

**“I FEEL LIKE A PROFESSIONAL INJURED PERSON”: NON-ELITE ATHLETES’
EXPERIENCES, APPRAISALS, AND COPING STRATEGIES WITH PERSISTENT
POST-CONCUSSIVE SYMPTOMS**

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“I Feel like a Professional Injured Person”: Non-elite Athletes’ Experiences, Appraisals, and Coping Strategies with Persistent Post-Concussive Symptoms

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Abstract

Approximately 15% of athletes who sustain concussions experience prolonged symptoms beyond the expected recovery timeline (10-14 days) (McCrorry et al., 2013; McCrorry et al., 2017). The presence of psychological distress can contribute to the lingering symptomology (Sandel et al., 2017), but there is limited knowledge on psychological processes (e.g., appraisal and coping patterns) through which it may be elicited and maintained. Non-elite athletes may be at a higher risk of prolonged recoveries due to having limited access to specialized concussion care compared to their elite counterparts (Putukian, Aubry & McCrorry, 2009).

This thematic analysis of semi-structured interviews explored experiences, appraisals and coping strategies of 12 non-elite athletes that on average experienced persistent post-concussive symptoms for 16 months. Three themes were identified. *Evolving appraisals amidst concussion ambiguity* suggested that a lack of recovery-related information available from health care practitioners allowed the participants to experience fluid understandings of their injury. While they initially perceived their concussion to be inconsequential, they eventually believed to have developed a serious health condition with organic origins and limited rehabilitation strategies. *Burgeoning psychological distress* highlighted how expectations of lasting negative consequences elicited growing distress for the participants regarding their health status, self-identity, and appropriate methods to manage their symptoms. They questioned whether they would ever be able to re-engage with their valued activities, and eventually prioritized work, school, and exercise over their return to organized sport. Lastly, *“I’m just trying anything to get better”* reflected participants’ transition from passive to more active coping methods in attempts to manage their ongoing symptoms. Positive reappraisal and acknowledging/addressing psychological recovery barriers (e.g., anxiety) seemed to positively impact recovery.

This study enhances the understanding of persistent post-concussive symptoms through examination of the participants' subjective experiences. Findings suggest that interventions should disseminate current knowledge on psychological aspects of concussion recovery to health care practitioners, so they can in turn communicate a more complete understanding of the injury to affected individuals. The goal of this knowledge transfer would be to reduce illness uncertainty, mitigate a source of psychological distress, and to promote adaptive appraisal and coping patterns.

Lay Summary

Non-elite (or recreational) athletes were interviewed about their experiences with prolonged concussion recoveries. Specifically, this study explored the relationship between their understandings of their ongoing symptoms and corresponding management strategies. The findings indicate that prolonged concussion recoveries are stressful, primarily because of the lack of information available to manage the injury. Participants struggled with understanding how to appropriately cope with their recovery and knowing what long-term consequences it would have to their health, identity, and lifestyle. They believed their symptoms originated from body-related or brain-related impairments and were initially informed that rest was the only way to heal. However, this strategy was not helpful, and some participants realized it was actually counterproductive to their overall wellbeing. Therefore, they began to engage in alternative management strategies for their recovery. Accepting limitations, focusing on positive aspects, and addressing psychological recovery barriers seemed to help some of the participants feel better.

Preface

This research was approved by the University of British Columbia's Behavioural Research Ethics Board (H18-00367). A version of this work will be submitted for publication. I conceptualized, designed and carried out this research with the support of my supervisor, Dr. Peter Crocker. I was responsible for developing the research questions, participant recruitment, data collection/interviews, transcription, analysis, and thesis preparation. Dr. Peter Crocker, Dr. Moss Norman, and Dr. Noah Silverberg are co-authors on this thesis. The co-authors provided guidance, comments, and feedback on the study design, literature review, data interpretation, and final thesis preparation.

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This study could not have been accomplished without the contributions of the 12 participants who shared their experience with me, so I would like to thank them for their willingness to participate and their candor during the interviews.

Dedication

To my family.

Abue, Dad, Mom, Daniel, Andy, and Linda, you all supported me in specific and special ways throughout my own concussion recovery and this degree – I truly could not be here without you.

Felix, you met me when I was at my lowest, and now I am at my trending towards my highest thanks to your support and encouragement.

Chapter 1: Introduction

It is estimated that 1.6 to 3.8 million individuals sustain concussions every year while participating in sport or physical activity in the United States (Langlois, Rutland-Brown, & Wald, 2006). Assuming a similar incidence rate per capita in Canada would explain why sport concussions have become a public health concern (Tator, 2009). Research on the injury has grown exponentially in the past few decades and has provided valuable knowledge in terms of symptom identification, diagnostic neurocognitive evaluations, and gradual return-to-activity protocols. McCrory et al. (2017) define concussion as a neurological disturbance that can result in an array of physical, somatic, and cognitive symptoms. These symptoms can be reported by injured individuals, detected visually, or through neuropsychological testing. When a concussion is sustained, a period of 24–48 hours of physical rest and cognitive rest is recommended before gradually returning to normal activity. Recovery then follows a sequential and short-lived course that typically lasts 10 to 14 days in adults. These are general understandings of the injury, but researchers note that recoveries are highly individualized, and some may become prolonged (King, Brughelli, Hume & Gisanne, 2014).

Approximately 15% of concussed individuals do not recover within the expected timeframe of 10 to 14 days, and instead endure persistent and debilitating physical, cognitive and emotional symptoms for prolonged periods of time (McCrory et al., 2013). The recognition of prolonged concussion recoveries has been longstanding (e.g. Russell, 1932; Adler, 1945) and has received increasing attention. The Concussion in Sport Group (CISG) – an international assembly of renowned sport concussion experts – now refers to the condition as “persistent post-concussive symptoms” (McCrory et al., 2017). Despite the awareness of prolonged concussion recoveries however, there is no research or medical consensus on why symptoms linger and no

widespread understanding on how to manage them. Therefore, Ruff's (1996) term "miserable minority," referring to the subgroup of individuals who experience persistent symptoms, remains relevant.

The origin of these persistent symptoms has been debated in the literature, but there is a growing consensus that psychological factors play a prominent role in concussion recovery and can therefore influence the development of the condition (McCrory et al., 2017). Quantitative studies with athletes have revealed that affective responses of psychological distress (e.g., depression, anxiety, irritability, general mood disturbance) are often reported after SRC (Mainwaring et al., 2009; Mainwaring, Hutchison, Bishop, Comper & Richards, 2010). These symptoms are understood to be subjective experiences of athletes following injury, developing in unique patterns for each individual (Wiese-Bjornstal, White, Russell & Smith, 2015). Their presence is theorized to prolong recovery, but it is unclear to what extent these symptoms are a direct result of neurological and physiological disturbance following concussion, and to what extent they are a consequence of contextual stressors associated with the injury. The latter consideration is garnering increasing research interest as it can provide a modifiable target of intervention (Silverberg & Iverson, 2011). That is, understanding the specific stressors involved in concussion recovery could provide an opportunity to address these in order to decrease the risk of developing persistent symptoms.

The sporting context can present a unique set of stressors for concussion recovery. Although a sport organization can provide access to concussion management resources and social support, a team environment can also put negative pressure on the concussed individual. For example, teammates and coaches can influence the individual to hide their injury or to return to play before symptoms have resolved (Bloom, Horton, McCrory, & Johnston, 2004). When

removed from their team for prolonged periods of time, athletes can question their sport identity (Putukian, 2016). While rehabilitating injury might be common for them, they might feel distressed when they are not able to implement habitual strategies for concussions as they do for musculoskeletal injuries (McGrath, 2010). Non-elite athletes face specific implications after concussions. Compared to the relatively resource-rich and multidisciplinary healthcare access available to many elite athletes, concussion management resources may not be available to them (Putukian, Aubry & McCrory, 2009). Therefore, when analyzing psychological factors of concussion, it is important to consider the environment in which recovery is happening (Wiese-Bjornstal et al., 2015).

The research literature has revealed an eclectic mix of psychological precursors and consequences of sport concussions but have neglected key psychological processes that can further illuminate the occurrence of persistent post-concussive symptoms. The stress and coping literature, which provides the basis for some key sport injury psychology models, posits that cognitive appraisal and coping are key components that can mediate recovery outcomes. Cognitive appraisal determines whether or not, and to what extent, a situation is perceived as stressful depending on how it relates to personal goals. If a situation is perceived as stressful, an individual then determines what kind of coping methods are available to manage the threat. Different cognitive and behavioural coping methods are then used in an attempt to subdue the stressful encounter (Lazarus & Folkman, 1984). The effectiveness of the methods is dependent on a good fit between environmental demands and the individual's goals and actions (Lazarus, 2000). This framework provides a relevant approach to concussion-related stress, given that the injury is understood to be stressful and individualized.

This study explored cognitive appraisal and coping as they relate to experiences of non-elite athletes with persistent post-concussive symptoms. Qualitative methodology was utilized as it is considered useful in exploring complicated phenomena (Marshall & Rossman, 2011). The process allowed for the production of data surrounding contexts, beliefs, and personal values that aided in the understanding of the individual meanings assigned to concussion recovery.

Borrowing from previous research findings and the stress and coping literature, an interpretive paradigm guided a semi-structured interview and thematic analysis (Braun & Clarke, 2006) process that explored the participants' subjective experiences. The findings help to provide a better understanding of psychological mechanisms involved in the development of persistent post-concussive symptoms.

The specific question that guided the study was:

- How do non-elite athletes perceive, experience, and cope with persistent post-concussive symptoms?

Chapter 2: Literature Review

2.1 Sport-related concussion

Sport-related concussions (SRC) differ from those sustained in other settings (e.g. motor vehicle accidents) because they are typically a result of lower velocity impacts, and lead to disorientation and confusion more often than loss of consciousness (Erlanger, Kutner, Barth, & Barnes, 1999; Barth, Freeman, Broshek, & Varney, 2001; McCrory et al., 2017). Compared to patients sustaining concussions in non-sport contexts, athletes have shown on average to experience faster recoveries and less disability (Rabinowitz, Li, & Levin, 2014). Sport also provides a specific social context that can influence the risk, response and recovery of concussions (Wiese-Bjornstal, 2010). Traditionally, sport has adopted a “culture of risk” (Frey, 1991) in which behavior that induces pain and injury is not only accepted, but encouraged as “part of the game” and “good of the team” (Nixon, 1992). This risk culture encourages athletes to push the physical boundaries of their bodies and to normalize or downplay pain. The combination of this mentality with the physical demands of sport is conducive to injuries, such as concussions. When concussed, athletes tend to respond differently compared with other injuries because they typically do not result in obvious signs or symptoms (Kontos, Elbin, Appaneal, Covassin & Collins, 2013). This may lead athletes to downplay their injury, not be aware of it, or neglect to report it. In fact, it is estimated that most concussions go unreported due to players not seeking medical attention, not wanting to be removed from competition, or having a lack of awareness of the injury (Delaney, Lacroix, Leclerc & Johnston, 2002; McCrea, Hammack, Olsen, Leo, & Guskiewicz, 2004).

The recognition of sport concussion prevalence has provoked a surge in research seeking

to understand the injury. From 1980 to 1989 there was a total of 40 studies published on “concussion and sport”. Those numbers are projected to grow to a total of 2416 publications in this decade (Kontos & Reynolds, 2015). While the growing awareness and research interest has been good for the production of knowledge, findings have not always aligned. This is reflected by the existence of at least 16 different guidelines on how to evaluate and manage sport concussion prior to 2001 (Hayden, Jandial, Duenas, Mahajan, & Levy, 2007). The increasing, yet divergent growth of research culminated in the formation of the Concussion in Sport Group (CISG) in 2001 – an international assembly of the leading researchers of sport concussions that deliberates on recent findings and publishes a consensus every four years. The goal of the consensus statements is “to serve as a scientific tool to widely disseminate the knowledge in order to achieve maximum impact on both current health care practice and future medical research” (McCrory et al., 2009, p. 42). The vast scope of the latest 2017 was demonstrated by the estimated 60 000 published articles that were screened and synthesized in preparation (McCrory et al., 2017). The consensus statements have evolved to become the most comprehensive and updated source of information regarding concussions in sport and have grown to dominate the landscape of concussion policy, assessment, and management.

The CISG group defines concussion as a traumatic brain injuries induced by biomechanical forces with the following common features: (a) caused by impact to the head or elsewhere in the body that transmits an impulsive force to the head, (b) typically resulting in a rapid onset of transient neurological impairments that resolve spontaneously, (c) resulting in acute symptoms that are believed to be produced by a functional disturbance rather than a focal structural injury (i.e., no abnormality is detected on standard structural neuroimaging studies), and (d) the symptoms may or may not include loss of consciousness. These symptoms typically

involve one or more of the following: physical signs (e.g. loss of consciousness, amnesia), somatic symptoms (e.g. headache), cognitive difficulties (e.g. slowed reaction times, confusion), emotional/behavioural abnormalities (e.g. irritability), and balance impairments (e.g. unsteadiness) (McCrorry et al., 2017). Due to the lack of biomarkers associated with the injury, concussions remain a clinical diagnosis based on observable signs or athletes' reported symptoms (McCrea, Nelson, & Guskiewicz, 2017). Even though these signs and symptoms indicate that a concussion may have occurred, the injury may still happen without the presence of any overt indications (Delaney, Lamfookon, Bloom, Al-Kashmiri, & Correa, 2015; King et al., 2014). Following injury, the brain acts to repair the damage by diverting energy from regular function (Giza & Hovda, 2014). Due to this process, the brain is said to be in a vulnerable state during which an additional impact can have amplified neurological consequences (Prins, Alexander, Giza & Hovda, 2013). This neurological disturbance caused by a concussion is expected to resolve itself spontaneously and relatively quickly. It is understood that regular function should resume within minutes and at most within two weeks in adults; the developing brains of children and adolescents may take up to 4 weeks for recovery (McCrorry et al., 2017).

Due to the recognition of the high incidence of sport concussions, there has been a growing interest to develop methods that can help diagnose the injury and assess recovery. The identification of biomarkers (e.g., neuroimaging, fluid markers) to improve concussion diagnosis and management has become a popular area of research, however they currently remain clinically unproven (Snyder & Giza, 2019). Neuropsychological testing has emerged as the most commonly recognized standardized assessment method, with the Sport Concussion Assessment Tool – 5th Edition (SCAT5) now widely accepted in sporting realms as a sideline evaluation (Echemendria et al., 2017). The assessment should be administered by a healthcare professional

and measures orientation, consciousness, memory, and balance. A score is calculated based on these domains to determine whether a concussion is suspected or not. However, an athlete may still have a concussion even if the scores reflect normal function (Guskiewicz et al., 2013), which explains why the SCAT5 should not be used as a stand-alone method to screen for concussion and track recovery (Echemendria et al., 2017). It is recommended that a follow-up exam be performed by a doctor that includes a comprehensive medical history and a detailed neurological examination of mental status, cognitive functioning, ocular and vestibular function, gait and balance. This process is important to rule out a more serious brain injury such as structural damage (McCrorry et al., 2017) or other concurrent injuries to the cervical spine and peripheral vestibular system (Leddy, Baker & Willer, 2016). As prominent as neuropsychological testing has become however, it still remains “imperfect” (McCrorry et al., 2017, p. 843). Concerns remain regarding the reliability of evaluations and their susceptibility to influences by situational factors (e.g., group versus individual setting, quality of sleep the previous night) and characteristics of certain test takers (e.g., anxiety, motivation, learning disabilities, age) that remove objectivity from the process (Kontos, Sufrinko, Womble, & Kegel, 2016). Additionally, neuropsychological testing is only used when the resources are accessible and when there is a neuropsychologist available to interpret the results, which poses accessibility barriers (Echemendria et al., 2007; King et al., 2014). As such, athletes involved in amateur or recreational sport may not have access to the recommended screening tools because their concussion evaluation typically occurs in the emergency room or a general practitioner’s office where concussion expertise may be limited (Putukian et al., 2009).

When a concussion is suspected or clinically diagnosed, the injured individual should progress through a recovery protocol that begins with rest and ends with return to full activity.

Cognitive and physical rest is the first recommended step to ease discomfort of acute symptoms and to minimize brain energy demands. Following a 24 to 48-hour rest period, the individual should slowly incorporate more physical and cognitive activity as symptoms allow, progressing through increments until regular activity levels are tolerated (McCrory et al. 2017). This contrasts previous recommendations that concussed individuals should engage in physical and cognitive rest until complete symptoms resolution (e.g., McCrory et al., 2004).

Sport-specific protocols that dictate a progression from rest, symptom-limited activity, light aerobic exercise, sport-specific exercise, non-contact training drills, and conclude with a full return to sport are available on the CISG Consensus Statements (e.g., McCrory et al., 2017). The 2017 statement also includes a return-to-school protocol for youth, which specifically addresses how scholastic demands, such as regular schoolwork, homework and testing should be addressed. It is recommended that a successful return to school be completed before starting a return to sport (McCrory, et al, 2017). These protocols can be accessed online and have encouraged the creation of additional tools that guide the return to other activity (e.g., work) for non-athletes and non-youth (e.g., Hatton, Bacon, McKinney, Schell, 2019). In addition to gradual return to activity, active rehabilitation to mitigate or treat prolonged symptoms is now preferred in lieu of rest, since the latter has triggered concerns. For example, researchers have expressed that strict rest may trigger physical deconditioning (Giza, Choe & Barlow, 2018), psychological consequences from removing individuals from their vocational and social settings (DiFazio et al., 2016; Leddy et al., 2016; Silverberg & Iverson, 2013) and delayed return to work or school (Silverberg & Otamendi, 2019). Therefore, a growing body of research focuses on guided and prescribed active rehabilitation treatments (e.g., aerobic exercise, cervical, vestibular) that may improve recovery from concussion (Leddy, Baker & Willer, 2016).

An individual is deemed to have clinically recovered from concussion when they can resume pre-injury activity levels without the presence of symptoms and when they are experiencing regular cognitive functioning and balance (McCrea et al., 2013; McCrory et al., 2017). The former is self-reported by the injured individual and the standard and simplest determinant of recovery (Putukian et al., 2009); the latter is determined by neuropsychological testing, which once again is only used when the resources and medical practitioners are accessible (Echemendia et al., 2012). There is speculation that physiological recovery may outlast the presence of symptoms, but to date there is little evidence to confirm this or to suggest certain implications (McCrory et al., 2017).

While tools like the SCAT5 have provided accessible and standardized methods to diagnose and manage concussions, it is important to note that concussions are nuanced injuries that are unique to each individual and therefore manifest themselves differently from person to person (King et al., 2014; Guay et al., 2016). In addition, the fact that they are rapidly evolving injuries makes them “among the most complex injuries in sports medicine to diagnose, assess and manage” (McCrory et al, 2017, p.2). This is evidenced by the wide array of possible symptom manifestations, and the fact that individuals may progress through the recovery protocols at different paces (King et al., 2014). It has also been difficult to find conclusive associations between overt signs (e.g. loss of consciousness; retrograde or post-traumatic amnesia) to different recovery times, making it difficult to speculate as to the severity of the injury and how this relates to recovery (McCrory et al., 2017). Finally, unlike the rest of athletic injuries, concussions are “invisible” in the sense that there is no swelling or bruising that requires casts, braces, or crutches (Bloom, Horton, McCrory, & Johnston, 2004). In other words, a concussed individual who is experiencing lingering headaches does not ostensibly appear

different from uninjured teammates, which may make it difficult to recognize and acknowledge the injury. Despite a wide array of input and empirical evidence, the CISG recognizes that “the science of SRC is evolving and therefore individual management and return-to-play decisions remain in the realm of clinical judgement” (McCrorry et al., 2017, p. 1).

It is important to highlight that in the absence of objective biomarkers, concussion progress remains interpreted by individuals’ symptom self-reporting. As previously alluded to, these reports may be influenced by an array of factors not directly related to the injury (i.e. psychological factors) that may be present at different points of the injury (Leddy et al., 2017; McCrorry et al., 2017; Wiese-Bjornstal et al., 2015). For example, the common comorbidity of depression is known to affect neurocognitive test performance (Terry et al., 2019). Considering that individualized assessment relies on the concussed individual’s understanding of the event, exploring the experiences of athletes with concussions, including interpretations and coping strategies of the symptoms, could help to guide clinical understanding of the injury.

2.2 Non-elite athletes

Since concussion knowledge is constantly evolving, the most updated information and management methods may not be applied equally across different athletic populations. This may result in certain groups having a greater risk of impairment following concussion due to less access to appropriate care and follow-up (Bazarian, Pope, McClung, Cheng, & Flesher, 2003; Kontos, Elbin, Covassin, & Larson, 2010). Non-elite athletes may be an example of an athletic subpopulation that does not have professional training programs and therefore limited access to consultants with expertise in concussion, a concussion program as part of sideline preparedness, or access to neuropsychological testing (Delaney, Orenstein & Steins, 2019; Putukian et al,

2009). Although these individuals do not compete at elite levels, it is likely that they exercise and compete frequently, therefore still considering themselves as athletes. It has been reported that recreational participants still tie their identity to sport and see it as a domain of value to their self-worth compared to non-participants of sport (Lamont-Mills & Christensen, 2006). This means threats of non-participation for these individuals (e.g. injury) may be associated with negative self-consequences. Therefore, it is important to include non-elite athletes in concussion research since they may encounter specific implications after injury.

2.3 Persistent post-concussive symptoms

As aforementioned, not all concussed individuals experience a typical recovery within expected timeframe of 10 to 14 days (4 weeks for children and adolescents) and are therefore not able to successfully return to pre-injury activity levels. There are various estimates of the prevalence of prolonged recoveries in athletic populations with most reporting from 10 to 30% (e.g. Guskiewicz et al., 2003; Makdissi, Cantu, Johnston, McCrory, & Meeuwisse, 2013; McCrea et al., 2005, 2013). The different estimates may be related to the characteristics of the populations studies (e.g. sport type, age) (Makdissi et al., 2013). The 2017 CISG Consensus refers to these atypical recoveries as “persistent post-concussive symptoms” (PPCS), a term which will be used in this study to refer to symptoms reported in chronic phase (> 4 weeks) following a concussion and which individuals attribute to their injury.

