

FACILITATORS AND BARRIERS TO POST-REHABILITATION EXERCISE FOLLOWING
MODERATE TO SEVERE TRAUMATIC BRAIN INJURY

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Abstract

Traumatic brain injury (TBI) is a major public health concern due to its growing incidence as well as the resulting physical, cognitive, social and emotional consequences. Exercise may promote the alleviation of TBI-related sequelae. However, there is a lack of information about the exercise experiences of individuals with TBI after rehabilitation. This Interpretive Phenomenological Analysis (IPA) explored the facilitators and barriers to exercise through the experiences of seven individuals with a severe TBI who live in the community. Semi-structured, in-depth interviews were conducted with participants to explore post-TBI exercise in the post-rehabilitation period. Interviews were audio-recorded and transcribed verbatim for the analysis. Four themes emerged. *Impact of TBI* addressed how physical and psychological impairments affected the participants' ability to participate in activities of daily living. *Personal development after TBI* highlighted greater awareness, emotional development and emphasized the importance of accepting disability-related impairments. *Facilitators and Barriers to Exercise* identified available time, planning, resources and transportation as well as weather conditions, organization, support and motivation. *Exercise after TBI* revealed exercise habits, productive activity and importance of exercise as well as physical, social and psychological effects of exercise.

Résumé

Le traumatisme crânio-cérébral (TCC) est une préoccupation majeure de santé publique en raison de son incidence croissante et de ses conséquences physiques, cognitives et émotionnelles.

L'exercice physique favorise la réduction des séquelles liées au TCC. Toutefois, il ya un manque d'information sur les expériences d'exercice des individus avec un TCC après la période de réadaptation. Cette analyse phénoménologique d'interprétation (API) a exploré les facteurs qui facilitent et empêchent l'exercice à travers les expériences de sept personnes avec un TCC sévère qui vivent dans la communauté. Des entrevues semi-structurées ont été menées avec les participants pour explorer en profondeur l'exercice post-TCC dans la période post-réadaptation. Les entrevues ont été enregistrées sur bande sonore et transcrites pour l'analyse. Quatre thèmes ont émergé. *L'impact d'un TCC* a montré que les déficiences physiques et psychologiques des participants nuisent à leur capacité à participer à des activités de la vie quotidienne. *Le développement personnel après un TCC* a démontré la sensibilité accrue, le développement affectif, et a souligné l'importance de l'acceptation des déficiences liées au handicap. *Des facteurs facilitant ou empêchant l'exercice* a identifié la disponibilité, la planification, les ressources et le transport ainsi que le temps, l'organisation, le support, et la motivation. *L'exercice après un TCC* a révélé les habitudes d'exercice, l'activité productive et l'importance de l'exercice ainsi que les effets physiques, sociaux et psychologiques de l'exercice.

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Introduction

Traumatic Brain Injury (TBI) is a type injury that is caused by an external trauma to the brain and may result in significant physical, psychological and social impairments for moderate to severe cases. TBI is a major problem due to the profound impact it has on an individual's health, social functioning and quality of life. It is suggested that exercise may promote the alleviation of TBI-related impairments. However, physical activity levels decrease after TBI. The rationale for this interpretive phenomenological analysis (IPA) study was to explore the facilitators and barriers to post-rehabilitation exercise after moderate to severe TBI. This document is a manuscript-based Master's thesis that conforms to McGill University's standards. There are two chapters included with this Master's thesis. The first chapter is a literature review that includes three sections. The first section is a broad review of the literature about the biological, psychological and social impact of TBI. The second section provides more details about exercise and physical activity (PA) interventions after TBI. The final section is a brief review about the origins of interpretive phenomenological analysis (IPA) and its use in health research. Chapter two is a manuscript about the current study which explored the lived experience of post-rehabilitation exercise for individuals with a moderate to severe TBI. The manuscript is divided into four sections. First, the reader is introduced to TBI and associated exercise research. Second, the qualitative methods used for the study including the design, participants, data collection and analysis are provided. Third, the results are presented through participants' quotes through the higher order themes that emerged from the analysis. Finally, a discussion is provided about the findings and their implications as well as the strengths, limitations and recommendations for future research.

Chapter I

Literature Review

The purpose of this interpretive phenomenological analysis (IPA) study was to explore the facilitators and barriers to post-rehabilitation exercise through the experiences of seven individuals with a moderate to severe TBI. The following comprehensive review of literature will provide background information about the short- and long-term problems associated with TBI, describe how exercise may be used to manage TBI-related challenges and present the interpretive phenomenological analysis (IPA) methodology that was used to answer the study's central research question. The first section will review the etiology and classifications of TBI as well as the resulting cognitive impairment, mental disorder(s), social functioning and outcomes associated with TBI. The second section will review research about the effects of exercise on cognitive function, physical fitness and mood after TBI. This information will also include research about health promotion for people with disabilities as well as health promotion and PA after TBI. Finally, the review will identify the historical origins of IPA and how this approach may contribute to health research through an exploration of injury and exercise experiences.

Traumatic Brain Injury (TBI)

Etiology. TBI is defined as an injury to the brain caused by the application of external forces to the skull which may lead to concussion, contusion, or diffuse injuries that result in neurological damage (World Health Organization [WHO], 2006). There are many ways to incur a TBI. For example, the acquisition of TBI may be related to transport, falls, being struck by/against something or assaults. However, there are two principal inner causes of incurring traumatic brain injury: contact to the skull or acceleration/deceleration of the brain within the skull (Silver, MacAllister, & Yudofsky, 2011). Brain lesions or subdural hematomas result from

the TBI. Immediately following impact, intracranial pressure (ICP) is commonly elevated due to swelling that occurs within the enclosed space of the skull. The pressure that builds within the skull can be hazardous and should be measured as soon as possible with a computerized tomography (CT) scan before choosing the appropriate course of action (Silver, et al., 2011). A craniotomy is a common and successful way of alleviating pressure (Silver, et al., 2011) where part of the skull is surgically removed for a period of time. The piece of skull is put back in place when the brain swelling subsides.

Classification of Traumatic Brain Injuries. There are varying outcomes related to TBI depending on the magnitude and location of injury. The severity of TBI is most often classified with the Glasgow Comma Scale (GCS), although less used methods include the Loss of Consciousness Scale (LOC) and the Post Traumatic Amnesia Scale (PTA; Silver, et al., 2011). The GCS scale measures the depth of coma following acute injury by observing eye opening as well as motor and verbal responses to stimuli (Silver, et al., 2011). The GCS is divided into three general categories: mild 13-15, moderate 9-12 and severe 1-8. The general consensus about the distribution of TBI severity in the United States of America for surviving TBI patients, admitted to hospitals, is 80% mild, 10% moderate and 10% severe (Silver, et al., 2011).

The classification of brain damage after trauma is generally associated with the type of injury. The signs and symptoms after TBI, of any severity, are related to both the focal or diffuse (multifocal) injury and its anatomical location (Silver, et al., 2011). For example, it is generally agreed that focal pathologies are typically the result of falls and contact whereas focal diffuse pathologies are typically associated with traffic accidents and acceleration/deceleration (Silver, et al., 2011). Similarly, TBI related impairments are often connected to the lobar, or regional,

area of the brain that is injured. However, the manifestations of TBI are by no means limited to these initial impairments as many persist with time.

The terms Mild TBI (mTBI) and concussion are often used interchangeably; however, concussion and mTBI technically refer to different constructs. According to the Fourth International Consensus Statement on Concussion in Sport, concussion is a subset of TBI and represents low-velocity injuries to the brain which result in clinical symptoms that may or may not be related to pathological injury (McCrory, et al., 2013). When individuals sustain a concussion, there is usually a rapid onset of short-lived impairments that reflect functional disturbances as opposed to structural injury and those impairments commonly follow a sequential course that is resolved within 7-10 days (McCrory, et al., 2005).

Symptoms after concussion may be clinical and include physical signs, cognitive impairments, neurobehavioral features or sleep disturbances. Symptoms that persist beyond 10 days occur with 10 to 15% of concussions (McCrory, et al., 2013). In contrast, mTBI is typically measured by a loss of consciousness (LOC) which does not persist beyond 30 minutes or post traumatic amnesia (PTA) which does not persist beyond 24 hours (Rabinowitz & Harvey, 2014). The relationship between TBI severity and cognitive sequelae is linear (Dikmen, Ross, Machamer, & Temkin, 1995); therefore, lower severity usually equates to less cognitive sequelae. In this case, cognitive impairments after mTBI are resolved in three to six months for 80 to 85% of cases (Belanger & Vanderploeg, 2005). There have been reports for cases that extend beyond this period but the research in this area is scarce. More importantly, up to 65% of moderate to severe cases of TBI result in long-term cognitive functioning problems (Whiteneck, Gerhart, & Cusick, 2004) which demonstrate, once again, more severe TBI is associated with greater cognitive impairment.

Cognitive Function after TBI

Post-acute impairment. Cognitive deficits are the direct result of TBI and they are most apparent immediately following the injury. The more commonly affected cognitive areas are information processing speed, attention, memory, and executive functioning (Skandsen, Finnanger, Andersson, Lydersen, Brunner, & Vik, 2010). A prospective follow-up study explored the magnitude and frequency of cognitive impairment at three and 12 months after a moderate to severe TBI for 61 individuals and found marked cognitive improvements in the first year of recovery (Skandsen et al., 2010). The assessments evaluated motor function, information processing, attention and vigilance, visual learning and memory, verbal learning and memory, working memory and executive functions.

Neuropsychological assessments were done at 3 months and the Glasgow Outcome Scale Extended (GOSE; Wilson, Pettigrew, & Teasdale, 1998) was used at 3 months and 1 year after injury. The GOSE evaluated disability, activity participation and symptoms after TBI with scores between 0-2 (mild), 3-4 (moderate) and 5-6 (severe). According to the results, all patients with moderate to severe TBI performed worse in information processing speed and verbal memory when compared with healthy controls (Skandsen, et al., 2010). One year post injury, disability in global cognitive functioning was present in 57% of people with a 2 or more impaired scores (i.e. moderate-severe) on the GOSE at 3 months and in 21% of those participants with a 0 or 1 impaired score (i.e. mild) at 3 months (Skandsen, et al., 2010). Therefore, even though half of the participants with moderate TBI and one third of the participants with severe TBI were functioning at the normal cognitive range three months after injury, it was concluded that patients with TBI performed worse than controls on the cognitive measures. These impairments were also associated with subjective complaints and future disability according to the GOSE

(Skandsen, et al., 2010). The findings suggest that although cognitive impairment improves in the first year of recovery after TBI, cognitive impairment may still be associated with future disability.

Long-term impairment. Studies do not always provide a clear description of the time course for cognitive recovery after TBI. However, Novack, Alderson, Bush, Meythaler and Canupp (2000) prospectively followed 72 individuals from 6-12 months after mild to severe TBI and found that similar rates of recovery were present across TBI severity levels. Recovery was measured with the Glasgow Outcome Scale (Jennett, Snoek, & Bond, 1981), which is now replaced by the GOSE. Results showed increases in cognitive abilities from 6-12 months and most significantly with memory (Novack, et al., 2000). Overall, participants with less severe TBI levels performed better than individuals with more severe cases as observed with modest gains in speed of response, language skills and constructional abilities (Novack, et al., 2000). Interestingly, both groups improved at similar rates, even if they did not improve by the same amount. However, the authors noted that individuals with severe TBIs were still functioning in the impaired range in cognitive tasks after 12 months (Novack, et al., 2000) which demonstrates, once again, that cognitive impairments may persist beyond one year after TBI.

More recently, Dikmen et al. (2009) examined the relationships between cognitive impairments and brain injury for six months or more after adult-onset injury with a systematic review of the literature. The authors retained 11 primary and 22 secondary, peer-reviewed studies that employed comparison groups with performance-based, neuropsychological measures for a broad range of TBI. According to their findings, there was an association between lasting cognitive impairments and penetrating brain injuries (Dikmen, et al., 2009). However, penetrating head injuries were more conducive to war zones and closed head injuries were more

commonly experienced in civilian populations. In contrast, the authors found that long-term cognitive impairments were not associated with mild TBI, although it was emphasized that repeated mild head injuries were shown to have an accumulated effect that may impair long-term cognitive outcomes (Dikmen, et al., 2009). Finally, the authors asserted that outcome studies about moderate to severe TBI consistently found significant, long-term cognitive deficits related to attention, memory, processing speed and executive functions (Dikmen, et al., 2009). Therefore, based on these findings, as well as the aforementioned studies, cognitive impairment may be a persistent difficulty after TBI that is more present for moderate and severe cases.

Mental Health after TBI

Major depressive disorder. Depression is one of the leading psychiatric difficulties after TBI, despite the severity of injury. Kreutzer, Seel and Gourley (2001) comprehensively examined the rates and symptoms of depression for 722 individuals with TBI who were referred to a comprehensive outpatient assessment centre. The participants had a broad range of TBI severities and were assessed an average of 2.5 years after injury. The participants' symptoms of major depression were measured according to the *Diagnostic Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; American Psychiatric Association, 1994). According to these findings, major depressive disorder was present in 42% of the cases, associated with poor psychosocial functioning, reduced quality of life and health related impairment as well as decreased employment, community engagement and motivation to participate in rehabilitation (Kreutzer, et al., 2001). Therefore, it was hypothesized that individuals with TBI may subsequently experience higher rates of depression due to difficulties originating from their injury. As such, the possible relationship between depression and TBI-related sequelae warranted further investigation.

Various patterns of depression may occur after TBI and psychosocial functioning appears to vary according to these patterns. Hibbard, et al. (2004) conducted a five-year longitudinal cohort study that included 188 adults with a broad range of TBI severity levels. Major depression and the most severe kind of depressive symptoms were examined in this study and according to the *Diagnostic Statistical Manual of Mental Disorders* (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000). Two assessments were carried out, one year apart, for each participant. Both assessments included (a) clinical interviews to evaluate depression and (b) self-reports of depression severity, functional symptoms and quality of life.

Four subgroups were created to analyze the results: no depression, resolved depression, late-onset depression, and chronic depression. According to the findings, the no depression group reported “fewer levels of depressive symptoms and higher levels of psychosocial functioning,” while the chronic group “reported the poorest psychosocial functioning and further decline in quality of life” (Hibbard, et al., 2004, p. 43). The resolved depression and late-onset depression groups reported similar functioning in the first assessment; although, depression improved for the resolved-group and declined for the late-onset group at the second assessment (Hibbard, et al., 2004). Importantly, these results demonstrated that individuals with TBI experienced varying degrees of depression and at varying times which highlights the risk of depression at a later stage in the TBI recovery process. Hibbard et al. (2004) suggested that continued assessments for depression after TBI may help treat long-term comorbidity.

More recently, Pagulayan, Hoffman, Temkin, Machamer and Dikmen (2008) conducted a longitudinal cohort study that measured the temporal relationship between functional limitations and depression after TBI. In this study, adolescents and adults with a broad severity of TBI levels were evaluated at one month, six months and 12 months after injury. The main measures for the

study included the Sickness Impact Profile (Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976) that measured health related quality of life and the Center for Epidemiology Studies – Depression Scale (Radloff, 1977) that measured depressive symptoms. The results showed that 44% of the participants reported clinically significant depressive symptomatology one month after TBI and this result declined to 29% by one year after TBI (Pagulayan, et al., 2008). Interestingly, individuals with higher levels of depression consistently reported more difficulties related to their injury. The analysis also demonstrated “a stronger relationship between early level of injury-related impairment and later depressive symptomatology than the reverse temporal relationship” (Pagulayan, et al., 2008, p. 1890). These findings suggest that depression may indeed be the result of TBI-related impairment because changes in daily functioning that resulted from the injury appeared to influence emotional well-being over time.

Psychiatric disorders. Diaz, et al. (2012) conducted a prospective study that followed and evaluated 33 participants for 18 months after hospitalization for severe TBI. Demographic and clinical characteristics as well as psychiatric manifestations and health related quality of life (HRQOL) were evaluated. The *DSM-IV-TR* was used as the criterion for personality change along with Brazilian versions of the *Hospitalization Anxiety and Depression Scale* (HADS; Snaith & Zigmund, 1986) for other psychiatric symptoms and the *Medical Outcomes Study 36-Item Short Form Health Survey* (SF-36; McHorney, Ware, & Raczek, 1993) for HRQOL. According to the results, there was an increase in the rate of major depressive disorder (MDD) as well as personality changes and both were associated with impairment in HRQOL (Diaz et al., 2012). Additionally, it was suggested that a cyclical relationship may exist between trauma-related factors, psychiatric conditions and HRQOL as evidenced by the range of psychiatric symptoms which affected HRQOL for participants in the study (Diaz, et al., 2012). Therefore,

similar to the temporal relationship between TBI-related impairments and depression, it is possible that depression may subsequently affect HRQOL.

Depression and anxiety are long-term psychiatric problems after TBI that may persist, especially for more severe cases. Hoofien, Gilboa, Vakil and Donovan (2001) conducted a seminal research project that measured psychosocial outcomes 10-20 years after severe TBI. This study contributed to the literature by providing a long-term perspective of common psychiatric manifestations that occur after brain injury. The study examined major domains of functioning as well as mental functions for an average of 14.1 years after injury. There were measures for psychiatric symptomatology and cognitive ability as well as vocational status, social functioning and independence in daily routines for 76 individuals with severe TBI (Hoofien, et al., 2001). Each participant underwent a series of four psychological assessments. The main measures for psychiatric symptoms examined the clinical severity of the symptoms and according to the *Diagnostic Statistical Manual for Mental Disorders* (3rd ed.; *DSM-III*; American Psychiatric Association, 1980). The authors identified severe long-term problems with depression, anxiety and hostility, along with similar levels of obsessive-compulsive disorder as well as post-traumatic stress syndrome amongst the 76 participants (Hoofien, et al., 2001). In this case, the long-term disability following severe TBI was related to psychiatric and behavioural symptoms as opposed to cognitive impairment. These findings had tremendous implications about the persistent nature of TBI related disabilities as well as the type of impairments which require attention many years after the injury occurs.

Social Functioning after TBI

The resulting psychological difficulty associated with TBI has major social ramifications. For example, social areas that may be affected include functional status, employment, academics,

independent living, social relationships, as well as leisure and recreational activities. Temkin, Corrigan, Dikmen and Machamer (2009) detailed relationships between injury severity and reported social dysfunction after TBI in a systematic review of 14 primary and 25 secondary peer-reviewed studies. According to their findings, most patients with TBI do not return to independent living and commonly live with family members after their injury. In addition, there was also evidence for a significant reduction in the number of friends as well as a disruption in vocational, leisure and recreational activities (Temkin, et al., 2009). The authors concluded that TBI involves long-term consequences in functional status, independence, as well as the resumption of social roles and this last factor was more severe in terms of poor outcome (Temkin, et al., 2009).

Fatigue. Despite rehabilitative efforts, fatigue is one of the lasting physical difficulties after TBI that persistently surfaces in the literature and is related to social functioning. Juengst, Skidmore, Arenth, Niyonkuru, and Raina (2013) examined the unique contribution of fatigue to disability in adults with TBI who lived in their home community. The main measures included the Mayo-Portland Adaptability Inventory (MPAI; Malec, et al. 2003) for disability and the Modified Fatigue Impact Scale (MFIS; Fisk, et al., 1994). According to the results, 50-80% of individuals with TBI experienced significant fatigue that contributed to disability (Juengst, et al., 2013). As evidenced by their findings, fatigue may persist chronically after TBI and result in secondary disabilities related to social, physical and cognitive functioning. For example, fatigue was found to be the most significant and independent predictor of disability even when controlling for injury severity, executive function and depression status (Juengst, et al., 2013). Interestingly, increased fatigue was directly related to increased impairment in executive functions that, unsurprisingly, identified a connection between fatigue and cognitive impairment

as well (Juengst, et al., 2013). The findings make it clear that fatigue is a significant problem after TBI that should be considered separately and be linked to other TBI related sequelae to promote the best form of treatment.

Impaired self-awareness (ISA). ISA is a common difficulty which may amplify social problems after TBI. In the case of head injury, damage to the frontal lobes may affect an individual's ability to plan, coordinate and monitor behaviour and it is widely acknowledged that ISA is related to the integrity of the frontal lobes (FitzGerald, Carlton, O'Keeffe, Coen, & Dockree, 2012). ISA can potentially be problematic after TBI as it may negatively impact an individual's participation with treatment and rehabilitation after injury. Therefore, addressing individual ISA issues in the recovery process may help clinicians treat other TBI-related problems.

