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The experiences of female adolescents who have sustained a concussion through sport participation: A consideration of an occupational perspective during recovery

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences

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ABSTRACT

Adolescence is a time of rapid and tumultuous development in the physical, cognitive and psychosocial domains. Sustaining a concussion during this time period may complicate this development, particularly when symptoms are prolonged. Of particular importance is the study of adolescent females, as this population has been under-evaluated within the literature. This is especially troubling due to the number of concussions that occur among adolescent females, as concussions within this population reportedly occur at twice the frequency of adolescent males. This dissertation presents a qualitative case study investigation that explores the recovery experiences of adolescent female athletes who have sustained a concussion and are facing post-concussion syndrome. Six adolescent females (age range, 15-18 years) who sustained a sport-related concussion with symptoms lasting longer than one month (range, 10-18 months) were included. Twelve semi-structured one-on-one interviews were conducted, followed by two focus groups. Photoelicitation was used as a method of establishing a “language bridge,” such that photographs produced by the participants act as a stimulus and guide within the interviews and focus groups. A conceptual framework emerged where recovery was conceptualized in terms of symptom burden, activity changes and restrictions, and both emotional and psychosocial sequelae. The risk of long-term consequences was explored in the context of pre-injury susceptibility and post-injury resilience. There is a discussion of mental and emotional well-being during adolescence, with the presentation of the role of occupational therapists and multidisciplinary care teams as a “support buffer” during recovery.

KEY TERMS: Case study, photoelicitation, adolescence, concussion, post-concussion syndrome, recovery, occupational perspective.

LAY SUMMARY

A concussion is a complex brain injury. There is an abundance of research surrounding the identification of concussion, but what is often left out is the holistic or “whole person” assessment of concussion recovery. Current post-concussion monitoring scales (i.e., Post-Concussion Symptom Scale) address the physical symptoms of concussion, but there is little information and monitoring of one’s mental, emotional and social well-being. This research project aims to explore concussion recovery experiences from a “whole person” perspective. The population of interest was adolescent females. Adolescent females are underrepresented in the research literature. This is problematic because they sustain more concussions and their recoveries are said to be longer (as compared to adolescent males). This dissertation presents a qualitative case study investigation that explores the recovery experiences of adolescent female athletes who have sustained a concussion and are facing persistent symptoms. Six adolescent females (age range, 15-18 years) who sustained a sport-related concussion with symptoms lasting longer than one month (range, 10-18 months) were included. Twelve semi-structured one-on-one interviews were conducted, followed by two focus groups. Photoelicitation was used as a method of establishing a “language bridge,” such that photographs produced by the participants act as a stimulus and guide within the interviews and focus groups. A conceptual framework emerged where recovery was conceptualized in terms of symptom burden, activity changes and restrictions, and both emotional and psychosocial sequelae. The risk of long-term consequences was explored in the context of pre-injury susceptibility and post-injury resilience. There is a discussion of mental and emotional well-being during adolescence, with the presentation of the role of occupational therapists and multidisciplinary care teams as a “support buffer” during recovery.

CO-AUTHORSHIP STATEMENT

A version of Chapter 3 will be submitted to the Open Journal of Occupational Therapy for publication (see citation below). Annalise Tichenoff was responsible for identifying the research question, conducting the scoping review search, selecting the studies, charting the data, both summarizing and reporting the results, and writing the chapter. Naomi Sanderson was involved in selecting the studies by assessing full-length articles for eligibility. Dr. Andrew Johnson provided constructive comments throughout the writing process.

Tichenoff, A., Sanderson, N.M., Johnson, A.M. A scoping review: Adolescent recovery experiences and perspectives following a concussion sustained through sport participation. To be submitted to the *Open Journal of Occupational Therapy* for publication.

A version of Chapter 5 was submitted for the completion of the Candidacy Examination. Another version will also be submitted to the Open Journal of Occupational Therapy for publication (see citation below). Annalise Tichenoff was responsible for conducting the literatures searches, making connections between the Occupational Risk Factors theoretical perspective and concussion care, writing the chapter, and writing the original draft of the manuscript. Dr. Andrew Johnson provided guidance in identifying the utility of considering Occupational Deprivation during concussion care and provided constructive comments throughout the writing process. Dr. Jeffrey Holmes' involvement surfaced later in the manuscript process, and not during the writing of Chapter 5.