PPCS can last for weeks, months, and even years (Caron, Bloom, Johnston, & Sabiston, 2013; Guskiewicz et al., 2011). They can include the typical effects of a concussion, such as headaches and dizziness, but more commonly include cognitive and affective difficulties like concentration issues, memory problems, irritability, sleep disturbance, anxiety, depression and

fatigue (Cancelliere et al., 2014). This non-specific symptomology does not represent a single pathophysiological entity, and in fact overlaps with broader symptom manifestations associated with chronic pain, fatigue and psychiatric disorders, such as depression (Makdissi et al., 2017). As such, persistent symptoms do not necessarily reflect an ongoing injury to the brain, making it important to consider comorbidities that may influence recovery (Harmon et al., 2019). This ambiguity surrounding the injury has made it difficult for the literature to define, describe, and, most importantly, to determine how to manage the condition (Leddy et al., 2017).

Researchers have attempted for decades to identify certain injury features that can predict protracted recoveries but have experienced limited success. It was previously believed that the injury severity could be graded on different levels of loss of consciousness, retrograde amnesia, or post-traumatic amnesia, and that these in turn could predict an approximate recovery timeline (McCrory et al., 2013). However, support for these theorized predictors has diminished due to inconclusive evidence (McCrory et al., 2017). Currently the 2017 CISG Consensus declares that the most consistent predictor of prolonged recovery from SRC is the severity of the individual's symptoms in the first day or few days following injury. However, the researchers also emphasize that "there is a growing body of literature indicating that psychological factors play a significant role in symptom recovery and contribute to risk of persistent symptoms in some cases" (McCrory et al., 2013, p. 6).

2.4 Biopsychosocial framework

To understand the psychological factors can be involved in sport concussion recovery, it is useful to draw on sport injury psychology literature. A broad but helpful framework is the biopsychosocial model (Appendix A), which provides an integrative approach to understand the

sport injury rehabilitation process (Brewer, Andersen & Van Raatle, 2002). The model provides a multi-channel and multi-directional path of recovery where several dynamics can come into play to affect the final outcome. Brewer et al. (2002) give psychological factors (e.g. personality, cognition, affect) a central role in their model as these are considered to have reciprocal relationships with both biological factors and social/contextual ones. The interactions of these three dynamics produce intermediary biopsychosocial ones (e.g. range of motion, perception of pain, rate of recovery), which eventually determine the sport injury rehabilitation outcomes (e.g. functional performance, treatment satisfaction, quality of life, and readiness to return to sport). This biopsychosocial model broadly highlights the centrality of psychological influences of any sport injury rehabilitation process, which provides insight into the complexity of the recovery process, especially for complicated injuries like concussions.

While Brewer et al.'s (2002) model highlights the significance of psychological factors following a sport injury, it does not explore more specific processes that may be involved. Therefore, cognitive appraisal models are currently favoured in the literature. As indicated by their label, these models focus on the role of cognition in the process of injury rehabilitation. Wiese-Bjornstal et al. (1998) posit that pre-injury variables such as personality, and post-injury variables such as the appraisal of the injury, affect the individual's emotional responses, behavioural responses, and recovery outcomes (Appendix B). The responses and cognitive processes are in constant interaction with each other and can perpetuate positive or negative thought-behaviour-emotion cycles that can lead to successful or poor recovery outcomes. Personal characteristics (e.g. injury characteristics, personality differences, self-motivation) and the situation (i.e. rehabilitation environment, type of sport, level of competition) are theorized to have direct influence on cognitive appraisals. Most importantly, the individual's *perception*,

which is influenced by the situation and personal factors, forms the basis for cognitive appraisal; this appraisal then serves as the basis for the individual's emotional and behavioural responses to the injury, that can consequently impact recovery outcomes.

2.5 Stress and coping

Cognitive appraisal models are founded on the theory of psychological stress and coping developed by Lazarus and colleagues (e.g. Lazarus & Folkman, 1984; Folkman, Lazarus, Gruen & DeLongis, 1986; Lazarus, 1991). In this framework, stress is understood to be the imbalance between environmental demands and resources available to cope with these demands. The individuality of stress is highlighted, as an individual's subjective interpretation of the demands and available resources determines whether a situation will result in a stress response or not (Lazarus & Folkman, 1984). It is therefore important to analyze an individual's perception of a situation to understand the development of stress.

Cognitive appraisal is the process through which an individual interprets whether or not, and to what extent, a particular encounter with the environment is relevant and threatening to their well-being. Through *primary appraisal*, the individual evaluates whether they have anything at stake in the particular situation (Lazarus & Folkman, 1991). In other words, an individual evaluates whether there is potential harm or benefit when considering their own values, commitments and goals. There are three possible types of primary appraisals: *goal relevance* evaluates if there is potential for harm/loss (damage that has already occurred), threat (anticipated damage), or challenge (threat that can be overcome for gain or growth); *goal congruence* examines whether the encounter with the environment is harmful or beneficial; and *goal content* assesses which kind of goal is at stake (Lazarus, 1991). Primary appraisal is formed

by a range of personal and situational factors, such as personal beliefs and commitments. Concurrently, *secondary appraisal* assesses possible actions and the resources available for these actions to subdue the perceived threat. The individual considers, “what, if anything, can I do in this encounter, and how will what I do and what is going to happen affect my well-being?” (Lazarus, 1991, p.134). There are three possible types of secondary appraisal: *blame or credit*, which determines if there is accountability or responsibility in the situation, and how much control over it is possible; *coping potential*, which considers how the relationship with the environment can be influenced for the betterment of the individual; and *future expectations*, which considers the potential results of different coping methods (Lazarus, 1991). Secondary appraisals rely on an individual determining the extent to which a situation can be changed, has to be accepted, requires more information, or requires holding oneself back (Lazarus & Folkman, 1984). Perceived personal control is a key as it empowers the individual to analyze how the situation can be changed to subdue the threat (Compas, Worsham, Ey & Howell, 1996). Together, primary and secondary appraisals determine whether the person-environment transaction is perceived as significant and taxing for well-being, and if and how it can be addressed. Since environmental encounters are constantly changing, both primary and secondary appraisals are also constantly changing – a process known as *reappraisal* (Folkman et al., 1986). Reappraisal can happen in light of feedback about or from the environment, as well as from one’s own actions and reactions. (Lazarus, 1991).

Coping methods are employed when an individual perceives the situation as a stressor. That is, the individual perceives that the situation exceeds the resources available to effectively respond. Coping refers to anything that the individual does or thinks (whether effective or not) as an effort to manage a stressful encounter. This involves constantly changing cognitive and

behavioral efforts to manage the particular demands of the situation (Lazarus & Folkman, 1984). This process is also seen as contextual as it is influenced by personal and situational variables that together shape coping efforts. Coping strategies can include minimizing, avoiding, tolerating or accepting the conditions of stress, creating an overall attempt to master the stressful interaction with the environment (Lazarus and Folkman, 1984).

Coping has some major functions that are widely recognized. *Emotion-focused coping* is an attempt to change the way the stressful situation is interpreted or attended to in order to regulate the emotions that arise (Lazarus & Folkman, 1984). By changing how an individual frames a situation, the problem can be neutralized conceptually. Examples include accepting responsibility in a conflict, seeking positive ways in which to view a stressful scenario (Lazarus & Folkman, 1984), as well as drinking alcohol or consuming drugs in order to regulate the emotional arousal (Penley, Tomaka, & Wiebe, 2012). *Problem-focused coping* involves efforts in changing the actual situation in order to remove the actual source of stress (Lazarus & Folkman, 1984). Examples can include seeking information in order to take action, or managing time more effectively (Lazarus & Folkman, 1984). Problem-focused approaches are more often used when a situation is perceived as controllable, and emotion-focused approaches are used when the situation is uncontrollable (Tamminen, Kowalski & Gaudreau, 2016). It is understood that people use both methods of coping in essentially every type of stressful encounter and that a single coping response can be “dual-focused” (Compas et al., 1996; Folkman et al., 1986). For example, when dealing with a health issue, an individual may engage in exercise to attempt to promote their physical health but also as a means to manage anxiety about the illness. The focus of the coping strategies and how they are used in relation to others however, is determined by the individual’s appraisal of the stressful situation and their specific intention on how to manage

certain aspects (Lazarus & Folkman, 1984). A third form of coping that has been identified in the literature is *avoidance coping*, in which an individual actively ignores a stressful situation that may create adverse feelings, such as anxiety (Roth & Cohen, 1986). The stressor can be reappraised as the situation evolves, as the resources available for responding change, and as coping methods are adjusted. This infers that reappraisal itself be an emotion-focused coping method (Penley et al., 2012). It is important to note that although problem-focused coping is associated with more adaptive outcomes, the efficacy of the method relies on the context of the situation, which may determine which coping strategy is more appropriate (Folkman et al., 1986).

Several emotions can be involved in the coping process, depending on the subjective appraisal of the stressful encounter (Lazarus, 2000). These emotions can also reveal what an individual is experiencing, the meaning of a situation to the individual, and how that individual is likely to respond to the situation (Tamminen et al., 2016). Therefore, as the entire process of stress and coping is explored, it is important to consider evolving affective responses as they might influence and reflect appraisals and coping. Lazarus (1991) identified the following positive and negative 15 core emotions in his cognitive-motivational-relational theory (CMRT): anger, anxiety, fright, guilt, shame, sadness, envy, jealousy, happiness, pride, relief, hope, love, gratitude, and compassion. These emotions reveal information about what is at stake for the individual and their perceived resources to cope with the situation (Lazarus, 1999). Consequently, to understand emotions it is useful to recognize the individual's perception of a situation; but understanding the type of emotions that are experienced can also help explain a person's interpretation of the situation.

In summary, how an individual appraises a stressor (e.g. injury) regulates the meaning that individual assigns to the event, and what kind of coping strategies or reactions they will engage in. This in turn, can influence how that individual continues to perceive and act in a certain situation. The two processes of cognitive appraisal and coping can thus be seen as important factors in how individuals interpret, manage, and influence their stressful situations (Folkman et al., 1986).

2.6 Research on psychological influences on sport-related concussion

Research on the psychological aspects of sport concussions has typically lagged behind the clinical physical signs and return-to-play guidelines. However, the recognized importance of psychological influences on concussion risk, response, and recovery has caused a recent surge of studies on the subject. Researchers have associated certain pre-existing psychological risk factors with prolonged recoveries such as personality traits of neuroticism (Merritt, Rabinowitz, & Arnett, 2015), activity disorders like ADHD (Mautner, Sussman, Axtman, Al-Farsi & Al-Adawi, 2015), and psychiatric conditions like anxiety and depression (Hutchinson, Comper, Csenge, & Richards, 2014). Certain post-injury factors have also been theorized to prolong recovery, and these have garnered more attention given that some of these are modifiable and can provide viable targets for interventions. These factors include the presence of psychological distress (e.g., depression, anxiety, feeling more emotional, moodiness, irritability), which is understood to be common, but its origin remains uncertain (Kontos, Sufrinko, Sandel, Emami & Collins, 2019). That is, it is currently unclear to what extent the distress is caused by the neurological disturbance of concussion, and to what extent it is caused by concussion-specific stressors. The

latter is important to consider since several concussion-specific challenges have been identified in the literature that may present intervention targets.

As is common with other long-term injuries, concussed athletes often experience a shaken sense of identity and alienation from their team when they are forced to abandon their sport for a prolonged period of time (Putukian et al., 2009). This is especially true for those whose involvement is their primary source of financial funding (e.g. salary or scholarship), those who spend significant time and effort on their sport, and those who rely on sport for their social support network - all signs of a high athletic identity (Brewer, 2007; Broshek, De Marco & Freeman, 2015). Supporting this notion, Caron, Bloom, Johnston & Sabiston (2013) found in their qualitative study that “not being around the guys” was one of the toughest emotional challenges that former NHL players experienced after a concussion. Conversely, athletes often feel an overall lack of concussion knowledge and pressure to return to play from teammates and coaches, which can provoke psychological distress (André-Morin et al., 2017; Bloom et al., 20014; Morgan et al., 2015). A general lack of concussion-specific knowledge may be why concussed athletes have reported being less satisfied with social support despite having access to the same sources as athletes with orthopedic injuries (Covassin et al., 2014). Lastly, concussed athletes who are usually accustomed to implementing rehabilitation protocols after any injury cannot do this due to the lack of evidence-based options to implement. This has resulted in higher frustration in concussed athletes compared to those with other injuries (McGrath, 2010; Shapcott, Bloom, Johnston, Loughead, & Delaney, 2007).

Concussion symptoms tend to be pervasive and can affect areas of life outside the sporting realm. Decreased concentration, attention, and working memory can be particularly stressful when individuals have other responsibilities outside of sport (McCrea et al., 2003).

Mainwaring, Hutchinson, Camper, & Richards (2012) suggested that varsity athletes begin to experience a lack of mental acuteness in non-sport realms, such as schoolwork or family demands. André-Morin et al. (2017) confirmed this by reporting that academic issues such as reduced class attendance, diminished study habits, and poor grades were on the forefront of athletes' concerns following a concussion. Moreover, these difficulties can affect social functioning with friends and family which may further deplete resources of social support (McGrath, 2010). Increased fatigue is often reported by concussed athletes and can be emotionally detrimental in all aspects of life (Hutchison et al., 2010; Lovell et al., 2003). All of these sport and non-sport challenges that supersede those of musculoskeletal injuries can overwhelm athletes with negative emotions and psychological distress.

These concussion-specific challenges can lead to emotional distress. Concussed athletes routinely report elevated anxiety, depression, and overall elevated mood disturbances when assessed after concussion compared to athletes dealing with other injuries. Hutchison et al. (2009) highlighted this finding by comparing the emotional responses in samples of collegiate athletes with SRC, musculoskeletal injuries, and non-injured control group. Concussed participants demonstrated elevated fatigue, decreased vigor, and an overall negative mood reaction following injury, whereas athletes with musculoskeletal injuries only exhibited significant increases in anger. Mainwaring et al. (2004) administered the Profile of Mood States (POMS) to a sample of collegiate athletes with concussions, uninjured collegiate athletes, and a non-athlete student control group. These researchers found that mood scores were not different between the groups at baseline, but at 14 days after the injury concussed athletes reported higher POMS scores for depression, confusion, and total mood disturbance. Other studies have revealed that over one third of the concussed collegiate athletes experienced state anxiety following SRC,

and one fifth experienced depression symptoms (Yang et al., 2015). These findings have been corroborated by neuroimaging studies that have shown that concussed individuals show neural activation patterns resembling those of fear and depression (Chen, Johnston, Petrides, & Ptito, 2008; Dischinger, Ryb, Kufera & Auman, 2009; Reger et al., 2012). It is important to note that these emotional states can both be a function of, and response to, the lingering effects of a concussion (Kontos et al., 2004). Regardless of their origin however, emotional states should be assessed and monitored following SRC as they can over time have a negative impact on cognitive performance and overall recovery (Hutchinson et al., 2009; Kontos et al., 2012).

Concussion studies directly related to stress and coping are scarce, but some findings suggest that this subject is worth exploring further to illuminate the role of emotional and psychological states in recovery. Kontos et al. (2013) compared the coping responses of concussed athletes with athletes who sustained an orthopedic injury and healthy controls using the Brief COPE inventory (measure of different coping strategies such as planning, positive reinterpretation, acceptance, humor, seeking emotional social support, and seeking informational support). The researchers found that concussed athletes reported overall lower levels of coping but suggested that concussions may require different coping strategies that were not included in the COPE inventory such as increased sleep, restriction of physical activity, and proper nutrition (Kontos et al., 2013). In addition, these athletes were tested a week after their injury, which may not be the most informative time frame as distress regarding the injury is theorized to increase over time (Broshek et al, 2015; Grubenhoff et al., 2016). Covassin et al. (2013) studied the relationship between coping methods and cognitive symptom reporting of concussed athletes. Avoidance coping was used by athletes who reported more symptoms, inherently linking this type of coping to adverse results. The researchers suggested that this strategy could be favoured

due to the lack of options to actively rehabilitate, as well as due to the unclear prognosis. They cited individuals' tendency to use avoidance coping to gain control over situations that are perceived as uncontrollable, such as concussion (Covassin et al., 2013). Finally, although not directly related to stress and coping, research continuously reports some of Lazarus's CMRT (1991) negative core emotions after concussion such as anger (e.g. Hutchinson et al., 2010), anxiety (e.g. O'Rourke et al., 2017), fright (e.g. André-Morin et al., 2017), and sadness (e.g. Mainwaring et al., 2012).

Considering the recognition of concussion as an injury that can exhibit adverse emotions and psychological distress beyond that of other injuries, it is imperative that research further investigates the cognitive and emotional dimensions of the injury (Mainwaring et al., 2004). Lazarus' (1966) theory of stress and coping which includes both cognitive and emotional dimensions could be informational in this aspect. In the context of sport concussions, an individual's primary appraisal could assess the meaning of the injury to the athlete's sport involvement (e.g. loss of playing time), and general well-being (e.g. decreased capacity to meet other life demands). Secondary appraisal could analyze what options are available to subdue the injury stressor (e.g. managing symptoms) and what resources are available for this (e.g. direction from team practitioners or a general practitioner). This is especially interesting as it relates to concussion because of the scarce rehabilitation and management strategies. As prescribed by the CISG (2017) guidelines, an athlete can only rest in the acute stage of the injury and gradually reincorporate activity as symptoms allow. Because this method is typically unsuccessful with fully returning to activity in individuals with PPCS, it is important to analyze how individuals interpret these failures and psychologically react to them.

Since this subject is largely unknown and under researched, it was useful to use an exploratory qualitative research methodology that allows for a detailed investigation of complex and nuanced phenomena (Mason, 2002). Using methods such as semi-structured interviews that ask the participants about their own interpretations of the symptoms and efforts to manage them, allowed for detailed findings framed around the subjective experience of individuals struggling with PPCS. For example, because researchers have previously suggested that individuals may use different coping methods not captured in Brief COPE questionnaire (Kontos et al., 2013), the study explored how different strategies were developed and utilized.

When considering that psychological factors are involved in the development of PPCS, and that the injury is understood to be a stressful experience, investigating individuals' experiences and appraisal processes provided rich data regarding the contextual, emotional and cognitive processes involved. These findings could supplement previous research or guide future inquiries and interventions for individuals experiencing PPCS.

Chapter 3: Methods

3.1 Paradigmatic position

The exploration of non-elite athletes' experiences with PPCS was guided by an interpretivist paradigmatic worldview. Rather than explaining why the participants are experiencing prolonged symptoms, I sought to empathically understand the meanings the individuals have assigned to their experiences, and their thoughts, feelings, and reactions (Bryman, 2015). Guided by a relativist ontological standpoint, I acknowledged that reality is socially constructed, meaning that the participants' accounts reflected their subjective realities rather than one objective truth (Guba & Lincoln, 2005). Therefore, the meanings that participants attached to situations could have been shaped by their environment and how they interpreted it. This perspective yields to the subjectivist and constructionist epistemology that acknowledged the findings revealed by this study were co-constructed by the participant and me, the researcher (Sparkes & Smith, 2014). Therefore, my own experiences, thoughts and feelings may have influenced how the research was conducted. These standpoints are congruent with the stress and coping framework that advocates for the subjectivity of situations based on individual interpretations of them. Overall, the goal of the research was not to explain the existence of PPCS, but to build on the understanding of this phenomenon through exploration of individual experiences (Sparkes & Smith, 2014).

3.2 Participants

Prior to participant recruitment, ethical approval was obtained from the Behavioural Research Ethics Board (H18-00367) at the University of British Columbia. Criterion-based

sampling was then used to recruit a sample of twelve non-elite athletes, ages 18 to 35, that had suffered a concussion and were still experiencing, or had experienced, symptoms between 4 weeks and 3 years after their injury. This method of sampling enabled me to recruit a relatively homogenous sample of participants who had experienced a similar experience (Sparkes & Smith, 2014).

Participants had to be experiencing symptoms for a minimum of 4 weeks given that adolescents' developing brains may take up to 4 weeks to neurologically recovery from a concussion (McCroory et al., 2017; Leddy et al., 2017). Although no adolescents were recruited for the proposed study, the brains of young adults may still be developing (Wierenga et al., 2014). The population of non-elite athletes was chosen due to their limited access to appropriate care and follow-up treatment and the proposed increased risk of experiencing prolonged recoveries (Putukian et al., 2009). For this study, non-elite athletes were defined as individuals who participated and/or competed in sport at least 2 times a week at the time of their concussion but did not follow a professionally designed training regimen (Chappell, Yu, Kirkendall & Garrett, 2002). Gender was not a recruitment factor (though the final sample was reasonably balanced) given the exploratory nature of this study.

This sample provided thorough knowledge about their experiences with PPCS in order to build on the certain criteria of interest (Sparkes & Smith, 2014). The proposed sample size was practical, which is important given that this is a Master's thesis project (Smith & Sparkes, 2016). Additionally, Clarke and Braun (2016) recommend a sample size of at least six, due to the emphasis on patterned meaning, which become apparent approximately six interviews into data collection. It was also seen as advantageous for this study since it allowed a close involvement with the participants. Interviews with 12 participants facilitated the production of detailed data,

which enabled me to answer my research questions (Braun, Clarke & Weate, 2016; Bryman, 2015).

Participant demographics and characteristics are found in Table 3.2.1. They ranged in age from 21-35 years old, with an average age of 25.9 years. Seven participants identified as female, five as male, and all of them as non-elite athletes. Six identified to have sustained 1 concussion, four participants identified to have sustained 2 concussions, and two participants identified to have sustained 3 concussions. At the time of the interview, they all identified to be experiencing or have experienced persistent post-concussive symptoms between 4 weeks and 3 years after their injury. Participants ranged from experiencing or having experienced recoveries lasting 4 months to 36 months, with an average of 15.6 months. During the interview, 8 participants described to still be experiencing debilitating symptoms that interfered with their everyday physical and cognitive activities, 1 as back to most regular activities, and 3 as recovered. The SCAT5 symptom evaluation was administered to the participants, and the frequency of symptoms endorsed are found in Table 3.2.2. The most common symptoms endorsed were 'More emotional' (n=9), 'Headache'(n=8), 'Don't feel right'(n=7) and 'Nervous or anxious'(n=7).