One longitudinal study investigated the effects of awareness after TBI. The study included 120 adolescents and adults with mild to severe TBI who were evaluated at one month and 12 months post injury. In order to identify awareness problems, ratings were compared between TBI patients and their significant others/clinicians. According to the results, there were relatively good rating agreements about the extent of injury related difficulties. However, there was also a large amount of participants who were hyperaware of their difficulties (Pagulayan, Temkin, Machamer, & Dikmen, 2007). As such, the authors concluded that greater awareness problems may be seen with more severe TBIs but a lack of awareness should not be generalized to milder TBI severity levels (Pagulayan, et al., 2007). However, based on the broad range of scores, the study also highlighted the inherent difficulty with measuring self-awareness after TBI.

Social support. Individuals with TBI require social support after their injury in addition to the care they receive in a clinical setting. For example, support may come from caregivers and family who provide assistance during the rehabilitation process. Therefore, Vangel, Rappaport and Hanks (2011) sought to measure the predictive value of caregivers in contrast to the well-being of people with TBI in order to examine the effect of perceived social support on the individual. The study included 109 pairs of adults and measured psychosocial functioning that included TBI-related symptoms, satisfaction with life, disability, social provision, family assessment and neuropsychological functioning.

According to the findings, life satisfaction predicted emotional distress for the individual with a TBI and life satisfaction was strongly associated with a caregiver's perceived level of support (Vangel, et al., 2011). Interestingly, the authors identified a general pattern where social support, perceived by the caregiver, moderated the adverse effects of TBI on the well-being of the individual (Vangel, et al., 2011). In addition, it was found that the well-being of caregivers has a reciprocal effect on the individuals with TBI whom they cared for (Vangel, et al., 2011). This study demonstrated that caregivers have a direct impact on the well being of people who experienced a TBI which, in turn, implies that caregivers play a fundamental role in promoting health and quality of life after injury.

Quality of life. One common method of assessing outcome after TBI is to examine quality of life (QOL) and related domains to determine an objective description of what it may be like to live with a TBI. QOL is related to subjective well-being, shared characteristics about what people consider essential to a good life, and health status (Dijkers, 2004). Areas that may affect QOL are employment, leisure activity and interpersonal relationships. Dijkers (2004) conducted an extensive review about the QOL after TBI and assessed the existing knowledge in

this area at that time. The selection criteria for the review included published articles about QOL indicators that focussed on TBI versus non-TBI differences.

Employment, for example, is related to QOL. According to the Dijkers (2004) review, people with moderate to severe TBI lost their employment and had difficulty regaining it despite rehabilitative efforts. Loss of employment is related to a reduction in financial income that, in turn, may subsequently affect QOL. Interpersonal relationships change after TBI as well. For example, TBI commonly results in divorce and/or the loss of intimate and supportive relationships (Dijkers, 2004). As a result, family and caregivers typically assume these interpersonal roles may lead to added amounts of stress. In addition, poor self-control and interpersonal skills typically result in the loss of friendships with difficulty forming new ones for people with moderate to severe TBI (Dijkers, 2004). Similarly, individuals with moderate to severe TBI participate in fewer leisure activities and more unproductive activities (Dijkers, 2004). Therefore, based on the loss of employment, decreasing interpersonal and social relationships as well as a reduction in leisure activities, the findings emphasize a similar trend of poor social outcomes after TBI that is further accentuated by an increased severity of injury.

Recovery after TBI

Post-acute recovery. Persistent cognitive, psychological and behavioural difficulties after TBI highlight the importance of treatment during the post-acute phase of recovery. Therefore, the exploration of factors that may improve outcome after TBI warranted investigation. Andelic, et al. (2010) examined disability-related impairments in a cohort study of 85 participants with moderate to severe TBI who were between 16-55 years of age. The International Classification of Functioning, Disability and Health (ICF) model, developed by the WHO, was used to gauge the outcome measures for the TBI sample, one year after injury

(Bilbao, et al., 2003). The ICF measure endorsed a bio-psycho-socio approach and the authors were, therefore, able to quantify a broad spectrum of global recovery after TBI. In addition, the measures for structural brain damage, injury severity, functional activity limitations, community participation restrictions, rehabilitation support and medical health had been validated for use with the TBI population (Andelic, et al., 2010). As such, the study provided an accurate description of the range of associated difficulties after TBI.

According to the results, a significant number of the 85 patients still faced substantial disability and health-related impairments at one year follow-up (Andelic et al., 2010). These findings were considered generalizable to larger populations based on the demographics and injury characteristics of the participants included in the sample. According to the statistical predictor models used in this study, high levels of activity and participation strongly predicted better overall health one year after TBI (Andelic, et al., 2010). Therefore, the connection between activity participation and health after TBI highlights that interventions, geared toward promoting higher levels activity post injury, may be an efficient way to promote improved health after injury. This contention is supported by literature that demonstrated meaningful activity after TBI is the greatest predictor for improving quality of life (Andelic, et al., 2010). Therefore, it is clear that interventions which target activity participation and mood may improve QOL after TBI.

The Andelic (2010) study demonstrated that TBI patients were not independent in cognitive activity one year after injury despite being highly independent in PA. This finding is in contrast with earlier study findings about cognitive improvement within the first year of recovery after TBI. It is worth noting that, despite the prevalence of psychiatric conditions after TBI, these problems were not being addressed in post-acute care. For example, one third of the 66% of

patients who reported poor mental health were not being treated for these problems at one-year follow-up (Andelic, et al., 2010). In addition, 50% of the patients with severe TBI were not considered to be productive and only 25% were working full-time at one-year follow-up (Andelic, et al., 2010). As such, the findings suggest that long-term interventions are needed after TBI and especially for more severe cases.

Long-Term Recovery. It is relevant to assess the long-term outcome after TBI in order to identify the best possible methods of treatment. One method of measuring long-term outcome is to examine morbidity (i.e., incidence of disease) and mortality (i.e., death) after injury. A Canadian study provided an excellent depiction of the long-term health service use (HSU) and mortality after TBI by conducting a population-based matched cohort design that measured death rate, hospitalizations, length of stay in hospital as well as physician claims after injury (Cameron, Purdie, Kliewer, & McClure, 2008). The participants in the study were between the ages of 18 and 64 years. They all resided in the province of Manitoba and the information was gathered from administrative health data. In total, 1290 hospitalised cases with TBI were matched with 1290 non-injured comparison controls who were followed for 10 years after the TBI.

The data collected for this study was adjusted for age, gender, injury severity and pre-injury health status. The results clearly demonstrated that people, who survived TBI, experienced increased long-term morbidity when compared to the general population despite the level of injury severity (Cameron, et al., 2008). For example, individuals were more likely to be readmitted to a hospital or to have sought out a physician due to mental health conditions after the TBI (Cameron, et al., 2008). The greatest rate of mortality was found in the first 60 days after TBI. However, when the first 60 days were excluded from the analysis, it appeared that although mortality rates were higher for the TBI group, they were not significantly different from the non-

injured cohort for any individual time period (Cameron, et al., 2008). Perhaps the most important finding was the greater amounts of health services required after TBI. For example, “people with TBI had higher rates of HSU in almost every year of the post-injury study period than members of the non-injured cohort” (Cameron, et al., 2008, p. 442). Therefore, as one of the first population-based cohorts of this kind, it was apparent that for individuals who have had a TBI and survived the acute recovery, there is a pressing need to develop long-term, health promoting interventions to reduce the increased rates of mental health conditions and of HSU after injury.

Exercise and Cognitive Function after TBI

Animal studies. Recent study findings described the positive effect that exercise may have on neural plasticity and neuro-protection after TBI (Griesbach, 2011). In fact, exercise has been linked to the improvements of TBI-related deficits by increasing neuroplasticity (i.e. ability to adapt to environmental changes) as well as having an anti-apoptotic effect (i.e. preventing programmed cell death) to the brain (Archer, 2012). The majority of research that examined how exercise specifically impacted the brain was done through animal experimentation as it would not be deemed ethical to conduct such invasive research on human beings. Here, the key element found to help recover brain functions in rats is brain derived neurotrophic factor (BDNF), a protein that is involved with synaptic function (Griesbach, 2011). Therefore, the investigation of methods to increase BDNF after TBI was justified to help improve cognitive sequelae.

In 2004, Griesbach, Havda, Molteni, Wu and Gomez-Pinilla evaluated the effects of acute and delayed exercise after TBI and determined a specific time window for improvement. In this case, the effects of voluntary exercise on spatial learning and memory were evaluated with 161 male Sprague-Dawley adult rats that were subjected to a fluid percussion TBI, voluntary wheel exercise and water-maze training. According to the results, voluntary exercise

following TBI, led to the upregulation of BDNF and associated proteins (Griesbach, et al., 2004). However, given the restorative processes in the brain directly after injury, when exercise was administered too soon, a molecular response to the exercise was disrupted and recovery may have been delayed (Griesbach, et al., 2004). As such, there is a critical time window for exercise to be positive after TBI which, in turn, has major implications for its use as a method of treatment.

The results of the 2004 study showed that premature exercise after TBI was associated with impairment in cognitive tasks. However, after a 14-20 day delay, exercise provided an upregulation of BDNF and enhanced performance on cognitive tasks for the male, Sprague-Dawley rats that were tested (Griesbach, et al., 2004). It was, therefore, concluded that in order for exercise to have a positive effect, the brain must be capable of increasing BDNF and associated proteins in response to activations involved with exercise that may require a period of approximately 10 days for the Sprague-Dawley rats (Griesbach, et al., 2004).

Griesbach (2011) suggested that specifically tailored and timely exercise programs are required to produce favourable results on the brain after TBI. There are general guidelines about returning to activity after brain injury; however, existing knowledge about exercise prescription after TBI is scarce (Griesbach, 2011). Timelines may be determined for animal models, as seen with the Griesbach study (2004), but these were not human cases. Therefore, future clinical studies could potentially explore measurable ways of achieving exercise-induced benefits to the human brain after TBI. Griesbach (2011) asserted that more studies about exercise and brain injury would contribute enormously to the body of knowledge about the use of exercise as a therapeutic tool for TBI-related impairments. Animal studies demonstrate that exercise may

benefit cognitive recovery in the brain after TBI; however, there are less conclusive findings about the cognitive benefits of exercise after TBI in humans.

Human studies. Exercise is typically part of the rehabilitation process after brain injury and 15 years ago; Grealy, Johnson, and Rushton (1999) examined the specific effect exercise had on cognitive functions after TBI. They measured reaction time (RT) and movement time (MT) before and after bouts of exercise using virtual reality (VR) for 13 individuals with TBI who were compared with a control TBI population group. The premise for investigating the VR exercise was based on developing environments that engaged individuals in more stimulating situations while exercising, hence to work the brain while training the rest of the body.

More specifically, the experiment consisted of a 4 week intervention followed by a random allocation crossover trial which measured RT and MT after a single session of VR exercise (Grealy, et al., 1999). The functions measured included attention, information processing, learning and memory. These measures were then matched with a control group that had similar age, injury severity, and time since the injury. The volunteers exercised for 25 minutes, three times a week, on a VR exercise bicycle, with the screen mounted at eye level in front of the device. The resistance and degree of incline corresponded to the visual stimulation program running on the screen. After the treatment, Grealy et al. (1999) found significant improvements in auditory and visual learning as well as the digit symbol test.

The second trial of the study consisted of performing a single session of VR exercise on the same bicycle while RT and MT were measured (Grealy, et al., 1999). According to the results, the mean scores for RT and MT decreased significantly and these results were not matched by the control group (Grealy, et al., 1999). Additionally, the fastest response for RT, following a single exercise session, increased significantly which suggested “that a single bout of

exercise improves consistency and concentration rather than speed of information processing or attentional processes” (Greal, et al., 1999, p. 665). According to these findings, exercise interventions could indeed help with cognitive recovery after TBI. However, more current studies about exercise and cognitive function following TBI are required.

Exercise and Physical Fitness after TBI

Aerobic exercise. Neurological damage to the brain after TBI is often associated with secondary problems such as altered muscle function and reduced aerobic capacity (Bateman et al., 2001). In addition, bed rest and limited mobility directly following a TBI may lead to a detraining effect that negatively influences an individual’s ability to participate in functional tasks and rehabilitation. Therefore, a study hypothesized that aerobic exercise, a viable means of improving cardiorespiratory fitness for health benefits, may improve problems related to functional and psychological status after TBI. Thus, Bateman et al. 2001 developed a randomized control trial (RCT) to measure the effect of aerobic exercise following TBI for 157 participants who were randomly allocated to either heart rate monitored ergometer training or a control treatment of relaxation training for 3 months. The researchers conducted blind assessments of each group before and after the 12-week exercise intervention and 12 week post training period.

According to the results, the significant improvements in exercise capacity did not extend to measurable changes in functioning status, nor did they extend to measurable changes in psychological state (Bateman, et al., 2001). More specifically, the experiment group showed greater improvement than the control group in peak work rate from baseline but they did not differ in the degree of change for functional independence or psychological measures. Mobility, functional independence and impairment improved at an equal rate in both groups which implied

that improvements were the result of time and not the specific exercise treatment (Bateman, et al., 2001). However, despite the fact that aerobic exercise did not extend to functional and psychological measures in this study, it is important to point out that the participants had varying degrees of TBI. Therefore, it is plausible that the lack of homogeneity led to the mixed results. In other words, if all the participants had a severe TBI, the gains in exercise capacity may have extended to functional capacities as well.

Circuit training. Different modalities of fitness training have been examined with the TBI population. For example, one method was circuit training that involved aerobic, strength and endurance exercises that were combined in one workout session. Bhambhani, Rowland and Farag (2005) examined the effects of circuit training on body composition and peak cardiorespiratory fitness for individuals with a moderate to severe TBI. For the purposes of this study, 26 participants who were recruited from an in-patient brain injury rehabilitation program at a community hospital took part in a 12 week circuit training intervention. According to the results, there were no significant changes in body mass during the study, despite significant increases in peak values for power output, oxygen uptake and ventilation rate. However, it is important to note that caloric intake (i.e., eating habits) was not measured or controlled during this study. Therefore, the result that some participants increased their body mass index (BMI) may have been the direct result of a positive caloric balance. Despite the BMI results, the increases in power output without concomitant increases in heart rate implied an improvement in cardiorespiratory fitness. Interestingly, cardiorespiratory responses only became apparent after completion of the third and final phase of the intervention (e.g., 32 training sessions) and not the case after phase two (e.g., 18 sessions). Therefore, Bhambhani, et al. (2005) suggested that individuals with TBI may require longer periods of training for health-related benefits.

Aerobic capacity. TBI is often associated with inactivity which may have a detrimental effect on the body as people with TBI have reported low tolerance for PA and increased levels of fatigue (Mossberg, Ayala, Baker, Heard, & Masel, 2007). Therefore, improvement in aerobic capacity after TBI was examined to determine its relationship with TBI-related impairments and productivity. Mossberg et al. (2007) performed a descriptive comparative study of peak and sub-maximal physiological responses to a graded maximal treadmill test for 13 individuals with TBI (11 severe, 1 moderate, and 1 mild) who were recruited from a post acute treatment centre. The study compared the aerobic capacity between people recovering from TBI and otherwise healthy, sedentary, age and sex matched controls. This study included measures for heart rate, minute ventilation, oxygen consumption, carbon dioxide production and respiratory exchange ratio. The results indicated that the TBI group, who had a TBI an average of 10.4 months prior to the study, had limitations in cardiovascular and pulmonary endurance activities. For example, the comparison group attained 90% of their age-predicted maximal heart rate while only 8 of the 13 individuals from the TBI group could achieve the same level. Hence, a clear indication of limitations was imposed by TBI. Mossberg et al. (2007) speculated that TBI-related activity limitations may have been the cause for reduced fitness gains.

Based on the results, aerobic fitness was compromised for individuals recovering from TBI as evidenced by the participants who were significantly less physically conditioned than the otherwise healthy, sedentary, age and sex matched controls (Mossberg, et al., 2007). As such, the authors suggested that aerobic training be an essential part of rehabilitation programs in order to increase tolerance for work-related tasks. They added that endurance training could be a method used to help social reintegration as well. Therefore, investigations that measure different methods

of improving physical fitness after TBI are warranted to help resolve poor aerobic fitness levels as well as to promote improved functionality and social interaction.

Endurance training. Mossberg, Amonette and Masel (2010) recognized the importance of endurance training after TBI as well as the need for long-term and follow-up studies about cardiorespiratory programs after injury. Therefore, an extensive literature review about endurance training and cardiorespiratory conditioning after TBI was conducted. The authors explained that aerobic capacity is a common measurement to assess overall physical fitness and this factor may be improved through cardiorespiratory training for the general population as well as people who live with disabilities (e.g., TBI). It was further explained that, based on their earlier findings, individuals with TBI reported rates of peak aerobic capacity between 65-75% of the general population (Mossberg et al., 2007). This reduced aerobic capacity supported the purpose of reviewing the exercise and TBI literature in order to assess the importance of endurance training programs with the TBI population.

According to the findings, Mossberg et al. (2010) explained that very few studies investigated the long-term effects of endurance training after TBI, despite the fact that significant improvements were possible with aerobic capacity and cardiorespiratory fitness. The authors emphasized that the relationship between fitness improvements and functional gains was not well established due to a lack of studies in this area which, in turn, established a need for more investigations in this area. The authors also stated that although some individuals do not have physical impairments after TBI, the cognitive, behavioural and executive impairments related to the TBI may create a number of barriers to exercise participation. Therefore, the need for an investigation of barriers to exercise for the TBI population was established as well.

Exercise and Mood after TBI

Aquatics program. Driver and Ede (2009) investigated the effects that an aquatic PA program on the mood of 16 community dwelling adults, who were between 33-45 years and had a TBI at least one year prior to the intervention. The PA program spanned for 8 weeks and consisted of three, one-hour sessions per week for a total of 24 sessions. Each session included aerobic exercise as well as resistance training in the water. The participants' heart rates were controlled between 50-70% of their maximal value. In addition, a control group participated in return to work activities as part of the rehabilitation program and for the same amount of time as the aquatics sessions. The main measure was the Profile of Mood States (POMS; McNair & Droppleman, 1971) that measured six dimensions of overall mood for the participants with TBI.

According to the POMS results between the groups, there were significant differences and a large effect size for improving tension, depression, anger, vigour, fatigue and confusion in the experimental group (Driver & Ede, 2009). Therefore, the authors concluded that participation in a PA program may significantly increase positive mood states for individuals with TBI (Driver & Ede, 2009). Here, it is important to note that despite the small sample size of the study, the positive findings promoted alternative PA methods to improve mood for individuals who live with TBI as evidenced by the success of the aquatics program.

Aerobic exercise. One RCT aimed to determine how structured aerobic exercise could decrease depressive symptoms for people with TBI (Hoffman, et al., 2010). For the purposes of the study, 40 participants were recruited from the community. The experimental group participated in supervised exercise sessions that targeted 60% of individual maximal heart rates in order to obtain aerobic improvements. The participants were supervised for one aerobic training session per week. They were asked to complete additional aerobic exercise for 30

minutes, four times per week by researcher telephone follow-ups to support exercise maintenance. The main measure for this study was the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961).

According to the results, no significant differences were found for BDI scores between the experiment and control group (Hoffman, et al., 2010). However, the authors hypothesized that other factors may have led to the insignificant results because they found that mood was significantly higher for participants who exercised for more than 90 minutes per week. Therefore, it was possible that the full extent of exercise-related benefits on mood after TBI were not fully explored which should lead to further investigations of these phenomena.

Exercise maintenance. Wise, Hoffman, Powell, Bombardier, and Bell (2012) conducted a follow-up study to measure the effects of an exercise intervention on exercise maintenance, depression, QOL and mental health for individuals with TBI. The researchers followed a treatment group of 40 individuals, who completed an original 10-week aerobic exercise intervention, to measure how a focus on community-based exercise and education would extend to a real world setting. According to the results, there was an increase in exercise per week after the intervention for some of the study participants but others participants were unable to maintain the same amounts of exercise at the 6-month follow-up. More specifically, 48% of the participants achieved and maintained the increased PA for six months after the intervention. In addition, and similar to the results from the previous 2010 study, individuals who maintained more than 90 minutes of exercise per week (higher activity group) had lower BDI scores at 10 weeks and 6 months. Given the encouraging results from the 6-month assessment, it is apparent that continued exercise may contribute to the improvement of mood and quality of life after TBI.

Wise et al. (2012) also speculated that increased exercise intensities may be needed to provide significant improvement in depression after TBI due to the fact that higher doses of exercise intensity led to more favourable results. However, due to the study's limitations, the researchers were not able to determine whether or not exercise led to the improvement in mood and QOL or whether an improvement in mood and QOL led to more exercise. These results are valuable because they supported the use of exercise as an effective treatment for post-TBI depression.

