome (PCS) is a term often used along with MTBI (Makdissi et al., 2013). It also appears in the literature every bit as confusing and hotly debated, with contested definitions, usage, and outcomes. Like the challenges discussed with defining MTBI, the term PCS has been criticized for ambiguity. Several differing definitions exist and are used today. Two of the most widely used criteria for diagnosing PCS are the *International Classification of Diseases (ICD-10)* (2013) and the *4<sup>th</sup> Edition of the Diagnostic and Statistical Manual (DSM-IV)* (2000). The latest version of the DSM (V) (2013) has omitted PCS as a distinct condition and currently refers to MTBI as "mild neurocognitive disorder," requesting diagnosing health professionals to specify the exact cause of the neurological insult (e.g., TBI, Parkinson's,

Alzheimer's, etc.) as part of the diagnosis. The DSM IV PCS diagnostic criteria were, however, widely used. Definitions used by the International Classification of Diseases (ICD-10) and Diagnostic and Statistical Manual's 5<sup>th</sup> edition (DSM-IV) may be found in the comparison below:

International Classification of Diseases (ICD-10) definition:

- a) A history of head trauma with loss of consciousness preceding symptom onset by a maximum of 4 wks.
- b) Symptoms in 3 or more of the following symptom categories:
  - i. Headache, dizziness, malaise, fatigue, noise intolerance;
  - ii. Irritability, depression, anxiety, emotional lability;
  - iii. Subjective concentration, memory, or intellectual difficulties without neurophysiological evidence of marked impairment
  - iv. Insomnia
  - v. Reduced alcohol tolerance
  - vi. Preoccupation with above symptoms and fear of brain damage with hypochondriacal concern and adoption of sick role

Diagnostic and Statistical Manual (5<sup>th</sup> edition) definition:

- a) A history of head trauma that has caused considerable concussion.
- b) Evidence from neuropsychological testing or quantified cognitive assessment of difficulty in attention (concentrating, shifting focus of attention, performing simultaneous cognitive tasks) or memory (learning or recall of information).
- c) Three or more of the following shortly after the trauma and last at least 3 months:
  - i. becoming easily fatigued
  - ii. disordered sleep
  - iii. headache
  - iv. vertigo or dizziness
  - v. irritability or aggression on little or no provocation
  - vi. anxiety, depression, or affective instability
  - vii. changes in personality (e.g. social and sexual inappropriateness) or
  - viii. apathy or lack of social spontaneity
- d) The symptoms in criteria B and C have their onset following head trauma or else represent a substantial worsening or pre-existing symptoms.
- e) The disturbance causes considerable impairment in social or occupational functioning and represents a considerable decline from a previous level of

- functioning. In school-aged children, the impairment might manifest as a substantial worsening in school or academic performance dating from the trauma.
- f) The symptoms do not meet the criteria for dementia due to head trauma and are not better accounted for by another mental disorder (e.g. amnesic disorder due to head trauma, personality change due to head trauma).

There are differences between the two sets of criteria: the ICD-10 *requires* a direct head injury to have occurred, and is characterized by symptoms in 3 or more categories, which must have been preceded by a head injury no more than 4 weeks earlier (McCrea, 2008). It also *requires* a loss of consciousness (LOC) for a PCS diagnosis, despite the fact research has repeatedly shown MTBI is possible without a LOC (Van der Horn, Spikman, Jacobs, & van der Naalt, 2013). In fact, the overwhelming majority of individuals with MTBI experience an altered state, not loss, of consciousness (e.g., disorientation or confusion). The ICD definition excludes them from diagnosis. Most would agree that MTBI precedes PCS (like a stuffy nose or headache prior to a head cold). Similarly, the DSM-IV required a LOC, again excluding the vast majority of MTBI survivors from diagnosis. Unlike the ICD-10 however, the DSM-IV required neuropsychological “evidence” of difficulty in areas of attention and memory (Baggerly, 2009). It also required 3 or more symptoms that last at least 3 months and had an onset shortly after head trauma, or represent worsening of symptoms (McCrea, 2008). The DSM-IV also required significant disturbance in occupational or social functioning, and a decline from the individual’s previous level of functioning. It has been suggested that perhaps the most obvious problem with both the ICD-10 and DSM-IV criteria for PCS is casually linking the subjective, self-reported, long-term symptoms *to* the original MTBI (Zasler, 2008).