Table 3.2.1: Patient characteristics

Characteristics	Participants (n=12)
Age (M=25.9)	
21-25	5
26-30	5
31-35	2
Gender	
Male	5
Female	7
Vocational status pre-injury	
Full time worker	7
Full time student	5
Number of concussions	
1	6
2	4
3	2
Recovery length in months (M=15.6)	
1-6	3
7-12	2
13-18	4
19-24	1
25-36	2
Symptom/activity status	
Currently experiencing debilitating symptoms	8
Back to most regular activities	1
Recovered*	3

*Average months since recovery = 5

Table 3.2.2: Symptoms endorsed

SCAT5 Symptom	# participants endorsed
More emotional	9
Headache	8
“Don’t feel right”	7
Nervous or Anxious	7
Sensitivity to light	6
Feeling slowed down	6
Sadness	6
Feeling like “in a fog”	6
Irritability	6
Pressure in the head	5
Neck pain	5
Dizziness	5
Blurred vision	5
Balance problems	5
Difficulty remembering	5
Sensitivity to noise	5
Nausea or vomiting	4
Difficulty concentrating	4
Fatigue or low energy	4
Drowsiness	4
Confusion	2
Trouble falling asleep	2

3.3 Procedures

Participants were recruited by information posters (Appendix C) containing information about the study and the recruitment criteria. These were posted around sport and recreation centres on the University of British Columbia (UBC) campus as well as the surrounding communities. I also presented my study and recruitment criteria at different UBC undergraduate classes and at an informal presentation on campus regarding concussions. I sent the information to two recreational adult sport leagues and asked for them to be disseminated amongst their members. Lastly, I talked about my research with personal acquaintances involved in sport who also sent the information to potential participants. Five participants were recruited with the UBC campus posters, three through the sport organizations, two through the informal on-campus presentation, one through personal acquaintances, and one through snowball sampling within the study participants.

Initial recruitment began in April 2018. Potential participants contacted me via email, I replied with the letter of introduction (Appendix D) for them to review prior to consenting to participate, and I enquired if they had any questions about the study. Potential participants were given a minimum of 24 hours to decide whether they wanted to participate. When they confirmed their interest, an interview was scheduled at a mutually convenient time in the participants' preferred location. Interviews took place in a private room in the War Memorial Gymnasium, coffee shops, the participants' homes, and via teleconference. I provided the participants the option of venue with consideration that they might still be symptomatic and may not want to travel anywhere for the interview. Those who preferred to have their interview at their homes mentioned that they preferred to do so because of their symptoms. Two participants

asked if they could do the interview via teleconference because it was not convenient to meet in person. This was added as a possibility after ethics approval. When meeting with the participants, they were provided with a copy of the consent form (Appendix E) and signed one for me to keep. They then filled out a demographic questionnaire (Appendix F), which included questions about their sport participation and concussion history. Following the interview, the participants completed the Sport Concussion Assessment Tool – 5th Edition (SCAT5) symptom evaluation (Appendix G).

Throughout the recruitment and interview process, confidentiality and anonymity were emphasized considering that the research topic could be sensitive. All participants were made aware that they would be assigned a pseudonym in the study. To further ensure they would not be identifiable by anyone reading the document, I removed any potential identifier such as names of people, sport organizations, locations or places that they mentioned. All transcripts were kept on my personal laptop which is password protected. At the start of each interview, confidentiality was explained verbally to each participant to ensure that they understood it and answer any questions they may have had. They were also reminded that the interview would be audio recorded and asked if they agreed to start the recording. Additionally, it was emphasized that their participation was voluntary, and they could withdraw at any time without any consequences.

Each participant took part in one semi-structured interview. The semi-structured format was selected because it allowed the interview to be flexible and evolve as the conversation between the participants and myself broached different topics of interest; it also allowed me to probe on those topics that need more depth or clarification (Bryman, 2015). Open-ended questions encouraged participants to elaborate on their experiences. This type of procedure is

interactive in nature and was adapted as the interview naturally developed to allow for detailed and comprehensive insight into the experiences of the participants (Sparkes & Smith, 2014). Considering the complex nature of PPCS, semi-structured interviews were useful for producing detailed data for a phenomenon that is not yet well understood. The interview (Appendix H) was focused on the participants' experience with PPCS and their interpretations of the symptoms and coping strategies used to manage them. All interviews were audio recorded and transcribed verbatim. The interviews ranged from 41 minutes to 99 minutes in length, with an average time of 66 minutes, for a total of 799 minutes (13 hours and 19 minutes), which yielded a total of 272 pages of transcripts. Interviews were audio recorded on an iPhone 7 Plus and an iPad Air 2 using the voice memo application.

3.4 Data analysis

Following data collection and transcription, the analysis was abductive, which entailed a mix of both deductive and inductive approaches (Bryman, 2015). As evident by the literature review and interview guide, this study borrows from the stress and coping literature as well as empirical concussion data and therefore cannot be divorced from theory. However, during data analysis there was an openness for other themes to emerge that were not fully attached to previous findings or theories. This combination allowed for the findings to potentially build on previous research without limiting the participants from only touching on previously researched aspects of PPCS. As is common with qualitative methodology, I utilized an iterative data analysis that occurred concurrently with data collection so that I could remain flexible in the interview process to uncover how the participants' experiences relate to the research questions (Sparkes & Smith, 2014).

Thematic analysis of the transcripts was performed following Braun and Clarke's (2006) guidelines to explore how the participants' experiences, perceptions and coping methods. Thematic analysis is an established qualitative method for "identifying, analyzing, and reporting patterns (themes) within data," with great detail (Braun & Clarke, 2006, p.6). It is often used for exploring how individuals make sense of their experiences, making a relevant approach to achieve the goals of the study.

Braun and Clarke (2006) outline six stages for implementing thematic analysis, but state that these are not linear and should be used flexibly. In fact, it is emphasized that the researcher should move back and forth between the stages as appropriate to determine and report representative themes that will inform the research questions. My procedure with Braun and Clarke's (2006) six stages was:

1) During *data familiarization* I immersed myself in the data by actively reading the interview transcripts several times to start identifying meanings and patterns.

2) *Generating initial codes* involved me looking for aspects and patterns of the individuals' accounts that seem prevalent and relevant to my research question. Software program Nvivo 12 was used for this process. Following a complete coding approach, I coded anything that may be relevant to the research questions (Braun & Clarke, 2013). My paradigmatic standpoint allowed me to interpret meaning beyond that of the participants' spoken words, so I coded both latent and semantic excerpts. Through this process, I was able to attempt to make sense of tensions within the participants' accounts. For example, when they described that the recovery-related challenges resulted in strong feelings of anxiety and depression, but were less forthcoming about mentioning these emotional issues when talking about possible symptom origins. I coded these paradoxical accounts under a code named "tensions when talking

about mental health”. Transcripts were reviewed several times to make sure that anything potentially relevant was included in the analysis. This process resulted in a total of 433 coding instances across all 12 transcripts. Codes that had similar meanings were organized as child nodes under an overarching parent node in NVivo. Throughout the coding process, I started to make connections between the categories in my reflexive journal.

3) While *searching for themes*, I relied on theory, previous research findings, or emergent categories to begin to organize the codes and start to look for themes and subthemes. A thematic map was used to illustrate the sorting process and to represent the relationships between different codes and themes, and subthemes. To begin to make sense of them, I followed the recursive process of thematic analysis that allowed me to go back and forth between the codes, the transcripts, and the writing (Clarke & Braun, 2016).

4) I *reviewed themes* throughout the writing process and refined each one so that all content within them devised a clear pattern. Data that was not representative of the corresponding theme was excluded from the analysis or added to another one. In some cases, this happened with the consultation of a committee member. I then compared the themes and the thematic map to the data set as a whole to ensure all aspects were representative of each other, and to give me the opportunity to recognize any key data excerpts that were missed at any step. This phase continued until the end of the writing process as my final themes and sub-themes were revised throughout. These final themes told a coherent story of each participants’ concussion experience while ensuring the individuality of each participants’ experience was accounted for.

5) I *defined and named themes* by producing names and definitions for each theme that captured the essence of the data set contained within it.

6) I *produced the report* by composing the final writeup using the themes and the relationships between them. Throughout this process I continued to further refine themes, as Braun and Clarke (2013) state there is no finite point for analysis.

3.5 Quality of the research

3.5.1 Validity

In order to produce worthy findings, this study adhered to the relativist approach to judging qualitative inquiry, where appropriate characterizing traits are applied to the research rather than to a set list of universal criteria (Burke, 2016). This study included: worthiness of topic, rich rigour, transparency and coherence, as well as credibility.

The worthiness of the proposed research project and its contribution was reflected in the research gaps I attempted to address. The growing concern of the health consequences associated with concussions, and the research gaps that revolve around PPCS, made this study relevant, timely, significant, and interesting (Tracy, 2010). Although generalizability in the conventional sense (i.e., through statistical-probabilistic generalizability) is not a common goal of qualitative research, naturalistic generalizability and inferential generalization can be (Smith, 2018). Through these generalizations, readers that have experienced similar experiences (i.e. experienced a prolonged concussion recovery) or those that might find them applicable (e.g., clinicians working in a concussion rehabilitation setting) may be able to relate to them and find them useful. To achieve these goals, detailed accounts of the participants' lives were included through proper 'evidence' (e.g. direct quotations), contextual details that might help readers connect with the findings, and accessible writing. Overall, the purpose of the study was to situate

worthy findings within previous research and theory in order to advance the knowledge of PPCS in ways that can be useful to different individuals (Sparkes and Smith, 2014).

Rich rigour was achieved through thoroughness and complexity of data collection, analysis and reporting (Yardley, 2000; Tracy, 2010). Along with an appropriate sample to answer the research question, rigour was facilitated through the reporting of meaningful and significant claims that attempted to answer research gaps in the literature (Burke, 2016). These were accomplished by a thorough literature review that helped me compose the interview guide. A rigorous data analysis process also involved me reviewing the literature comprehensively in order to situate my findings. This process was aided through the use of ‘critical friends’ (my committee members), who challenged me during the exploration of data and the development of the findings (Smith & Sparkes, 2012).

Transparency and coherence were achieved through consistency, organization, and documentation in order to produce a study that is logical and traceable (Sparkes & Smith, 2014). By reading the entirety of this study, the reader should understand how the purpose, methods and results follow a rational path and fit together (Tracy, 2010; Yardley, 2000), which creates “auditable” work (Bryman, 2015). I also used a reflexive journal throughout every step of the research process to document my awareness around personal values, biases and inclinations may impact the research process (elaborated on below). The journal was especially important considering that I also experienced a prolonged concussion recovery with several similarities to the participants’ stories. By being forthcoming about my experience and how this may have influenced the research process, I hope to have established trust in the process (Bryman, 2015).

Credibility was achieved through the formation of findings are plausible and dependable enough to act on (Tracy, 2010). This is important since the paradigm guiding the study

acknowledges that the findings are co-constructed by the researcher and the participants, and therefore reflect one of several possible social realities (Bryman, 2015). A key method also relied on to achieve credibility was to provide a thick description of the individuals' accounts supplemented by their direct quotations (Tracy, 2010). The reader will note that detailed and multiple quotes are included. Considering my own experience with a concussion recovery, I used these interview excerpts to further establish trust in the process. Although my experience with the injury may have influenced the way I conducted the interviews and analysis in some instances (elaborated on below), the reader should sense how the final report reflects the participants' accounts rather than my own. The hope is that thorough reporting, readers will make their own conclusions that align with those of the study.

3.5.2. Reflexivity

Reflexivity means to “bend back upon oneself” and become critically self-aware of the potential influence one has on the interactive and dynamic research process (Sparkes & Smith, 2014, p. 20). In order to remain aware of how my own personal values, preconceived notions, biases, and decisions influenced the research, I kept a reflexive journal (Brocki & Wearden, 2006). I documented my thoughts and feelings throughout participant recruitment, participant interviews, data analysis and final report writeup. By doing so, I kept the research sincere by maintaining honesty with myself, my research, my audience, and my participants, which is an important part of quality research (Tracy, 2010).

Engaging in reflexivity was especially relevant considering my own personal experiences that were relevant to the study. Firstly, I have considered myself an athlete since I moved from Mexico to Canada when I was nine years old and received the first opportunity to participate in organized sport. Soccer, basketball, volleyball, and track and field quickly became a part of my

identity and helped shape my character during important formation years. Sport taught me important values such as leadership, teamwork, respect, and commitment. It also importantly allowed me to form new friendships, which was important for a recently immigrated young person. Sport remains an important part of my life today. Although I do not play at a high level like I did throughout high school and university, it is still important for me to seek out opportunities to compete, exercise, and socialize in a sport setting. The reason I no longer engage in high-level sport is my own experience with a prolonged concussion recovery from 2013 to 2015.

As much as I celebrate the positive aspects of sport, I also recognize the negative ones such as the normalization of pain and injury. When I sustained my concussion, this sporting norm influenced me to not disclose my injury and instead to keep playing during a soccer game. It also influenced me to go to work the next few days and push through my symptoms despite feeling like it was not the right thing to do. These two decisions were likely involved in the prolongation of my recovery, as I eventually reached a point where I could not push any longer. I could not focus on conversation or read comfortably on my computer screen, I was bothered by the ringing of my work phone, and I experienced the anecdotal “crash” that some of the study participants also talked about. Not being able to explain what was happening and not feeling it was safe for me to drive home, I became very scared. This feeling stayed with me for a long time, as every health care practitioner I approached did not have answers for me and told me that the best thing I could do was to rest until I felt better. I sat in a dark room for weeks thinking it would be beneficial, but in retrospect I know that it was the worst thing I could have done. Every time I came out of my dark room, everything seemed louder and brighter than before and I started to feel worse about doing anything. I thought my brain was damaged and getting worse

day by day. More than a year later, with the help of a neuropsychiatrist, I eventually identified that I had become anxious and depressed, and that this was withholding me from recovering. The realization that part of my problem had been psychological and that the majority of practitioners could not identify this, motivated me to quit my job and return to school to study the psychological influences on concussion recovery.

As the reader will notice, my story was reflected in the participants' experiences, so during the interviews I related to a lot of the occurrences, thoughts, and feelings that they described. I also experienced certain instances differently, which made me realize how similar experiences could be perceived in other ways. By engaging in reflexivity, I was able to write journal entries that helped me understand my role in co-constructing the findings (Smith & Sparkes, 2016). For example, I related to the participants when they expressed their frustration with not being able to participate in sport like they used to prior to their injury. However, when I thought back to my experience, I just remembered generally missing sport, but not specific aspects of it. Listening to the participants' accounts, I noticed the different facets of sport that could be missed and a common difference between the participants and me. While the participants seemed to mostly miss the physical activity component of sport, my inability to engage in the competitive and social aspects was what made me most upset about my injury. My reflexive journal entry from May 2018 stated:

It's interesting that [participant's initials] emphasized their desire to return to running and biking (instead of playing soccer with their team) as often as they did. I think they valued the workout aspect more (as it helped them unwind) than sport participation. It made me realize similarities with [participant's initials], who also mentioned how much they missed the ability to go on frequent runs. I think my experience was different, as I was mainly upset about missing games and tournaments with my team, as well as the ability to hang out afterwards. I don't remember missing the ability to go on a run. I played on sport teams 3 times per week at the time of my concussion, so maybe I did passively enjoy the physical workouts because I remember feeling good after games, but I certainly don't remember thinking 'a run would help my stress levels right now.' For me,

it was more like, 'ughh, I wonder how my team will do in the game next Sunday... I wish I could play.'

My methodology allowed me to be flexible when topics like these emerged, for example, by probing during the interviews so I could better understand these different perspectives (Smith & Sparkes, 2016). I was able to ask unplanned questions (while remaining mindful of not being guiding) as conversations unfolded, wondering why the participants had reacted differently or similarly than me to certain situations, thus providing nuanced accounts to answer my research question. In the example above, this procedure allowed me to realize the distinction between competition, socialization, and exercise aspects of sport participation, and the different effects that they could have on different individuals.

The disclosure of my own experience also led to certain challenges and some decision making during the study. First, I did not know if and how I should disclose to the participants why I was motivated to conduct my study. After conversations with one of my committee members, we decided it would be ethical and potentially helpful in developing rapport to briefly reveal that I also experienced a prolonged concussion recovery at the beginning of the interviews. I would then let the participants probe about my experience after the interview if they were interested. As written down in my reflexive journal, I would mention to the participants while introducing the study:

I am motivated to conduct study this topic because of my own experience with a long concussion recovery that made me realize it is still a poorly understood injury. With this research I hope to provide insights into the subjective experience of prolonged concussion recovery with the help of your story.

This disclosure certainly helped me develop a connection with the participants, as evident by their insertion of phrases such as “as you probably know”, or “you probably experienced the same thing”, or “I probably don’t have to tell you this, but...” during their interviews. The

challenge associated with this disclosure, was that some participants were also curious to talk about my experience at length and find out how I had recovered. To focus the interview on the participants' perspectives however, I was as brief as possible if the participants asked me questions during their interview, mentioning that I could elaborate more when we were finished with the questions. Another challenge was sometimes having to hold back opinions I had (based on the research literature) about the participants' experience. For example, when they seemed resistant to practitioners' suggestions that mental health was involved in concussion recovery. Similarly, when some participants asked questions about my knowledge of the literature and I initially was not sure of how to answer. During these instances, I had to realize what was within my scope to say and what was not. Again, in conversation with my committee member, we decided that if the participants asked me questions about my knowledge of the research, I should answer questions I was comfortable with, citing the literature, while emphasizing that I am a master's student and I am not certified to give any medical advice.

My reflexive journal entries helped me keep track of thoughts and feelings associated with these situations and allowed me to reflect back on past interviews to prepare myself for future ones. Ultimately, it helped me deal with challenges and decision-making by keeping me focused on my goal on focusing the interviews on the participants' stories, but remaining open (within my scope and comfort) and honest if they wanted to hear about my mine after their interviews. The journal entries also allowed me to develop my interviewing skills as I met more participants. I would write down instances, for example, of when I thought I should have probed more or not asked such a leading question. For one of the interviews, I got curious about an unrelated topic to the research question and started to ask questions at length about it, which were unhelpful for the research. Situations like that were good to write down and remember for

next time. Lastly, these entries helped me with preliminary data analysis, as I started to write down notes of different patterns and nuances within the participants' interviews. In all, my journal became a guide for me on how to be ethical, mindful, and successful in my interviewing, while helping me to start to make sense of my findings.

3.5.3 Ethical considerations

This study observed procedural ethics by submitting the proposal to University of British Columbia's Behavioural Research Ethics Board and did not begin until ethical clearance was granted. Participants who chose to participate in this were considered at minimal risk, meaning any potential harm or danger imposed by the study were not expected to be more than that encountered by the individuals in everyday life (Canadian Institutes of Health Research et al., 2014, p. 22). While I interviewed individuals who were still symptomatic, their consent to participate at a location of their choosing indicated their willingness and capability to be present. There were no known risks to participants other than potentially triggering symptoms, feeling uncomfortable answering certain questions, or becoming emotional by describing their experience. However, they were under no obligation to answer any questions they did not feel comfortable responding; this was made clear at first contact and during the interview. Individuals were also reminded that they could skip any questions they were uncomfortable with, that they could ask to stop the interview at any time, and could withdraw from the study at any point. Additionally, considering that the interviews broached potentially sensitive topics, participants were given a list of free or low-cost counselling services that they could access. Above all, I ensured that the participants were comfortable and willing to share their stories and accommodated in any way possible.

Chapter 4: Findings

All participants experienced symptoms for months or years after their concussion that they perceived to be related to their injury. Their symptoms included headaches, being more emotional, not feeling right, feeling nervous or anxious, and sensitivity to light and noise (a more complete list can be found in table 3.2.2). These were debilitating, interfered with their pre-injury lives, and were mostly unexplainable or untreatable by health care professionals. The participants were at different timepoints since their injury, but similarities between them were still identifiable. These patterns formed the three themes described in this section: (1) *evolving appraisals amidst concussion ambiguity*, reflecting the participants' changing understandings of their injury and recovery throughout their experience; (2) *burgeoning psychological distress*, describing growing uncertainty and concern about their self-identity and health status; and (3) *"I'm just trying anything to get better"*, reflecting more active coping strategies when they perceived initial medical advice (i.e. to rest) as ineffective in helping them recover. All themes and subthemes are listed in Table 4.1 and are presented in the subsequent sections.

Table 4.1: Themes and subthemes

Themes	Subthemes
Evolving appraisals amidst concussion ambiguity	A. "It's just a concussion"
	B. Rest is beneficial; activity is harmful.
	C. A serious injury
	D. Organic origins
	E. "It's not mental health stuff, it's my brain"
Burgeoning psychological distress	A. Isolated and alone
	B. Indefinite identity loss
	C. Anxiety towards symptom triggers
	D. Feeling depressed
"I'm just trying anything to get better"	A. Therapy seeking and persistence
	B. Symptom tracking
	C. Addressing psychological barriers to recovery
	D. Acceptance

4.1 Evolving appraisals amidst concussion ambiguity

Concussions are ambiguous injuries. They are invisible, subjective, individualized, and to date, not well understood by the research and medical community. This theme demonstrates how this ambiguity manifests in the lived experiences of concussed individuals with prolonged symptoms, facilitating fluid understandings of the injury and recovery. With limited information to make sense of their injury, participants' understanding of their injury evolved throughout their experience. Originally, they perceived they sustained a benign injury that could only be treated with rest. As symptoms persisted for weeks and months however, they eventually assumed that their injury was in fact serious, and that their ongoing issues stemmed from physiological or neurological (hereafter referred to as "organic" [Lishman, 1988]) deficits that needed to be addressed with rehabilitation therapies. While this conception of a chronic condition with organic origins was well-received by participants, there was resistance to the notion that their psychological state could be involved in their prolonged recovery, though some indirectly (sometimes unknowingly) implied that this could be the case. Overall, the participants developed the following important understandings that were fundamental to their cognitive, emotional, and behavioural reactions throughout their experience.