Feasibility and efficacy. Shwandt et al. (2012) examined whether aerobic exercise was feasible and may improve symptoms associated with depression for individuals with moderate to severe TBI who lived in the community. In this pilot study, four participants met with a physical therapist on three separate occasions each week for a 12-week period in order to participate in 30 minutes of aerobic exercise on a cycle ergometer at 60 to 70% of their age-predicted maximum heart rate level. The main measures were the Hamilton Rating Scale for Depression (HAM-D; Hamilton, 1960) and the Rosenberg Self-Esteem Scale (Rosenberg, 1965). According to the results, there were consistent decreases in depressive symptoms found with time as well as improvement in self-reported self-esteem (Shwandt, et al., 2012). In addition, it is worth noting that the study participants were in the chronic phases (i.e., more than six months after the injury) of TBI recovery which implies that positive benefits associated with post-TBI exercise may not be not limited to acute phases after injury. Despite the small scale of the study, these findings uniquely contributed to the literature about the feasibility of exercise and the related benefits for individuals with moderate to severe TBI. More research is required with larger studies to support these conclusions.

Treatment preference. Fann et al. (2009) explored depression treatment options for people with TBI and found very encouraging results because matching patient preferences to treatment methods may potentially improve outcomes. One hundred and forty-five participants completed a telephone survey in which depression status was determined through the Patient Health Questionnaire-9 that had been previously validated for this population (Fann, et al., 2005). The sample consisted of individuals with complicated mild to severe TBI who were assessed for depression every month for a six month period and then at 8, 10 and 12 months after their injury. According to results, “43.2% of the participants chose physical exercise, 15.8% favored alternative herbal medicine, 15.1% selected counselling or psychotherapy, 9.4% chose anti-depressants, 8.6% chose group therapy or support groups and 7.2% chose self-help materials” (Fann et al., 2009, p. 275). The authors explained that even though exercise is not typically considered a first line choice for depression treatment after TBI, it had been effective in treating depression in older and sedentary people as an adjunct to pharmacological and therapeutic treatment (Fann, et al., 2009). Therefore, according to the aforementioned studies, exercise may be an effective and feasible method of improving mood and depressive symptoms after TBI as well as being the preferred method of treatment. In addition, individuals with disabilities (i.e., TBI) may be at a greater risk to develop other secondary health conditions.

Health Promotion (HP) after TBI

Secondary health conditions. The concept of reducing secondary health conditions for people with disabilities was gradually introduced in the late 1990’s. Rimmer (1999) described secondary conditions as health problems that may directly, or indirectly, relate to a primary disability. He explained that secondary health conditions may refer to obesity, hypertension, depression, osteoporosis, reduced functional capacities, leisure activities and overall quality of

life. As such, health promotion for people with disabilities was proposed as one method to prevent secondary health conditions. Rimmer also suggested that more emphasis was needed on community-based health promotion initiatives in order to achieve this objective.

Rimmer (1999) suggested that fitness centres could potentially become the logical extension of rehabilitation. For example, fitness centres could offer an environment that provides individuals who live with disabilities (e.g., TBI) with access to health promotion activities. In Rimmer's (1999) conceptual model, physical therapy progresses toward general fitness through three different phases: rehabilitation, clinically supervised health promotion and community-based health promotion. However, for this model to be successful, there were three essential factors: (a) fitness professionals had to increase their health promotion skills for populations with disabilities, (b) rehabilitation professionals had to embrace the extension of services in the community and (c) government or insurance companies had to provide the necessary funding to support this venture. In this way, community-based health promotion programs for people with disabilities could support the necessary behaviours required to improve lifestyle habits and potentially reduce secondary health conditions.

Accessible environments. Health disparities between the general population and people who live with disabilities are not just related to disability but rather accessibility to community programs and services (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Accessibility was the incentive to develop new programs that were sensitive to individuals with disabilities and their environments. Therefore, Rimmer, et al. (2004) examined PA for people living with a disability in order to consider the barriers and facilitators to participating in a fitness and recreation program. The study conducted focus groups with four different types of participants: individuals with disabilities, architects, fitness and recreation professionals, city planners and

district park managers across the United States. Rimmer et al. (2004) hypothesized that health promotion for individuals with disabilities could be improved with knowledge about facilitators and barriers to PA in the community.

According to the results, all the groups agreed that making fitness environments more accessible would benefit populations with disabilities. Thus, the authors suggested that accessibility was a major factor when building fitness facilities (Rimmer, et al., 2004). The community also identified a lack of information about available facilities and a lack of professional knowledge about people with disabilities to highlight a need for additional resources and specialised professional training. Interestingly, the most frequent emotional and psychological barriers for participants were feeling that environments were unfriendly and being self-conscious, and lack of peer support, facility orientations, and rehab-assisted transitions. Therefore, the authors proposed that this qualitative data about the complexities of living with a disability and leading an active lifestyle would contribute to an ecological model that may offer solutions.

More recently, Rimmer and Rowland (2008) explained that universally accessible environments could promote independence and community participation for people with disabilities. However, environments are often exacerbated with barriers that discourage or prevent participation in PA. For example, the general population has greater access to outdoor PA settings like parks, cycling/jogging paths yet individuals with mobility impairments may not be able to access these environments as easily. Rimmer and Rowland asserted the importance for health professionals and service providers to recognize different personal and environmental factors for people with disabilities to enhance participation in health promotion activities.

Rimmer and Rowland (2008) suggested the common problem with health promotion interventions is that a generic community setting may be assumed, although much greater attention is required to accommodate individual disabilities. According to their perspective, if individuals with disabilities were enabled to overcome the barriers involved with leading a healthier lifestyle independently, self-efficacy may be enhanced which could promote an intrinsic motivation to continue improving individual health situations. As such, enabling environments and developing specialised programs for individuals with various forms of disability became a major facet of the equation.

Social support. There may be several causes for the reduction of physical activities after TBI and given the global impact this kind of injury has on peoples' lives and those around them, social support merited closer inspection. One report discussed the influence of social support on the specific PA behaviours of people with TBI in order to develop a guiding framework to inform health promoting TBI programs and future research (Driver, 2005). According to the article, social support was defined as a resource that is exchanged between individuals and described in terms of the source and type of support provided. For example, social support in rehabilitation may help TBI victims deal with the stress related to newfound physical, cognitive and psychosocial impairments as well as help maintain active participation with rehabilitation classes and exercise. Support may come from relationships with family, friends or professionals and understanding how these social influences impact PA behaviours after TBI may contribute to health promotion for this population. Driver asserted that social support was necessary to help promote health behaviours for the TBI population. Yet, he also noted that individuals with TBI may interpret social support differently than the general population due to the variability of

injury-related cognitive, functional and neurobehavioral impairments. Therefore, future research should explore how social support influences PA for the TBI population.

Leisure activity. The encouragement of exercise, PA and health promotion for people with TBI is a multidimensional challenge. For example, the resumption of leisure activities after TBI may be difficult due to injury related sequelae. One study investigated this phenomenon for adults with moderate to severe TBI and prospectively followed 160 individuals for one year following injury to measure participation in leisure activities after TBI (Wise, et al., 2010). The purpose of the study was to develop measures for leisure activity that could be compared with age, sex and subjective perceptions to potentially inform future leisure activity promoting interventions. The main measure was the Functional Status Examination (FSE; Dikmen, Machamer, Miller, Doctor, & Temkin, 2001) that assessed functional changes associated with traumatic injury. The FSE measured personal care, ambulation, travel, work/school, home management, leisure and recreation, social integration, standard of living, financial independence and executive function. According to the results from the FSE that was administered to 125 of the 160 participants, the majority of individuals experienced a substantial decrease in leisure activities one year after TBI. More specifically, 12 participants had trouble performing leisure activities, 23 performed activities less frequently and/or required assistance, 59 stopped some leisure activities and 36 almost stopped all leisure activities completely. In addition, individuals typically engaged in sedentary and isolating activities after TBI.

Health interventions after TBI should be sensitive to activity participation because according to the results of the 2010 study, moderate to severe TBI had a measurable effect on the quantity, quality and type of leisure activities after injury. Therefore, Wise et al. (2010) discouraged matching activities before the TBI to activities after the TBI because adapted

versions of pre-injury activity may not align with the individual's goals and this contention may also apply to health promoting activities (e.g., routine exercise). It was suggested that controlled or predictable environments may better suit PA participation after TBI and the identification of facilitators and barriers to leisure activity participation for this population may better inform future interventions.

Exercise adherence. Another way to encourage health promotion after TBI is through home-based exercise programs. Home-based exercise is a convenient, cost effective and efficient way for people with and without disabilities to maintain their general fitness levels (Hassett, Tate, Moseley, & Gillett, 2011). Interestingly, according to a previous RCT, it was found that exercise adherence for people with TBI was more successful with fitness centre-based exercise programs than home-based exercise programs (Hassett et al., 2009). However, according to the earlier results, a small number of individuals in the home-based group successfully maintained the prescribed sessions which, in turn, led to further investigations.

Therefore, Hassett et al. (2011) conducted a follow-up study that explored factors related to exercise adherence according to the International Classification of Functioning, Disability and Health model (WHO, 2001), to identify factors that may predict exercise adherence for people with TBI after discharge from the hospital. Impairment in body functions, personal factors and environmental factors were explored for 30 participants with very severe TBI from the initial RCT. Exercise adherence was calculated by the number of sessions recorded by participants in their exercise diary and the home-based program that was completed in a 1-hour session, three times per week for 12 weeks in total. According to the analysis, three variables reached a significant level of between group differences as the exercise adherers were more likely to (a) have an extremely severe injury, (b) be older and (c) have had a history of walking or jogging 6

months prior to injury. Therefore, the researchers concluded that individuals with more severe cases of TBI may exercise independently as evidenced by their positive adherence to the home-based program and that age, injury severity and exercise history were significant predictors for positive exercise adherence. Based on these findings, it is clear that both pre- and post-injury factors may influence exercise participation after TBI and future research should be sensitive to these findings.

Health promotion programs. Programs developed for individuals with TBI must be appropriately designed to consider their physical, cognitive, and psychosocial impairments (Driver, Irwin, Woolsey, & Pawlowski, 2012). It was suggested that identification is the first step required to profile the intended population's expectations, intentions, perceived barriers and motivations to participate in PA (Driver, et al., 2012). An appropriate health promotion program and curriculum may be developed with this profiled information. For example, the Physical Activity Centred Education (PACE) program was created specifically for individuals with brain injury (Driver, et al., 2012). The PACE program proposes to increase self-efficacy, intention to change PA behaviours, amounts of regular PA and positive rehabilitation outcomes after TBI through goal-setting, creating social supports, employing self-reward and using problem-solving strategies. However, the success of the PACE program has yet to be tested. Future research in this area is expected.

PA and TBI

Determinants of PA. The investigation of factors related to PA participation for the TBI population has been conducted previously. Reavenhall and Blake (2010) examined the environmental, social and personal determinants of PA for adults with TBI through a multi-centre, cross-sectional survey questionnaire for 63 individuals from eight different community

centres in the United Kingdom. The questions measured daily activity, PA, self-efficacy, support and mood. According to the self-reported results, more than half of the participants did not complete the national recommended amount of PA for health benefits (e.g., 30 minutes a day, on most days of the week). Personal concerns were the most frequent barrier to PA and active participants were more independent in activities of daily living with higher levels self-reported self-efficacy. Therefore, the authors suggested that self-efficacy could be used to encourage PA participation. For example, interventions which specifically target the improvement of self-efficacy after TBI could potentially enhance the confidence required to be active, reduce personal barriers to PA and enable individuals to complete recommended amounts of PA.

Barriers to PA. Barriers to PA may be amplified with TBI-related disability which emphasizes the value of understanding barriers to help facilitate more participation in PA. In one study, the identification of barriers to PA after TBI was geared toward improving the effectiveness of health promotion programs for this population (Driver, Ede, Dodd, Stevens, & Warren, 2012). The study examined barriers to PA participation, how barriers differed based on demographics variables, self-reported PA levels, the importance placed on PA and exercise stage of change (Prochaska, DiClemente, & Norcross, 1992) for 28 individuals with mild to moderate TBI who were outpatients in a rehabilitation centre. The main measure was a questionnaire with seven demographic and nine content-based questions.

According to the results, the participants faced an average of 2.25 barriers and completed a mean of 46 minutes of PA per week. The majority of participants (51.9%) were classified as being in the action stage of change (Driver, et al., 2012). A closer analysis of the findings indicated that the barriers also varied according to demographic variables and although participants did not complete the recommended amounts of PA for individuals with a disability

(e.g., 150 minutes/week), they still believed PA was important. Despite that the majority of the sample reported being in the action stage for PA participation, the amount of completed PA was still low. Driver et al. (2012) suggested that low levels of PA may be caused by a lack of awareness as well as a lack of knowledge about the recommended amounts of PA.

Driver et al. (2012) emphasized the importance of educating individuals with TBI about PA participation in rehabilitation, the tools necessary to overcome common barriers to PA and the importance of tailoring exercise interventions to the individual. However, the findings were limited by the mild to moderate severity levels of TBI and most importantly, by the participants' ongoing participation in a comprehensive rehabilitation program. Despite these limitations, Driver et al. asserted that although individuals with TBI may identify the importance of PA and report participating in regular PA, they may not be aware that their exercise habits do not meet recommended guidelines for health-related benefits.

Experiences with PA. The subjective experiences of PA for the TBI population had yet to be examined until recently. The knowledge, attitudes, intentions and barriers to PA were explored qualitatively for 17 individuals with a range of TBI severity levels (Self, Driver, Stevens, & Warren, 2013). The participants were recruited from a comprehensive rehabilitation centre and they participated in a series of focus group interviews. The audio-recordings of the interviews were transcribed and analyzed with a cross-case analysis which compared similarities and differences between identified patterns and emerging themes (Creswell, 2007). According to the results, the main motivation to be physically active after TBI was returning to a preinjury lifestyle. The participants' expectations of PA included better health outcomes as well as potentially long-term cognitive benefits. However, the rehabilitative benefits of PA after TBI was not always clear. For example, one of the participants stated that the purpose of physical

therapy (PT) was for recovery whereas PA was for recreation. Apparently, individuals may not necessarily recognize the role of PA in recovery after TBI. Self, et al. (2013) emphasized that such findings pointed toward specific areas that required more attention like differentiation between PA and PT as well as education about PA health benefits after TBI.

Self, et al. (2013) found that participants reported being physically active but they were not completing the nationally recommended amounts of PA for health benefits, nor were they aware of what exactly constitutes PA. These findings emphasized a pressing need for more PA education after TBI. In addition, and due to the unrealistic fitness goals that emerged from participants' accounts, it was apparent that some individuals must reassess pre-injury goals in light of injury-related deficits and begin to recognize PA as a rehabilitative tool. However, the study explored exercise experiences for individuals with TBI who were still participating in a comprehensive rehabilitation program. Therefore, the findings provided insightful and relevant information but they are limited by a time frame when individuals still receive support from rehabilitation professionals which may not be representative of typical PA (i.e., exercise experiences) in the community. Thus, this study utilized focus group interviews as an effective way to explore the knowledge, attitudes, intentions and barriers to PA for individuals who recently experienced a TBI. Clearly, the voice of people with TBI was important to hear in the exercise context. This study will build upon this notion by including a person with a TBI as the principal investigator to explore the exercise voices of people with TBI from the perspective of an insider.

Interpretive Phenomenological Analysis (IPA)

IPA was first introduced by Jonathan Smith (1996) who promoted for its use in health psychology. IPA seeks to explore the unique experience of human phenomena and how this is

interpreted by individuals and researchers. It was Smith's belief that IPA may enrich areas of health research that had only been studied quantitatively. He argued that a qualitative perspective could provide a subjective and richer account of health related issues that may inform better clinical practice. For example, Smith introduced IPA with one woman's experience of dialysis treatment for renal disease and provided concrete examples of how a collection and interpretation of verbal reports of this phenomenon could make a valuable contribution to health psychology through a representation of what dialysis meant to the patient.

IPA originates from phenomenology that was introduced by Edmund Husserl (1927) as a philosophical method that examines the intentional human experience. The central focus of this philosophical method was to explore the totality of the lived experience, the phenomenon of consciousness. Phenomenological reduction, which plays a vital part in translating individual experience to philosophical theory, reduces experiences to their primal, intentional form (Smith et al., 1999). In Husserl's (1927) phenomenology, the researcher practices "epoche," which refers to the process of bracketing the world being studied from all prior knowing and subjectivity in order to preserve the purity of experience under investigation.

This phenomenological method in current scientific inquiry is often unclear (Giorgi, 1997). For example, the essential features of Husserl's (1927) pure, descriptive phenomenology include reduction, description and a search for essence that are not commonly acknowledged. Modifications are required to use phenomenology as a method of science instead of philosophy. Giorgi (1997) proposed that withholding past knowledge and existential claims, providing vivid detail of lived experiences, and searching for a *scientific essence* adequately stand for reduction, description and searching for *philosophical essence* in his description of the phenomenological psychological method. However, Smith contended that a researcher should identify his or her

relational self within the phenomena being studied in order to provide an interpretative analysis from the researcher's theoretical position (1999). This resulted in a division between Smith's IPA and Giorgi's phenomenological psychological method.

Smith's IPA did not just account for a phenomenon descriptively. It provided an interpretative analysis of human experience from the comprehensive perspective of the individual and researchers involved with the project. Lopez and Willis (2012) explained that there may be confusion between interpretative and descriptive methods because descriptive phenomenology brackets prior knowledge and identifies commonality across cases, whereas interpretative phenomenology looks for meaning across cases which can be translated into more explicit health care knowledge. Therefore, Lopez and Willis (2012) suggested that demonstrating a philosophical appreciation of this difference is an ethical way to handle the situation.

The study of interpretation in IPA is exemplified by Martin Heidegger's (1962) work with hermeneutics and emphasizes the situated quality of being human as well as the contextual understanding of human experience. Smith and Osborn (2008) extended this interpretative understanding of experience with the concept of a "double hermeneutic" which focuses on personal meaning and sense-making for people who share a particular experience but through the interpretative lens of a researcher (Smith, Flowers, & Larkin 2009). This method accounted for both the participant's and researcher's interpretation which may contribute to a transparent and reflexive perspective of the phenomenon (Reid, Flowers, & Larkin, 2005). When conducted successfully, Smith (1999) asserted that IPA may provide a rich subjective interpretation of the participant's experience as well as an interpretative analysis from the researcher's theoretical position.

In addition, IPA is committed to the *individual* despite the fact that it typically explores a homogeneous *group* of participants. This principle stems from the work of Gordon Allport (1942) who proposed that an idiographic commitment to the particular is achieved through the exploration of singular cases as opposed to nomothetic generalisations which are derived from larger samples (Smith et al., 2009). Although IPA is idiographic in nature, it extracts theory inductively with an analysis of a small group of individual accounts. Smith (2011) explained that capturing similarity and difference in this way, as well as convergence and divergence, exemplified good IPA.

IPA in the TBI Community

IPA has developed a distinctive approach to the examination and interpretation of lived experiences as it develops theory with an in-depth analysis of detailed personal accounts (Smith, 2011). Reid et al. (2005) suggested that IPA is ideally suited for unexplored experiential territory that is lacking theoretical analysis. For example, illness experience constitutes the largest amount of published IPA work in health research (Smith, 2011). As such, the purpose of many health-related IPA studies is to sensitize clinicians and practitioners to the subjective experiences of patients in order to inform better practice.

In one review of IPA studies in health psychology, 52 articles were assessed with regard to their methods of sampling, data collection, analysis and applicability (Brocki & Wearden, 2006). The authors claimed that IPA was particularly suited for health psychology because of its ability to illuminate inner processes versus outcome measures because comprehensive language and straightforward guidelines are easily accessible (Brocki & Wearden, 2006). As a caution, it was emphasized that the interpretative nature of IPA requires researchers to address their specific

role in the research directly. Yet when conducted in an ethical manner, Bocki and Wearden (2006) claimed the interpretative approach of IPA proved to be its strength.

IPA was used with the TBI population in a study that investigated the recovery process after injury for women (Howes, Benton, & Edwards, 2005). Six participants, with varying degrees of TBI severity levels, were interviewed on two separate occasions, one year apart, about their subjective experience of TBI recovery. Howes et al. (2005) identified four major themes based on their in-depth analysis of the personal experiences that were shared by the participants: “awareness of change” which referred to the way the women perceived themselves differently after TBI, “emotional reaction” which referred to the profound responses to newfound functional disabilities, “struggle to make sense” which referred to the difficulty of coming to terms with the injury, as well as “adaptation and acceptance” which referred to the way some of the women dealt with their TBI more successfully. The authors suggested that each one of the emerging themes could be accommodated in rehabilitation by acknowledging this series of adaptations after TBI and addressing each theme separately to promote better outcomes. This research exemplifies how IPA applies to clinical practice based on the suggested guidelines that were rooted within the context and experiences of women with TBI.