### **Concerns About PCS Diagnosis**



To date, the cause of persistent PCS has not been agreed upon in research, and physicians and researchers continue to question the validity of it as an actual condition (Meares et al., 2011). Some have speculated that the true cause of PCS may lie outside the biological realm, residing in psychological and social facets (Lange, Iverson, & Rose, 2011). As a result of this ongoing controversy, it is worthy of discussion here due to the fact that the participants in this study will continue to experience symptoms associated with their MTBI, even years after their original head trauma. Specifically, the majority of skeptics about this condition have proposed that PCS is merely a result of numerous setbacks in an individual's life: physical, emotional, cognitive, psychosocial, vocational, financial, and recreational disruptions which contribute to what appear to be confirmed MTBI symptoms (King & Kirwilliam, 2011). They postulate that such setbacks serve as cumulative stressors which interact with personality and pre-existing physical and mental health factors, resulting in an apparent syndrome. In other words, they claim that various factors may reinforce or perpetuate post-concussion like symptoms, but they are psychosocial in origin, rather than neurological (Dischinger, Ryb, Kufera, & Auman, 2009).

### **Post-concussion Syndrome – Complications**

Alongside critique about the validity of PCS itself, researchers have argued about and questioned the reliability and validity of both diagnostic criteria listed above. Essentially, investigators have reached consensus that the two approaches may be limited by different prevalence's and thresholds, which pose potential downfalls for subsequent clinical and research use (Guinto & Guinto-Nishimura, 2013). Confusion also

exists surrounding the use of the term PCS. Some have used the diagnosis to refer to the symptoms which occur shortly (a few days) after an initial injury (Guinto & Guinto-Nishimura, 2013); others have used it to describe symptoms 4-6 weeks post-injury (Anderson, 2010); while others define it by the number and duration of symptoms (Bazarian et al., 2005). At present however, most clinicians and researchers use the diagnosis/term to refer to a group of symptoms which persist beyond the 3 month mark (Guinto & Guinto-Nishimura, 2013) after an MTBI.

In general, the definition of PCS contains more than 20 symptoms including: headache, dizziness, memory loss, nausea, sensitivity to light and noise, diplopia, tinnitus, irritability, and attentional deficits (ICD, 2013). Others include fatigue, intolerance to alcohol, nervousness, and agitation (Lew, Cifu, Crowder, & Grimes, 2012). Interestingly, it is noteworthy to highlight that several alternate conditions or diagnoses also present with a similar cluster of symptoms, including cervical injuries, whiplash, cranial trauma, chronic pain, fibromyalgia, visual problems, olfactory and gustatory problems, severe headaches, and neck pain (Bosco, Murphy, & Clark, 2013). To illustrate this point, for example, a patient may experience chronic, severe headaches, however researchers have argued that it is difficult to determine whether the original injury is the underlying cause of the headaches, and the extent to which other factors have contributed to the persistence of the headaches (Gallagher, Drance, & Higginbotham, 2006). More interestingly, several well documented, reputable studies have shown a consistent correlation between PCS and depression, anxiety, chronic stress, and somatic preoccupation (Bay & Donders, 2008; Bryant et al., 2010; Edmed & Sullivan, 2012; & Guinto & Guinto-Nishimura, 2013). Depression may be prevalent following traumatic

brain injuries as a result of increased disability in this patient population (Bay & Covassin, 2012). However, this does not necessarily negate the possibility of ongoing MTBI symptoms that may include depression. Depression, in other words, may represent one of the many consequences of an MTBI, contributing to a PCS diagnosis, may be comorbid with PCS, or may masquerade as PCS. All are plausible.

Post-traumatic stress disorder, chronic pain, anxiety, and substance use/abuse have also been documented co-morbidities (Bryant et al., 2012), however again, many researchers have countered that they occur post-injury, or post MTBI. Also, distinct personality characteristics (including individuals who overemphasize cognitive and physical symptoms, are highly emotional, and/or have unresolved emotional issues) tend to be associated with higher rates of PCS. Further, social-psychological factors have been shown to impact the diagnosis of PCS including: patients who might “expect” to experience ongoing symptoms after a brain injury, also called the *Nocebo Effect* (Mittenberg et al., 1992); patients who may overestimate the actual degree of change that has taken place post-injury, also called the *Good Old Days* bias (Gunstad & Suhr, 2001); and patients who are clearly pre-occupied with physical and/or cognitive limitations post-injury (Tanev, Pentel, Kredlow, & Charney, 2014). Perceptions of patient stress, exaggeration, and malingering (Carone & Bush, 2013) associated with litigation have also been shown to affect rates of PCS diagnosis (Binder, 1990).



## Appendix B- Recruitment Poster

### Participants needed for research on BRAIN INJURY

We are looking for volunteers to take part in a study on Mild Traumatic Brain Injury (also called MTBI or Post-concussion Syndrome)

You would be asked to: provide information about what it is to live with a mild traumatic brain injury, through interviews with the investigator.

Your participation would involve 2 sessions,  
each session will be about *1.5-2 hours* long.