4.1.1 "It's just a concussion"

Initially, most participants downplayed or disregarded their injury. While some of them recognized the fact that they had sustained a strong impact to their head, they did not seem to think it was health-threatening and should be addressed as such. Others described not feeling immediate symptoms, and therefore not realizing they were injured. These perceptions led them to continue the activity they were engaged in (e.g., snowboarding, hockey). Some of them were

influenced by internalized sporting norms to prioritize competition over acknowledging their injury. For example, Michelle described how she felt after getting hit in the head by another player during a soccer game:

Yeah, headaches, loud noises, the lights were bugging me but it's one of those things you're a soccer player and you're used to fighting through things... you're like "whatever"... like especially and we don't know that much about concussions so it's like, "it's just a concussion"

Similarly, Rob described the immediate desire to want to win a game of hockey after getting hit instead of addressing his symptoms:

I didn't feel great... I would say like a bit of a headache, mostly just a bit foggy I would say... but I was more angry than anything and I wanted to get back out there and be like "what! this guy is a dick!" like... their whole team... I hate them, I just wanted to win all of a sudden, you know what I mean? Like my competitive nature came out...

Those that did experience and acknowledge their immediate symptoms did not place a lot of importance on them, thinking that they would eventually “clear up” (Rick) and that they would not cause a significant disruption in their lives. While some participants saw a doctor within a few days of their injury, others did not because they believed the injury was minor or did not think that they would receive information beyond what they already knew or could easily access.

Michelle recalled:

the doctor is not going to help me with it... like I just need rest... that's what I need... and I'll dim the lights, right?... because that's what you hear.

While some participants carried on with their daily activities, others like Jen, tried to take a break from work or school. As evident by her account, this was simply precautionary and not a reaction to her thinking she had sustained a serious injury:

In retrospect, I didn't feel like it was gonna be the extent [of severity] of what it was by any means... it happened and I was like, “do I go to work tomorrow?” He [personal acquaintance who is a practicing physiotherapist] was like, “you should probably take the day off [...] honestly, I'd take the whole week off and relax, no screens and

whatever... you'll be right back to it" kind of thing. But it ended up being that work was pretty intense at that time and I'm really bad at disconnecting... I would get on my laptop sometimes and still be responsive... so it was more just resting at home, versus thinking that it was anything severe.

While most participants trivialized the injury for the initial days, the limiting nature of the prolonging symptoms became more apparent as time passed and the participants continued to engage in cognitively demanding tasks. Kristin described the progression of becoming increasingly aware that she had sustained an injury that should be addressed:

I don't remember feeling badly that day... except I was getting a little bit of bruising under my eyes so I was like "umm, I think I actually got hit really hard." But I don't remember feeling too terrible... maybe I was still getting that adrenaline rush that you feel afterwards. But then since I was feeling ok I thought "maybe this is a good sign." Monday again, feeling pretty good. Tuesday started feeling a bit wonky at work and just like... not that focused. And then by Wednesday my boss was like "you need to go to the doctor, you have a concussion. And I was like "nahhh"- again just thinking that I didn't. Umm and then, yeah, by the end of that week it kinda progressively got to the point where I remember feeling quite foggy and really tired and not really dizzy or nauseous or anything like that... but just like not right.

Jon recalled a similar experience:

so essentially the first two weeks is me just like trying to push through all these concussion symptoms being like, "oh it'll get better"- not realizing that you don't make it better by trying to push through them. So then about a week and a half in I guess, on Monday, I went to work and partway through the day I just couldn't even do anything, like I couldn't even... people were trying to talk to me about stuff that was going on and I just couldn't even comprehend it and I just like went to my car and was just like... and I just like shut down and collapsed ... so I was like okay, I need to take time off work.

Most of the participants believed initially that the injury they sustained was not going to have profound consequences, so they downplayed or ignored it for various reasons; these included sport ideals that influenced them to focus on the competition rather than their symptoms, not thinking it was a significant injury, or finding it inconvenient to take time off work or school in the days and weeks that followed. However, as symptoms persisted beyond the

initial days or weeks, the participants started to realize that their symptoms were debilitating and that they should address their injury. This realization instigated their first feelings of concern.

4.1.2. Rest is beneficial; activity is harmful.

Eventually, participants saw a general practitioner (e.g., family doctor, walk-in clinic doctor) after symptoms persisted beyond days or weeks. Confirming Michelle's notion above however, most did not recall receiving sufficient information to help them make sense of their injury and how to manage it. Instead, participants received vague advice to "rest" in order to allow the injury to heal before returning back to activity. This advice was initially interpreted differently between the participants, but eventually transformed into the notion that strict rest was necessary to prevent and manage ongoing symptoms.

Megan recalled her initial interaction with her doctor:

He said "yes, you do have a minor concussion, go home and rest." And I was like "Okay... what does that mean?" And he gave me no outlines or like recovery plans or anything, he's just like "Yeah, check back in a week and see... wait until your symptoms reside before you get back into activities." That was very vague... in retrospect I should have asked more questions, but I just said "Okay, like I'll go home and rest"

Kristin, who played varsity soccer two years prior to her injury, knew some things about concussions. Her doctor relied on this previous knowledge to make her recommendations:

I went to the walk-in clinic and they asked me "what do you know about concussions?" [...] so I was like "blah blah blah" kind of like said all of the things I knew, and she said "good, go do that". She didn't really have any new information for me besides what I already know which was like: stay away from screens, give yourself a brain break, and try to be by yourself, and don't have too much light around you, and just like give yourself some time to rest and heal and stay away from that stuff.

The remaining participants described receiving similar non-specific advice, which re-introduced the idea that the injury was inconsequential and that would resolve after a bout of rest. Rick described:

I took a break from classes for two weeks and thought that if I rested and took care of myself, I could return at the end of January and pick up where I left off.

The lack of specific directions facilitated different interpretations of the advice to “rest”. Some rested completely in a dark room for a few days, while others initially allowed themselves to do light activities such as going on walks, listening to podcasts or music, cooking, gardening, or meeting friends in quiet settings. However, if symptoms persisted or were triggered upon returning to activities, participants presumed that additional and stricter rest was necessary. For example, Dan took a break from school and experienced some symptom relief after resting for a few days, but not completely. After consulting with his doctor, he determined that stricter rest was needed to completely heal. In order to do this, he withdrew from school and flew home to his parents’ house. He described:

those two weeks in [city name] I took the darkness so seriously... I was so determined to just get better and come back to school... I was in deeper darkness, less activity, my parents made me all of my meals... you know... I was literally in complete cocoon for another two weeks... so now we're 2.5 weeks in and I've basically done nothing but lie in the dark...

Similarly, Emma talked about withdrawing from her school semester to focus on resting after an initial rest period did not provide relief:

I ended up going home so that my - I could rest comfortably at my own house and have my mom help take care of me... you know, make sure everything was okay.

Megan also described:

I remember my sisters and parents were in town for their birthday and they're like "Let's go kayaking, let's do these fun things!" And I was like "I am not leaving my room, I need complete darkness, no sounds, talk quietly to me, I can't go outside because it's way too sunny."

Due to explicit recommendations or interpretations of vague medical advice, all participants eventually engaged in a similar strict rest period at some point in their recovery that involved strict quietness, darkness, and disengagement from school or work. This was understood to be the only strategy to heal, so most participants were diligent in how much and how strictly they rested.

4.1.3. A serious injury

Despite resting for prolonged periods however, participants did not experience substantial symptom relief to the point where they could fully return to normalcy. Eventually, all participants were either advised to gradually return to activity or became frustrated that rest was not working so tried to return to work or school as best they could. Both of these strategies were generally unsuccessful for the participants however, as certain activities or exertion levels kept triggering their symptoms. Constant failings prompted them to realize “how serious a minor concussion can become if you don't treat it properly” (Jon).

Michelle described the gradual return with resting breaks that was advised by a concussion clinic to cope with her symptoms upon returning to her teaching job:

Can you do one hour a day?... then can you do two hours every day? If it didn't work, we would scrap it we would go even less... and essentially what they said is that whenever my headaches would increase that's when I should technically stop work, I should go home, I should rest... umm so that was part of it and then the other part was taking lots of brain breaks... so during recess time, instead of going to the staff room, going to a dark room, putting some headphones on... just totally black yourself out from all of the stimulation going on... so that was a consistent part of my routine... every lunch, every recess, I would find a dark room and sit by myself...

The participants who attempted this strategy eventually experienced a symptoms setback however, perceived to be caused by instances of “pushing too hard.” For example, Megan was

encouraged by her doctor and physiotherapist to gradually reincorporate physical activity which she attempted to on a stationary bike. In her efforts to do so however, she tried to do too much which caused a setback:

I think it may have been a combination of taking the bus home and pushing myself too hard. That evening, the pounding headache had come back and so I was like, "well that's not good, maybe I shouldn't be biking." So I was really conflicted about whether I should continue trying to exercise or just take it completely easy and... uh my sports med doctor is like "No, no, keep going, like you definitely just pushed past your threshold."

Those who described pushing through their symptoms while returning to activity seemed to do it because they did not know how else to proceed after resting had not been beneficial. Lauren described the routine of trying to return to her pre-injury life as best as she could, but with difficulties that persisted for months:

I was just so, so tired all of the time. And then like I would work and then I would come home and I'd lay down and then I'd fall asleep at like... I don't know nine, nine thirty, and just sleep all night until morning.... And then I would drag myself out of bed like 20 minutes before I had to be at work... drag myself to work and then some days [...] I'd be sick and I couldn't go because I'd feel so nauseous.

Rob, who employed a similar strategy, described how it eventually became unsustainable for him when work became more demanding:

after all of the overtime that I worked in December it was very much clear that I could not keep that up... so the symptoms had gotten so much stronger... it was a daily struggle for me [...] because I was working many hours a day, I was stressed, I was pushing myself mentally to a point where I hadn't in the past six months...

Both of these ineffective strategies encouraged some participants to perceive increases in activity levels as detrimental to recovery, and to resort to the only strategy they felt comfortable with – additional rest. Tom, who sustained his concussion a few weeks after graduating university, did not start a job for a few months because of his symptoms. The job did not go well for him because of his symptoms, and he eventually quit after six months of struggling to manage work demands with his limited capacity. He described:

yeah that job really did not go well... I just did not feel good every day...so yeah... I only worked there for 6 months... and after that I was just like "yeah, I hate this, I need another break"... then my idea was taking a break and not going back until I felt good again...

The impenetrable threshold of symptom-tolerated activity started to feel somewhat permanent, and the longer it lasted, the more the participants started to believe that they had sustained a serious injury or developed a serious condition. Some described it as a disability that could have lasting or permanent impacts. For example, Rick talked about relating to people with disabilities he had worked in for a class project. Similarly, Rob described his outlook:

I didn't want people to go have to change for me so I just worked to accommodate - essentially the disability that I had...

The perceived seriousness of their situation instilled feelings of regret and guilt for the initial disregard for their injury. Some participants believed that if they had addressed it from the beginning, they could have prevented their prolonged recovery.

4.1.4. Organic origins

Desperate for answers, participants consulted various information sources (described in the third theme) about the origin of their persistent symptoms and possible strategies to manage or rehabilitate them. Through these sources, participants eventually understood that there was likely a range of organic (e.g., physiological or neurological) reasons why their recovery was prolonged and concluded that these should be attended to in order to heal. For example, a prime concern for the participants seemed to be that their neck was injured. Taylor recalled a comment from her first physiotherapist:

my original physio was like "well yeah you're not going to have a concussion without having some neck issues."

Similarly, Jen described the information she also received from a physiotherapist:

so my neck – at the end of the day – I think it is one of the biggest drivers of this... which is kind of weird... I got pretty bad whiplash on my neck. I have a long neck - it's what I've been told - I never realized, but now I look and I have a very long neck.... and when it hit it, I think it pulled a lot of my muscles or nerves, I don't know really. Basically, a lot of work's been done on my neck.... um, which I think when it inflames, it enhances my dizziness, which is kind of weird.

Megan described doing thorough research online to try to understand her symptoms and recalled some information she encountered on an online video – notably using her background in neuroscience studies to shape and relay her understanding:

One of their videos is talking about neck muscles, and how the tightness in your neck muscles can trick your brain into thinking you have a headache, because like C1 and C2 nerves converge and you can't really tell the difference between neck and head pain, and then if that also compresses your vagus nerve then it releases anxiety like hormones... and can cause anxiety symptoms... so that was a major turning point, I was like "Oh, I definitely need to work on my neck!"

In addition to the neck, other participants also suspected further ailments suggested by their own research or by practitioners. For example, Lauren described a deficit in brain regulation:

my voluntary functions of the brain just regulate on its own became kind of wack and weren't being regulated.... and ... so my brain's not working how it should help keep my body running how it should

Emma seemingly used her nursing background to describe in detail a complex physiological relationship that she perceived to be the origin of the symptoms:

There was probably some neurosynapse damage that has never fully healed.. And because of the inflammatory process prompted from the injury, and then just how many food allergies I have now... umm... I know having, being in this chronic state of inflammation is probably the reason why the migraines continue...

Others received the suggestion that their eyes could be malfunctioning and influencing the symptoms. Kristin recalled being referred to a specialist to help her manage her light sensitivity:

They referred me to an [...] optometrist who does like sport injury, basically like concussion injury eye assessment - so they look at all the different eye assessment of the eyes and they can help prescribe glasses for you to deal with your light sensitivity.

Similarly, Emma described an eye issue that was noticed by her family doctor:

I also started having... umm... some eye issue, where you would bring something close and my eye pops out. And I had never noticed that before....

Overall, the understanding that the ongoing symptoms emerged from a combination of deficits in bodily systems, led to the conclusion that the path to recovery would be through the therapies suggested by different health practitioners that could address these. Michelle described her broad understanding:

my physio just said that we're just trying to get your body aligned... and get it in a position where healing can happen... and I thought that was an interesting way to look at it... and I think in some sense that's really true... I think of all of the treatments that I've had... and the fact that I'm kind of still where I'm at and it's a year later... it's like yeah, this brain thing doesn't heal on its own.

Rob also explained how a concussion clinic would help:

umm so their hope is to retrain those systems, to normalize some of the issues and to clear up these signals that go from my eyes and from my balance and from my sense of positioning to my brain so that they all match up... and then the hope is... that then frees up a lot of mental capacity that the fog will disappear and that I will have a greater ability to continue on and do work and that symptoms caused by these conflicting signals will no longer be present...

Due to seemingly unexplainable persistent symptoms, participants concluded with the help of various information sources that serious organic impairments that were not allowing them to heal. Correspondingly, all participants explored with a variety of treatments to try to address these (explained in the third theme).

4.1.5. “It's not mental health stuff, it's my brain”

While participants seemed very receptive to suggestions that organic causes were involved in their symptoms, there was a palpable dissonance when they explicitly or implicitly discussed their psychological ill-being and its role in recovery. This was an important finding, considering that participants seemed desperate for answers, but rejected this idea because it seemed a like a less legitimate source of symptoms to them. There were tensions and contradictions in their accounts when discussing the topic, as they would describe psychological turmoil (discussed in the second theme) but avoid linking it to their ongoing symptoms. For example, Emma preferred to attribute what she described as depression to her physical injury. When she was asked what she attributed the depression to, she rationalized:

It was definitely from the injury. Umm... because the depression, it was not targeted at anything.... I'm sure the whole, like the process of, you know, not being able to do anything - I'm sure that didn't help, but I didn't notice the like depression onset until after the injury...and there was, there wasn't a rhyme or reason to it, and it was so sporadic, and it would be over the silliest things, and it was like I just couldn't control what was happening.

This resistance seemed to provide barriers for the few practitioners who attempted to address mental health with the participants. For example, Michelle talked about her doctor's suggestion that anxiety may be involved in her prolonged recovery and how she disagreed with it. She acknowledged she was emotional about her situation (this was also evident as she became tearful during her interview), but resisted the notion that this could be influencing her recovery and perceived it as unhelpful:

I get really emotional when I talk about my concussion... but like I don't find I cling on to the emotional part, I'm pretty positive that I can get past it... but I felt like my doctor was being like "I don't know how I can -" like he's just trying to figure out how he can help me, and I'm like just trying to tell him my symptoms to see how he can help me...umm, but he thinks it can be an anxiety thing... and that that could be withholding me from my injury as well because anxiety plays a role in the healing process as well, right? but I

really disagree with him in that... because I'll have one emotional day a month where I just cry.... or like when I talk about it... [voice cracks] like I'll talk about it with you and you're probably thinking "oh she's very emotional and anxious," right? And I go to my new physio and I've had that, but in all of my appointments with my chiro I never cried once... there's just... I don't know... it's weird. So I don't know, I don't want to see my doctor now... because I feel like he's not taking my word for it... so... yeah... and he's not being helpful either... like he doesn't have anything really to suggest.

Similarly, Taylor attended an appointment with a neuropsychiatrist who suggested mental health was influencing her ongoing symptoms and prescribed anti-depressant medication. She talked about her initial unwillingness to take this medication, and her eventual agreement when she was told it would address a vestibular condition. Interestingly, when mentioning that the medication did help, she referenced benefits to her emotional state rather than the vestibular condition. Her eventual willingness seemed to be influenced by preferring a biological attribution of the symptoms and having better rapport with the doctor who prescribed it:

When I went to the neuropsychiatrist he wanted me to go on medication and I was very reluctant, but also I feel like he kind of circumvented the actual injury - he was like "I don't think your injury was that serious, I think you have this historical mental health thing" and blah blah blah... so I called bullshit on that, but I really trust the doctors at [hospital name] because I had seen them for years... so I just trust them... so eventually when the dizziness was the thing that really lingered and they had wanted me to come back for some more tests... something we talked about was that [doctor name] said "I'm thinking of this thing and it's kind of new... it's new research... it's called perceptual persistent postural dizziness... it's PPPD, so what it is, is that you had a vestibular condition [...] so what's happening is that you already kind of had this condition and then you have brain trauma and your brain cannot reconfigure to a non-vestibular issue condition... it can't re-write itself... so we want you to take anti-depressants. It's a small dose, you never have to go beyond that, but like we found it does help people"... and at first I was like "well..." and he was like "I know, I've read the review from the doctor at [clinic name] and I understand your reluctance and stuff, but like I'm really encouraging you - it's up to you, but I think it can help"... and I've been on it for almost a year, and I don't want to stay on it forever, but I do think it has helped, I think it just calms me down a bit...

Some participants did consider that mental health could be involved in their recovery, but still expressed their preference to blame organic symptom sources. Tom specifically talked about this:

I started to realize that yeah it's probably mental health stuff, but it's hard to say because I've always believed there is some concussion piece - maybe I'm just kind of holding on to that and just being like "it's not just mental health."

Similar to the participants above, this resistance did not let him engage in treatment that would specifically address his mental health. He described his disappointment when his first appointment at a concussion involved "talk therapy" instead of physical exercises:

I remember being really excited about it because it was a concussion clinic but I remember after the first appointment I was just like "this is not what I wanted"... it was just talk therapy and I thought it was going to be me doing exercises and this and that and something to get me better because I was just like "it's not mental health stuff, it's my brain, it's not like how I'm feeling and stuff"

While it is difficult to speculate why participants preferred to blame their physical injury, there were underlying suggestions that a mental health stigma or a challenge to the athletic identity could be involved. Again, Tom explained:

I felt like it was just embarrassing that I still wasn't feeling good and I'm not really sure why... I feel like maybe just being into sports and contact sports and like that was kind of my identity - being tough - and that got stripped away from me...

This theme highlights the fluid fashion in which different understandings of the injury, rest, activity, and symptom origin developed for participants. These interpretations were fundamental in shaping the cognitive, emotional, and behavioral reactions that they engaged in, which determined how the experience developed for the participants. The next theme elaborates on the profound psychological distress that evolved from these understandings as well as the heavy reliance on rest as a management strategy for the symptoms. The third theme describes how the perceived lack of knowledge from doctors and the futility of rest encouraged the participants to become more active in their own recovery to directly or indirectly ease their symptoms and burgeoning psychological burden.

4.2 Burgeoning Psychological Distress

As with other health conditions, psychological distress can be involved in a pain-stress cycle, in which one reinforces the other. This is an important consideration since participants seemed to neglect the notion that their psychological state could be involved in their recovery despite describing profound distress. This theme focuses on the contextual injury and recovery-related situations that triggered emotional and cognitive strain for the participants. Isolation combined with health uncertainty triggered feelings of loneliness, identity loss, and desperation for the participants. With uncontrollable symptoms and various speculations on their origins, participants struggled to comprehend which activities and effort levels were appropriate for their recovery. Because of this uncertainty, most participants seemed to develop anxiety towards any actions that could result in symptom prolongation or an additional injury, as well as depressive symptoms from their overall situation. While they were candid about these emotional difficulties, it was evident that they still separated them from any influence they might have on their recovery.

4.2.1 Isolated and alone

The heavy reliance on resting as a symptom management strategy generated profound feelings of being “isolated and alone” (Rob). This was accompanied by additional emotions including anxiety and sadness. For example, Michelle describes transitioning from being happy to have time off to rest, to eventually becoming emotional and anxious:

so originally being at home I was like "ok good, two weeks off I can just rest"... kind of happy about that, umm but then just being alone all of the time... it's crappy... it gets sucky, you do feel lonely and you get emotional about... like my routine would be to wake up in the morning, I would read, I would close my eyes for a bit. I closed my eyes a lot because you're in a dark room. Reading was one of the things that I kind of did and

I felt ok because you can't have screen time and you can't do this and that... so yeah... lonely... I started feeling anxious...and really like shaky and stuff, it was super weird.

Jon also talked about feeling distress from being alone. He did recognize that these feelings could be involved in triggering psychological symptoms, but notably in discord with a later segment of his interview where he attributed his anxiety to brain inflammation. He explained:

like people don't realize how much umm... social isolation can bring on like just uncalled for anxiety [...] unfortunately I was in a house in [city name], almost all by myself for weeks there, so I think a lot of the emotional pain and stress I went through was really just because I was lonely, not because of anything the concussion was causing.

Jen, who had tried to push through her symptoms for two months working part-time without success, eventually decided she would take a leave from work to focus on recovering.

When asked how that made her feel, she answered:

I think I went into a darker place, if that makes sense... It's like - you're so isolated. I moved back in with my mom, I lived downtown and she lives in [city name] [...] So I was there the whole time, but I wasn't doing anything... I wasn't watching TV, because I can't – it would bother me, so I would sometimes literally lay in my room and stare at a wall...