More recently, the phenomenon of noise sensitivity was explored for individuals with TBI in order to provide a qualitative examination of this common injury-related disturbance (Landon, Sheppard, Stuart, Theadom, & Freundlich, 2012). Data for the analysis was collected from a single, semi-structured interview with six participants who had experienced a TBI and were recruited from a regional brain injury association. The major themes that emerged from the analysis were “having to find out for myself” which referred to the general lack of understanding about the injury, “hearing every footstep” which referred to their new and heightened awareness

of noise, “being overwhelmed” which referred to the difficulty of trying to comprehend the changes being experienced and “you have to plan” which referred to a safe and stress free coping strategy to avoid difficult situations. The authors went on to discuss how the emerging themes and other relevant observations related to the literature in this area. In their conclusion, they emphasized the need to specifically recognize noise sensitivity after brain injury and the associated symptoms to help individuals with TBI manage noise sensitivity more effectively.

IPA Sport and Exercise Research

Allen-Collinson (2009) promoted the use of IPA in health research and explained that phenomenology offered a unique embodiment of experiential potential for sport and exercise. For example, IPA was successfully used in a study that investigated exercise adherence through an exploration of gym-based exercise experiences for 14 young adult, males and females who either maintained their gym membership or did not. Pridgeon and Grogan (2012) were able to identify shared themes like “upward social comparisons,” “gym culture” and “habit” that were experienced and interpreted differently by men and women who both adhered to and dropped out of a gym-based exercise programs. Additional themes included “exercise dependency” that was only discussed by adherers and “social support” that was only discussed by non-adherers. The IPA methodology allowed the authors to discuss the similarities and differences of the aforementioned themes and provide strategies in support and in promotion of exercise adherence for the two groups of exercisers.

In another sport and exercise related study, IPA was successfully used to provide an accurate and vivid description of experiencing multiple concussions from the perspective of five national level hockey players. The analysis was led by a young scholar who was intimately familiar with both competitive hockey and concussions. Caron, Bloom, Johnston and Sabiston

(2013) focused on the physical, psychological and social levels of interpretation for the professional hockey players who retired due to concussion related difficulties. According to the results, emerging themes included: “uncertainty of concussion events” referred to the participants’ inability to recollect the number of concussions they had experienced; “physical symptoms” referred to the physical manifestations that were experienced due to the concussions; “isolation and withdrawal” referred to the psychological repercussions of the injuries; “emotional turmoil” referred to the participants’ difficulty with anxiety and depression; “social influences” referred to the contrasting support received from family and friends versus coaches and medical professionals; and “professional sport transition” referred to the termination of athletic careers. The analysis and findings provided unique insights about the short- and long-term psychological effects of concussion. IPA was effectively used in a theoretical and practical manner to describe the lived experience of injury as well as contribute to future health promotion guidelines that stemmed from subjective, individual accounts.

There are several reasons to conduct more qualitative research about post-TBI exercise in the post-rehabilitation period. There is a lack of individual voice in this area and the subjective experience of exercise with a TBI in the community has been relatively unexplored. Knowledge about exercise for people with TBI may be influenced by using the information gained in this study. For example, exercise prescriptions should be developed with an awareness of the types of internal and external factors that may influence regular exercise habits in the post-rehabilitation time period because individuals with TBI may not have access to the same level of support from rehabilitation professionals outside of the clinical setting. Further, the study findings may promote the creation of tools and strategies for the maintenance of lifelong healthy behaviours for people with TBI who are living in the community and are no longer part of a clinical setting.

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August, 2014

To Whom It May Concern:

This contribution letter confirms that the co-authors (William Harvey & Jeffrey Caron) and the candidate (Enrico Quilico) are in agreement that the manuscript entitled *Facilitators and Barriers to Post-Rehabilitation Exercise after Moderate to Severe Traumatic Brain Injury* be placed in the candidates Master's thesis. The candidate's role in this study included collecting and organizing the data, conducting a qualitative analysis of the data, and writing the manuscript under the guidance of the co-authors as well as modifying the document in response to their comments.

I, the candidate, acknowledge the roles and the co-authors (William Harvey & Jeffrey Caron) contributions to the manuscript entitled *Facilitators and Barriers to Post-Rehabilitation Exercise after Moderate to Severe Traumatic Brain Injury*.

Enrico Quilico

We, the co-authors, agree that the candidate, Enrico Quilico, include the manuscript entitled *Facilitators and Barriers to Post-Rehabilitation Exercise after Moderate to Severe Traumatic Brain Injury* in his Master's thesis.

William Harvey

Jeffrey Caron

Running head: FACILITATORS AND BARRIERS TO EXERCISE

Facilitators and Barriers to Post-Rehabilitation Exercise following Moderate to Severe Traumatic
Brain Injury

(August 2014)

Abstract

Traumatic brain injury (TBI) is a major public health concern due to its growing incidence as well as the resulting physical, cognitive, social and emotional consequences. Exercise may promote the alleviation of TBI-related sequelae. However, there is a lack of information about the exercise experiences of individuals with TBI after rehabilitation. This Interpretive Phenomenological Analysis (IPA) explored the facilitators and barriers to exercise through the experiences of seven individuals with a severe TBI who live in the community. Semi-structured, in-depth interviews were conducted with participants to explore post-TBI exercise in the post-rehabilitation period. Interviews were audio-recorded and transcribed verbatim for the analysis. Four themes emerged. *Impact of TBI* addressed how physical and psychological impairments affected the participants' ability to participate in activities of daily living. *Personal development after TBI* highlighted greater awareness, emotional development and emphasized the importance of accepting disability-related impairments. *Facilitators and Barriers to Exercise* identified available time, planning, resources and transportation as well as weather conditions, organization, support and motivation. *Exercise after TBI* revealed exercise habits, productive activity and importance of exercise as well as physical, social and psychological effects of exercise.

(185 words)

Introduction

Traumatic Brain Injury (TBI)

Traumatic brain injury (TBI) is referred to as a “silent epidemic” because of the millions of people worldwide who are affected by the injury and the resulting mortality, associated morbidity and health-related costs for those people who survive (Langlois, Rutland-Brown, & Wald, 2006). TBI is the number one cause of death and disability for people in Canada under the age of 40 years, with 50,000 brain injuries that occur annually (Canadian Institute of Health Research [CIHR], 2012). There are approximately 1.7 million brain injuries that occur every year in the United States which accounts for one third of total injury-related deaths (Centers for Disease Control and Prevention [CDC], 2010). It was estimated that 57 million people worldwide have been hospitalized with one or more TBIs (World Health Organization [WHO], 1996). It has also been predicted that TBI will surpass many diseases as the leading cause of death and disability by 2020 (Hyder, Wundrich, Puvanachandra, Gururaj, & Kobusingye, 2007). The long-term or lifelong physical, cognitive and psychosocial impairments that result from TBI demonstrate a major public health problem and a pressing need for community based, non-medical interventions to help resolve the social cost related to TBI (National Institute of Health [NIH], 1998).

TBI is an invisible disability due to the nature of persistent cognitive and psychological problems that negatively affect overall health after the initial injury (Langlois, et al., 2006). Four important examples illustrate this reality. First, individuals with TBI experienced long-term health-related problems as evidenced by an increased use of health care services for 10 years post-TBI (Cameron, Purdie, Kliwer, McClure, 2008). Second, cognitive impairments may last for up to 10 years after TBI (Dikmen, et al., 2009; Draper & Ponsford, 2008; Colantonio et al.,

2004) and they may be considered as barriers to participation in independent and community activities (Skandsen et al., 2010; Andelic et al., 2010). Third, depression may be present for up to 10-20 years post-TBI (Kreutzer, Seel, & Gourley, 2001; Hoofien, Gilboa, Vakil, & Donovan, 2001). Depression has also been linked to reduced quality of life, increased impairment, injury-related disability and poor psychosocial functioning (Hibbard et al., 2004; Pagulayan, Hoffman, Temkin, Machamer & Dikmen, 2008; Diaz et al., 2012; Draper, Ponsford, & Schönberger, 2007). Fourth, behavioural difficulties have negatively impacted the social and functional lives of people with TBI for up to six years after injury as demonstrated by social problems in excess of pre-injury conditions (Fitzgerald, Carton, O'keeffe, Coen, & Dockree, 2012; Temkin, Corrigan, Dikmen, & Machamer, 2009). Therefore, the investigation of methods to improve the health status, cognitive functions, psychiatric conditions and behavioural difficulties for individuals with TBI is warranted.

Exercise after TBI

Exercise is one proposed method of alleviating some of the health-related burdens of TBI and it may be an efficient way to manage long-term care for this population (Hassett, Moseley, Tate, & Harmer, 2008; Mossberg, Amonette, & Masel, 2010). For example, it was suggested that regular exercise may (a) promote the alleviation of specific TBI deficits and related sequelae (Archer, Svensson, & Alricsson, 2012) and (b) lead to improvements in cognitive abilities (Griesbach, Hovda, & Gomez-Pinilla, 2009), general fitness (Hasset, et al., 2008; Bhambhani, Rowland, & Farag, 2005), mood and quality of life (Driver & Ede, 2009; Hoffman, et al., 2010; Wise, Hoffman, Powell, Bombardier, & Bell, 2012; Shwandt, et al., 2012). Exercise interventions for people with TBI have been promising because emerging studies have demonstrated its capacity to improve cognitive and motor function recovery after mild, moderate and severe TBI

(Fogelman & Zafonte, 2012). For example, neurocognitive training through virtual reality (VR) exercise resulted in significant improvements in working memory and processing speed (Grealy, et al., 1999). VR training after TBI was also shown to improve balance and confidence (Thornton, et al., 2005). McDonnell, Smith and Mackintosh (2011) suggested there is a continued need for long-term and follow-up studies that explore the effects of exercise on cognition for people with neurological disorders (i.e., TBI) to determine the full extent of exercise-related benefits.

Exercise may improve declining fitness levels associated with TBI because fitness training has been a safe and effective method to improve aerobic capacity for people with TBI (Hasset, et al., 2008; Bhambhani, Rowland, & Farag, 2003, 2005). For example, physical therapy and aerobic training have improved sub-maximal ambulatory efficiency and aerobic capacity for people with TBI and, hence, the reason exercise is considered as an important part of the rehabilitation process (Mossberg, et al., 2010). However, it was shown that people with TBI are in a significantly poorer physically conditioned state after rehabilitation when compared with sedentary individuals (Mossberg, Ayala, Baker, Heard, & Masel, 2007). This fact may indicate that physical problems are not necessarily resolved after rehabilitation services have ceased. Hence, there is a need for follow-up studies that specifically examine the full range of exercise-related benefits post-TBI because they may translate into fitness gains that extend beyond the rehabilitation period (Mossberg, et al., 2010).

Individuals with disabilities (i.e., TBI) may develop secondary health problems like weight gain, pressure sores, pain, fatigue and depression that are associated with lifestyle changes that result from the primary disability (Rimmer & Rowland, 2008). For example, fatigue is significantly elevated after TBI (Borgaro, Baker, Wethe, Prigatano, & Kwasnica, 2005) and it

is a major contributor to the disability (Juenst, Skidmore, Arenth, Niyonkuru, & Raina, 2013). Fatigue may be the cause for significant reductions in leisure activities, like physical activity (PA), when compared with pre-injury levels (Fleming, et al., 2011; Wise, et al., 2010). Thus, there is a need to support activities, like fitness training, which may improve physical endurance after TBI and potentially help to resolve the downward spiral of declining activities (i.e., PA).

Similarly, depression is the leading psychiatric disorder that may be comorbid with TBI (Bryant, O'Donnell, Creamer, McFarlane, & Clark, 2010) and it is linked to reduced quality of life, increased impairment, and injury related disability (Hibbard et al., 2004; Pagulayan, Hoffman, Temkin, Machamer & Dikmen, 2008; Diaz et al., 2012). Exercise has also been an accepted and preferred method to alleviate symptoms of depression following TBI (Driver & Ede, 2009; Fann, et al., 2009; Shwandt, et al., 2012). It has further been associated with improved mood, sleep, community participation and quality of life (Hoffman, et al., 2010; Wise, et al., 2012).

Reavenhall and Blake (2010) suggested more research about the determinants of PA for the TBI population could inform service providers about effective methods of developing community-based PA interventions. Driver, Ede, Dodd, Stevens, and Warren (2012) identified the barriers related to PA for individuals who recently experienced a TBI (e.g., lack of transportation, don't have enough endurance) and found that barriers varied by demographic variables. Self, Driver, Stevens, and Warren (2013) explored PA experiences for individual with TBI and found that participants demonstrated a desire to be active so they could return to a preinjury lifestyle but they were unsure about what could be constituted as PA. Collectively their findings emphasized the kind of health-related needs and exercise modifications required to promote more PA for individuals with TBI, such as education about PA, differentiation between

PA and physical therapy, and reassessment of post-injury PA related-goals (Driver, et al., 2012; Self, et al., 2013). Both studies investigated PA when individuals with TBI were still participating in a comprehensive rehabilitation program. However, it is important to distinguish exercise in and out of the rehabilitation context. For example, exercise in rehabilitation has support from a team of professionals whereas post-rehabilitation exercise typically occurs when the rehabilitation support team, who encourage PA, is no longer present.

Thus, the post-rehabilitation time frame is relevant because it reflects the time when individuals with a TBI are no longer receiving health-related services for their injury and must, therefore, participate in exercise independently. Hassett, Tate, Moseley, and Gillett (2011) suggested that the cognitive and psychological impairments associated with TBI, as well as the lack of structure and support when individuals are discharged from the clinical setting, may contribute to poor exercise adherence in the community. Consequently, there was a need to explore barriers and experiences with PA for individuals with TBI who live in the community after rehabilitation has ceased.

The purpose of this study was to provide an experiential account of the facilitators and barriers to exercise that individuals with TBI may face outside of the rehabilitation context. Hence, the needs and challenges of this population may be better defined in order to develop future health behaviour promotion (Glanz, Rimer, & Viswanath, 2008). The study also explores the phenomenon of post-TBI exercise from the perspective of the principal investigator (PI) who is an insider with first-hand personal experience of TBI and exercise. The following central research question guided this study: what are the perceived facilitators and barriers to post-rehabilitation exercise for individuals with a moderate to severe traumatic brain injury?

Method

Design

Interpretive Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) was chosen to explore the phenomenon of post-rehabilitation exercise for persons with a moderate to severe TBI. IPA supports the interpretation of phenomena from various theoretical backgrounds, including the perspective of an insider (Caron, Bloom, Johnston, & Sabiston, 2013). IPA has also been used successfully for people with TBI (Howes, Benton, & Edwards, 2005; Hooson, Coetzer, Stew, & Moore, 2013). This study was led by a PI with a severe TBI and as such, IPA provided an accessible, in-depth and evidence-based analysis of the phenomenon (Pringle, Drummond, McLafferty, & Hendry, 2011) of post-rehabilitation exercise for individuals with TBI.

Participants

Approval from the institute's Research Ethics Board (REB) was obtained before this research project began. A sample of 4-6 male participants was sought from a provincial TBI association in Eastern Canada (See Appendices A, B, & C). Participants, with a moderate to severe TBI, were purposefully selected for the study and asked to provide their consent (See Appendix D). Participant inclusion criteria included individuals who: (a) were adults between 18-50 years to reflect an able-bodied time period to freely engage in exercise; (b) had a moderate to severe TBI according to self-reported medical documentation, conducive to disabling sequelae (Glasgow Comma Scale $GCS \leq 12$); (c) had not participated in a rehabilitation program for one year or more to reflect the phenomenon of independent exercise in the community without any support whatsoever from rehabilitation professionals. Exclusion criteria for study participants included: (a) physical disabilities which prevent general forms of exercise because they may have impaired mobility; (b) medical conditions other than the TBI which prevented general

forms of exercise because they may have been unsafe or harmful to the individual; and (c) participation in an ongoing exercise intervention because this may have involved external support for PA behaviours which may not have reflected independent exercise in the general community.

Data gathering procedures

Two separate interviews were held with the participants to gather data for this study. The first interview was designed to collect more information so each participant could be well described and the second interview was a semi-structured interview to gather information about post-TBI experiences (See Table 1, Appendix E).

Interview I

Demographic information, TBI information and self-reported exercise history were gathered in the first interview. The first interview followed a detailed guide (See Appendix F). First, demographic questions addressed the participant's age, level of education, employment (including hours worked per week), income level, marital status and family status. TBI questions explored the cause of brain injury, time elapse since the injury, the rehabilitation process and lasting TBI-related impairments. Second, the interview focused primarily on the time before the TBI and it was used as a prompt for further discussion in the second interview (Smith, 1994). The interview allowed the PI to develop a rapport with each participant, a fundamental part of the data collection process in IPA (Smith, et al., 2009).

Finally, exercise history before TBI was gathered because it had positively influenced adherence to a home-based exercise program for people with TBI (Hassett, et al., 2011). Participants provided background information about self-reported PA levels to describe pre-TBI exercise habits. The exercise history questions addressed the frequency, intensity, type, and time

(FITT) of exercise habits, the facilitators and barriers to exercise, as well as the experience of exercise in the year preceding the TBI. These parameters were deemed as important factors that may influence exercise adherence for individuals with TBI who live in the community. For the purposes of the study, exercise was defined as planned, moderate to vigorous aerobic activity and muscle strengthening activities (Canadian Society for Exercise Physiology [CSEP], 2012). All of the information from this interview was not coded, rather it informed individual narratives, contextualized each participant within the study and contributed to the depth of information about their lived experiences. The PI also recorded information from this initial interview in his personal field journal. The first interview was approximately 20-30 minutes in length.

Interview II

Interview two focused on each participant's unique experiences with post-TBI exercise. Semi-structured interviews were conducted because they are a preferred data collection method in IPA to gather a detailed account of participant experiences (Smith, et al., 2009). The semi-structured format enabled each individual to discuss and expand about post-rehabilitation exercise experiences. Interview procedures followed a detailed guide (See appendix G). The five main interview questions helped guide each participant to speak about exercise participation. The questions addressed the frequency, intensity, type and time (FITT) of exercise habits following rehabilitation; facilitators and barriers to exercise in the community and the experience of independent exercise with a TBI in the post-rehabilitation context. Participants were asked five main questions followed by probes: (1) Tell me about your current exercise habits? (2) What kinds of factors allow you to exercise? (3) What kinds of factors stop you from exercising? (4) What do you think about exercise after your TBI? (5) How do you experience exercise after your TBI? The open-ended questions allowed the participants to provide more detail and richer

accounts of the phenomenon. The second interview was approximately 60-90 minutes in length and it was audio-recorded for transcription and analysis purposes.

Data Analysis

The second, semi-structured, interview was transcribed verbatim for analysis purposes. Data analysis followed the step-by-step process for IPA (Smith, et al., 2009). Reading and re-reading the transcripts allowed the PI to record powerful recollections from the interview. Notes from the PI's personal field journal helped in this process by providing additional information about the participant's non-verbal language. Descriptive comments were written about the intended meaning and choice of language from the participant interview responses and everything the participant said during the interview. These comments maintained clear ties with the phenomenon of post-rehabilitation exercise and described how this was interpreted by the participant. The PI then reviewed each transcript to include his own interpretations alongside the interview texts based on his insider knowledge of TBI. Emerging lower-order themes were developed from the initial transcript and provided concise yet all encompassing statements that represented the participants' interview responses as well as the analyst's interpretations. Commonalities were identified across cases for reoccurring themes and higher order concepts so that experiences of post-rehabilitation exercise could be described within and across the participants.

Validity

Validity in qualitative research involves credibility, confirmability, and reflexivity that may enhance the trustworthiness of the findings (Sparkes & Smith, 2014). Tracy (2010) suggested researchers include an abundance of description, detail and tacit knowledge that may make findings more plausible and credible for readers. Sparkes and Smith (2014) suggested that

authors provide an assurance that research findings originate from the source of study and are free of a researcher's subjectivity to ensure the confirmability of a study. Finally, in order to be reflexive, Shaw (2010) suggests that researchers need to be transparent about their beliefs and presuppositions, turn their gaze inward, understand the co-construction of meaning and assert that experiences must be understood in their own context. The following methods were used to enhance the credibility, confirmability and reflexivity of this study.

Researcher Triangulation. Triangulation is a method of enhancing the credibility of a study by matching a participant's reality to the researcher's representation of that reality (Sparkes & Smith, 2014). For the purposes of this study, researcher triangulation was obtained with the PI, the supervising professor and a doctoral student who was part of the research committee. The findings were deemed more credible because three researchers converged on the same conclusions (Tracy, 2010).

Confirmability audit. The confirmability audit is a method for assuring that the research findings are rooted in the contexts and participants (Sparkes & Smith, 2014). In order to make a believable case for the interpretations that are generated from qualitative research, they must originate from the participants being investigated. One hundred percent of the gathered data for interview two was accounted for (See Table 2, Appendix H). Excerpts from the interview were included in support of the interpretive claims so that readers would be able to evaluate the legitimacy of findings.