In appreciation for your time, you will receive  
*a \$25 gift card.*

For more information about this study, or to volunteer for this study,  
please contact:

*Amy Butler*

*Dalhousie School of Occupational Therapy*

902-210-0345 or

Email: [butleramy@hotmail.com](mailto:butleramy@hotmail.com)

**This study has been reviewed by, and received ethics clearance from Dalhousie**

**University's Research Ethics Board**



## Appendix C- Consent Form

**Project Title:** “There’s nothing mild about it:” What is the lived experience of mild traumatic brain injury from an occupational perspective?

**Lead researcher:** Amy Butler, Student Researcher  
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**Supervisor:** Brenda Beagan  
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### Introduction

We invite you to take part in a research study being conducted by Amy Butler, School of Occupational Therapy, Dalhousie University. **Taking part in the research or not is entirely your choice.** There will be no negative impact if you decide not to participate in the research. The information below tells you about what is involved in the research, what you will be asked to do and about any benefit, risk, inconvenience or discomfort that you might experience. You should discuss any questions you have about this study with the research assistant, or any team member. Please ask as many questions as you like. If you have questions later, please contact the lead researcher (above).

### Purpose and outline of the research study

The primary goal of this study is to explore the lived experience of mild traumatic brain injury (also called post-concussion syndrome). The study wishes to gain increased understanding about the effect of MTBI on the everyday things that head injury survivors do and don’t do. I will examine how MTBI affects the activities people engage in, the meanings of those activities, and potential changes in daily roles, routines and identities. While several studies have explored traumatic brain injury from the perspective of the survivor, most research has focused on moderate to severe injury.

### Who can take part in the research study

You may take part in this study if you self-identify as follows:

- Have been diagnosed with MTBI or post-concussion syndrome within the last 5 years
- Have had symptoms associated with MTBI for at least a year after diagnosis

- Are between the ages of 35-60
- Experience significant disability or interference in everyday life (work, home, school)
- Did not have pre-existing mental health problems prior to your head injury
- Speak English as a first language

### **What you will be asked to do**

Should you agree to participate, you will be contacted to arrange an individual interview at the location of your choosing. There will be 2 interviews in total – each will take approximately 90 minutes, and the 1<sup>st</sup> and 2<sup>nd</sup> interviews will be about 2 weeks apart from one another. Both interviews will be audio recorded.

You may stop the interview at any time, or choose not to answer any questions. You may contact us any time up to two months after your second interview to withdraw from the study. After that, it will be impossible to remove your information from analyses. Simply contact the lead researcher (above) and ask to have your interview deleted.

After your interview, it will be typed up, and any identifying information removed. The research team will then read the typed version repeatedly, to create a 4-6 page summary of what you told us. To make sure we have accurately captured your story, we will send that summary to you, with your permission. You will then have 2 weeks to send us any feedback.

### **Possible benefits, risks and discomforts**

The study is unlikely to benefit you directly, though you may experience indirect benefit from talking about your experiences with someone who understands MTBI. We hope the study results will also contribute to better understanding about the everyday experience of MTBI from the individual's personal perspective.

The biggest risk is to your **privacy**. We are taking several steps to safeguard the confidentiality of your information (see below). Should you agree to participate, we will conduct the interview where and when you choose – please think about who may be around to observe or overhear.

You may also experience **difficult emotions** should you agree to participate. We want to know about your everyday experiences of MTBI including survival, achievement, progression, individual strength, love, support, and connectedness, however we will also be asking you about the cause of your injury, your struggles, challenges, isolation, substance use, grief, loss of relationships and other sensitive topics. Talking about such things may be painful and you may become emotional. We will only be able to offer empathy, support and listening. Though potentially painful, those stories are important, and we will ask how you cope with emotional challenges in your everyday life with MTBI.

**How your information will be protected**

The audio recording of your interview will be assigned an ID# and false name. All electronic files will be password-protected, accessible only to the lead researcher on a password-protected computer. This consent form, which has your name on it, and the file linking ID#s with real names, plus any contact information we have for you will be secured in locked storage in the lead researcher's office, separate from the typed-up versions of your interviews. Once your interview has been typed, only one copy of the audio file will be kept, on a password-protected external hard-drive locked in the lead researcher's office. All audio files will be destroyed once the thesis is complete.

The person who types your interview has signed a confidentiality agreement. She will delete identifying information as she types. The lead researcher will make sure there is nothing identifiable remaining in the typed interview.

Data will be retained by the lead researcher in locked storage and in password-protected files for 5 years following thesis completion. At that point, paper files will be shredded and electronic files will be deleted.

We will quote from the interviews in presentations and publications. Those quotes will be identified by false names. We will also mask other identifying information as needed, while seeking not to alter the important contextual facts of people's experiences with MTBI. For example, we might report that someone is male, when in fact they're female, or we might change someone's age, job, and other obvious identifying information. Nonetheless, you should be aware that if you frequently speak about your story in public, and especially if your story is quite distinctive, people in the brain injury community may be able to figure out who you are.