Even if participants did interact with friends, family, or acquaintances, they still described feeling isolated because of the invisibility of their injury and symptoms. Despite feeling like people cared about them, they thought others could not really understand what they were going through. Rick described:

no one really understands what you're going through... they'll ask, they'll check how you're doing but they don't really get it... umm no one gets it, so that's also a hard part, right? it's not it's not a visual thing and people don't see it.

Rob corroborated this feeling:

It took a massive strain on my relationship, and I think to a certain extent it still does... because I haven't felt like people never really fully understood... and still don't understand because like I said, you don't wear a cast on your head.

Even talking with other individuals who had had complicated concussion recoveries did not prove to be helpful for the participants. Most of them understood that concussions manifest differently for everyone, so something that helped someone else recover was not necessarily going to work for them. Kristin described:

I feel like speaking to some of my friends about it in December almost created false expectations for me around what my recovery ended up looking like, because I was like “oh, so and so said it was a month and they were better, so that’s probably what is going to be the case for me.” So I mean it was helpful in the emotional support sense, but I think in the long run, probably not having those conversations would have been better for me

Overall, participants felt like they were struggling with their ongoing symptoms on their own. They either felt this way because they had withdrawn from all activities to focus on resting, or because they perceived that others could not understand what they were experiencing. The persistent nature of the symptoms and the continuing reliance on rest to manage symptoms strengthened these feelings as time progressed.

4.2.2 Indefinite identity loss

Initial negative emotions grew in intensity as the participants developed the understanding that they had sustained a serious injury. While in the acute injury phase their main concern revolved around daily symptom management, it gradually shifted to considering the potential long-term ramifications of their condition. These thoughts triggered feelings of identity loss because the participants started to question whether they would ever recover normal function and be able to return to meaningful or regular activities that fulfilled them. Rob articulated how his individual symptom worry transcended to the potential permanency of them:

It's not so much the headache or the dizziness or the fogginess... it's the persistence, it's the constant nature of it, and the fact that you don't know if it's ever going to end... and I feel like those things combined completely change your attitude and the way that you

approach people because you don't feel like "oh you have a headache, take some advil" or "you're not feeling well, go home for an hour"... like I can go home for an hour and it doesn't matter... I can go home for four days and it doesn't matter - I'm still going to feel this way...

Taylor described the emotional toll she experienced that originated from being withheld from daily activities that she was passionate about, as well as parts of her identity she was proud of:

no working, no trail running, no soccer, no coaching, no reading books, no watching shows, like - that went on for at least 6 months [...] and my whole identity has always been around having a strong work ethic, and playing sports, and trail running, and you know, I've been trail running for years, right?... so not being able to do those things suddenly I was like "oh, who am I now?" I'm just this like kind of average person who can't do the things I'm passionate about... like even reading - like I've been a voracious reader for years and even that, it was so sad because literally the week before my concussion I had just ordered 6 books - I got this whole box from Amazon and they sat on my shelf to this day basically, right? so that was always a constant reminder too, of something that I was really passionate about. And I just felt dumb too... I struggled to find words and be in conversations and I would just lose track of the conversation and be like "what did you say?" sort of like a bit infantile... so that was really hard because I have a pretty sharp mind and it felt weird to like suddenly be muted, you know what I mean?

Participants seemed very worried that they would not be able to return to full capacity at work or school, which put their personal and career futures at peril. Megan described:

not being able to go to classes and learn, because that was a part of my identity was "I am a smart person, I go to school to learn and improve my brain" and that gave me a big sense of identity was being able to critically think, and I think that might have been the scariest part was when I couldn't do simple math problems, that was like a very scary alarm being like... "are you ever gonna recover? Are you ever gonna have full normal brain function again?"

It was also evident that most participants had a strong athletic identity that was affected by the chronicity of their symptoms. They appreciated the values that sport had taught them and talked about how integral their sport involvement had been in developing their self-concept. Like most other participants, Kristin described the importance of sport in her life:

I do feel like it has always been a constant in my life and it's just one of those things that makes me feel like the best version of myself. Like I get that time to shut my brain off and do something that I'm good at and I always feel really really good afterwards. So yeah,

sport has played such a positive role in my life and my self-esteem, and my connection to people. And yeah, I love the team setting. I love working together as a team on anything... so... yeah... sport is very important to me.

In addition to being a part of their identity, most participants also valued sport and exercise as a stress-management tool to help them cope with daily stressors. Jon described how this was so engrained in his lifestyle, that after sustaining his concussion his immediate reaction was to manage the symptoms by going on a run:

Activity was just a good medicine for me as far as, you know, de-stressing, de-everything, like, you know, it was my go-to. I felt shitty, I went for a run. I felt stressed, I went for a run. I felt... you know... I dunno... like even like if I ate unhealthy the night before, I went for a run, right? Like it was just kinda my answer to everything. Which kinda answers why I kept running in the fall for a couple days after [the concussion], I was just like, "we'll solve this with running."

In addition to experiencing disruption in integral facets of their identity and lifestyle, the participants' injuries also interrupted regular daily activities, which further contributed to their identity loss. Over time, these became prioritized over sport as important aspects to return to. For example, Rob described finding it extremely stressful to walk into a grocery store after his physio appointment that triggered his symptoms:

I just remember the lights being - like these are the brightest lights in the planet right now... I might as well be walking into a sun... and people were just going and you know, looking at different types of hummus, and I just remember thinking to myself, like I'm going to break down... because I can't function in this environment... like this place isn't for me anymore...

Similarly, Jon described becoming avoidant of busy streets and loud environments:

[I still have] increased awareness of just like background noise. Like I'm still very sensitive to like - not very sensitive - but I don't like walking on busy streets still... whereas before I didn't even notice it at all.

Dan also explained how even if returning to exercise was important to him, he prioritized being able to read and use his phone in terms of feeling normal again:

exercise helped me, but ultimately my goals were to go back to school... if exercise took longer to come back I would have been very fine with that.... but [without] reading and using a phone screen.... you can't live normal life like that...

Being restricted from core meaningful activities (e.g., sport, work, school) as well as regular daily ones deeply affected the participants in terms of not feeling like themselves. The uncertainty of whether they would ever recover or not heightened the sense of identity loss because participants started wondering if they would have to accept their limitations as part of their new lives.

4.2.3 Anxiety towards symptom triggers

Incessant symptoms and unsuccessful activity reincorporation gave most of the participants a sense of not knowing how to manage the situation beyond resting and managing activity. These strategies were not always helpful or straightforward either. The lack of control and uncertainty of how to proceed created significant stress for the participants and generated fear towards anything that could potentially trigger their symptoms. A lack of direction on how to manage the symptoms was especially challenging for the participants, who as athletes were used to structured rehabilitation strategies for their injuries. Kristin described:

I guess I really just had this expectation that it was not going to take me this long to get over it. And I think being a goal-oriented rehab kind of person, and having experiences with injuries that are more cut-and-dry, this has just been really strange for me. Even if I'm doing everything right, I have bad weeks and there's no real explanation around it... and I don't know what to think. And I try to make sense of it, but it just doesn't really make sense. So that's been a really weird piece of this... it's just... kind of being along for the ride... and sometimes it's good and sometimes it's bad, and I often, my behavior doesn't have a whole lot to do of when I'm feeling good and feeling bad, I guess?

The common understanding was that sometimes decreasing their activity levels or resting was the only strategy to feel better. This strategy was reinforced by doctors and other practitioners who encouraged them to rest when they did not feel well. Even then however, some

of the symptoms were beyond their control. When asked if she had any control over her symptoms, Michelle answered:

I guess If I slow things down, that's about it... but even still... I don't have any control over my just my soreness... every morning I wake up and I'm sore, yeah, in my neck and upper back, and it doesn't seem like there's anything I can do, sometimes when I get adjustment at the chiro, that helps... but I feel like I'm back where I was kind of like at the very beginning

Without feeling like their behaviour significantly influenced their symptoms, participants felt confused and frustrated about how to manage them. Therefore, they described starting to feel nervous about increasing their activity levels that would trigger their symptoms. Although they were motivated to return to their valued activities, there was tension with the concern of pushing too hard or engaging in over-demanding activity would instead trigger a recovery setback.

Michelle described being nervous about returning to work for fear of triggering symptoms:

when I would go back to school, I would go to school for an hour to see how I felt, I would be anxious and be like "oh great, if this doesn't work out for this hour, then I would have a setback again, and then I don't get to work again and that means I'm away from people again."

For some participants, the uncertainty of which activity levels were safe to engage in was furthered by contradictory advice from different practitioners. Lauren recounted:

I just felt very confused because he [physiotherapist] was telling me to do less, my doctor was saying if you just do more, you'll feel better. And I was just like "what the heck? I don't know what to do." With the concussion clinic, they're all about pacing. Like if you feel worse, then you stop, but I couldn't grasp that because I never felt better. Like if I did nothing, I didn't feel better, if I did more I definitely felt worse. I couldn't understand like when it was okay to do something and when it wasn't....

Jon also recalled:

that's maybe the one failing of all these specialists that got to help me... is nobody was able to properly relay to me like what was going to make me worst and better...

Most participants also recognized that previous traumatic symptom relapses, provoked by exerting themselves too much, also contributed to their constant apprehension of activity

engagement. Rick talked about pushing himself too much one day while studying and experiencing a frightening setback:

that half hour for me is when I felt like I did too much... so I was working and the analogy that I used at the time was that it felt like I blew a fuse in my brain, felt like I was just working, working and then all of a sudden... poof! I had nothing left in me, and I just immediately felt my energy drop, I clouded, I felt like I was getting really foggy, I had a headache and... just had nothing left in the tank to even make... small decisions... so I remember that being a really scary feeling for me.

Jen shared a similar experience:

part of my anxiety - like, "oh my god, I'm going backwards" was because I think when I kind of went back to work, I pushed myself... and then I just fully crashed... so I think I was just scared that anything would just set me back.

Another potential symptom trigger that some participants feared was the possibility of sustaining another injury through any contact to the head or body. The participants believed that this would mean starting their recovery from the very beginning. Dan explained his understanding that double or triple “concussing” himself, during sports or otherwise, would protract his recovery. Despite wanting to convince himself that any head impact would not cause a concussion, he struggled to believe it. He recalled:

I was incredibly anxious... I was so nervous... I was like so scared that I was going to double concuss myself, which is what they tell you is the worst thing, right? Going back to sports too early? Or just prolong[ing] this nightmare, you know? And what's really telling is that a few days later [...] I just lightly tapped my head against a rock... like literally nothing, and I had this genuine like anxiety attack, like a breakdown where I just thought I had triple concussed myself...

Rob also broached this topic when he recalled his return to hockey despite not feeling completely recovered. He remembered having to negotiate this fear of re-injury with his desire to return to sport, with the latter prevailing for a brief period. However, his belief that hitting his head again while symptomatic could make things much worse, provoked significant anxiety that eventually influenced him to stop playing again. He described:

I would get really anxious before games... I wouldn't say I would have full blown anxiety attacks, but I was terrified because I was starting to come to terms that I shouldn't still be playing and that the next hit - you know - it's all about if you haven't recovered and you keep getting hit - that's the problem, right?

Tom, who described himself as almost recovered, was back to working full-time and was slowly starting to reincorporate non-contact organized sport into his life. He shared that the main issue remaining from his injury was his inability to control his reactions to light contact to his head or body. He was ostensibly aware that this would not cause him to sustain a concussion, but he struggled with opposite inner thoughts and feelings:

certain times at volleyball I'll bump into someone and then I'm like - literally just from being stressed and putting myself under stress – just thinking that my head is hurting and this and that... and like convincing myself that I had a concussion...

Overall, it was evident that participants had become quite sensitive to any activity that they perceived could trigger their symptoms, and started avoiding or being overly aware of how they were feeling during these activities. As Lauren stated, the participants seemed “for the most part just scared of making things worse,” (Rob), either by exerting themselves too hard, doing certain movements, or getting an additional concussion that would compound the effects of their original one. Instead, they preferred to do “safer” (Jon) activities that would not put them at risk of these potential recovery setbacks.

4.2.4 Feeling depressed

The combination of feeling isolated, sad over indefinite identity loss, and anxiety over what activities they could safely engage in, seemingly culminated in what some participants described as depressive moments. Participants were open to discussing the emotional toll of their experience, but were less so when discussing how their psychological state could be involved in the prolongation of their recovery. For example, Taylor was forthcoming in suggesting that she

experienced depression and suicidal thoughts associated with thinking that she was going to struggle with her ongoing symptoms for the rest of her life:

I was really depressed and like pretty like suicidal towards the latter part of that window cause I was just like "I'm never going to get better" like "this is just my life"... like basically if this is my life I don't really want to do this... because this is terrible...

Megan recalled the “lowest point” in her recovery after failing to see progress in her symptoms for weeks at a time. While she described herself as a typically optimistic person, her ongoing symptoms made her feel unmotivated to do things that previously made her happy:

I remember one day I felt very depressed, like I'm usually a very optimistic and positive person and I've always had the like work hard, you can get through this, like just keep pushing... and I've always seen good results so the hardest part for me was being shut down so many times, like over and over again it would be like "Oh yeah, I should be all better, or at least significantly better two weeks from now." And then two weeks would go by and I would barely see improvements... and then again two more weeks would go by, and it'd be just very depressing...

Rob described how the uncertainty that revolved around him losing important aspects of his identity affected him emotionally:

those kinds of errors and those kinds of omissions in abilities that I took pride in... umm... left me feeling a bit terrified but yeah - like quite depressed... and I've always been an athletic person... so I've had sport to a certain degree taken away from me... I've had things, like characteristics about myself that I view as positive - taken away from me... and... I'm left with a lot of question marks... will I ever get these things back? Will I ever be able to participate in these activities again? And when the answer is "maybe"... or when the answer is not one that you can get from someone, then there is a lot of doubt... is this how I'm just going to be from now on? Do I like this person?

Jen recognized that she was depressed and consulted with her doctor about going on medication to help her not go to the “dark place”:

I was definitely depressed... I ended up going on medication for sure. From August, doing a half a pill or something like that... I don't know... not even a full dose or anything, but just something to get me motivated and not feeling like absolute shit.

The combination of isolation, health uncertainty, and identity loss seemed to contribute to profound psychological turmoil for the participants. Desperate and not knowing how to proceed, most resorted to other behavioural or cognitive strategies to directly or indirectly, consciously or unconsciously, address the psychological turmoil they were experiencing. These are discussed in the next theme.

4.3 “I’m just trying anything to get better”

Considering that rest did not help the participants alleviate their symptoms, they eventually engaged in alternative strategies to help them gain control over their situation. First, they sought and persisted with different rehabilitation treatments that were supposed to address the organic origins of their symptoms. While these did not actually provide significant symptom relief, their accounts latently revealed that this strategy provided validation to their struggles, an active component for recovery, and positive expectations. Without access to biomarkers to track their recovery, participants also developed their own symptom-tracking strategies in order to assess recovery and whether or not they should engage in certain activities; this was helpful in helping participants gain some control over their recovery, but also became counterproductive when it influenced participants to be hypersensitive to their symptoms. Finally, few participants – notably those who had recovered or were close to recovering – attributed part of their recovery progression to acknowledging and addressing psychological barriers (e.g., anxiety) they had developed throughout their experience. Those that were still experiencing symptoms but described to feel better emotionally, explained how gaining acceptance towards their symptoms relieved them of some distress and helped them to feel better overall. The development of these

strategies and the psychological influences or outcomes associated with them are discussed in this theme.

4.3.1 Therapy seeking and persistence

While some participants entertained the possibility of accepting their perceived serious condition as their new normal, the strong desire to understand why their symptoms were persisting and how they could be addressed eventually prevailed for all. In light of what they perceived to be unhelpful medical advice, the participants adopted a more active role by seeking explanations, a diagnosis, and a potential treatment plan from other sources. The overall feeling was that they needed to “advocate for [themselves]” on what “actually makes concussions better versus what most doctors know for treating concussions” (Emma) and look for this information elsewhere. Jen remembered this moment after noticing that prolonged rest suggested by her doctor was affecting her emotionally and not helping subdue her symptoms:

just not seeing that there was any improvement eventually pushed me to be like, "okay, I have to do something to change this, because this is getting insane."

Tom also recalled:

I remember my family doctor at the time... when I went to him maybe 3 months after my concussion asking him for advice, he was very dismissive... he told me like "there is nothing you can really do... look at the hockey players [...] you can't really do anything with concussions... just rest and wait"... and I was like [sarcastic laugh]... so I didn't really feel like I had any guidance, so I just did it on my own... kind of researching and my mom would be doing her research too...

Collectively, participants consulted with paramedical practitioners such as physiotherapists, chiropractors, nutritionists, occupational therapists, counselors, optometrists, massage therapists, and alternative practitioners, such as acupuncturists, homeopathic doctors, craniosacral therapists, and osteopaths. They also did their own research in news stories,

academic research articles, and the internet. This extensive investigation was driven by desperation of trying to make sense of their injury and address it in any way possible. As mentioned in the first theme, most practitioners attributed the persistent symptoms to different organic ailments and treated these accordingly. This involved significant time commitment and financial cost for the participants. Taylor explained that her routine made her feel like a “professional injured person.” Lauren, who resides in a rural community, found it difficult to consult care beyond primary physicians. After 10 months of unexplainable symptoms, she consulted a private concussion clinic in the closest city that was a 10-hour drive away. She explained what followed:

and they said, like “you have concussion, but like you'll get better and you shouldn't work... you should just focus on getting better.” So I quit my job and I started going to a concussion clinic. I went monthly because I live like a thousand kilometers away from it, so I flew there monthly and did Skype appointments weekly. [...] I went there monthly for March, April, May and I wasn't getting any better so then they're like “oh well, maybe if you lived here we could see you more frequently...” so I moved there for six weeks.

Some participants found success with their therapies, but not to the extent that they could return to their daily activities. For example, Jon described encountering a recovery “plateau” where his treatments were not helping him feel better anymore:

basically I got better, better, better, and then February or March I hit this plateau... and at this point I was doing acupuncture twice a week, I was doing all types of things to help my neck.. you know like maybe it's my neck, maybe it's my eyes... you know I was trying literally everything... light therapy, got special glasses, saw an optometrist... anyway... I hit a big plateau in March... where I could just not shake headaches...

Michelle also explained:

I am making progress... it's just very much... it's been like that the whole time... I go up a little bit, I plateau, maybe decrease a little bit and then I go up a bit more... and then plateau for months...

Their accounts revealed that there were possible underlying cognitive and emotional reasons that influenced their commitment to their therapies. For example, consulting various

practitioners seemed to offer validation for their condition by identifying tangible symptom sources. This provided legitimacy for their symptoms and comfort that there was a strategy available to deal with them. Kristin described the relief she felt when attending a private concussion clinic in relation to disappointing appointments with walk-in clinic doctors:

it was just really nice to have somebody who knew what they were talking about and who could tell me what was going on, like “yep, no, that’s normal, that’s not normal” ... and I did the ImPACT test and they sent me my scores and it was kind of validating for me to read all the things and to be like “oh, ok, I’m not normal right now.”

Michelle recalled her similar experience:

I went to my physio now and she's like "oh sometimes people will get pressure because of this" and I'm like "whoa, you know!" ... so not a lot of people do...

In addition to addressing tangible problems, the appointments also provided the participants the opportunity of having a more active role in recovery and something to do to that countered the idleness of resting. For some, such as Tom, just the act of doing something seemed better than doing nothing at home:

I remember at [clinic name] it really helped me to get out of the house and have something to do... I would drive there and it would take up a day... like leave at 10am and come back at 2pm.... when I had nothing going on at least that was something to kind of do....

Others sounded encouraged by the specific exercises that were given to them by practitioners that seemed to resemble rehabilitation treatments with previous injuries. Jen described her vision exercises:

I went once a week to therapy. They would give me those take-home assignments... umm the coin exercises, where you have two coins on a piece of paper and you try to bring them to see three coins... that's one example. I did a lot of like hang a ball and work on my peripherals, where I am in space kind of thing. And the reading one, where you have a flipper that changes the magnification... umm anyway, there's a bunch of ones I did, like bug on a string... but like every week I had new things that I would kind of be doing.

These exercises seemed to be associated with hope and positive expectations of recovery. Rob explained what they meant to him:

I have exercises to do... like I have appointments to go to... just the fact that I have something on the books... umm... it's just like at least I'm doing something.... at least I have a reason to give a shit... so people are like "oh you have these weird shapes and colors on your wall"... and I'm like "yeah, to you that just seems like a game... to me that's my ticket... it's my ticket back"... all these weird funny shapes, all these stupid balance exercises... I can't let that go.

While different therapies were somewhat helpful for some participants, most of them described encountering a recovery plateau that they could not overcome. However, they still persisted with the treatments for weeks and months, which suggested that these strategies may have been more strongly associated with easing the psychological burden (i.e. granting them a perceived sense of control, agency, and positive expectations), rather than whether or not they were successful in reducing their persistent symptoms.

4.3.2. Symptom tracking

In the absence of objective ways to assess their recovery progress, participants resorted to becoming very “in tune” (Rick) with their body to assess daily symptom levels. Some developed this strategy on their own to evaluate whether they could engage in a particular activity, and others through the encouragement of practitioners to assess recovery trajectory. Sudden or strong symptom occurrences were again perceived as detrimental signs to recovery that should be managed by rest and activity disengagement. Rob described advice given to him at a concussion clinic:

for all of the time that you're symptomatic and working away, you are not getting better... so they have symptom scales that I'm very much aware of... and trying to ensure that I'm not symptomatic and exerting myself because that's just going to delay my recovery

Kristin described waking up every morning asking herself how her “concussion was doing,” and having to constantly keep track of her symptoms so they wouldn’t worsen. Her symptom awareness became evident during her interview when discussing the topic, as she asked to switch seats because of the glare coming in from the window was reflecting off the ground and making her uncomfortable:

I think about them all the time... like its all-consuming because, yeah, all the time. Especially with the light sensitivity. Every room I’m in I’m assessing where the light is... and on that note, can we switch spots because that [points to window]?