Reflexive self-awareness. Sparkes and Smith (2014) explained that it is the responsibility of researchers to identify the perspectives they bring to their studies and anticipate how these perspectives may affect their analyses, interpretations and reports. Reflexive self-awareness for this study was accomplished through a reflexive account of my own TBI, my personal field

journal and critical friends who were involved with the research project. Thus, I attempted to understand my own assumptions and display my biases as openly as I could.

First, I was the victim of a highway motorcycle accident in 2006 when I was 23 years old. I had a severe TBI upon impact with the car which caused the accident, along with serious injuries to the rest of my body. I was in a coma for 13 days and remained in intensive care for four weeks before moving to the head injury unit. After two months in hospital, I was transferred to a rehabilitation centre where the initial phase of my recovery began. I worked with a team of professionals to regain all my functional capacities. This team included a psychiatrist, psychologist, speech pathologist, occupational therapist, physiotherapist, and social worker. After a month of in-patient rehabilitation services, I was transferred to an out-patient centre with another team of professionals who supported my reintegration in society. I completed rehabilitation in June 2008, two years after my accident had occurred.

I have been extensively involved with exercise following the injury and it has played a vital role in my recovery. Physiotherapy in the hospital focused primarily on my physical abilities to stand upright and learning how to walk again for short periods of time. Physiotherapy in rehabilitation progressively focused on improving my cardiovascular fitness, muscular strength, and endurance. Then, in the final phases of rehabilitation, physiotherapists aided my return to a fitness centre where I could exercise independently. Exercise helped enormously with emotional difficulties that were associated with my TBI recovery over the course of the following year by providing a positive outlet to channel my energies. Regular exercise continues to help with a number of the resulting sequelae that I experienced following the TBI, the most prominent being fatigue and mood. However, I am well aware that independent exercise following TBI is particular to the individual and unique situation. For example, TBI survivors are

responsible for continuing to exercise independently when they have left or finished with rehabilitation and the level or degree of exercise related benefits is both highly variable and subjective.

Second, I accounted for my dual role in the study, as researcher and interpreter, with the use of a personal field journal. Journals and diaries are a way of engaging participants and researchers in a form of reflexive practice about the study (Smith, 1994). It accounted for my background knowledge and relationship to the phenomenon through critical self-reflection (Shwandt, 2001; Luttrell, 2009). Entries were maintained before and after all interviews to attempt to account for the influence of the researcher on each participant (Maxwell, 2004). The logs included my reactions to responses during the interview, with reflective notes about the general demeanour of each participant including tonality, facial expressions and body language. I explored my biases, motivations, assumptions and documented my interpersonal reactions about the study participants through journal entries during every step of the process because I was inextricably part of the research project (Hammersley & Atkinson, 2007). I reviewed the journal entries throughout the project to critically explore my assumptions and predispositions to the phenomenon in question. Self-review enhanced the coherence and transparency of the study (Yardley, 2008).

Third, critical friends are individuals who provide an outside perspective for the researcher. Sparkes and Smith (2014) explained that critical friends may encourage reflection and the exploration of alternative interpretations of collected data. My critical friends were the professors and the doctoral student who were part of the research team involved with the study. The team included the (a) PI who is a member of the TBI community, (b) his supervising professor who is a researcher and PA specialist in disability and people with mental health

problems and (c) a doctoral student who was a former professional athlete that experienced career-ending concussions and the PI of an IPA study in sport psychology. They contributed to the development of an interpretive account for the findings (Smith, et al., 2009). These individuals helped me to self-evaluate a pilot interview and challenged my interpretations as a researcher and insider in the exploration of the phenomenon. Dialogues between the PI, supervising professor and doctoral student contributed to the development of an interpretive account for the findings (Smith, et al., 2009). In this way, my critical friends helped to ensure the findings of the study were transparent, coherent, and communicable (Rubin & Rubin, 2012).

Results

Participant Profiles

Alex, 41 years, lives with his partner and does not work. He had a motorcycle accident 16 years ago where he broke his left leg and had a severe TBI. Alex has a number of mobility problems. His right leg is partially paralyzed. He walks with two canes, with 80% of his time spent in a wheelchair. Alex exercised three times a week at a moderate to vigorous intensity for two hours per day prior to his TBI. He participated in competitive road cycling and tennis in summer and competitive hockey and intense weight training during winter. Alex currently exercises twice per week at a moderate to vigorous intensity for at least two hours per day. He exercises on his adapted three-wheel bicycle and rides on off-road trails with his wheelchair during summer. Alex participates in adapted skiing and weight training during winter.

Ben, 27 years, is engaged to be married. He lives with his two sisters and does not work. Ben was the victim of an assault five years ago where he incurred damages to his head that led to a severe TBI. He has no other injuries to his body. Ben explained that 90% of his problems are related to brain functioning. For example, he cannot regulate his body temperature and struggles

with severe emotional and attentional difficulties. His left leg is partially paralyzed which requires him to walk with a cane. Ben exercised 6-7 times per week before his TBI. He exercised at a moderate to vigorous intensity for 1-2 hours per day. He played competitive basketball and participated regularly in resistance training at home or the gym. Today, Ben can no longer play competitive basketball but he still engages in resistance training seven times per week for 12 months of the year. He trains at a moderate to vigorous intensity for at least one hour per day.

Chris, 35 years, is single and a part-time university student who still lives with his family. He had a severe TBI as the result of a car accident 15 years ago. He did not sustain injuries to the rest of his body. He does have memory and concentration problems. Chris is unable to participate in activities of daily living when tired. He exercised at least four times per week at a vigorous intensity for 60-150 minutes before the TBI. He played competitive soccer and jogged regularly. Chris currently maintains his exercise 3-7 times per week at a moderate to vigorous intensity for 60-90 minutes per day. He jogs regularly for 12 months of the year and participates in outdoor soccer during summer and basketball, floor hockey and indoor soccer during winter.

David, 37 years, is a single man who lives alone and does not work. When he was six years old, David had a severe TBI because he was hit by a car. Thus, David has lived the majority of his life with TBI-related impairments. He currently struggles with concentration, memory, persistent fatigue and episodic seizures that affect all functional domains of his life. Before the TBI, David said he was like any other child because he was active every day of the week. He participated in biking, swimming and soccer. David is currently passionate about ultimate Frisbee. He practices up to seven times a week at a moderate to vigorous intensity for 1-2 hours per day during 12 months of the year. David also rides his bike, roller blades in summer and he ice skates and participates in badminton and basketball during winter.

Eric, 40 years, is a single man who lives alone and does not work. He was involved in a motorcycle accident, 21 years ago, where he had a severe TBI. He presently deals with fatigue, attention and emotional difficulties with his self-esteem. Before the TBI, Eric exercised 2-3 times a week at a vigorous intensity for 1-3 hours per day. Eric played competitive hockey for 12 months per year and used to ski, rollerblade, swim, play baseball and football. He currently exercises 3-4 times per week at a moderate to vigorous intensity for 30-60 minutes per day. He participates in soccer and ultimate Frisbee during summer and basketball and floor hockey during winter. Eric tries to walk regularly to maintain a minimal amount of physical activity per day.

Felix, 37 years, is a single man who lives alone and does not work. He had a car accident, 16 years ago. The impact to the front of his head and frontal lobes caused a severe TBI. Felix has severe attentional difficulties, mobility impairments due to balance problems and struggles with chronic fatigue. Before the TBI, Felix exercised 1-3 times per week at a vigorous intensity for 30-60 minutes per day. He participated in skiing, swimming and cycling. Felix currently exercises twice per week at a moderate to vigorous intensity for 30-60 minutes per day. He participates in biking and swimming in summer and occasional skiing in winter.

Greg, 46 years, lives with his wife and two young children. He does not work. Greg had a severe TBI in a road traffic accident 21 years ago. He struggles with attention difficulties with memory and concentration. The left side of Greg's body is partially paralyzed so he has difficulty walking and a speech impairment. Fatigue is a major problem and he requires one nap per day. He was a ski and sailing instructor before the TBI. He exercised five times per week, at a vigorous intensity, for 60-70 minutes per day. He participated in aerobic classes and downhill skiing during winter as well as wind surfing and sailing in summer. Greg currently exercises 2-4

times a week, at a moderate to vigorous intensity for 60-70 minutes per day. He bikes during summer and participates in resistance training and downhill skiing during winter.

Interpretative Phenomenological Analysis

Twenty-two lower-ordered themes emerged from the 131 pages of interview transcripts with the seven participants. A number of similarities were identified across the lower-order themes. They were categorized into four higher-order themes that were labelled *Impact of TBI*, *Personal Development after TBI*, *Facilitators and Barriers to Exercise*, and *Exercise after TBI* (See Table 3, Appendix I). These higher-order themes and subthemes are presented using selected quotes from the interviews. Consistent with an IPA approach, interpretations are also included based on the first author's TBI experience as well as his field journal notes.

Impact of TBI

“Comme TBI sévère, on a une vision assez pessimiste de la vie suite à la réadaptation. Alors je pensais que je ne pouvais pas faire grand-chose.” – Alex

TBI had a life-altering impact on each man. In this higher-order theme, participants discussed the physical abilities and psychological changes that resulted from TBI and explained how their self-perceptions were affected. The men spoke about their physical abilities for the first subtheme. For example, three participants experienced varying degrees of paralysis to one side of their body. “When I first woke up, my left hand was weak and my right leg had a bit of a limp” (Ben). “My whole left side is paralyzed. I am able to make fine motor movements with one of my hands but the other one is much slower” (Greg). This kind of physical impairment influenced the participants' abilities to engage in physical activities. However, participants described the ways in which they adapted. “The problem with lifting free weights is that I'm not

sure how much I can trust my arm because it's weaker since the accident. Now I use machines because I don't want to drop weights on myself" (Greg).

Physical impairments, related to functional physical abilities, were exacerbated by increased levels of fatigue. The men described their lack of energy with frustration. "I'm too tired to do anything and it pisses me off! My brain wants to do it but my body is telling me you can't do it because you're too tired" (Chris). Fatigue levels required daily adaptations.

Il fallait vraiment que je fasse une sieste régulièrement à chaque jour, pouvoir être capable de bien performer dans toute ma journée. Si je ne fais pas au moins une sieste pendant la journée, je vais avoir tendance à être fatigué dans les activités que je fais. (David)

The men referred to their personal energy as a limited resource that required constant monitoring and contrasted it with their pre-TBI lifestyles. Chris shared this example:

I used to work. I used to go to school. I used to go for jogs. I didn't know about the word *fatigue*. I actually figured it out a couple years ago that I cannot stress my body physically for long periods of time. So I've had to adjust.

Chris' comments made me reflect on my own physical abilities after TBI and personal experiences with accumulated fatigue. For example, I did not understand why my energy was compromised until I looked back at my daily activities or sleeping habits during the week and then I realized that I had been accumulating fatigue for several days in a row.

The men emphasized psychological changes that resulted from TBI for the second subtheme. For example, Eric spoke about his cognitive abilities and described short-term memory problems. "Mettons tu me dis ton nom. Tu t'appelles Enrico, mais moi je vais t'appeler mettons Raphael au bout d'une demi-heure." When asked about how this made him feel, he added, "C'était comme vraiment mélangé dans ma tête. J'avais de la difficulté, je mélangeais

tout.” Some participants also described cognitive adaptations required to carry out their day-to-day lives. For example, David explained, “Depuis deux ans, il ya des gens qui m’aident avec mes finances, avec ma gestion des finances et ma gestion du courrier et la planification.” He continued to live his life independently but with minor adaptations and assistance from others. Chris spoke about the kind of changes in relation to school:

Before my TBI, my grades were very high because everything used to register. Even if I didn’t even take notes in class, everything seemed to register. But after my TBI, it changed and now I can only manage two classes.

I noted in my journal logs that these men spoke about cognitive difficulties with a sombre tone and looks of despair. Perhaps they were behavioural indications of the effects that psychological changes had on their post-TBI lives.

The final subtheme was self-perceptions. The men spoke about how TBI-related changes affected the ways they perceived themselves and how they felt others perceived them as well. Alex noted, “j’avais des problèmes physiques, mais c’est surtout au niveau psychologique que je trouvais. Je me pensais pas assez bon. Je me trouvais pas assez fort.” Felix shared similar feelings and explained, “I knew from the start (of my recovery) that I was diminished, weakened, or whatever you want to call it. I’m not the same as I was.” Some participants were concerned about how athletic abilities would be perceived by others. “Ils voyaient que j’avais des difficultés. Ils voyaient que j’étais capable quand même d’en faire mais j’étais pas au même niveau” (Eric). David, who grew up with a TBI since six years old, described how the reactions of others made him feel. “Ça me faisait sentir médiocre – pas bon. Dans le fond, c’était poche un peu la manière que les gens me traitaient.” The negative self-perceptions about their weakened state and athletic abilities indicated that the physical and psychological changes affected the

men's emotional well-being. I perceived that the return to pre-injury life, with newly discovered impairments, may be the most challenging aspect of surviving a TBI. To summarize this higher order theme, the men spoke about physical impairments, increased levels of fatigue, cognitive difficulties, lifestyle adaptations and negative self-perceptions which demonstrated the effects of TBI on their lives.

Personal Development after TBI

“Through tough situations, you find your deepest strength and the will not to give up. Stay strong.” – Ben

Within this higher order theme, the participants discussed their pre-injury outlook on life, post-injury awareness and emotional development with an emphasis on the importance of accepting TBI. The first subtheme in this higher-order category was pre-injury mentality. The men discussed their thoughts and behaviours about life before and after TBI. For example, Alex stated “ce qui est très différent d’avant l’accident. Moi, *I was willing to do anything*. Je m’impliquais dans plein d’affaires. Ce qui est moins le cas maintenant.”

Six of the seven participants spoke about a greater awareness of risks for themselves and others during the second subtheme. The men appeared to be more cognisant of potential harms and hazardous behaviours after TBI. For example, Alex explained:

O.K. oui, dans le fond de mon esprit, je voudrais être encore cascadeur, mais aussi ma raison, elle est plus forte maintenant. Ça fait que ma raison me dit "non, non, tu ferais pas ça non plus, parce que maintenant tu sais quels sont les dangers possibles.

The participants' heightened awareness likely resulted from the severe traumas they had acquired through engagement in risky behaviours. For example, Alex acquired his TBI as the result of racing his motorcycle. Similarly, a number of the participants explained how they now

avoided certain activities that could be harmful. Felix said that he no longer rides his bike at night. “When the sun goes down, I don’t want to be on the road anymore.” When asked to elaborate, he explained that, “I’ve got a lot more paranoia now than before the crash. I didn’t have enough paranoia and that’s why I ended up with my TBI.”

The men spoke about being more aware of others’ abilities and how this awareness helped in the acceptance of new TBI-related realities for the third subtheme. For example, the community TBI association often organized physical activities for their members (e.g., soccer & floor hockey). Some men in this study participated in these activities. They were exposed to other individuals with TBI, many of whom with physical disabilities that prevented vigorous play. Chris explained, “I was pushing very hard (at first) and I saw other people, you know, were not trying very hard. I was getting frustrated because they couldn’t run as fast as me and they weren’t even trying. That pissed me off.” The men also spoke about accepting themselves and others in relation to sports.

J’étais encore dans le déni. J’avais pas encore fait le deuil. Je m’étais pas encore accepté totalement moi-même, le nouveau Alex. Alors, ça, c’est un processus global, mais le sport m’a aidé beaucoup à l’accepter. Parce que, o.k. j’étais moins performant, mais c’est pas grave, ça me faisait du bien. (Alex)

Not everybody is capable of playing with the same intensity. Not everybody is in shape because there are disabilities. I realized that everybody is not at the same level. Now I adapted and I help out people that need help. Like I know if that person is weaker, I will stay near him so I can help him play. (Chris)

Participants were sensitized to TBI-related impairments through sports and interactions with others which, in turn, forced them to acknowledge the reality of their post-TBI lives. This type of acknowledgement, to each unique reality, was mentioned by five of the participants.

All of the men spoke about personal growth after TBI for the final subtheme. For example, more than half of the men explained the acceptance of injury-related impairments as the most important part of their recovery. “Je m’accepte totalement comme je suis maintenant et je fais ce que je peux avec ce que j’ai. C’est moi maintenant et je suis parfaitement heureux avec ça” (Alex). Others suggested a successful strategy for TBI was the way you choose to look at life and your abilities. After 22 years of living with a TBI and partial paralysis to one side of his body, Greg spoke about his newfound thinking with conviction in his voice:

I don’t think about what I *can’t* do anymore. I just think about what I *can* do. There’s no point in racking your brain. So why think about it? Why waste your energy? Think of what you can do. Of course, I have an injury and it sucks but I think about what I can do.

Greg’s proactive view about life after TBI was not shared by every participant. Each person had a distinct way of adapting to injuries. Greg’s comments made me reflect on my own experiences where I realized an important part of moving forward in my life was the acceptance of responsibility for the accident that caused my injury and my newfound limitations.

Five of the participants found meaning from their TBI-related experiences and identified a newfound purpose in life. Eric spoke about wanting to get better, “Il me semble que la vie est supposé d’être comme ça. Tu tombes et tu te relèves – ça fait partie. T’es pas supposé rester tout le temps comme que t’es. Faut juste s’améliorer dans la vie, je pense.”

We survived, so we should be happy. If you’re still alive, you should be moving yourself to do something. That’s my belief. It’s tough for people with a TBI but it gives you a deep

strength to go ‘come on, come on, don’t give up, I can do that, I can do it’. Because we didn’t die, we’re alive. (Ben)

We interpreted this result as personal development that occurred due to injury and the consequent rehabilitation process. In summary of the higher-order theme, the men spoke about their pre-injury outlook on life, risky behaviours, abilities levels, acceptance of TBI and finding newfound purpose for life.

Facilitators and Barriers to Exercise

“I have time to do these things because I’m not working presently, the government declared that I was disabled and I can’t work.” – Chris

In this higher-order theme, the men spoke about (a) issues related to the available time and planning involved with their exercise participation and (b) the resources and transportation that made exercise accessible. They also discussed the weather conditions, organized sports and exercise support from others, and the personal motivation that prevented or enabled exercise on a regular basis. The men spoke about their availability of time for the first subtheme. None of the men were able to work after their TBI. Alex explained how unemployment influenced his exercise habits. “Je peux pas dire que j’ai pas de temps pour l’exercice parce que j’ai été déclaré inapte au travail, ça fait que moi je ne travaille plus. Alors ce n’est pas le temps qui m’empêche.” Most of the men felt that unemployment provided them with more time to exercise, some individuals did not account for their increased levels of fatigue.

When I’m in school, then it’s kind of hard. Let’s say I have class in the morning, by the time I get home, then I’m tired from my day and it’s kind of hard to fit in a day of jogging or doing any physical activity. (Chris)

I interpreted that while Chris suggested a flexible schedule may have permitted opportunities to engage in daily exercise, he did not account for his level of fatigue which influenced the number of activities that could be performed within each day. Therefore, the availability of free time may not facilitate exercise for individuals with TBI without considering injury-related impairments like fatigue.

The men spoke about the importance of planning for the second subtheme. Three of the men emphasized how planning allowed them to (a) manage TBI-related impairments with memory and fatigue and (b) participate in exercise more easily. For example, David spoke about the use of his phone to plan reminders:

Je peux préparer des alertes pour me préparer à l'avance, ou même pour me rappeler avant même de me préparer. Donc je me rappelle trois, ou des fois, cinq heures avant de faire l'exercice juste pour que j'aie ça en tête.

Eric detailed the way that he planned his weekly schedule. “Je suis capable d'en faire deux ou trois activités sportifs parce que je me dis toujours: j'ai besoin de repos. J'ai besoin de relaxer, faire mes choses chez moi.” I interpreted that planning of exercise was a facilitator for the men because it allowed them to compensate for their cognitive impairments and reduced energy levels. I identified with these examples because structure and planning became a huge part of my post-TBI life. I was also able to resume part-time employment as well as full-time university studies by including structure and planning in my daily living habits.

The participants spoke about their accessibility to resources (i.e., adapted equipment, money) and how this accessibility influenced post-TBI exercise participation for the third subtheme. Alex suggested that adapted equipment allowed him to exercise throughout the year:

Le *freewheel* est une roue que je mets en avant de mon fauteuil roulant, qui lève un peu les petites roues, et qui permet de faire du fauteuil roulant sur tout type de revêtement. Le *ski-vel* est cadre avec deux skis, avec un bras de levier qu'on peut pousser, où j'installe mon fauteuil roulant pour l'hiver.

Other participants spoke about financial resources. Felix explained, "I'm compensated by the car insurance and they told me that I will only be compensated until I get my first post-TBI job. If you're unemployed, you're covered." In contrast, David mentioned: "Il y a eu des fois que j'aurais voulu participer, exemple, à des activités physiques. Mais parce que j'ai pas, j'ai un faible revenu, donc mon budget est serré, je peux pas vraiment m'inscrire." David was the only participant who felt that his budget constraints were a problem. Therefore, all but one of the participants stated that they had access to finances required to maintain positive exercise habits.