**You may decide to withdraw**

As noted above, you may stop the interview at any time, or choose not to answer any questions. You may contact us any time up to two months after your second interview to withdraw from the study. Simply contact the lead researcher (above) and ask to have your interview deleted.

**Questions or concerns**

We are happy to talk with you about any questions or concerns you may have about potential or actual participation in this research study. Please contact Amy Butler at (902) 210-0345 or email at: [butleramy@hotmail.com](mailto:butleramy@hotmail.com) at any time with questions, comments, or concerns about the research study.

If you have any ethical concerns about your participation in this research, you may also contact Catherine Connors, Director, Research Ethics, Dalhousie University at (902) 494-1462, or email: [ethics@dal.ca](mailto:ethics@dal.ca)





## **Appendix D – Interview Guide – (Lived Experience - Mild Traumatic Brain Injury)**

[This is intended to be a guide, rather than a script. The interviewer will follow participants' lead, exploring these general topics but not always in this order. Ideally the participant's narrative will unfold with fewer questions rather than more.]

- Tell me a bit about yourself before your injury? (Probes: Type of work, social life involvement/activities, relationships (e.g. partner, family, friends), school, living condition, leisure (e.g. travel, sports, hobbies).
- Can you describe a typical day in your life, before your injury?
- Please describe the nature of your injury? What were the circumstances that led up to the injury? How did it happen? Ongoing symptoms?
- Please describe a typical day in your life, currently?
- I'm interested in how your life has changed since your head injury. (Probes: social, physical, vocational, leisure, financial, spiritual etc. Ask about before and after injury  
If need be, probe more specifically into:
  - Tell me about your current ability to take care of yourself and others (Probes: self-care, dressing, eating, grocery shopping, managing finances, caring for children and/or partners, friends, etc.).
  - Tell me about your current ability to participate in hobbies (fun) activities (Probes: sports, crafts, social involvement, spontaneous activities, changes in the things you do for fun or the ways in which you do them).
  - Tell me about your current ability to participate in paid work or volunteer. (Probes: full versus part-time status? Changes in job duties? Adjustments to workplace or duties? Relationships with boss and coworkers? Overall job performance and job satisfaction?).
  - Tell me about your current social relationships. (Probes: changes in relationship status, quality, types of relationships, type or frequency of participation, social isolation, spontaneity, desire to form new relationships, strain, and unhealthy relationships).
  - What ways do you cope with the symptoms associated with your head injury? (Probes: control over conditions, pacing, supports, substance use, other?).

## Interview Guide 2 – (Lived Experience - Mild Traumatic Brain Injury)

- Last time we met you told me about... [summarize highlights from interview 1]
- How would you describe the transition from your pre-accident to current life? (Probes: difficulties, changes, struggles, positive aspects, factors that contributed to the transition, etc.).
- In your opinion, do you experience any mental health issues since your accident? How is your overall psychological well-being? (Probes: anxiety, depression, grief, fear, loss of hope, denial, etc.).
- Tell me a bit about your perspective on hope and your future. Have you ever entertained suicidal thoughts? What brought on those thoughts? How did you cope/deal with them? Do you still think about this?
- In which ways do you feel that you have adapted to your current new life as a brain injury survivor? (Probes: types of activities that they do or engage in, compared with old activities? Positive aspects of occupational adjustments? Do their occupations affect who they are now and if so, how? How does who they are now, post-injury, affect their choice or engagement in occupations? What were the challenges to adapting? Fully adapted or still evolving?).
- Please describe any changes you've experienced in your identity since the accident/injury? (Probes: Identity as a mother, friend, wife, sister, co-worker, etc., factors which contributed to a new identity? Factors that have negatively impacted your identity? Is your current identity still changing?).
- Have there been times, since your accident/injury, that you have tried to hide the effects of your head injury or concealed the symptoms? (Probes: specific examples? Why? How did it make you feel? How did you cope with this or what did you do about it? Has it stopped or is it ongoing?). How has trying to hide the effects of your head injury changed your life or affected your identity? Have you ever felt you've had to convince people of your brain injury? (Probes: e.g. in interactions with the legal or medical systems, or with others in your life. Seek specific examples. How does that feel?).
- Some people with head injuries have reported experiencing positive changes within themselves and their lives post-accident/injury. Please describe any positive changes you've experienced in your life.
- Tell me a bit about how you've positively coped with life (and yourself) since your accident/injury. (Probes: reaching out to others, new social supports, hobbies, supportive factors, positive self-talk, sharing the common experience, etc.).
- Is there anything you'd like the public to know about the ongoing effects of head injury on people's lives? Is there anything else you'd like to tell me in relation to what we've been talking about?