Dan also described becoming very in tune with his body and symptoms to have a better grasp of what made him feel better or worse. He explained how this eventually developed into an obsession of tracking the intensity and duration of the symptoms:

I was very obsessed with my own condition and recovery... like I was obsessed with the science that could have been happening [...] I had charts with every activity I did and the symptoms it provoked... and I developed a headache categorization system of umm numbers and - mostly numbers, and uhh just different things to denote like duration, severity, location... so I knew exactly what my headaches were...

Rick shared a similar strategy:

and one of the things that I was really looking for was a way to measure progress, because I felt like that was really frustrating for me, not... seeing or tracking any improvement [...] So [the concussion clinic] had the list of symptoms... so I thought to myself... okay I'm gonna... look at all these lists of symptoms and I'm gonna look at this every single day and see how I feel, so I set up a spread sheet and just started... and the end of every day I'll just give myself a score and total it up and graph it...

Even though symptom monitoring developed as a method to gain knowledge of their recovery, some participants also realized that they had become too aware of their symptoms, resulting in consequences that they deemed were counterproductive to their goals of activity re-engagement. Lauren described that she became so conscious of her symptoms that they sometimes “took over.” Similarly, Rick talked about how close symptom monitoring sometimes provoked anxiety:

tracking my symptoms... in such detail made me think about them too much... to the point where I would be constantly thinking about how I was feeling and trying to determine how severe my current symptoms were... In retrospect, I think the constant self-monitoring wasn't exactly productive... especially when I would become anxious overanalyzing everything and trying to figure out the reasons behind everything I was feeling.

Lauren compared the meanings she assigned to her symptoms before and after her visits to the concussion clinic. Prior to her appointments there, she had believed that her concussion was healed because different practitioners told her concussion symptoms shouldn't last that long and that her symptoms were likely emerging from her neck. This made her believe that activity engagement was not a bad thing. When consulting with the concussion clinic 10 months after her injury however, she understood that her symptoms were indeed concussion-related and should be managed by therapy and rest. Instead of experiencing symptom improvement though, these strategies led to a downturn in her psychological state:

Part of me feels that like when I went to the concussion clinic, it was like all about monitoring your symptoms, and all about your symptoms, and then I just became hyper aware of everything.... And then I didn't know how to - I was so focused on trying to get better that like, "oh, if I do this, my symptoms could get worse and that's not good," so I just like shut down... Whereas before I would like do things.... I might feel bad but I was supposed to be fine, so it was like okay. Well, not okay, but it was just what it was...

While most practitioners encouraged monitoring of symptoms in order to track recovery, some argued against this strategy for the potential consequences that were described by the aforementioned participants. Tom who remained anxious about potentially sustaining another concussion with minor impacts to the body or head, developed a strategy to track his heart rate to convince himself he is not injured again. He described that he especially employs this while running on a treadmill, perceiving that if he can sustain 180 beats per minute pace without symptoms, he knows he is fine. When he mentioned this to a mental health practitioner, she

suggested that he was over-reliant on this strategy to engage in normal activities, which was ironically causing a barrier for normal functioning:

she was just like, "you need to start believing in yourself that it's not a concussion" and then she wanted me to stop the checking - the checking I would do after a head bump would be running and monitoring my heart rate and everything so she's like "just run and don't worry about everything else - just run," you know? "You don't have to get to that magical number to know you're ok." So I've been trying to do that now...

For Dan, success with a similar suggestion served as a first indication that anxiety was involved in his symptom manifestation. He described that when he started to read again, he would be overly conscious of his symptom levels before and during reading, and would immediately stop if he felt anything. With the help of a doctor and psychologist he consulted with several months after his injury, he found a different way to approach his reading. He described:

I started to feel better in early April because my doctor said "ok, we're going to try something different... just set a timer for 15 minutes and read... and when it's over, just notice if your headaches have gotten worse... don't stop no matter what." Because before I would stop if I got a bad symptom and I was doing 3 minute readings... so 15 minutes was like enormous... earth shattering... and that relaxed me a little bit... cause I didn't have to monitor - I didn't have to - I could actually just read and the timer would go off and amazingly it wasn't making the symptoms worse...it was stable, reading was stable...

Although the constant monitoring of symptoms was developed as a method to gain agency and control over their recovery, it was clear that some participants became too preoccupied with this strategy that it became an obstacle to re-engaging in activity. While most practitioners encouraged this practice, some were key in helping certain participants find a different method to engage in activity that relived them of their anxiety, and consequently helped them succeed with their activities.

4.3.3. Addressing psychological barriers to recovery

Dan's realization that symptom monitoring was anxiety-inducing and potentially a barrier to recovery was the first step for him to realize that there was a substantial psychological origin to his symptoms. This realization allowed him to gain knowledge and a strategy to manage his recovery. With the help of a doctor and psychologist, he was the only participant to explicitly address anxiety as the primary source of the symptoms. While others did not overtly address anxiety, some also insinuated that part of their progress was "mental."

Dan described an explanation from his doctor that helped him address his symptoms differently with the support of a doctor and psychologist:

his theory was that when I got lost in something and I wasn't thinking about it, I was totally fine... [but] when I was doing like setting up the books with like my pillows and my neck is perfectly relaxed and I have my timer and I'm like "I hope I can read" - I would get a headache immediately. He described headaches as a trained response to activities that for months I was worried about and had given me headaches in the past... and now they were just triggered by anxiety. And then my psychologist and I worked together in overcoming that... and it was like an incredible few weeks of like forcing myself to just like push through the symptoms and read I didn't get headaches then... and just like - I had to convince myself - which I so didn't want to do - that me doing something like reading was actually ok. [...] And then I got better pretty quickly after that... like overcoming the anxiety was crucial and then just relaxing and doing things and not worrying about them - I didn't get symptoms. [...]

While other participants did not fully ascribe to this concept of recovery, they did describe how acknowledging and addressing some emotional or cognitive barriers also helped them progress. For example, in addition to eating nutritiously, engaging in meditation every day, and learning how to lean on her social support network, Megan acknowledged that a turning point in her recovery was "mental." She realized that worrying less about her symptoms and normalizing them instead helped her be less stressed about engaging in activities:

So that was like another mental turning point where I was like "Okay, I'm just gonna tell myself that I'm better and I won't freak out about little things like... for example feeling

extra tired one day, it's like this is normal, you are a human, like you're allowed to have minor headaches if you don't drink water... it's hard to remember

Similarly, Rick, who knew Dan personally and was aware of his recovery, also talked about learning how anxiety was involved in his symptom manifestation. In addition to taking medicine prescribed by his doctor to help him sleep, he also learned that perceiving certain situations as less threatening would allow him to not worry about engaging in them:

Also, the kind of anxiety component, and having to address that. And that was something that I had started to see in myself, that I was getting so... worked up about any sort of social activity, and I would overthink... "Is this going to give me a headache? Do I need to give myself a break? Am I going to have a place to rest?"... and get so anxious just about that, that I think I was bringing on those symptoms myself. So when I had heard that that was a possibility, I thought, "okay, I'm gonna try and not worry so much about the specifics of everything that I'm doing... and... instead try to be a bit more in tune with my body while I'm doing those things," if that makes sense. So... I have noticed a bit of an improvement actually since doing that.

Jen, who described herself as recovered, credited a combination of strategies for her success. In addition to oculomotor therapy helping with her headaches, she described that antidepressant medication helped her not to fall into the "dark place" emotionally. She also credited her own mental strength as a major factor for her turnaround. She described:

I felt like a lot relied on my mental being to get through it. That was critical, in terms of getting out [...] just like pushing through and committing to even these small things are gonna help me get there and not being scared to do things because you're afraid that you're going to get a headache or anything like that. At first, I would shut down completely... but then when I kind of realized, it's like, "if you get a little bit of a headache, you're okay... like, let it calm down and get on with it." But before, if that happened, I isolated myself the rest of the day. I just thought I needed to.

These participants eventually acknowledged that there was a psychological reason that was fully or partly responsible for their recovery. Some with the help of acquaintances or practitioners, others on their own, they realized that the stress they were experiencing was self-induced and counterproductive to their recovery.

4.3.4 Acceptance

There were other participants who explained that they still had not recovered, but that they were in a better emotional state due to a change in perspective. Acknowledging the fact that there was not a “magic pill” (Taylor) that would help them quickly return to their previous selves, they talked about gaining a self of acceptance to help them cope. This reappraisal seemed to relieve some of the psychological burden of the situation, which in turn seemed to help them feel better overall. Taylor described:

I feel like I'm in a place of acceptance now because I know how to manage it better and I know the things - I know that if I'm tired and I don't eat properly, like general health, I feel more symptoms... and I stretch my neck every night, I'm very conscious of maintaining a certain level of stretching and physio and these things... so I'll just never let it slide either... and when I feel crappy I rest... I don't - I try not to put myself in environments that trigger stuff - I don't go to concerts, I don't go to loud restaurants, and I'm fine with that - that's just - my life is just different and I rest more and it bothered me at first, and now I feel like this is just how life is... what's wrong with having a nap? like I've spent my whole life being an overachiever... and now I need to rest more, so what? Like, naps rule!

These participants described lowering or changing their expectations in order to relieve the immense pressure they were putting on themselves to return to their previous activities and activity levels. Rob described reducing the amount of hope he had and the rush he was in to return to his previous life, in an attempt to not keep on disappointing himself when he had setbacks:

What I'm realizing now is changing your outlook can make a huge difference on your mental state... I was in a big rush to come back before and I'm not going to make that mistake... I'm very careful with the amount of hope that I have.

Similarly, Kristin talked about reliving herself of the pressure to return to sports, which had been her initial main concern, and instead focus on more core daily activities such as work and exercise. She described adopting a new definition to what normal life meant:

I think I'm slowly taking a bit of that pressure off myself and kind of redefining what my goals and expectations are around like returning back to my normal life... and what that really means. Umm, I would really like to play soccer again. But I'm kinda starting to recognize that that shouldn't be my priority or definition of returning to normal functioning...

Lauren talked about focusing on living rather than trying to heal. She described how more than a year and half into her recovery, after many failed therapies and strategies that did not relieve her of her symptoms, it had become more important to her to focus on being emotionally well. She decided that constant rest was no longer therapeutic and instead detrimental to her, and started becoming more active despite her symptoms:

I just do more things because I know doing nothing makes me feel emotionally bad and physically bad, so I'd rather feel somewhat emotionally okay and physically bad, if that makes sense? Because doing nothing wasn't helping so....I think the biggest thing I've learned is you have to live too [...] I've spent a year and a half on being so focused on just getting better at doing everything that I'm supposed to do to get better, but that didn't work... so then I've just tried to have a better balance [and focusing on] just living.

Michelle also experienced a change in outlook, by deciding to replace her previous physical activities with others that did not trigger symptoms. She explained how swimming had become a part of her routine to replace running and playing soccer:

I'm trying to just focus on what I can do and be happy with that... so I'm so over the top that I'm able to swim. Like I not a swimmer... I wasn't at all... and it took me a while to just get into the pool, but when I did it was just... something about getting your head wet under the water that was just super refreshing.... I was happy I was able to bike... like if I wasn't able to do anything physical activity then I feel like I would be really like struggling...

For Emma, her feelings of acceptance culminated in focusing on long-term health rather than a return to sport. She described:

I wanted to stay active and I really like the aspect of team sports, and the socialization and working together and thriving off of each other successes... umm... but at the same time, I know it's very important to focus on my health, especially when I'm 24 and have a body of an 80-year-old sort of thing. So, yeah, just making sure I understand the importance of not going back....

The participants described that this acceptance and decreased self-pressure made them feel better overall, suggesting that this approach was better for their overall wellbeing. Lauren described:

I guess that's kind of where I'm at now. It's like... umm... not like as extreme, like I'm not going overboard with what I do but just allowing myself to do things if it's important to me.... And then I feel like I can do it.

Taylor ratified:

I stopped fighting it... at a certain point I was just like "i'm better enough", like I am back to trail running, I'm reffing soccer, and I work 35 hours a week... so my life is manageable and that's all I can hope for...

These participants described themselves as not having fully recovered, but being less stressed about their present limitations or future outcome. Engaging in this positive reappraisal, allowed them to gain acceptance, which in turn facilitated better overall wellbeing despite still experiencing some of their symptoms.

Overall, the participants experienced different levels of success with their active coping strategies. Seeking and persisting with different rehabilitation therapies and symptom monitoring seemed to provide participants with information and an active component that temporarily provided psychological relief. Those who gained acceptance towards their situation reduced their stress by changing the way they appraised their situation. Lastly, those who explicitly or implicitly addressed anxiety and stress as a recovery barrier seemed to be the most successful in their recovery.

Chapter 5: Discussion

The purpose of this study was to explore how non-elite athletes experience, appraise, and cope with persistent symptoms following sport-related concussion. This was explored through semi-structured interviews with twelve non-elite athletes who had experienced or were experiencing persistent post-concussive symptoms. To provide context for this chapter, a brief summary of these is included. It is followed by a discussion of how these findings fit within the broader context of sport and non-sport concussion, as well as health psychology research. Considering the paucity of sport-related studies focusing on appraisal and coping of PPCS, complimentary fields can help gain an understanding of the condition, as well as reflect the participants' non-athletic components. This amalgamation of the literature is also found in other publications (e.g., Broshek et al., 2015; Covassin et al., 2017; Sandel et al., 2017). The chapter concludes with a description of practical implications, strengths and limitations.

5.1 Summary of Findings

A thematic analysis identified the following themes.

Evolving appraisals amidst concussion ambiguity, the first theme, describes how the lack of information available to make sense of their injury and recovery allowed the participants' understandings to develop throughout their experience. Initially they believed their injury was "just a concussion" that could be treated with rest. As their recovery prolonged however, influenced by advice from different practitioners, participants understood that stricter rest was necessary and activity engagement was harmful because it triggered symptoms. These symptom exacerbations were perceived as a recovery setback. Resting was unsuccessful, which contributed to participants' understanding (also influenced by different practitioners) that they

had developed a serious health condition with organic (i.e., physiological, neurological) origins and should be rehabilitated with different treatment modalities (e.g., physiotherapy, chiropractic, massage). While participants seemed desperate to act on suggestions focusing on organic ailments, they were resistant to the notion that mental health complications could also contribute to their persistent symptoms.

Burgeoning psychological distress, the second theme, describes how perceptions of a serious health condition with no known rehabilitation strategy (other than rest), made the participants feel psychologically burdened. Heavy reliance on resting as a symptom management strategy led to withdrawal from family, friends, teammates, colleagues, etc., and made the participants to feel isolated and alone. Because the participants believed that engaging in activity was harmful, they grew fearful of any exertion that could trigger their symptoms, leading to further withdrawal. Perceiving that they were not rehabilitating created an identity disruption for them, since they did not know if they would be able to return to work, school, social, and sporting activities. Overall, the participants described feeling depressed about their ambiguous situation, understanding there was not a lot that they could do to help their recovery.

“I’m just trying anything to get better,” the third theme, portrays the participants’ shift from resting to more active coping efforts to reduce uncertainty and gain control and agency over their symptoms. This change was prompted by the participants’ realization that rest and withdrawal was actually counterproductive to their recovery. Their new strategies included seeking and persisting with different rehabilitation therapies, developing their own symptom-tracking strategies, gaining acceptance over their situation through reappraisal, and addressing psychological barriers to recovery. The first two were initially helpful in reducing stress, but generally not effective in addressing their symptoms long-term. Gaining acceptance seemed to

have a buffering effects on stress and promoted better overall wellbeing. Lastly, addressing psychological barriers to recovery seemed to be the most beneficial for stress and symptom alleviation.

These themes occurred in the context of the participants' self-identification as non-elite athletes, who considered sport and exercise as important components of their identity and lifestyle. They perceived that organized sport had taught them valuable life lessons and shaped their self-concept over their lifespan, therefore making it an important activity to return to. As their recovery lengthened however, other life domains (e.g., work, school) and "normal" activities (e.g., grocery shopping, using a phone) became prioritized over sport. While the participants accepted that they might not be able to participate in organized sport, a return to physical activity remained important to them in order to maintain physical and mental health.

5.2 Concussion ambiguity facilitates psychological distress

The first and second themes of the study elucidate how *evolving appraisals amidst concussion ambiguity* elicited *burgeoning psychological distress*, as participants' frustration grew when they constantly encountered difficulties in understanding their ongoing symptoms and their potential long-term consequences. This is an important finding considering that distress has been associated with prolonged concussion recoveries (Ponsford et al., 2012; Snell et al., 2015; Snell et al., 2018). It contributes to the debate in the literature that deliberates whether distress is a direct consequence of the neurological injury, an indirect psychological consequence related to concussion-specific adjustment challenges, or if one mechanism is a function of the other. A prominent theory is that symptom origins can "morph from the physiological to the psychosomatic" (Snell, Macleod & Anderson, 2016, p. 228), meaning that persistent symptoms

can provoke psychological distress, which in turn can maintain ongoing symptoms (Silverberg & Iverson, 2011). A recent study supported this theory by demonstrating that mental health problems arising after injury appear to have a unique influence on functional limitations for concussed individuals 3 months post-injury (Zahniser et al., 2019). As such, the relative symptom contributions of neurological versus psychological factors change over time, with the latter dominating in the chronic stages of recovery. Therefore, considering that the study participants were well beyond the expected recovery timeline of two weeks ($M = 15.6$ months post-injury), understanding situational challenges that the participants faced throughout their experience may be pertinent to understanding the emergence of distress and thus their prolonged recovery.

As highlighted in the first theme, injury, symptom, and recovery ambiguity appeared to be a significant challenge for the participants in this study as they became more desperate to understand why their symptoms were persisting. They were first challenged by invisibility of concussions and the lack of detectable signs or biomarkers to identify the injury and assess recovery (Bloom et al., 2004; Pennock, Tamminen & Mainwaring, 2019), which made it initially difficult for some to realize they were injured. This finding aligns with other studies where athletes have reported not knowing they had sustained a concussion (McCrea et al., 2009; Register-Mihalik et al., 2013). For others, it enabled the trivialization of the injury, supporting the suggestion that non-visible and non-specific concussion symptoms make it easy for athletes to not disclose or ignore them (Kontos, 2019). Similar to another qualitative study conducted with concussed non-athletes (Brunger et al., 2014), the participants only became aware of their limitations when their cognitive abilities were fully tested for the first time since injury at work or school. Once participants recognized their injury, the lack of overt signs made it difficult to

both identify a tangible reason why symptoms persisted and use appropriate strategies to manage them. This resulted in feelings of confusion, frustration, and limited validation to their struggle. The lack of a scan or test to assess recovery also meant that symptoms alone were used as a ‘temperature gauge’ (Anderson, Heitger & Macleod, 2006) that directed when to increase and decrease activities, which produced issues when the participants developed anxiety towards their symptoms (further discussed below).

As exhibited by the *indefinite identity loss* sub-theme, the pervasive effects of symptoms on physical, cognitive, and emotional functions were associated with a threat to the participants’ self-concept. The most pressing concern was the indefinite timeline of recovery, which caused the participants to question whether they would ever return to their previous selves. The participants seemed to have a strong athletic identity, as evident by their description of valuable life lessons learned and friendships gained in the sporting context, which initially made them prioritize a return to sport participation. Perhaps due to their non-elite competition levels, this pressure was self-induced and not traced to teammates or coaches as other studies have reported (Caron et al., 2013; Kroshus, Garnett, Hawrilenko, Baugh, & Calzo, 2015; McCrea et al., 2004). As time progressed from the injury however, other life domains or activities were perceived more important to leading a normal life and become prioritized over participation in organized sport. For example, participants wanted to regain their cognitive capacity to perform well in school or work as they mentioned the desire to have successful careers. They also talked about the importance of doing simple things such as going grocery shopping and using their phone. Although this shift in priorities could be attributed to their non-elite athlete status, previous studies with varsity athletes have also demonstrated that these participants also became

increasingly concerned with non-athletic aspects such as school performance and social belonging as time passed from their injury (André-Morin et al., 2017; Mainwaring et al., 2012).

Despite sport participation becoming less important as more time passed from their injury, engaging in physical activity remained a priority for the participants to maintain physical and psychological health. The participants described pre-injury exercise as a habitual coping strategy for managing daily stress, which made them miss the ability to exert themselves when they were emotionally burdened by their recovery. Their desire to return to some sort of exercise regime was evident when they actively sought physical activities (e.g., swimming, stationary bike) that would not trigger their symptoms, as exacerbations were perceived as a recovery setback. This finding aligns with sport literature suggesting that restricted physical activity may be a significant psychological stressor for injured athletes (Wiese-Bjornstal et al., 2015). However, this factor is less studied than the psychological protective effects of social support that have been reported with varsity and professional concussed athletes (André-Morin et al., 2017; Caron et al., 2013; Covassin et al., 2014; Kontos et al., 2013), and should be considered in studies that credit the physiological benefits of exercise for accelerating concussion recovery (Kurowski et al., 2017; Leddy et al., 2010; Leddy et al., 2019).

Another ambiguous aspect for the participants was the lack of information regarding appropriate rehabilitation strategies. Due to their minimal access to sport or concussion specialists, most relied on primary care physicians who might not have the training or resources to apply the most current knowledge on concussion recovery and symptom management (Zonfrillo et al., 2012). The participants' difficulty in accessing practitioners specializing in concussion management contrasts the experiences of varsity athletes' (i.e., elite athletes as per the definition used in this study) documented in a study revealing that informational and

emotional support from readily available doctors, athletic therapists, and coaches appeared to positively impact their recovery (André-Morin et al., 2017). Comparing the different experiences of non-elite athletes (in the current study) and elite athletes (André-Morin et al., 2017) in accessing specialized care supports the suggestion that different athletic populations may be face different contextual challenges in concussion recovery (Putukian et al., 2009).