The participants spoke about accessibility to transportation in the fourth subtheme. For example, Alex, who spends 80% of his time in a wheelchair, noted, "Je fais du sport maintenant, après le trauma, quand il y a une facilité pour le faire. Un exemple, le vélo. Si je n'avais pas de piste cyclable pas loin de chez moi, je pourrais pas en faire." Felix, who struggles with severe balance and coordination problems, explained that he takes public transportation and it requires more planning: "I either take the bus, metro, or walk but that's always a factor because when I have an appointment somewhere I usually have to leave my house roughly two hours early." The participants, who did not feel they had significant mobility impairments, suggested transportation did not hinder participation in exercise.

I could travel. I don't need to schedule adapted transportation to pick me up. I can go to a place by myself because I'm mobile enough to use public transit. I can get from A to B without any problems. (Chris)

The men spoke about the weather conditions that influenced motivation to exercise in the fifth subtheme. For example, they emphasized how “when it’s raining, or cloudy, or dark, or too damp, I’m not motivated to exercise” (Chris). One participant explained that although he may have gone for a run in the rain when he was younger, he would currently prefer to wait for more favourable conditions. “Quand il y a la pluie, je vais comme laisser tomber, je vais... Avant peut-être, j’y aurais été, mais aujourd’hui, je suis comme... je vais attendre la journée qu’il va faire un peu plus ensoleillé” (Eric). It was clear that poor weather conditions did not facilitate exercise for these men because it had a negative effect on motivation.

The men spoke about the organized sports that enabled them to participate in exercise more easily for the fifth subtheme. For example, the majority of participants were involved with organized soccer, basketball, badminton and ultimate Frisbee with the community TBI association. Participation in organized sports often included transportation and pre-determined costs. “Quand c’est vraiment trop compliqué pour le transport, je vais passer mon tour. Mais quand le transport est inclus, c’est plus facile pour moi. S’il y a un coût déterminé à l’avance, je paie, c’est moins compliqué.” (Eric). Chris spoke how organized sports facilitated participation:

It’s kind of hard to fit in a day of jogging or doing any physical activity, except for the days that I’m with the association that scheduled a trip to go play certain sports on that day.

I have it in my agenda so it’s easier because I’m scheduled for that place at that time.

I interpreted that tasks related to the cost, transportation, and planning (e.g., logistics) may have been challenging to manage for the men based on their TBI-related impairments. Therefore, organized sports facilitated exercise because the logistics were already prepared in advance.

The participants spoke about the type of exercise support they received from family, friends and professionals in the sixth subtheme. Some participants emphasized the importance of exercise support more than others. David explained that he did not have any exercise partners:

J'ai l'impression que s'il y aurait quelqu'un qui irait, si j'aurais quelqu'un avec qui je pourrais aller, on s'appelle, et puis on se motive, ça serait plus facile pour moi de... j'aurais moins tendance à mettre ça de côté, tu vois.

Alex also placed importance on exercise support after rehabilitation, which was evident in his passionate tone when he shared the following comments.

Moi je dis qu'il faudrait, à la fin de la réadaptation, les intervenants devraient... comme pour moi ça m'a été proposé, inculqué, de continuer... pas continuer, de m'impliquer dans des activités sportives pour mon bien-être. Et ça, je le dis et je l'affirme que oui, c'est essentiel. Parce que, pour m'encourager, on m'a dit oui, on m'a encouragé à le faire. Cet encouragement, j'en ai eu besoin et je l'ai fait, et c'était conclu. (Alex)

When asked why this time period was so important, he added, "Il nous faut, un petit *push*, ou un petit peu d'aide au tout début pour nous motiver à embarquer dans quelque chose. Et là, quand c'est fait, pour moi personnellement, ça a été, j'ai brisé la glace." I could not help but reflect about my own difficulties transitioning out of the rehabilitation care facility. Post-rehabilitation is a time when individuals with TBI are more vulnerable due to the challenge of returning to a previous life with functional impairments that did not exist before. Therefore, I perceived individuals with TBI require more support to resume activities like exercise during this time.

All of the men spoke about their motivation to exercise after TBI in the final subtheme. It appeared that personal incentive was the driving force behind positive exercise habits. Some participants were motivated by future health benefits. "Je fais l'exercice pour moi-même en

premier, parce que je veux être en santé. Je veux vivre vieux et en santé le plus possible”

(David). Other participants spoke about regaining better functioning capacity in activities of daily living and exercise.

Ça m’a pris du temps à réapprendre mon nom, à marcher, tout ça, puis les conditions que j’avais acquies après mon TBI, je voulais tout faire pour pas les perdre. C’est pour ça que le sport pour moi est important. (Eric)

I was motivated to work out the left side of my body because it’s more or less paralyzed.

When I first started skiing again, I made a right hand turn which caused me to put pressure on my left leg and it was weaker, so weak that I fell because it wouldn’t support me. In the gym I worked my left leg because it was weaker and then it was the same again. (Greg)

Other participants were motivated to get back to their pre-injury physical fitness or weight. “I want to be physically in shape like before. That’s why I have my mental image, my mirror self. That’s what I want to become. That’s why I push myself so, like nothing ever happened” (Chris).

After waking up from my coma, I lost 40 pounds and now, only 30 pounds are back but I grew nearly half an inch taller. I should weigh around 145 but I weigh 130 and strictly the only factor that’s missing is muscles. That comes back from working out. (Felix)

Thus, future health benefits and improving functional capacities motivated some men to participate in post-TBI exercise whereas returning to a pre-injury fitness level and comfortable body weight was motivation for others. I interpreted that participants identified a particular incentive to exercise after TBI and it became the motivating factor to facilitate continued exercise habits. To summarize the higher order theme, the men spoke about unemployment, difficulties with fatigue, financial assistance and adapted equipment. They further discussed access to bike paths, public transit, and the limited amount of activities that could be performed

due to negative weather conditions and the logistics related to organized activities. Effective planning, organized sports and external support enabled these men to participate in exercise.

Exercise after TBI

“L’exercice occupe mon temps de façon bénéfique et de façon heureuse. Bénéfique pour mon corps et heureuse pour ma psychologie.” – Alex

Within this higher order category, the men spoke about their current exercise habits, how exercise allowed them to engage in productive activity and why exercise was important after TBI. The participants discussed the various ways that post-TBI exercise improved their physical abilities and social lives. They emphasized exercise had a positive impact on attention and mood. All of the participants spoke about involvement in some form of post-TBI exercise for the first subtheme according to their self-reported exercise habits (See Table 4, Appendix J). My perception was the majority of participants engaged in the minimum amount of exercise to gain health related benefits (e.g., at least 150 minutes of moderate intensity exercise each week) according the American College of Sports Medicine (ACSM; Garber, et al., 2011).

The men indicated that exercise was a way to engage in productive activity for the second subtheme. More specifically, exercise was a positive way for participants to make use of free time and avoid sedentary behaviours.

Faire du sport, c’est bien pour tout le monde, mais pour moi un peu plus parce que j’en ai besoin. Sinon, j’ai tendance à rester devant la télé et à manger des chips! Faire m’apitoyer, j’aime pas ça. C’est mieux faire ça que de rien faire du tout. (Eric)

After consulting my field journal, I interpreted that Eric struggled with the amount of time that he spent in sedentary behaviour after his TBI. Clearly, it was necessary for Eric to participate in

sports after the accident. Exercise was also described as a productive use of time because individuals with severe TBI were not employed. Ben mentioned:

We don't work, so instead of sitting at home being bored, playing games or watching TV, you're doing something because we look for things to occupy our time. At least working out, you're doing something for your health, and it's good because it's time consuming.

Exercise may be a constructive way for individuals to perform activities that are good for health and well-being. According to the participants' experiences about being more active and making use of their time, exercise appeared to be an effective way to engage in productive activity for individuals with a severe TBI.

The men specifically discussed the importance of post-TBI exercise in the third subtheme. Some participants placed more importance on it than others. For example, Alex spoke about the key role that exercise plays in TBI recovery. He explained how, at first, he was unaware of all the related benefits but he now believes exercise is critical and should be encouraged after TBI.

Obligatoirement, si une personne avec TBI peut faire ou pourrait faire de l'exercice, il faut l'encourager à en faire. Surtout TBI parce que on peut pas imaginer les bénéfices qu'on peut en tirer. Moi je sais parce que j'en suis conscient maintenant. Mais quand on n'est pas, quand on n'a pas commencé on ne peut pas imaginer les bénéfices qu'on peut en tirer.

(Alex)

Eric also spoke about the importance of exercise and explained that it was a vital part of his rehabilitation after TBI. "L'exercice, ça m'aide à rester en vie. Parce que si j'aurais pas eu ça après, justement, ma réadaptation, l'exercice, parler à des gens, moi je suis une personne qui serait sûrement mort."

All of the participants described the physical effects of post-TBI exercise in the fourth subtheme. They provided examples about the ways that exercise led to the improvement of decreased physical functions and difficulties with fatigue. Alex, whose left leg is paralyzed, described the way that cycling has a positive effect on his motor skills.

Je me suis rendu compte que quand je fais du vélo, souvent, je marche mieux. Je marche mieux avec mes cannes, parce que le pattern, la motion de pédaler inculque dans mon cerveau une mobilité de mes jambes. Alors quand je fais du vélo l'été, je marche mieux. Je marche plus vite. Je marche de façon plus automatique, plus sécuritaire.

Ben felt that exercise allowed his body to send task-related signals from his brain to his limbs.

I have trouble making my legs work. So, every time I do an exercise, I tell my legs... 'you can do it, you can do it' and I train them to move. It helps my coordination and my thought process.

Some participants further spoke about the positive effects that exercise had on fatigue.

When I work out, I feel better inside. I feel more alive and more energetic. It activates me so I can do things. I work harder because I'm less tired. I still take a nap every day but I nap less when I work out more. (Greg)

Four participants provided examples of how frequent bouts of exercise increased energy levels. Therefore, based on personal examples about exercise-related improvements with their motor skill and energy levels, exercise appeared to help each man to improve some aspect of TBI-related physical impairments.

The fifth subtheme refers to the men's comments about the effects of exercise on attention. For example, six of the seven men spoke about experiences with regular exercise that improved functions related to memory, concentration and processing speed. David spoke about

his participation in ultimate Frisbee. “Fur et à mesure que j’ai joué du Frisbee, j’ai réalisé que j’avais développé beaucoup de réflexes en traversant, que j’avais développé aussi une acuité plus visuelle des objets qui se déplacent dans l’espace autour de moi.” Alex spoke about the effects of adapted skiing on concentration. “C’est beaucoup de contrôle neurologiquement. Il faut que je me concentre pour l’équilibre. Il faut que je me concentre pour prendre les virages. Ça fait un entraînement plus intellectuel ou cognitif.” Chris also noted: “When I exercise, my brain functions are, like, spot on and I don’t forget things, and I feel quicker, like I have answers for everything. My reaction time and everything is much quicker.” I related to these examples from personal experience because I attribute improved mental clarity/alertness to post-TBI exercise which helped me enormously in my return to university studies. Therefore, based on the positive influence that exercise had on the men’s memory, concentration and processing speed, as well as my own experiences, I interpreted that participation in exercise may be a way for men with TBI to improve difficulties with attention. It was also my perception that the participants chose to participate in physical activities that were cognitively demanding for this reason.

The men discussed the social effects of exercise in the sixth subtheme. Six of the participants provided examples related to engagement in social interactions, the avoidance of isolation, and the development of meaningful relationships. For example, Greg explained that he engaged in more social activity when he trained at his local YMCA.

It’s social exercise because I talk to people in the gym about what they’re doing. How their week was, everything. I just like people. I like to talk to people and I get some exercise too.

The reason why I bike and go to the gym is to socialize because I love socializing. However, Eric spoke about the way that sports helped him to avoid being isolated. “l’exercice ça m’aide à aller vers des gens justement et pas rester renfermé. D’après moi c’est efficace

l'exercice pour éviter de penser trop, écouter la télé, manger, ou dormir.” Some men also spoke about the kind of friendships they made. “Sports unite people. So any physical activity that you do with others is like being with your brothers because you make bonds for life” (Chris). I related to these comments because participation in post-TBI exercise and team sports also exposed me to individuals who shared a similar interest in achieving positive health benefits through exercise. Therefore, exercise may be a way for people with TBI to engage in positive social activity.

The final subtheme about the effect that exercise had on mood was spoken about most often among all of the themes that emerged from the participants' experiences about post-TBI exercise. This subtheme encompassed the ways that post-TBI exercise influenced the men's emotions and feelings. In particular, participants talked about the ways that exercise participation led to positive feelings of improved self-esteem, confidence and emotional well-being.

Exercise helps the ego. You don't think of yourself as being mister minus, the less, the diminished, weakened version of yourself anymore... the way you did when you left the hospital. Maybe I can't do a marathon but I can run a few kilometres. It brings back the ego and the pride. I feel like I'm not the second Felix anymore. (Felix)

Felix's negative perception of his “second, diminished, weakened self” prompted my reflection that participation in exercise enabled him to re-establish his ego and pride. It speaks volumes about the positive effect that exercise has had on his self-esteem. Eric also provided an example about the way exercise enabled him to feel positive.

L'exercice me fait sentir que je suis capable d'y aller tout seul. J'ai pas besoin de personne, Ca me fait sentir comme tout le monde qui s'arrange tout seul. Ça me fait sentir d'être

capable. D'être à peu près comme tout le monde qui fait du sport tout seul. Quand je suis en contexte sport, j'oubliais complètement que j'avais eu un TCC.

I reflected on these comments and interpreted Eric's desire to feel independent was explained by his diminished physical abilities after the TBI. In turn, he has experienced feelings of empowerment through exercise. Additionally, participants spoke about the way that exercise enhanced emotional well-being. Alex explained:

Quand je fais du sport, o.k. tu diras, ça sécrète de l'endorphine dans le cerveau, l'hormone du bonheur ou je sais pas quoi. Mais je me sens bien. Après une sortie de sport, ça va bien. Je suis heureux, puis je suis meilleur. Ah oui, c'est une bonne question ça, parce que l'activité physique pour moi est, d'une manière, essentielle.

I interpreted that the men used post-TBI exercise to regulate their mood. The powerful examples about the positive effects that post-TBI exercise had on self-esteem, motivation and emotional well-being indicated the area(s) where the men felt exercise had the greatest impact.

In summary of this higher order theme, the men spoke about their regular exercise habits that enabled them to make use of free time and avoid sedentary behaviour. Some individuals placed more importance on post-TBI exercise than others. The men discussed the positive effects that exercise had on their mobility, fatigue, memory, concentration and focus. They also added how exercise participation led to increased social interactions and the development of meaningful relationships. The men emphasized that exercise substantially improved their self-esteem, confidence and emotional well-being. Based on the men's comments and my own personal experiences, it can be surmised that regular exercise may improve many aspects of individuals' lives after suffering a TBI.

Discussion

The purpose of this IPA study was to explore the post-rehabilitation exercise experiences for individuals with a moderate to severe TBI. Seven men with severe TBI were interviewed to gain a better understanding of their exercise experiences in the community. This study provided a unique, qualitative account about the factors that enabled or prevented post-rehabilitation exercise after TBI. Participation in the study interviews enabled the participants to (a), reflect about the impact of TBI on their lives, (b) speak about personal development that occurred after TBI, (c) discuss facilitators and barriers to post-rehabilitation exercise in the community and (d) provide their perception of the post-TBI exercise experiences. While PA research for individuals with TBI is still in its infancy (Pawlowski, Dixon-Ibarra, Driver, 2013), our study results demonstrate that post-rehabilitation exercise is a well-perceived method for the improvement of life after TBI.

Implications

The men discussed the negative effects that TBI was perceived to exert on each man's life in the first theme about the impact of TBI. They spoke about mobility impairments, persistent fatigue as well as cognitive and emotional difficulties that prevented a return to a functional and independent life. The men, who felt weakened and diminished by the TBI, seemed to be preoccupied with how their physical abilities were perceived by other people. We suspect that the physical and psychological changes, resulting from TBI, led to these negative self-perceptions. Howes, Edwards and Benton (2005b) similarly found that males with acquired brain injury (ABI), which includes TBI, were less satisfied with aspects of their physical functioning and suggested that reduced body-image and self-esteem were important problems after brain injury. Furthermore, Ponsford, Kelly and Couchman (2014) investigated self-concept

and self-esteem after ABI and found that changes in self-perceived abilities were associated with depression and anxiety. The men in our study spoke about negative self-perceptions that were experienced many years after the initial TBI, emphasizing a potential concern for the onset of depression and anxiety after rehabilitation has ceased.

Positive changes appeared to have occurred since the onset of the men's injuries in the personal development after TBI theme. We found that participants spoke about competitive desires and willingness to engage in thrill-seeking behaviour before their accidents in contrast to their newfound awareness of potential harms and participation in safer physical activities within their current TBI realities. These changes were interpreted as personal development that occurred in the post-TBI period. Self et al. (2013) also found that acceptance of TBI-related impairments was an important step in the rehabilitation process. Our study participants seemed to accept their own limitations through social interactions with others with TBI. Arenth, Corrigan and Schmidt (2006) explained that people may use social comparisons to evaluate their own abilities and found that individuals with TBI successfully used social comparison to adjust to injury in the early phases of TBI recovery. Our findings during the post-rehabilitation time frame would indicate that social comparisons may continue to be effective many years after injury.

Exercise barriers related to the TBI predominated in the theme about the facilitators and barriers to exercise. We found, that the men discussed their increased levels of fatigue, mobility restrictions and the logistics involved with organized activities. These findings are supported by the realities of many people with disabilities who face a substantial amount of barriers to exercise outside of the clinical setting and are, therefore, at risk for developing secondary health conditions (Rimmer, 2008). For example, the men described how fatigue constrained their available time for exercise. Problems with fatigue have previously shown to affect PA for

individuals with TBI (Driver, et al., 2012; Reavenhall & Blake, 2010). Therefore, it indicates a PA research area that requires much more attention. In short, the men's TBI-related impairments appeared to make exercise more difficult for the men.

The men discussed the factors that helped them overcome challenges to post-TBI exercise in the facilitators and barriers to exercise theme. They spoke about the ways that effective planning, accessible resources and transportation, organized sports, and personal incentives helped them to maintain their positive exercise habits. They were better able to manage their time by accounting for the rest they required and planning the amount of activities in one day. The men emphasized personal incentive(s) that motivated continued participation in exercise. They provided examples about maintaining future health benefits, regaining functional capacity and their desires to return to pre-injury fitness levels and comfortable body weights. Self et al. (2013) also found that individuals, who had recently experienced a TBI, set PA goals and were motivated to return to a pre-injury lifestyle. Thus, our participants' personal goal-setting appeared to facilitate positive exercise habits. This finding is important for health promotion and people with TBI because a lack of motivation is one of the most frequently reported barriers to PA (Reavenhall & Blake, 2010). Driver, Irwin, Woolsey and Palowski (2012) also recommended that goal-setting should be a fundamental part of health promotion for individuals with TBI. Thus, an emphasis needs to be placed on exercise-related goals to promote exercise participation beyond the final phases of rehabilitation.

Driver, Ede, Dodd, Stevens and Warren (2012) also found that individuals with TBI, who participated in the final phases of rehabilitation, faced many exercise barriers (i.e., lack of transportation, don't have enough endurance). Thus, we addressed the areas where the individuals felt would further promote their exercise participation after TBI. The men shared

their personal stories about exercising in the community with a severe TBI and spoke about exercise support in the post-rehabilitation time frame. This finding is supported by Driver (2005) who suggested increased support may enhance the motivation to participate in positive health behaviours after acquiring TBI (i.e., regular exercise). We further suggest that the men's emphasis of support after rehabilitation indicated a time when they were most vulnerable and, therefore, required more assistance. Similar to findings from Reavenhall and Blake (2010), the majority of the men shared positive experiences about exercise support provided by the community TBI association. Hence, community exercise support may be the most logical extension of health promotion for people with TBI outside of the clinical setting.

The fourth theme, exercise after TBI, highlighted the ways that exercise allowed the men to engage in productive activity and manage their TBI-related impairments. The men with severe TBI felt their regular exercise habits were productive because they helped with the avoidance of sedentary behaviours. The men could then make use of free-time with activities that were positive for individual health and, in turn, engage in positive social interactions. This finding is supported by other studies that found people with TBI experienced long-term challenges with functional status, independence and social activities (Temkin, et al. 2009; Dijkers, 2004). Wise et al. (2010) also found that individuals with moderate to severe TBI had a reduced number of leisure activities that were typically home-based, sedentary and performed in isolation. Lefebvre, Cloutier and Levert (2008) also stated that social integration post-TBI is an ongoing process for up to 10 years after injury, with the inability to return to productive occupation as a barrier to social integration. The stories of the men in our study suggest that exercise participation could assist the social integration process through health promoting behaviours in the post-rehabilitation period.