Participants commonly received ambiguous advice to rest from primary practitioners, which facilitated different interpretations of how to do so. Importantly, combined with allied health care practitioners' advice to monitor and avoid symptoms (further discussed below), it prompted them to reason that if rest is beneficial, then activity must be harmful (second sub-theme) for the participants. The participants engaged in prolonged stretches of resting, which stands in contradiction to the most recent sport and non-sport knowledge protocols proposing that rest beyond 2 days is not helpful following a concussion (McCrory et al., 2017; Ontario Neurotrauma Foundation, 2018). Researchers have expressed concerns that prolonged rest may be detrimental for recovery as it may trigger physical deconditioning (Giza, Choe & Barlow, 2018), psychological harm from removing individuals from their valued activities (e.g., exercise as mentioned above) (DiFazio et al., 2016; Leddy et al., 2016; Silverberg & Iverson, 2013) and delayed return to work or school (Silverberg & Otamendi, 2019). As such, following a maximum 48-hour resting period, concussed individuals are now recommended to gradually reintroduce their usual activities as symptoms allow (McCrory et al., 2017). Different active rehabilitation modalities focusing on vestibular, vision, and exertion-based therapies that have been theorized to prevent persistent symptoms and aid gradual activity progression (Kontos et al., 2019). Particularly, prescribed subsymptom threshold aerobic exercise has been deemed safe (Leddy et al., 2018; Prince, Schussler & McCann, 2019) and effective (Leddy et al., 2019) in accelerating

recovery. This study showed some evidence that active rehabilitation was implemented with the participants, but only after several months and years following their injury, and only in private clinical settings.

Further to ambiguous rest advice, participants also faced the challenge of receiving contradictory or confusing recommendations from additional practitioners. Some of the treatment modalities they pursued are supported by the literature; for example, physiotherapy treatment for cervical and vestibular issues is considered useful for addressing persistent balance impairment, dizziness, and neck pain (Harmon et al., 2019; Snyder & Giza, 2019). However, other alternative and complimentary treatments that are not endorsed by expert consensus (Schneider et al., 2017) were also pursued (e.g., osteopathy, chiropractic, massage). While the growing awareness of concussion has been positive for the study of best concussion management practices, the participants may have been drawn to the emerging “concussion industry” that offers numerous treatment modalities that do not follow evidence-based practice (McNamee & Partridge, 2013). This is important considering that contradictory and inaccurate health advice may lead to anxiety and medical skepticism (Alaszewski & Horlick-Jones, 2003; Han et al., 2007; Leydon et al., 2000). By association, multiple messages from multiple practitioners may have exacerbated confusion for the participants, especially when the different treatment modalities were not successful in the long term.

The *Illness Uncertainty Theory* (Mishel 1981; 1988; 1990) may be helpful in understanding how certainty about felt symptoms vis-à-vis uncertainty about proper recovery management induced profound psychological burden for the participants. Borrowing from Lazarus and Folkman’s (1984) stress appraisal coping framework, Mishel’s model focuses on individuals’ cognitive processes when coping with health situations that have the following

characteristics: ambiguity concerning the state of the illness, complexity regarding treatment and the health care system, lack of information about the diagnosis or severity of the illness, and the unpredictability of disease course – all which seemed present in the experiences of the participants. According to this theory, individuals can appraise (i.e., through primary appraisal) uncertainty as an opportunity for a positive outcome, or as a dangerous threat. The participants that initially trivialized their injury were perhaps engaging in an opportunity appraisal, hoping for a positive outcome based on the lack of obvious signs that they had indeed sustained a concussion. However, as symptoms began to increasingly interfere with their lives, all participants eventually appraised the situation as a threat.

Incoherence in understanding the source of the health threat and resources available to manage it can magnify stress (Mishel, 1981). Through secondary appraisal, study participants were not able to answer “what, if anything, can I do, and how will what I do and what is going to happen affect my well-being?” (Lazarus, 1991, p.134). This was evident as the participants grew increasingly frustrated when they were not able to find information to appropriately manage their ongoing symptoms. The result was participants having to cope with both their ongoing symptoms as well as growing distress towards their situation, but not finding methods to successfully cope with either, thus creating a potential situation where one factor reinforced the other. Although there is a paucity of studies that have investigated illness uncertainty following sport or non-sport concussion, studies investigating other chronic health complications have found that uncertainty is strongly associated with anxiety, tension, anger, and depression (Johnson, Zautra & Davis, 2006; Lillrank, 2003; Wright, Afari, & Zautra, 2009). Some studies have found this factor to be a stronger predictor of these negative psychological states than illness severity (McNulty, Livneh, & Wilson, 2004; Wineman et al., 1996). Therefore, illness

uncertainty may be a key risk factor of maladaptive adjustment to PPCS and may provide an important target for stress-reduction interventions.

5.3 (Mis)appraisals & coping

The first theme of the study explains how *evolving appraisals amidst concussion ambiguity* influenced the participants to increasingly appraise their symptoms as a serious threat. In light of prolonged rest not being beneficial to recovery, these appraisals corresponded with more active coping efforts (highlighted in the third theme “*I’m just trying anything to get better*”) that were effective in reducing uncertainty and/or distress. This increased use of coping methods is consistent with findings suggesting that individuals use limited coping strategies in the few days after concussion (Kontos et al., 2013), but increasingly rely on them as symptoms persist over time (Snell et al., 2011). It also aligns with Mishel’s (1990) suggestion that individuals in uncertain health situations become motivated to reduce the sources of uncertainty (and distress) by using coping strategies to increase control over their situation. He posits that individuals can engage in behavioural strategies to understand the origin of their illness, decide on which treatments are appropriate, and predict when and if they will recover (Brashers, Goldsmith & Hsieh, 2002; Mishel, 1990). They can also use cognitive strategies to manage their emotional distress (e.g., emotional disengagement, seeking emotional support) (Mishel, 1990).

Initial problem-solving strategies by the participants were directed towards making sense of their persistent symptoms and gathering information that would allow them to problem solve. Methods included seeking information from different practitioners (e.g., physiotherapists, chiropractors, massage therapists), persisting with the different treatment modalities proposed by them, and using self-developed recovery measures (e.g., symptom charting). These were initially

successful in providing some information on symptom origin, possible rehabilitation strategies, agency, and positive recovery expectations, which seemed to provide a more coherent understanding of their condition. Aligning with study findings that diagnosis of a tangible problems in chronic health conditions brings about patient relief (Lillrank, 2003; Zhang, 2017), the reduction of uncertainty seemed to have a buffering effect on stress.

Some of these treatment modalities were successful in directly addressing the participants' symptoms but only to a certain extent as the participants described reaching an eventual recovery plateau. These unsuccessful attempts at completely addressing symptoms suggests that the organic symptom attributions (e.g., neck, eyes, body alignment) identified by most practitioners did not fully capture the source of participants' ongoing problems. The current understanding that concussion be viewed and treated with a collaborative approach (McCrorry et al., 2017; Schneider et al., 2017; Snyder & Giza, 2019; Snell et al., 2016) could indicate that additional symptom origins (e.g., psychological) were neglected by most practitioners. Some practitioners did attempt to explain the possibility that psychological factors may be involved in recovery and tried to address these. However, as evident in the "*it's not mental health stuff, it's my brain*" sub-theme, participants exhibited strong resistance to this notion as they considered mental health attributions less desirable than organic ones (suggesting the presence of a mental health stigma). Therefore, by emphasizing the organic component of their injury participants were not privy or were resistant to the entirety of information available to fully understand their symptoms, potentially contributing to the ambiguity of their situation. This is significant considering that individuals' beliefs about their illness precede attitudes, behaviours, and ability to cope with it (Lazarus & Folkman, 1984).

The participants' understandings of their ongoing symptoms as having organic origins with potential permanent consequences is relevant to comprehensive literature suggesting that negative injury beliefs can elicit maladaptive cognitive, emotional, and behavioural responses (King et al., 2018; Silverberg & Iverson, 2011; Wiese-Bjornstal et al., 2015). They are referred to as *illness beliefs* (e.g., Silverberg et al., 2018) and *illness perceptions* (e.g., Snell et al., 2011). Focusing on these participants' understandings of their symptoms may be of particular importance in concussion recovery given the knowledge gaps that remain in its understanding and management. For example, in the absence of objective recovery assessments, using symptom reports as a 'temperature gauge' (Anderson, Heitger & Macleod, 2006) could have triggered maladaptive reactions to symptoms when the participants interpreted them as a threat (i.e., participants' perceptions that symptoms were a sign that they were not recovered, that their injury had developed into a serious condition, and that they could be easily re-injured). Cognitive biases that the participants could have been involved in these understandings include 'expectation as etiology' referring to individuals' attributions of common complaints (e.g., headache, confusion, and irritability) to their injury rather than other factors (e.g. stress) (Mittenberg et al., 1992). Study participants showed signs of this bias when they preferred to attribute their ongoing issues to their concussion. Additionally, 'diagnosis threat' refers to individuals' diminished cognitive performance associated with increased attention to their concussion or symptoms when performing tasks (Suhr & Gunstad, 2002). Participants may have been susceptible to this bias when advised by practitioners to monitor their symptoms when engaging in activities, which may have contributed to their diminished success in them. The strength of these negative perceptions has been emphasized by findings suggesting they are better predictors of prolonged concussion recoveries than emotional (i.e., anxiety and depression)

and social factors (i.e., social support) in the development of PPCS at 3 and 6 months after injury (Hou et al., 2012).

Literature suggests that these negative illness expectations can further influence recovery through the development of self-limiting beliefs that lead to negative emotions and poor coping strategies (Moore & Stambrooke, 1995). As noted in the second theme, the study participants expressed several negative emotions (e.g., sadness, frustration, anger, fright, anxiety, guilt, depression) over not knowing how to manage their prolonged recovery. Additionally, they demonstrated the maladaptive coping strategy of fear-avoidance behaviour. Fear-avoidance refers to the avoidance of activities based on fear of triggering physical or psychological discomfort. It has also been suggested as a potential mechanism capable of maintaining PPCS (Silverberg, Panenka & Iverson, 2018). Considering the physical and cognitive dimensions involved in concussion recovery, both mental and physical activity apprehension are referred to as *cogniphobia* (Silverberg, Iverson & Panenka, 2017) or *kinesiphobia* (Suhr & Spickard, 2012) respectively. The study participants engaged in both as they discussed fears of engaging in anything that could trigger symptoms, including exercise, reading, working on a computer, socializing, and even simple head movements or loud and bright environments. Although avoiding or stopping activity can result in a temporary amelioration of symptoms, it can also lead to unnecessarily strict isolation as well as mental and physical deconditioning that can trigger secondary emotional and physical symptoms (Silverberg & Iverson, 2011; Snell et al., 2018; Thomas et al., 2015). The participants engaged in withdrawal and isolation when they preferred to do “safer” activities or completely avoid any situation that could trigger their symptoms. Fear-avoidance behaviours have been studied in other clinical populations has been shown to

contribute to physical deconditioning, depression, and disability (Pincus et al., 2010; Wertli et al., 2014).

Further to identifying fear-avoidance behaviour, findings from this study also give insight into the less-understood origins of these maladaptive fears. As suggested by the *rest is beneficial; activity is harmful* and *organic origins* sub-themes, various sources of information influenced the participants' understandings of their symptoms. Participants researched in news stories, academic research articles, and the internet, but were mostly influenced by allied health care practitioners (e.g., physiotherapists, chiropractors, optometrists), most of which offered simplified organic explanations of the illness and emphasized the importance of rest and symptom monitoring. This seemingly encouraged participants to become overly aware of their symptoms, potentially leading to somatic hypersensitivity, which has also been associated with fear-avoidance behaviour (Craton & Leslie, 2014). Importantly, symptom relapses following activity could have confirmed the idea that activity should be avoided (Potter & Brown, 2012). Although these symptom episodes do not appear to be detrimental to recovery (Silverberg et al., 2016), they were implicitly or explicitly conveyed as such by different practitioners. It is conceivable that combined with the uncomfortable physical sensation of them, participants developed apprehension towards symptom exacerbations. In the non-sport literature, psychoeducational programs after injury that reassure individuals of the normality of concussion symptoms, as well as emphasize the expectation that the symptoms will resolve over time, have demonstrated positive results in recovery outcomes (Comper, Bisschop, Carnide, & Tricco, 2005, Cooper et al., 2015; Mittenberg, Canyock, & Patton, 2001; Ponsford et al., 2001; Snell et al., 2009). However, the findings of this study do not show evidence of having received timely, evidence-based education regarding their symptoms from practitioners. Instead, reinforcement

from practitioners that symptoms had organic origins and should be monitored and avoided may have reinforced the participants' perceptions that symptoms were a threat to their wellbeing.

Adaptive appraisal and coping patterns in individuals with PPCS are less studied in the sport and non-sport concussion literature, but the third theme revealed two beneficial strategies that participants engaged in: positive reappraisal of the situation leading to acceptance, and acknowledging psychological barriers (e.g., anxiety) of recovery leading to successful problem-solving. Positive reappraisal is a form of emotion-based coping involves construing a stressful situation in a way that changes its emotional impact (Lazarus & Alfert, 1964). It can also be considered a cognitive strategy to manage emotional responses (Mishel, 1990). The participants engaged in positive reappraisal when they decided to focus on the positive aspects of their experience (e.g., trying new methods of exercise) and redefined goals (i.e., lowering their expectations in everyday activities), which led to an acceptance of their situation. Participants who engaged in this strategy were uncertain if they would ever recover, and as a result, they decided to switch their focus on "living rather than healing" in order to relieve themselves of their self-induced pressure to return to their pre-injury activities as soon as possible.

Interestingly, employing this method of emotion-focused coping also led to better overall wellbeing for the participants, supporting proposed relationship between stress and symptoms. Although emotion-focused coping may not be perceived as being as effective as problem-focused coping because it does not directly address the root source of stress, it can be adaptive when the source of stress is outside the person's control (Penley, Tomaka, & Weibe, 2002). This has been ratified in studies of chronic health complications, where positive reappraisal and acceptance have been associated with lower symptom burden and higher quality of life (Lewko et al., 2007; Sirois et al., 2015).

In light of new information, either through self-discovery or through the suggestion of some practitioners, some participants engaged the problem-focused strategy of *addressing psychological barriers to recovery*. Although only one participant explicitly described and addressed their anxiety as the main contributor to their persistent symptoms, others also recognized its potential involvement and engaged in approaches that targeted psychological obstacles to recovery. Specifically, they recognized the presence of fear-avoidance patterns when they described becoming anxious about engaging in activity was counterproductive to their recovery. This realization allowed these participants to formally address their symptom-inducing anticipatory worries (e.g., by focusing on reading for 5 minutes rather than on the symptoms that could emerge), which alleviated both stress and symptoms. These participants also credited the importance of also engaging in other holistic management strategies (e.g., nutrition, sleep, exercise) that they perceived to contribute to their recovery. Importantly, these methods seemed to give participants feelings of controllability, which seemed to reduce the uncertainty of the situation. In all, the importance of providing complete information (i.e., the complex nature of PPCS) beyond that of organic contributions to symptoms, as well as emphasizing the importance of activity re-engagement and dangers of prolonged rest, seemed important to mitigate maladaptive patterns of appraisal and coping that can sustain PPCS.

5.4 Practical implications and future directions

This study aligns with the growing body of literature that advocates for the need to address psychological aspects in concussion recovery. Considering that psychological distress has been considered a risk factor for prolonged concussion recoveries, but that its origin remains unclear, the most significant finding of this study is the identification of recovery-specific

challenges that can provoke distress. Most importantly, concussion ambiguity seemed to generate profound illness uncertainty that precipitated anxiety as well as maladaptive appraisal and coping patterns for the participants. This finding supports the notion that individuals' understandings of their injury and corresponding reactions can be targeted with interventions to mitigate the risk of PPCS. Specifically, there are certain understandings of concussion and concussion recovery that should be clarified with individuals who sustain the injury. These include how to best utilize rest after a concussion, the complex nature of persistent symptoms, and the prevalence and treatability of mental health in concussion recovery. The goal of addressing these topics with affected individuals would be to reduce the ambiguity associated with concussion and persistent symptoms, thus decreasing illness uncertainty, and positively impacting recovery.

In order to target adaptive understandings of concussion for concussed individuals, knowledge translation initiatives must first be implemented with health care practitioners, particularly with primary physicians who are the most likely to provide acute concussion care (Cassidy et al., 2004). In this study, primary physicians' vague advice to rest seemed to contribute to the participants' ambiguous recovery expectations. Combined with recommendations from these and other practitioners to strictly monitor symptoms, it led to the conclusion that rest is therapeutic and that symptom-inducing activity should be avoided, therefore contributing to activity withdrawal and fear-avoidance behaviours. When rest was not successful, and alternative symptom managing methods were not readily accessible, increased ambiguity about how to best cope with the injury dominated the participants' growing distress. Importantly, these outcomes damaged the therapeutic alliance between the participants and their doctors by diminishing medical credibility and eliciting the desire to seek information elsewhere.

Interventions that disseminate the latest research to primary care practitioners are important to establish credibility in the medical system when dealing with concussions, as providing concussed individuals with more complete information to appropriately manage their injury may be critical in prompting adaptive reactions to their injury.

Primary care physicians and allied health care practitioners should also be informed on the potential dangers of only emphasizing simplified organic attributions to ongoing concussion symptoms. Physiotherapists for example, who commonly focus concussion care on physical symptoms and return to activity strategies, are most likely untrained and unaware of potential psychological barriers associated with recovery and may not screen for and address such complications (Seguin & Durand-Bush, 2019). These practitioners should be informed of the profound mood disturbance produced by recovery-related isolation, identity loss, and illness uncertainty that can contribute to the presence of PPCS. This knowledge might help them differentiate between organic and psychological-based symptomology (of which the latter likely dominate in the chronic stages of recovery), communicate a more complete conceptualization of recovery to their patients, be cognizant that complete symptom resolution may require a multidisciplinary care team that includes mental health professionals.

In addition to knowledge translation initiatives, further research should investigate the role of psychological aspects in current rehabilitation modalities. While active rehabilitation (e.g., sub-symptom threshold exercise) has been considered safe and effective in accelerating concussion recovery, this study proposes that the active component itself may alone be psychologically protective by granting patients agency and positive expectations for their recovery. This was evident when the psychological burden of the participants seemed to be partly alleviated by the different exercises they engaged in treatment modalities. As they

described, the mere feeling of “at least I’m doing something” provided relief. However, active rehabilitation treatments may not be sufficient when individuals are dealing with deeply embedded fear-avoidance behaviours. This is especially relevant when symptoms are relied on as a ‘temperature gauge’ (Anderson, Heitger & Macleod, 2006) because of their susceptibility to psychological factors. For example, the inherent invitation of increased attention towards the symptoms may provoke anxiety towards them, which in turn may be maladaptive for recovery. Clinicians should be careful to not misconstrue symptom threshold-based rehabilitation strategies as ones that should not elicit *any* symptoms at all (akin to interpretations of rest rehabilitation instigating advice to rest strictly for prolonged periods). Instead, borrowing from Lazarus and Folkman’s (1984) work, a potential suggestion would be to guide patients in reappraising *some* symptom provocation during or following activity as a challenge to be overcome, rather than a threat. The difference in perception may evade stress responses.

Psychological skills training or psychological treatment might have to be incorporated into rehabilitation to address psychological barriers to recovery. Research suggests that cognitive-behavioural therapy to target and modify self-limiting belief and coping patterns is effective in reducing symptoms of anxiety and depression in concussed populations (Mittenberg et al., 2001; Ponsford et al., 2016; Potter, Brown & Fleminger, 2016). Another emerging approach is mindfulness, which includes body scans, mindfulness breath, and a variety of yoga exercises. This method has been associated with improved quality of life and self-efficacy in patients with PPCS (Azulay et al., 2013). Lastly, for athletes, it is suggested that general sport psychological skills training commonly used in the injury rehabilitation setting (e.g., goal-setting, goal-management, relaxation, imagery) might also help athletes gain control over persisting symptoms (Seguin & Durand-Bush, 2019). The challenge in implementing these

psychological approaches to treatment however, might be to successfully communicate to concussed individuals that mental health may be involved in their recovery. As demonstrated by this study, they may resist this idea and reject psychologically orientated attributions and treatment. Educational programs focused on psychological consequences of concussion may help normalize this idea and reduce the stigma that may be particularly present in athletic populations who commonly downplay pain and discomfort and prefer to ‘push through’ psychological discomforts as they do physical ones (Putukian, 2016). The eventual aim would be to make psychological treatment as common as physical modalities in concussion rehabilitation settings.

5.5 Strengths and limitations

A strength of this study was exploring the subjective experience of PPCS, which allows for the generation of suggestions on how to best support affected individuals. Importantly, this study provides insight into how individuals can appraise and cope with their concussion in the context of rapidly evolving concussion research, limited knowledge translation initiatives to disseminate new knowledge, and lack of access to specialized care. The demonstration of illness uncertainty manifesting with individuals experiencing PPCS substantiates existing research on the role of psychological distress in concussion recovery. Additionally, the participants’ athletic (e.g., active lifestyle, athletic identity) and non-athletic (e.g., no access to specialized care, identity based in non-athletic realms) characteristics that presented as contextual factors in their experience, highlight the need for concussion care that considers individual psychosocial barriers in recovery. By providing more complete information and management tools to these individuals, maladaptive psychological reactions (e.g., fear-avoidance behaviour) that may perpetuate recovery can be avoided.

The use of qualitative methods allowed the exploration of detailed lived experiences, which aligns with the understanding that concussions are subjectively experienced injuries and should be viewed as such. The interpretivist constructionist paradigm provided the opportunity to investigate the contextual understanding of participants' experiences (Smith & Sparkes, 2016) by revealing more than solely the presence of psychological distress. Instead, participants' experiences presented a sequence of events (e.g., traumatizing early symptom occurrences) and factors (e.g., injury ambiguity, illness uncertainty) that preceded it. The semi-structured format provided flexibility to probe and explore topics that were relevant to the research questions. As such, the participants' experiences allowed the understanding of how certain appraisal and coping patterns were developed. These findings are important in providing examples of how PPCS can develop and be maintained following injury. Undoubtedly, my personal experience as a non-elite athlete who experienced a prolonged concussion recovery facilitated rapport with the participants, as I could relate to the participants' experiences. The perception that I was an insider who understood what they were going through, helped me establish rapport and may have been important in getting participants to elaborate on sensitive topics, such as the profound psychological reactions they experienced. The participants' lack of trust and skepticism about medical knowledge of concussions made them eager to share their experiences in the hope of providing information that could help better understand prolonged concussion recoveries, further facilitating openness by them. In all, the qualitative methodology strongly supported the goals of this study.

The focus on non-elite athletes allowed for an investigation of an understudied population that may be at higher risk of prolonged concussion recoveries. The study sample was diverse in the following participant characteristics: sport(s) involved in prior to the injury (e.g. soccer,

ultimate frisbee, snowboarding); type of sport (team or individual); time experiencing concussion symptoms (range: 4 months to 3 years); and the symptom and activity status at the time of the interview (most participants were experiencing debilitating symptoms, some were experiencing slight symptoms, and other considered themselves recovered or close to recovered). These factors allowed the exploration of prolonged concussion recovery from different perspectives at different stages, all the while investigating a similar experience which was evident by the socially constructed patterns in their stories.

There were also limitations associated with the study. The sample size of 12 athletes was not large enough to explore some issues in-depth, especially considering that only a few participants perceived themselves as recovered or close to recovering. For example, the finding that addressing psychological factors aided recovery would have been strengthened or more nuanced had the sample contained more than four participants who described symptom resolution. This was also related to only interviewing the participants at one point in time, not allowing further insight into how their experiences, thoughts, and feelings changed from one time to another. Although recruitment criteria (included in the recruitment posters) requested participation from individuals with 3 or less concussions, another limitation was that some participants during the interview expressed that they had sustained other head impacts that may have classified as concussions. Self-perceived concussion history may not align with true concussion history, which is important since the cumulative impact of multiple concussions is unknown and may have influenced how the symptoms manifested for the participants. Lastly, it is possible that the participants experienced recall bias or memory distortion while telling their stories. However, considering that the findings of the study revolve around the participants'

understanding of their experiences, their recollection of certain events is likely more relevant to the meaning they assigned to them.

Because of the sample size and the fact that all participants were non-elite athletes residing in Canada, it would not be possible to generalize in the conventional sense (i.e., through statistical-probabilistic generalizability) their experiences to other athletic or non-athletic populations. However, Smith (2018) proposes that there are two ways that can make these findings generalizable. The first through naturalistic generalizability, which suggests that results can resonate with a reader when they have experienced similar experiences (e.g. experienced a prolonged concussion recovery) and might find them useful. In order to enable naturalistic generalizability, this study provides thorough accounts of the participants' lives through proper 'evidence' (e.g. direct quotations) and contextual details that might help readers connect with the findings. The second is through inferential generalisation that allows a group (e.g. health educators) or individuals to consider adopting certain aspects from this research. Much like naturalistic generalizability, this is achieved through direct testimonials, rich descriptions and accessible writing. Because both of these methods rely on readers' engagement with the study, it is my hope that worthy and relevant focus of the findings invites such engagement from individuals in the research, health care, and athletic settings that wish to better understand concussion recoveries.

5.6 Concluding remarks

Persistent post-concussive symptoms are debilitating, distressing, and poorly understood by individuals who experience them. This study underscores the importance of emphasizing the psychological influence on recovery, potentially through knowledge translation initiatives with

practitioners so more complete understandings of the injury can percolate down to affected individuals. By disseminating and applying this information, treatment modalities will be better equipped to facilitate a return to valued activities for concussed patients, which should mitigate further psychological consequences such as depression and fear-avoidance behaviour. This research also serves as a reminder to consider individuals' lifestyles in the recovery setting. For athletes and active individuals, active rehabilitation options may be especially important to combat psychological consequences or persistent symptoms. This study aligns with previous research that identifies profound psychological distress as present in concussion recovery and importantly gives insight into contextual (i.e., concussion recovery-specific) factors that can provoke this consequence. These findings could help inform theories, models, and policies about the importance of reducing illness uncertainty and providing mental health support for those individuals experiencing persistent post-concussive symptoms in order to facilitate functional recovery.

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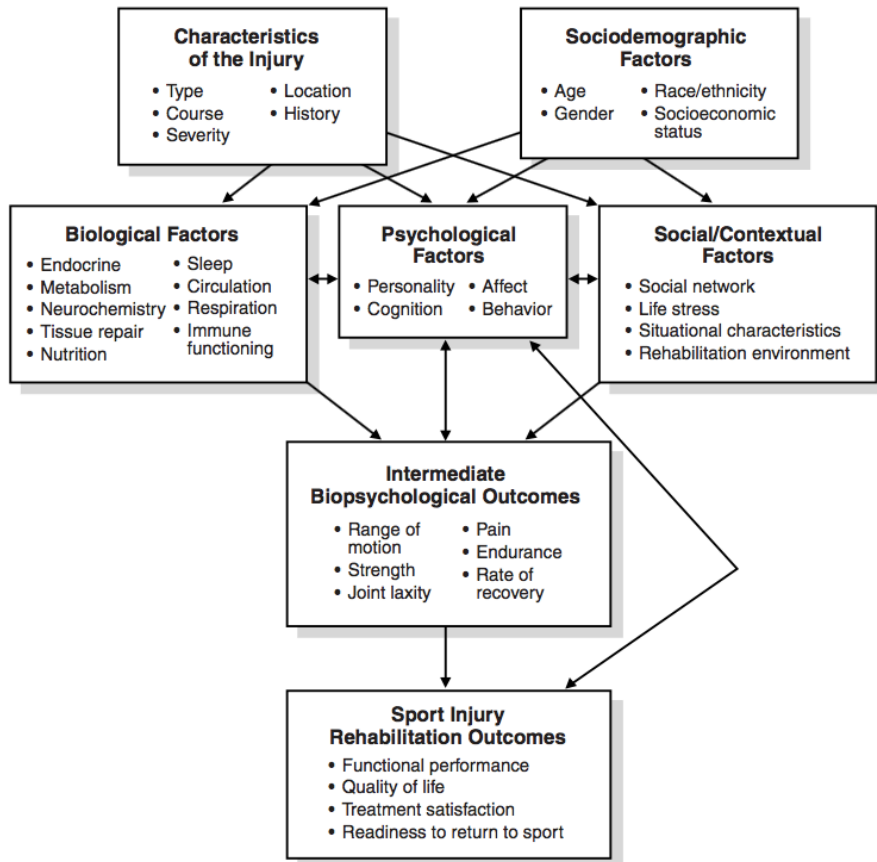
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Appendices

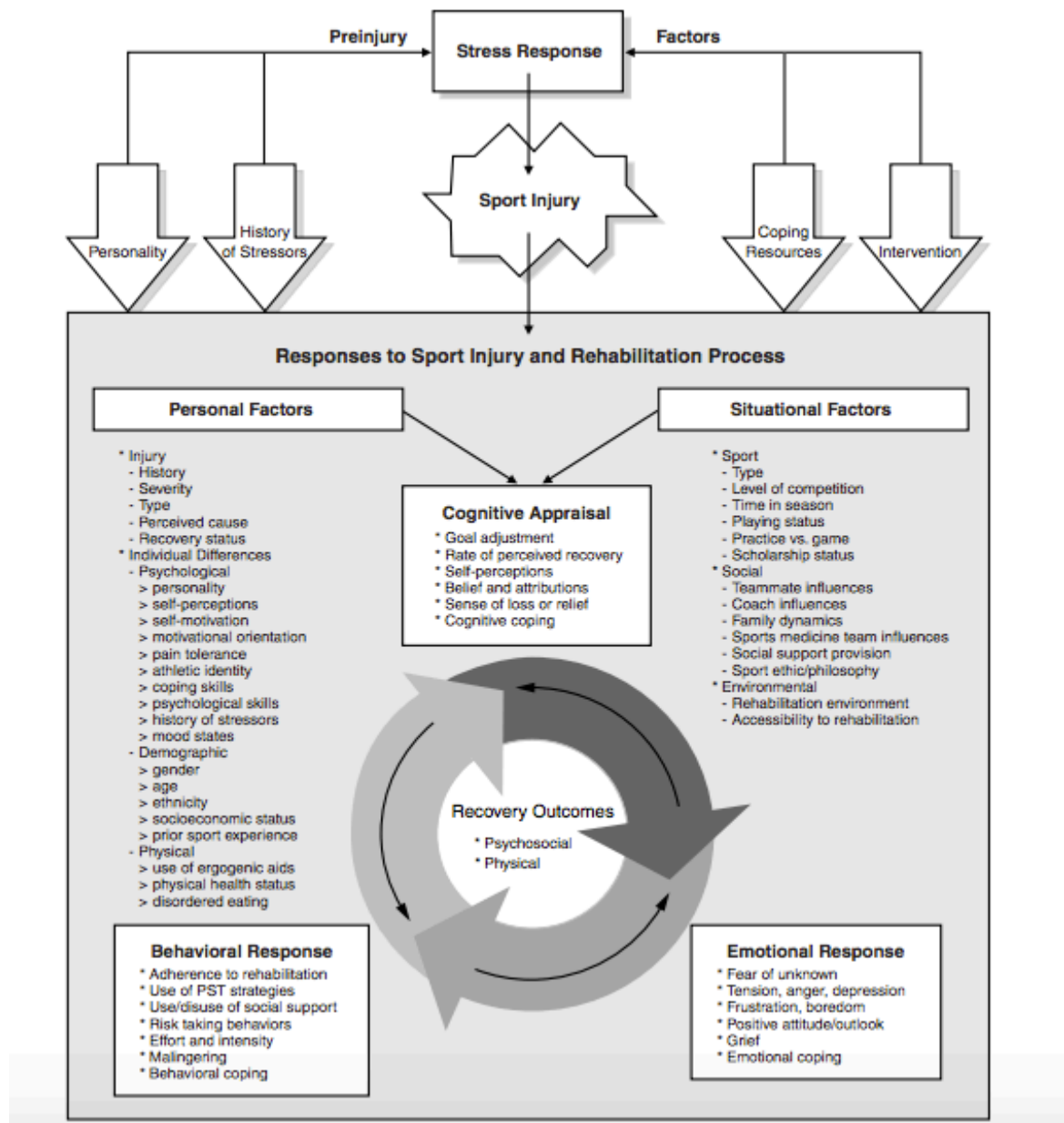
Appendix A



A biopsychosocial model of sport injury rehabilitation.

Source: “Psychological Aspects of Sport Injury Rehabilitation: Toward a Biopsychosocial Approach” (pp. 41–54), by B. W. Brewer, M. B. Andersen, and J. L. Van Raalte, in *Medical and Psychological Aspects of Sport and Exercise*, D. Mostofsky and L. Zaichkowsky (Eds.), 2002, Morgantown, WV.

Appendix B



Integrated model of psychological response to the sport injury and rehabilitation process.

Source: “An Integrated Model of Response to Sport Injury: Psychological and Sociological

Dimensions,” by D. M. Wiese-Bjornstal, A. M. Smith, S. M. Shaffer, and M. A. Morrey, 1998,

Journal of Applied Sport Psychology, 10, pp 49.



ARE YOU A RECREATIONAL ATHLETE EXPERIENCING A LONG CONCUSSION RECOVERY?

If so, we would love to talk to you!

WHAT IS THE STUDY ABOUT?

The purpose of this research is to explore how non-elite athletes experience, perceive and manage persistent symptoms following sport-related concussion.

WHAT IS INVOLVED?

If you agree to participate, you will be interviewed on one occasion at a location of your choosing. The interview will take approximately 1.5 hours.

WHO IS DOING THE RESEARCH?

Dr. Peter Crocker, Professor in the School of Kinesiology at the University of British Columbia and MA student Thalia Otamendi.

YOU CAN PARTICIPATE IF:

- You are 18 to 35 years old
- You sustained a concussion and are experiencing (or have experienced) concussion-related symptoms longer than 4 weeks and less than 3 years after the injury
- At the time of your concussion, you participated in recreational sport 2 or more times/week
- At the time of your concussion, you did not have professional coach or trainer
- You have a history of 3 or less concussions

If you would like to participate, please call

[REDACTED]
Thank you!



Cognitive Appraisal and Coping with Persistent Symptoms following Sport-Related Concussion

LETTER OF INTRODUCTION

Dr. Peter Crocker
School of Kinesiology
The University of British Columbia

Thalia Otamendi, BA
School of Kinesiology
The University of British Columbia



WHO IS DOING THE RESEARCH?

The principal investigator for this study is Dr. Peter Crocker, Professor in the School of Kinesiology at the University of British Columbia. Thalia Otamendi is a second-year graduate student working under the supervision of Dr. Crocker.

WHAT IS THE RESEARCH ABOUT?

We are interested in learning about how non-elite athletes perceive and manage the experience associated with persistent-symptoms following sport-related concussion (SRC).

WHAT WILL PARTICIPATING IN THE STUDY INVOLVE?

If you agree to participate, you will be invited to take part in at least one interview (conducted in English) that will be conducted at a place of personal convenience. The interview will be approximately 1.5 hours in length. The discussions that take place will be audio-recorded and transcribed (written out word for word) for analysis.

You do not need to talk about any issues you do not feel comfortable discussing and if you wish to withdraw from the study you may do so at any time without having to give any reason for doing so. There will be no negative consequences to you or anyone else if you chose to withdraw. This study will not subject you to any physical risk. Although we do not expect any psychological risk, in the event you would like to further discuss your feelings regarding the topics discussed in the interviews, accommodations will be made for you. We will accept participants for the study based on order of initial contact with the researcher.

WHAT WILL BE DONE WITH THE INFORMATION I PROVIDE?

Any information you provide within this interview will be made confidential. You will be identified by a pseudonym (fake name) and identifying information will be removed. All interview transcripts will be kept in a locked cabinet in the office of the principal investigator and no one other than the researchers associated with this study will have access to this information. The information collected will be written up for publication in a scholarly journal and/or presented at an academic conference.

WHAT IF I WISH TO WITHDRAW FROM THE STUDY?

Your participation in the research is entirely voluntary and you may withdraw from the study at any time without having to give any reason for doing so and without experiencing any negative consequences.

HOW WILL THE RESEARCH BE USEFUL?

Findings from this study will allow the researchers to gain insight into the emotional and cognitive dimensions of persistent symptoms following SRC. Such findings will further our understanding of how athletes experience, perceive and cope with the persistent symptoms, which can be used in the future to help guide interventions.

If you would like more information about this study or to learn how to become involved, please contact [REDACTED]

Thank you!

Appendix E

Cognitive Appraisal and Coping with Persistent Symptoms following Sport-Related Concussion Consent Form

Peter Crocker, PhD (Principal Investigator)
School of Kinesiology
The University of British Columbia

Thalia Otamendi, BA
School of Kinesiology
The University of British Columbia

PURPOSE OF THE STUDY:

The purpose of this study is to explore how non-elite athletes experience, perceive and manage persistent symptoms following sport-related concussion (SRC). Findings from this study will allow the researchers to gain insight into the emotional and cognitive dimensions of persistent symptoms following SRC, furthering the understanding of psychological factors in concussion recovery. This research is for a graduate degree and will contribute to a thesis (public document).

STUDY PROCEDURES:

You will be interviewed once at a location of your choosing by graduate student, Thalia Otamendi. The interview will take approximately 1.5 hours. With your permission, we will digitally record the interviews so that we can concentrate on what you have to say rather than on taking notes. 2 brief follow-up questionnaires will be administered following the interview.

CONFIDENTIALITY:

Your identity will be kept strictly private. Only Dr. Crocker and the graduate student involved in the project will have access to the digital recordings and study documents, which will be kept in a locked filing cabinet and on a password protected computer. All data will be encrypted. No names or information that might show who you are will be used when the results of the study are reported. The results of this study will be reported in a graduate thesis and may also be published in journal articles and books.

YOUR RIGHTS:

Your participation in the study is entirely voluntary. You may refuse to answer any question or withdraw from the study at any time without giving a reason and without penalty.

POTENTIAL RISKS:

This study will not subject you to any physical risk. You can refuse to answer any questions in the questionnaire package and/or withdraw from the study at any time and doing so will result in no penalty to you or anyone else. Although we do not expect any psychological risk, if we feel participating is placing you under undo stress, we will discontinue your involvement in the study and direct you to appropriate resources. Again, resulting in no penalty. Any data collected prior to this point will be omitted from the study and destroyed. In the event that you would like to further discuss your feelings regarding the topics discussed in the study, your student health/counselling services can be of assistance (UBC Counselling Services: 604-822-3811; UBC Student Health: 604-822-7011).

WHO TO CONTACT IF YOU HAVE COMPLAINTS OR CONCERNS ABOUT THE STUDY?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance email RSIL@ors.ubc.ca or call toll free 1-877-822-8595.

QUESTIONS?

If you have any questions or want further information about the study, please contact Thalia Otamendi via telephone at [REDACTED]

CONSENT

I have read the above and I consent to being part of this study of non-elite athletes' experiences with prolonged concussion recoveries.

I have received a copy of this consent form for my own records.

Signature: _____

Printed Name: _____

Date: _____



Cognitive Appraisal and Coping with Persistent Symptoms following Sport-Related Concussion

Demographic Information Questionnaire

The following questionnaire will ask for some background information and will be used for research purposes only. Accurate information is greatly appreciated; however, questions may be left un-answered if you do not feel comfortable providing certain information. All information recorded here will be kept strictly confidential.

If you would like to create your own pseudonym (fake name for confidentiality purposes), please include it here:

Note that a pseudonym will be created for you if you do not provide one – this will help promote confidentiality.

1. **Age:**

2. **Gender:**

3. **Please list all the organized sport activities you have been involved with:**

4. **Please provide the number of years you have been involved in organized sport:**

5. **What is the highest level you have played organized sport at? (e.g. recreational, competitive, club, varsity, provincial, national)**

6. **What is the latest level you play/have played sport at?**

7. How many concussions have you experienced?

The following is a summary table for you to record your concussive injuries. Please complete this information for every concussion that you have had:

Cause of concussion (e.g. sport, vehicle accident, etc)	Approximate date of concussion	Was it diagnosed or documented? By whom?	Were you knocked unconscious? If yes, for how long (approximately)?	What were your immediate symptoms?	How long did you experience symptoms?

Appendix G



Sport and Exercise Psychology Lab



Appraisal and Coping of Persistent Symptoms following Sport-Related Concussion

Follow-up Questionnaire

Please rate the following symptoms from 0 (none) to 6 (severe) based on what you typically feel, and answer the questions on the back side of this page.

	none	mild		moderate		severe	
Headache	0	1	2	3	4	5	6
Pressure in the head	0	1	2	3	4	5	6
Neck pain	0	1	2	3	4	5	6
Nausea or vomiting	0	1	2	3	4	5	6
Dizziness	0	1	2	3	4	5	6
Blurred vision	0	1	2	3	4	5	6
Balance problems	0	1	2	3	4	5	6
Sensitivity to light	0	1	2	3	4	5	6
Sensitivity to noise	0	1	2	3	4	5	6
Feeling slowed down	0	1	2	3	4	5	6
Feeling like "in a fog"	0	1	2	3	4	5	6
"Don't feel right"	0	1	2	3	4	5	6
Difficulty concentrating	0	1	2	3	4	5	6
Difficulty remembering	0	1	2	3	4	5	6
Fatigue or low energy	0	1	2	3	4	5	6
Confusion	0	1	2	3	4	5	6
Drowsiness	0	1	2	3	4	5	6
More emotional	0	1	2	3	4	5	6
Irritability	0	1	2	3	4	5	6
Sadness	0	1	2	3	4	5	6
Nervous or Anxious	0	1	2	3	4	5	6
Trouble falling asleep	0	1	2	3	4	5	6

Appendix H

Semi-Structured Interview Guide.

The following questions guided the semi-structured interview process. These questions were pursued with flexibility. Participants were reminded that they could skip any questions that make them uncomfortable by saying “pass” or that they could stop the interview at any point if they wish to do so.

1. Do you have any questions about the interview process or the study? Is there anything that you would like to mention before we begin?
2. Please tell me about the role that sport has had in your life.
 - a. What sports have you participated in? How long have you participated in these? What levels have you participated at? What does your sport involvement mean to you?
3. Have you had any long-term sport injuries other than concussions?
 - a. How did you manage them? Talk about any actions, thoughts or feelings that you used to make the situation better.
4. Can you tell me about your history with sport concussion(s)?
 - a. How many have you had? When did they occur? How did they occur?
5. Can you tell me about your latest sport concussion?
 - a. When did it happen? How did it occur? What immediate symptoms did you have?
 - b. Did any medical practitioner diagnose your concussion? What was the process like? What information and/or advice were you given?
 - c. Did your sport team/organization provide any information or resources in dealing with the concussion?

- d. What thoughts did you have right after the concussion?
 - e. What feelings did you have right after the concussion?
6. How long has it been since that concussion? Can you describe your experience since the concussion?
7. Let us talk about the symptoms that you are still experiencing. Can you describe them?
(probe for any pain, discomfort, difficulties; duration, frequency, and intensity; when they arise and when they subside)
- a. What do you think about these symptoms? What do you think they mean? Where do you think they originate from? How do they make you feel?
 - b. What do you know about these symptoms? How do you know these things? What do you wish you knew about them?
 - c. Do you think you have any control over these symptoms?
 - d. What have you done to manage these symptoms? Talk about any thoughts, actions, or feelings you have used to make the situation better.
 - i. What was your intention when using this strategy? *(probe for each strategy)*
 - ii. What strategy was the most helpful for you? What was the least helpful?
 - e. How have your thoughts or feelings about the symptoms changed throughout the course of your experience? What brought about these changes?
 - f. How have your strategies to manage the symptoms (actions, thoughts, feelings) changed throughout the course of your experience? What brought about these changes?
8. How have your prolonged symptoms changed your life, if at all?

- a. What have you done to adapt to the changes? Talk about any thoughts, actions, or feelings you have used to make the situation better.
9. How do you think these prolonged symptoms will impact your future, if at all?
 - a. How will you manage (with actions, thoughts, feelings) if the symptoms persist?
10. Have there been any positive aspects of your experience with the prolonged symptoms?
11. Have you sought any medical or professional advice or information on how to manage the symptoms?
 - a. What advice/information were you given? Was this helpful?
12. Have you sought any non-professional advice or help on how to manage your symptoms?
 - a. What advice/information were you given? Was this helpful?
13. How have others perceived your concussion? (*probe for friends, family, co-workers, etc*)
14. Has anyone played a major role in your experience with prolonged symptoms?
15. Do you think there are any major factors that have caused a change in your symptoms?
16. What do you know about concussions now?
 - a. What sources of information did you rely on for this knowledge?
 - b. How is this different than what you knew before?
17. How do you feel about being away from sport?
 - a. Have you returned, or tried to return to sport since your concussion? What was that experience like?
18. Do you have any other questions or comments you would like to share?