Exercise was described as a self-reported method for individuals with severe TBI to improve their TBI-related impairments. The seven study participants discussed the ways that exercise improved their (a) fatigue (b) cognitive functions and (c) their mood. For example, the men perceived that regular exercise improved personal energy levels. Self et al. (2013) also found individuals with TBI associated PA (i.e., exercise) with increased personal energy levels. Unfortunately, there seems to be no evidence-based treatments that attempt to increase levels of fatigue after TBI (Cantor, Gordon & Gumber, 2013). Our participant perceived that post-TBI exercise improved energy levels in the post-rehabilitation period which indicates another area that warrants further investigation.

The men also shared their perception that regular exercise had a positive effect on personal cognitive abilities (e.g., memory, concentration & thinking). We found that the seven men participated in exercise for the positive effects that it had on their cognitive impairments. This finding is consistent with the literature that supports the use of exercise for the enhancement of neurocognitive function after moderate to severe TBI (Fogelman & Zafonte, 2012). While aerobic exercise has been found to improve cognition in healthy adults, it seems there is insufficient evidence about the use of exercise to improve cognitive abilities for individuals with differing forms of neurological disorders such as TBI (McDonnell, et al., 2011). The men further discussed the effects that post-TBI exercise had on their mood. They emphasized positive feelings associated with exercise and confidence, self-esteem and emotional well-being. Previous research also found that participation in post-TBI exercise or PA programs may increase positive mood states (Driver & Ede, 2009; Wise, et al., 2012). This finding is very important for long-term rehabilitation of men with severe TBI due to the elevated risk of incurring major depressive disorder and general anxiety disorders (Diaz, et al., 2012). We suggest that the men in our study

used exercise as a method of managing their mood after TBI. Consistent with evidence that exercise is a preferred treatment for depression of individuals with TBI (Fann, et al., 2009), our findings highlight the importance of supporting post-rehabilitation exercise programs in the community to combat the risk of depression and anxiety.

Strengths and Limitations

This study has three unique strengths. First, the IPA methodology allowed the PI to interpret the phenomenon of exercise after severe TBI from the perspective of an insider. The PI was able to build a strong rapport with the seven study participants and access deep and rich information about the lived experience of post-TBI-exercise. Second, this study was conducted with individuals who are no longer involved in a formal rehabilitation program. Driver, Ede, Dodd, Stevens and Warren (2012) recommended that these types of post-rehabilitation exercise experiences be gathered to reflected exercise in the community without the support of rehabilitation professionals. Third, this was one of the first studies to explore the exercise experiences of people with a severe TBI.

There are two limitations of the study. The main limitation of this study is that the findings are not generalisable because we qualitatively explored the subjective experiences of post-rehabilitation exercise for a small, homogenous sample of men with severe TBI. However, the findings are more generalisable to the community-TBI association where the men were recruited (Creswell, 2007). The second limitation relates to memory impairment that may persist many years after severe TBI (Draper & Ponsford, 2008). The study participants spoke about difficulties with memory during the interviews and it is possible that individuals may have inaccurately self-reported their exercise habits. However, we purposely held two interview

meetings so the participants could speak comfortably and not be stressed to remember pre- and post-TBI exercise experiences during a single time period.

Recommendations for Future Research

There are five recommendations for future research. First, we suggest that internet friendly technologies and devices be utilized in future research that prompts people with TBI to engage in daily exercise (e.g., cell phone apps, automated reminders, etc.). This recommendation is based on the participants' discussions about availability of time for exercise and how it was affected by fatigue. For example, the men suggested that planning reminders and scheduling appropriate amount of rest time helped to overcome difficulties with fatigue and enabled them to take advantage of exercise opportunities. Second, it is suggested that group exercise programs be tested for their efficacy in reducing emotional difficulties for people with varying severity levels of TBI (i.e., mild-moderate). Our study demonstrated that participation in organized sports, along with other people who also had TBI, assisted with the emotional adaptation process for participants in the post-rehabilitation time period.

Third, we found that exercise support directly following rehabilitation is a critical time period for the men with severe TBI due to the transitional difficulties related to leaving a clinical setting and returning to home life but with TBI-related impairments. Individuals with TBI may benefit from additional transition services in the final phases of rehabilitation to bridge the gap between the clinical setting and the community. For example, post-rehabilitation exercise interventions may promote improved long-term health by providing individuals with the support and tools required to maintain positive health related behaviours. Since our study participants also responded positively to exercise support that was provided through community TBI

association, we recommend that a greater attention and resources be focused on community TBI programs so they can also provide exercise-related services.

Fourth, the men reported exercise as an important method to engage in productive activity after severe TBI. Exercise afforded the participants with the opportunity to engage in positive, social activity. We, therefore, recommend that future studies investigate the effects that exercise may have on individuals with more severe cases of TBI who tend to experience more social dysfunction related to reduced levels of employment, leisure activity and interpersonal relationships. Finally, the study participants made it clear that participation in exercise after rehabilitation had positive benefits for physical, cognitive and emotional functions after their severe TBIs. Therefore, long-term interventions are required to examine the full range of functional benefits that are accessible through exercise after TBI and may better assist with social reintegration after TBI.

The results from the current study contribute to existing research about exercise and health promotion for the TBI population. More specifically, exercise was perceived to improve the emotional adaptation, community reintegration and management of TBI-related impairments in the post-rehabilitation period. We hope that a better understanding of the post-rehabilitation exercise experience for people with TBI may contribute to the long-term development of guidelines for effective health related programs.

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Appendices

Appendix A

Formal Request to Association Québécoise des Traumatisés Crâniens

Dear (Name),

My name is Enrico Quilico and I am a graduate student, under the supervision of Dr. William Harvey, in the Department of Kinesiology and Physical Education at McGill University. I am conducting a research project about the exercise habits and experiences of people with traumatic brain injury (TBI) in Montreal and this is a request for you to participate by involving members of your community association in the study. I am an active member of the AQTC and first became involved with the association after suffering TBI in 2006. I am also a voice in prevention for Think First and have spoken to hundreds of students in the Quebec area about my personal TBI.

The purpose of the research project is to examine the exercise habits and experiences of people who (a) have suffered a TBI and (b) are no longer in treatment at a rehabilitation centre. The objective is to determine the facilitators and barriers to exercise for people with TBI after formal rehabilitation programs have stopped. This research will contribute to the existing body of knowledge about managing TBI related impairment as well as promoting overall health and well being.

We are looking for 4-6 male participants, between the ages of 18 and 40, who have suffered a moderate to severe TBI. Each participant will not have been involved with a rehabilitation centre for the period of one year or more. The participants will be involved in two separate interviews, compensated for transportation costs and/or parking with \$20.00 and will be provided a beverage and refreshment at each of these meetings (e.g., a bottle of water and a granola bar). Both interviews will be held at the Currie Gymnasium located at 475 avenue des Pins, in Montreal or at an agreed upon alternative private location. I will take notes during the first interview (20-30 minutes) which will focus on background information about the TBI and exercise history. The second interview (60-90 minutes) will be audio recorded with a digital voice recording device and will focus on current habits and experiences with exercise in the post-rehabilitation time frame. Participants will be informed about any potential risks or harms (although minimal) with written consent that must be agreed to and signed. Participation is voluntary and individuals may withdraw from the study at any time.

It is my hope that the AQTC agrees to be involved with this study, as it would be an honor to collaborate with your association in research about improving the lives of individuals with TBI.

If you have any questions about the study and would like to have more information, please do not hesitate to contact me at the information below.

Thank you for taking the time to consider and respond to this request.

Sincerely,

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Annexe A

Demande formelle à l'Association québécoise des traumatisés crâniens

Chère Madame, Cher Monsieur,

Je m'appelle Enrico Quilico. Je suis un étudiant de maîtrise supervisé par le professeur William Harvey au Département de kinésiologie et éducation physique à McGill. Je mène un projet de recherche sur les habitudes et les expériences en matière d'exercice physique chez des Montréalais qui ont subi un traumatisme cranio-cérébral (TCC) et sollicite votre participation en encourageant les membres de votre association à participer à cette étude. Je suis moi-même membre actif de l'AQTC depuis que j'ai subi un TCC en 2006. En tant que porte-parole en prévention pour Pensez d'abord, je suis allé parler à des centaines d'élèves du Québec de mon propre TCC.

Ce projet de recherche a pour but d'examiner les habitudes et les expériences en matière d'exercice physique chez les personnes qui ont a) subi un TCC et b) terminé leurs traitements en réadaptation. Son objectif est de déterminer les facteurs qui incitent les victimes d'un TCC à faire de l'exercice ou, au contraire, les en empêchent, une fois terminées les séances de réadaptation. Cette recherche sera versée au fonds actuel des connaissances sur la façon de gérer les séquelles d'un TCC et de promouvoir la santé et le mieux-être en général.

Nous sommes à la recherche de 4 à 6 hommes entre 18 et 40 ans qui ont subi un TCC de modéré à sévère. Ces sujets ne doivent pas avoir fréquenté un centre de réadaptation depuis au moins un an. Les participants sont rencontrés deux fois en entrevue et reçoivent chaque fois la somme de 20,00 \$ pour couvrir leur transport ou leur stationnement, ainsi qu'une légère collation (bouteille d'eau et barre granola). Ces deux entrevues ont lieu au Gymnase Currie, 475 avenue des Pins à Montréal, ou dans un lieu privé qui aura été convenu. Je prendrai des notes durant la première entrevue (20-30 minutes), qui portera sur des renseignements généraux concernant le TCC et les habitudes antérieures en matière d'exercice physique. La seconde entrevue (60-90 minutes) sera enregistrée avec un système d'enregistrement numérique de la voix et portera sur les habitudes et les expériences actuelles d'exercice, en période post-réadaptation. Les participants sont informés des risques potentiels (minimes) dans un formulaire de consentement qu'ils doivent lire et signer. La participation est volontaire et le participant est libre de se retirer de l'étude à n'importe quel moment.

Je souhaite ardemment que l'AQTC accepte d'appuyer cette étude, car je serais honoré de collaborer avec votre association à la recherche qui vise à améliorer la vie des personnes ayant subi un TCC.

N'hésitez pas à me contacter à l'adresse courriel ou au numéro de téléphone ci-dessous et je me ferai plaisir de répondre à toutes vos questions concernant cette étude.

En vous remerciant de prendre le temps d'étudier ma demande et en espérant que vous y répondrez favorablement, je vous prie d'agréer l'expression de mes sentiments les plus sincères,

Enrico Quilico

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Appendix B

Phone Script for Invitation to Participate in Research Project

Hello, my name is Enrico Quilico and I am a graduate student, under the supervision of Dr. William Harvey, in the Department of Kinesiology and Physical Education at McGill University. I was given your contact information by the AQTC.

How are you today?

- Wait for response and actively listen to what the participant has to say before following up with the next question.

As part of my master's thesis, I am conducting a research project about the exercise habits and experiences of people who suffered a traumatic brain injury (TBI). I am calling to invite you to participate in my study which is geared toward improving the quality of life for people who live with a TBI. Would you like to hear more about the study?

- Wait for response and actively listen to what the participant has to say before following up with the next statement.

The purpose of the research project is to examine the exercise habits of people who have suffered a moderate to severe TBI and are no longer in treatment at a rehabilitation centre. This research will contribute to the existing body of knowledge about health promotion for the TBI population. Would you like to hear about what is involved?

- Wait for response and actively listen to what the participant has to say before following up with the next statement.

The study involves two separate interviews and each interview will be scheduled at your convenience. The first interview will be for approximately 20-30 minutes and the second interview will be for approximately 60-90 minutes.

- Wait for response and actively listen to what the participant has to say before following up with the next statement.

Both interviews will be held at the Currie Gymnasium located at 475 avenue des Pins, in Montreal or an agreed upon alternative private location. I will take notes during the first interview which will focus on background information about your TBI and exercise history. The second interview will be audio recorded with a digital voice recording device and will focus on your current habits and experiences with exercise in the post-rehabilitation time frame. The second interview will last approximately 60-90 minutes. You will be compensated for transportation costs and/or parking with \$20.00 and will be provided a beverage and refreshment at each of these meetings (e.g., a bottle of water and a granola bar).

- Wait for response and actively listen to what the participant has to say before following up with the next question.

If you are interested to participate in this study, may I meet you or send you the consent form which provides you with more specific details about it?

- Wait for response and actively listen to what the participant has to say before following up with the next question.

Thank the individual for his time and leave the contact information where you may be reached.

Contact Information

Mr. Enrico Quilico: Phone 514-743-6788 or Email enrico.quilico@mail.mcgill.ca

Dr. William J. Harvey: Phone 514-398-4184, ext. 0488 or Email william.harvey@mcgill.ca

Annexe B

Invitation téléphonique à participer au projet de recherche

Bonjour. Je m'appelle Enrico Quilico. Je suis un étudiant de maîtrise supervisé par le professeur William Harvey au Département de kinésiologie et éducation physique à McGill. Votre nom m'a été donné par l'AQTC (l'Association québécoise des traumatisés crâniens).

J'espère que je ne vous dérange pas ?

- Attendre une réponse et prêter une écoute attentive à ce que l'interlocuteur pourrait avoir à dire avant d'aborder la question suivante.

Dans le cadre de mon mémoire de maîtrise, je mène un projet de recherche sur les habitudes et les expériences en matière d'exercice physique chez les personnes qui ont subi un traumatisme cranio-cérébral (un TCC). Le but de mon appel est de vous demander de participer à cette étude, qui vise à améliorer la qualité de vie des personnes qui ont subi un traumatisme cérébral.

Aimeriez-vous que je vous parle de cette recherche ?

- Attendre une réponse et prêter une écoute attentive à ce que l'interlocuteur pourrait avoir à dire avant d'aborder la question suivante.

L'objectif de ce projet de recherche est d'examiner les habitudes d'exercice chez les personnes qui ont subi un traumatisme crânien de modéré à sévère, une fois que leurs traitements en centre de réadaptation sont terminés. Cette recherche va s'ajouter à l'ensemble des connaissances existantes sur la promotion de la santé chez les victimes de traumatismes crâniens. Voulez-vous savoir comment vous pourriez participer ?

- Attendre une réponse et prêter une écoute attentive à ce que l'interlocuteur pourrait avoir à dire avant d'aborder la question suivante.

La participation à l'étude représente deux entrevues distinctes, aux dates et aux heures qui vous conviennent. La première entrevue dure entre 20 et 30 minutes et la seconde, entre une heure et une heure et demie.

- Attendre une réponse et prêter une écoute attentive à ce que l'interlocuteur pourrait avoir à dire avant d'aborder la question suivante.

Les deux entrevues ont lieu au Gymnase Currie, 475 avenue des Pins à Montréal, ou dans un endroit privé qui aura été convenu. Je prendrai des notes durant la première entrevue, qui va porter sur des renseignements généraux concernant votre TCC et vos habitudes en matière d'exercice physique. La seconde entrevue sera enregistrée avec un système d'enregistrement numérique de la voix et portera sur vos habitudes et vos expériences actuelles d'exercice dans la période post-réadaptation. Cette deuxième entrevue devrait durer de 60 à 90 minutes. Vous recevrez 20,00 \$ pour couvrir votre transport ou votre stationnement et une légère collation sera servie durant l'entrevue (bouteille d'eau et barre granola).

- Attendre une réponse et prêter une écoute attentive à ce que l'interlocuteur pourrait avoir à dire avant d'aborder la question suivante.

Si vous êtes intéressé à participer à l'étude, est-ce que je peux vous rencontrer, ou encore vous envoyer le formulaire de consentement qui donne davantage de précisions ?

- Attendre une réponse et prêter une écoute attentive à ce que l'interlocuteur pourrait avoir à dire avant de clore la conversation.

Remercier l'interlocuteur pour son temps et lui laisser vos coordonnées pour qu'il sache où vous rejoindre.

Coordonnées

Mr. Enrico Quilico: Tél. 514.743.6788 ou courriel <mailto:enrico.quilico@mail.mcgill.ca>
Dr. William J. Harvey: Tél. 514.398.4184, poste 0488 ou courriel
<mailto:william.harvey@mcgill.ca>

Appendix C

Email Script for Invitation to Participate in Research Project

Hello,

My name is Enrico Quilico and I am a graduate student, under the supervision of Dr. William Harvey, in the Department of Kinesiology and Physical Education at McGill University.

I would like to invite you to participate in a study that is geared toward improving health and quality of life for people who live with a TBI. The purpose of the project is to explore the exercise habits of people who have suffered a moderate to severe TBI and are no longer in treatment at a rehabilitation centre.

The study involves two separate interviews and each interview will be scheduled at your convenience. The first interview will be for approximately 20-30 minutes and the second interview will be for approximately 60-90 minutes. Both interviews will may be held at the Currie Gymnasium located at 475 avenue des Pins, in Montreal or an agreed upon alternative private location. I will take notes during the first interview which will focus on background information about your TBI and exercise history. The second interview will be audio recorded with a digital voice recording device and will focus on your current habits and experiences with exercise in the post-rehabilitation time frame. The second interview will last approximately 60-90 minutes. You will be compensated for transportation costs and/or parking with \$20.00 and will be provided a beverage and refreshment at each of these meetings (e.g., a bottle of water and a granola bar).

If you are interested to participate in this study, may I send you the consent form, which provides you with more information about the project?

Please, feel free to contact me at the information below if you have any questions about this study and thank you very much for letting me know, whatever your decision may be.

I hope you have a great day!!!

Enrico Quilico

B.Ed., M.A. Student
Adapted Physical Activity
Dept of Kinesiology & Physical Education
McGill University
enrico.quilico@mail.mcgill.ca
514.743.6788

William J. Harvey, Ph.D.

Associate Professor
Undergraduate Program Director
Dept of Kinesiology & Physical Education
McGill University
william.harvey@mcgill.ca
514.398.4184, ext. 0488

Annexe C

Invitation par courriel à participer au projet de recherche

Bonjour,

Je m'appelle Enrico Quilico. Je suis un étudiant de maîtrise supervisé par le professeur William Harvey au Département de kinésiologie et éducation physique à McGill.

J'aimerais vous inviter à participer à une étude qui a pour objectif d'améliorer la santé et la qualité de vie des gens qui ont subi un traumatisme cérébral. Le projet consiste à explorer les habitudes en matière d'exercice physique chez les personnes qui ont subi un traumatisme cranio-cérébral (un TCC) modéré à sévère et qui ne sont plus traités dans un centre de réadaptation.

La participation à l'étude représente deux entrevues distinctes, aux dates et aux heures qui vous conviennent. La première entrevue dure entre 20 et 30 minutes et la seconde, entre une heure et une heure et demie. Les deux entrevues ont lieu au Gymnase Currie, 475 avenue des Pins à Montréal, ou dans un endroit privé qui aura été convenu. Je prendrai des notes durant la première entrevue, qui portera sur des renseignements généraux concernant votre TCC et vos habitudes antérieures en matière d'exercice physique. La seconde entrevue sera enregistrée avec un système d'enregistrement numérique de la voix et portera sur vos habitudes et vos expériences actuelles d'exercice en période post-réadaptation. Cette deuxième entrevue devrait durer de 60 à 90 minutes. Vous recevrez 20,00 \$ pour couvrir votre transport ou votre stationnement et une légère collation sera servie durant l'entrevue (bouteille d'eau et barre granola).

Si vous êtes intéressé à participer à l'étude, pourrais-je vous envoyer le formulaire de consentement qui renferme tous les détails ?

N'hésitez pas à me contacter à l'adresse courriel ou au numéro de téléphone ci-dessous et je me ferai plaisir de répondre à toutes vos questions concernant cette étude. S'il vous plaît, laissez-moi savoir si vous êtes intéressé ou non.

Je vous souhaite une excellente journée !!!

Enrico Quilico

B. Éd., étudiant à la maîtrise
Activité physique adaptée
Département de kinésiologie et éducat.phys.
Université McGill
enrico.quilico@mail.mcgill.ca
514.743.6788

William J. Harvey, Ph.D.

Professeur agrégé
Directeur de programme de premier cycle
Département de kinésiologie et éducat.phys.
Université McGill
william.harvey@mcgill.ca
514.398.4184, poste 0488

Appendix D

Consent Form

Title: Facilitators and Barriers to Post-Rehabilitation Exercise following Moderate to Severe Traumatic Brain Injury

Principal Investigator: Mr. Enrico Quilico; McGill Faculty Supervisor: Dr. William Harvey

Department of Kinesiology and Physical Education, McGill University, Montreal (Quebec)

Dear participant,

My name is Enrico Quilico and I am a graduate student, under the supervision of Dr. William Harvey, in the Department of Kinesiology and Physical Education at McGill University. As part of my master's thesis, I am conducting a research project about the exercise habits and experiences of people with traumatic brain injuries (TBI) in Montreal (Quebec).

I am inviting you to participate in a study which is geared toward improving the quality of life for people who live with a TBI. The purpose of the research project is to examine the exercise habits of people who (a) have suffered a TBI and (b) are no longer in treatment at a rehabilitation centre. More specifically, the objective is to determine the facilitators and barriers to exercise for people with TBI outside of rehabilitation. This research will contribute to the existing body of knowledge about managing TBI related impairment as well as promoting overall health and well being.

We are asking your permission to participate in the study. If you accept, you will be involved in two separate, individual interviews and each interview will be scheduled at your convenience. I will take notes during the first interview which will focus on background information about the TBI and exercise history. The second interview will be audio recorded with a digital voice recording device and will focus on current habits and experiences with exercise in the post-rehabilitation time frame. The second interview will last approximately 60-90 minutes. Both interviews will be held in a private office in the Currie Gymnasium located at 475 avenue des Pins, Montreal (Quebec) H2W 1S4 or at an agreed upon alternative private location. You will be compensated for transportation costs and/or parking with \$20.00 and will be provided a beverage and refreshment at each of these meetings (e.g., a bottle of water and a granola bar).

The audio-recorded data collected from the interviews will be transcribed verbatim and coded for analysis purposes. Your name will be replaced with a pseudonym in order to protect your privacy. I will analyze this data with supervisor, members of my research committee and potentially other graduate students who are members of our research lab. However, only I will code the identifying information and guarantee your privacy. This study is expected to be

published and presented based on the valuable information that we expect to gather. However, this data will remain coded and your identity will remain undisclosed. The data bank of collected information will remain on my password protected computer in a password protected encrypted file. Any printed information will remain filed in a locked cabinet in my supervising professor Dr. Harvey's office in the faculty of Kinesiology and Physical Education at McGill University.

It may cause you discomfort to speak about your past experiences that involve your brain injury. However, your participation is completely voluntary and you can stop at any time or for any reason if you feel discomfort. You may decline to answer any of the interview questions and may withdraw from the study at any time and for any reason. You will also be encouraged to withhold any information that you are not comfortable sharing at the beginning of each interview in order to avoid potential discomfort.

This study has been reviewed by the McGill University Research Ethics Board II Committee.

You will be provided a copy of the consent document to keep for your own records.

If you have any questions or concerns regarding your rights or welfare as a participant in this research study, please contact the McGill Ethics Officer Ms. Lynda McNeil by telephone to 514-398-6831 or by email to lynda.mcneil@mcgill.ca.

If you have any questions or concerns about your participation in this study, please contact

Mr. Enrico Quilico (principal investigator) by telephone to 514-743-6788 or by email to enrico.quilico@mail.mcgill.ca

Dr. William Harvey (McGill Faculty supervisor) by telephone to 514-398-4184 (x0488) or by email to william.harvey@mcgill.ca

Please sign below if you agree to participate in this study.

Signature

Date

I agree to the audio-recording of the interviews with the understanding that these recordings will be used solely for the purpose of transcribing these sessions. Yes ☐ No ☐ _____ Initials

Annexe D

Formulaire de consentement

Titre : Analyse des facteurs facilitant ou empêchant l'exercice post-réadaptation à la suite d'un traumatisme crânio-cérébral modéré à sévère

Chercheur principal : M. Enrico Quilico; Superviseur de la recherche : Professeur William Harvey

Département de kinésiologie et éducation physique, Université McGill, Montréal (Québec)

Cher Monsieur,

Je m'appelle Enrico Quilico et je suis un étudiant de maîtrise supervisé par le professeur William Harvey au Département de kinésiologie et éducation physique à l'Université McGill. Dans le cadre de mon mémoire de maîtrise, je mène un projet de recherche sur les habitudes et les expériences d'exercice physique chez des Montréalais ayant subi un traumatisme crânio-cérébral (TCC).

Je vous invite à participer à une étude qui vise à améliorer la qualité de vie des personnes qui vivent avec les séquelles d'un TCC. Le but de ce projet de recherche est d'examiner les habitudes en termes d'exercice physique chez les personnes qui a) ont subi un traumatisme cérébral et b) ne sont plus traités dans un centre de réadaptation. Plus précisément, l'objectif est de déterminer les facteurs qui incitent les victimes d'un TCC à faire de l'exercice en dehors des séances de réadaptation, ou au contraire les en empêchent. Cette recherche sera versée au fonds actuel des connaissances sur la façon de gérer les séquelles d'un TCC et de promouvoir la santé et le mieux-être en général.

Nous vous demandons de consentir à participer à cette étude. Si vous y consentez, vous serez interviewé à deux reprises en privé, à la date et à l'heure qui vous conviennent. Je prendrai des notes durant la première entrevue, qui portera sur des renseignements généraux concernant votre TCC et vos habitudes antérieures en matière d'exercice physique. La seconde entrevue sera enregistrée avec un système d'enregistrement numérique de la voix et portera sur vos habitudes et vos expériences d'exercice actuellement, en période post-réadaptation. Cette deuxième entrevue devrait durer de 60 à 90 minutes. Les deux entrevues auront lieu au Gymnase Currie, 475 avenue des Pins à Montréal, ou dans un endroit privé qui aura été convenu. Vous recevrez 20,00 \$ pour couvrir votre transport ou votre stationnement et une légère collation sera servie durant l'entrevue (bouteille d'eau et barre granola).

L'enregistrement sonore des données recueillies durant la seconde entrevue sera transcrit mot à mot et codé aux fins de l'analyse. Votre nom sera remplacé par un pseudonyme afin de protéger

vosre identité. Je procéderai à l'analyse de ces données avec mon superviseur, les membres de mon comité de recherche et peut-être d'autres étudiants de deuxième cycle qui font partie de notre laboratoire de recherche. Cependant, je serai le seul à coder l'information susceptible de vous identifier et je garantis la confidentialité de vos renseignements. Cette étude sera probablement publiée et présentée afin de faire circuler les précieuses informations que nous nous attendons à colliger. Cependant, ses données demeureront codées et votre identité ne sera en aucun temps divulguée. La banque de données recueillies sera entreposée dans mon ordinateur protégé par un mot de passe. Toute information imprimée sera gardée sous clé dans un classeur du bureau de mon superviseur, le professeur Harvey du Département de kinésiologie et éducation physique à l'Université McGill.

Vous pourriez trouver pénible de parler des expériences qui entourent votre traumatisme cranio-cérébral. Toutefois, votre participation est entièrement volontaire et vous pouvez y mettre fin à n'importe quel moment si vous ne vous sentez pas à l'aise. Vous pouvez refuser de répondre à une ou plusieurs des questions et vous pouvez aussi vous retirer définitivement de l'étude, quelles que soient vos raisons. Au début des deux entrevues, vous serez encouragé à vous abstenir de donner des renseignements dont vous n'avez pas envie de parler, pour éviter que l'entrevue ne vous paraisse pénible.

Ce projet a été examiné par le Comité II du Conseil de l'éthique à la recherche de l'Université McGill.

Vous recevrez une copie du document de consentement à conserver pour vos dossiers.

Si vous avez des questions ou des inquiétudes concernant vos droits ou votre bien-être en tant que participant à cette étude, n'hésitez pas à contacter la directrice de l'éthique à la recherche à l'Université McGill, Mme Lynda McNeil par téléphone au 514-398-6831 ou par courriel à <mailto:lynda.mcneil@mcgill.ca>

Pour toute question ou toute inquiétude concernant votre participation à l'étude, vous pouvez rejoindre :

M. Enrico Quilico (chercheur principal) par téléphone au 514.743.6788 ou par courriel à <mailto:enrico.quilico@mail.mcgill.ca>

Professeur William Harvey (superviseur de la recherche à McGill) par téléphone au 514.398.4184, poste 0488, ou par courriel à <mailto:william.harvey@mcgill.ca>

S'il vous plaît signer ci-dessous si vous acceptez de participer à cette étude.

Signature

Date

Je consens à ce que mes entrevues soient enregistrées sur bande sonore, étant entendu que cet enregistrement ne servira qu'à en faire la transcription. Oui ☐ Non ☐ _____ Initiales

Appendix E

Table 1. *Data Gathering Procedures*

Semi-Structured Interview	Duration	Data
One	20-30 minutes	Demographic information Self-reported TBI information Self-reported exercise history
Two	60-90 minutes	Self-reported exercise habits Perceived facilitators and barriers to exercise General perceptions about exercise experiences

Appendix F

Interview Guide: One

Time of Interview:

Date:

Place:

Interviewer:

Interviewee:

Position of Interviewee:

Explain the purpose of conducting the study and how you are connected to the research about traumatic brain injuries before the questions begin. Explain that this first interview will focus on demographic information and their TBI, as well as their exercise history one year before the injury.

Inform the participant that speaking about his TBI and past may cause discomfort. Encourage the participant to specifically withhold information that he is not comfortable speaking about during the interview. Remind the participant that he may withdraw from the study at any time.

Questions (Main Questions followed by Probes):

1. How old are you?
2. What is your level of education?
3. Are you employed?
 - a. What kind of work do you do?
 - b. How many hours do you work a day?
 - c. How many hours do you work a week?
4. What is your income level?
5. What is your marital status?
 - a. Do you have any children?
 - b. If yes, how many?
 - c. If yes, how old?
6. Please tell me about your TBI?
7. What was the cause of the TBI?
8. How long has it been since the TBI?
9. What types of impairments do you still have?
10. How long were you in a clinical setting after the TBI?
 - a. How long were you in the hospital?
 - b. How long did you participate in rehabilitation as an inpatient?
 - c. How long did you participate in rehabilitation as an outpatient?

Define exercise according to Canadian Health Standards (2012) as planned, moderate to vigorous aerobic activity and muscle strengthening activities with clear examples provided. (e.g. brisk walking, bike riding, jogging, cross country skiing and weight bearing exercises).

Questions about exercise habits 1 year before your traumatic brain injury (Main Questions):

- How frequently did you exercise?
- How intense was the exercise?
- If you exercised, how long would you exercise for?
- If you exercised, what types of exercise did you do?

Thank the individual for participating in the interview. Explain that you may contact the individual again to confirm the data by telephone. Confirm and schedule the following interview.

Mr. Enrico Quilico: Phone 514-743-6788 or Email enrico.quilico@mail.mcgill.ca

Dr. William J. Harvey: Phone 514-398-4184, ext. 0488 or Email william.harvey@mcgill.ca

Annexe F

Protocole de la 1^{ère} entrevue

Heure de l'entrevue :

Date :

Endroit :

Intervieweur :

Interviewé :

Position de l'interviewé :

Avant tout, décrire l'objectif de l'étude et le rapport de l'intervieweur à la recherche sur le traumatisme crânio-cérébral (TCC). Expliquer à l'interviewé que cette première entrevue portera sur les données démographiques et les particularités de son TCC, de même que sur son activité physique dans l'année qui a précédé le traumatisme.

Avertir le participant que le fait de parler de son TCC et de ses expériences passées pourrait s'avérer pénible. L'encourager à s'abstenir de donner des renseignements dont il n'a pas envie de parler en entrevue. Lui rappeler qu'il est libre de se retirer de l'étude à n'importe quel moment.

Questions (Questions principales et complémentaires) :

11. Quel âge avez-vous ?
12. Quel niveau d'études avez-vous complété ?
13. Avez-vous un emploi ?
 - a. Quel genre de travail faites-vous ?
 - b. Combien d'heures par jour travaillez-vous ?
 - c. Combien d'heures par semaine travaillez-vous ?
14. À quel niveau de revenu vous situez-vous ?
15. Quelle est votre situation familiale ?
 - a. Avez-vous des enfants ?
 - b. Si oui, combien ?
 - c. Si oui, de quel âge ?
16. Voulez-vous me décrire les circonstances de votre TCC ?
17. Quelle a été la cause de votre TCC ?
18. À quand remonte ce TCC ?
19. Quels genres de séquelles éprouvez-vous encore aujourd'hui ?
20. Combien de temps avez-vous passé en milieu clinique à la suite de ce TCC ?
 - a. Combien de temps à l'hôpital ?
 - b. Combien de temps en réadaptation à l'interne ?
 - c. Combien de temps en réadaptation à l'externe ?

Définir l'exercice physique en fonction des normes canadiennes de santé (2012) et expliquer, à l'aide d'exemples clairs, en quoi consiste les activités aérobiques ou les exercices de musculation modérés à vigoureux qui sont envisagés (marche rapide, vélo, jogging, ski de fond, exercices de port de poids, etc.)

Questions concernant les habitudes en matière d'exercice physique 1 an avant le traumatisme cérébral (Questions principales) :

- À quelle fréquence faisiez-vous de l'exercice ?
- Quelle était l'intensité de ces exercices ?
- Si vous faisiez de l'exercice, combien de temps durait chaque séance ?
- Si vous faisiez de l'exercice, quel genre d'exercices pratiquiez-vous ?

Remercier le sujet d'avoir pris part à l'entrevue. Lui dire qu'il est possible que vous lui téléphoniez pour confirmer l'information recueillie. Fixer un rendez-vous pour la seconde entrevue.

Mr. Enrico Quilico: Tél. 514.743.6788 ou courriel <mailto:enrico.quilico@mail.mcgill.ca>
Dr. William J. Harvey: Tél. 514.398.4184, poste 0488 ou courriel <mailto:william.harvey@mcgill.ca>

Appendix G

Interview Guide: Two

Time of Interview:

Date:

Place:

Interviewer:

Interviewee:

Position of Interviewee:

Thank the participant for their involvement with the study and explain how the interview will be conducted like the first but in more depth and will now focus on the time after rehabilitation.

Inform the participant that speaking about his TBI and past may cause discomfort. Encourage the participant to specifically withhold information that he is not comfortable speaking about during the interview. Remind the participant that he may withdraw from the study at any time.

Questions (Main Questions followed by Probes):

1. Tell me about your current exercise habits?
 - a. How frequently do you exercise?
 - b. If you exercise, how intense is the exercise?
 - c. If you exercise, how long do you exercise for?
 - d. If you exercise, what types of exercise do you do?
2. What kinds of factors allow you to exercise?
 - a. Provide environmental examples like transportation, time, resources, etc.
 - b. Provide personal examples like motivation, abilities, etc.
3. What kinds of factors stop you from exercising?
 - a. Provide environmental examples like transportation, time, resources, etc.
 - b. Provide personal examples like motivation, abilities, etc.
4. What do you think about exercise after your TBI?
 - a. How do you think exercise is good for you?
 - b. How do you think exercise is bad for you?
5. How do you experience exercise after your traumatic brain injury?
 - a. What do you like about exercise?
 - b. What do you not like about exercise?

Thank the individual for participating in the interview and the study. Explain that you may contact the individual again to confirm data by telephone. Assure the participant about the confidentiality of responses as data will be coded.

Contact Information

Mr. Enrico Quilico: Phone 514-743-6788 or Email enrico.quilico@mail.mcgill.ca

Dr. William J. Harvey: Phone 514-398-4184, ext. 0488 or Email william.harvey@mcgill.ca

Annexe G

Protocole de la 2^e entrevue

Heure de l'entrevue :

Date

Endroit :

Intervieweur :

Interviewé :

Position de l'interviewé :

Remercier l'interviewé de participer à l'étude et lui expliquer que cette entrevue se déroulera un peu comme la première, mais qu'elle ira plus en profondeur en insistant cette fois sur la période post-réadaptation.

Avertir le participant que le fait de parler de son TCC et de ses expériences passées pourrait s'avérer pénible. L'encourager à s'abstenir de donner des renseignements dont il n'a pas envie de parler en entrevue. Lui rappeler qu'il est libre de se retirer de l'étude à n'importe quel moment.

Questions ((Questions principales et complémentaires):

1. Voulez-vous me parler de vos habitudes actuelles en termes d'exercice ?
 - a) À quelle fréquence faites-vous de l'exercice ?
 - b) Si vous en faites, quelle est l'intensité de cet exercice ?
 - c) Si vous en faites, combien de temps dure chaque séance d'exercice ?
 - d) Si vous en faites, quel type d'exercice pratiquez-vous ?
2. Quels types de facteurs vous facilitent l'exercice ?
 - a. Facteurs environnementaux : le temps, le transport, les ressources, etc.
 - b. Facteurs personnels : votre motivation, vos aptitudes, etc.
3. Quels types de facteurs vous empêchent de faire de l'exercice ?
 - a. Facteurs environnementaux : le temps, le transport, les ressources, etc.
 - b. Facteurs personnels : votre motivation, vos aptitudes, etc.
4. Que pensez-vous de l'exercice depuis que vous avez subi un TCC ?
 - a. Trouvez-vous que l'exercice vous fait du bien ?
 - b. Trouvez-vous que l'exercice vous fait du tort ?
5. Comment vous sentez-vous en faisant de l'exercice depuis votre TCC ?
 - a. Qu'est-ce qui vous plaît dans l'exercice ?
 - b. Qu'est-ce qui vous déplaît dans l'exercice ?

Remercier l'interviewé d'avoir pris part à l'entrevue et à l'étude. Lui dire que vous lui téléphonerez peut-être pour confirmer l'information recueillie. Le rassurer sur la confidentialité de ses réponses du fait que les données sont codées.

Coordonnées

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Appendix H

Table 2. *Confirmability Audit*

Theme 1

Impact of TBI

Lower Order Themes	Alex	Ben	Chris	David	Eric	Felix	Greg
Physical Changes after TBI	3	7	12	4	1	13	10
Psychological Changes after TBI	4	6	9	10	15	3	1
Self-Perceptions	1	7	-	4	6	7	-

Theme 2

Personal Development after TBI

Lower Order Themes	Alex	Ben	Chris	David	Eric	Felix	Greg
Pre-Injury Mentality	2	3	2	-	9	4	-
Awareness – Risks	2	2	13	-	1	-	-
Awareness – Others' Abilities	1	4	5	5	1	-	-
Personal Growth	7	10	2	2	10	1	10

Theme 3

Facilitators and Barriers to Exercise

Lower Order Themes	Alex	Ben	Chris	David	Eric	Felix	Greg
Availability of Time	2	5	6	2	2	1	6
Planning	-	-	2	4	1	-	-
Accessibility – Resources	4	2	1	5	1	4	3
Accessibility – Transport	2	2	3	1	6	5	2
Weather Conditions	4	-	2	1	3	-	1
Organized Sports	2	-	6	3	2	-	-
Exercise Support	13	2	3	5	2	3	2
Motivation to Exercise	12	7	9	12	14	13	19

Theme 4

Exercise after TBI

Lower Order Themes	Alex	Ben	Chris	David	Eric	Felix	Greg
Exercise Habits	12	7	9	12	14	13	19
Productive Activity with Exercise	2	4	16	1	8	1	2
Importance of Exercise after TBI	7	3	1	2	4	-	2
Effects of Exercise on Attention	1	3	6	2	4	-	1
Physical Effects of Exercise	4	8	8	6	4	3	7
Social Effects of Exercise	2	-	4	4	1	1	3
Effects of Exercise on Mood	10	11	7	18	17	10	9

Appendix I

Table 3. *Higher Order Categories of Lower Order Themes*

Impact of TBI	Personal Development after TBI	Facilitators and Barriers to Exercise	Exercise after TBI
Physical abilities after TBI	Pre-injury mentality	Availability of time	Exercise habits
Psychological changes after TBI	Awareness – risks	Planning	Productive activity with exercise
Self-perceptions	Awareness – others' abilities	Accessibility – resources	Importance of exercise after TBI
	Personal growth	Accessibility – transport	Physical effects of exercise
		Weather conditions	Effects of exercise on attention
		Organized sports	Social effects of exercise
		Exercise support	Effects of exercise on mood
		Motivation to exercise	

Appendix J

Table 4. *Self-Reported Exercise Habits*

Participants	Frequency	Intensity	Time	Type
Alex	2 x Week	Moderate to Vigorous	120 minutes	Adapted cycling Adapted skiing Wheelchair sports
Ben	6-7 x Week	Moderate to Vigorous	60 minutes	Resistance training
Chris	3-7 x Week	Moderate to Vigorous	60-90 minutes	Jogging Soccer Floor hockey, Basketball, Badminton
David	7 x Week	Moderate	60-120 minutes	Ultimate Frisbee Badminton
	2-3 x Week	Vigorous		Basketball Biking Roller blades
Eric	7 x Week	Moderate	30-60 minutes	Brisk walking Basketball
	1-2 x Week	Vigorous		Ultimate Frisbee Ping-pong Swimming
Felix	2 x Week	Moderate to Vigorous	30-60 minutes	Biking Swimming Skiing
Greg	2-4 x Week	Moderate to Vigorous	60-70 minutes	Biking Skiing Resistance training