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Chapter 1: INTRODUCTION

1.1 Project Overview

The purpose of this qualitative case study is to explore the recovery experiences of adolescent females who have sustained a concussion through sport participation (i.e., game, practice or recreational setting) and have experienced prolonged recovery profiles. The facilitators and barriers to recovery will be considered in an effort to improve the understanding of recovering adolescent females. This population is of particular importance, as adolescent females have been under-evaluated within the literature (Emmonds, Heyward, & Jones, 2019). This is especially troubling because preliminary research suggests that females who sustain a concussion experience higher symptom burden, longer overall recovery and perhaps worse long term outcomes (Berz et al., 2013; Brown et al., 2015; Covassin & Elbin, 2011). As such, it becomes critical to ensure that females have an equitable opportunity for experiencing an efficient recovery, safe return to daily activity and avoiding complications associated with prolonged recovery.

The Occupational Risk Factors theoretical perspective was used as the initial conceptual framework to guide data collection and analysis – exploring occupational deprivation, occupational imbalance and occupational alienation in relation to activity changes during recovery. The inclusion of an occupational perspective within concussion care is currently underutilized next to the biomedical model, however there may be utility in considering meaningful activity during the activity reintegration phase of recovery. Specifically, psychosocial needs should be considered when making treatment decisions surrounding rest and activity reintegration, as the removal of meaningful activity may lead to deleterious effects on an individual's mental health and well-being (Halstead, Brown, & McAvoy, 2017).

This dissertation presents a collective case study investigation, which aims to construct a new conceptual framework to improve understanding of the concussion recovery of adolescent female athletes who are experiencing prolonged symptoms. Six adolescent females (age range, 15-18 years) who sustained a sport-related concussion with symptoms lasting longer than one month (range, 10-18 months) were included. Twelve semi-structured one-on-one interviews were conducted, followed by two focus groups. Photoelicitation was used as a method of establishing a “language bridge,” such that photographs produced by the participants act as a stimulus and guide within the interviews and focus groups. The research questions are presented below.

1.2 Research Questions

- i) *How do female adolescents who have sustained a concussion through sport participation (e.g., game, practice or recreational setting) describe their recovery experiences of return to school, return to sport and return to occupation?*
- ii) *What are the barriers and facilitators that accompany one’s return to school, return to sport and/or return to occupation(s)?*
- iii) *How do female adolescents who have sustained a concussive injury interpret what has been asked of them in terms of return-to-activity protocol(s) or suggested activity modifications?*

1.3 Personal Positioning Statement

I believe that as a qualitative researcher, one must be critically self-aware of the potential assumptions, pre-understandings and preconceived notions that may influence the research process. This encourages researchers to be frank about their strengths and shortcomings while

engaging in the research process (Tracy, 2010). As researchers we want to examine where and how we are “situated” in relation to the research we conduct. With the end goal of transparency and authenticity, I started a reflexive journal early in the research process to reflect on my assumptions, taken-for-granted understandings and motivations, as well as to ask myself whether I am well suited to examine the research questions. My research journey has definitely evolved over the years. I started into a M.Sc. program after an undergraduate degree in B.HSc. where I completed a double major in Rehabilitation Sciences and Psychology. It will likely be clear that my initial research interests stemmed from my undergraduate education – a merging of functional and occupational perspectives as well as an interest in mind and behaviour. I ended up on a path where I fast-tracked from the M.Sc. program directly into the Ph.D. program.

I started on the path of concussion research out of general interest. I have not sustained a concussion myself, but each of my three siblings have, as well as many other close friends and family members. I saw first-hand the impacts that a concussion can have on all facets of one’s life, however I present my findings from the etic, or observer perspective. For me, it was interesting how mental health and well-being was impacted during recovery. I was interested in the vulnerabilities and susceptibilities associated with concussion recovery – particularly for adolescents. Ultimately, I wondered why adolescents were more likely to experience prolonged recovery profiles in light of current treatment recommendations suggested by the Consensus Statement on Concussion in Sport Guidelines. When I started this project, I was very much a young person myself (age 22), which is likely why I was drawn to this population. Due to my recent experience within the adolescence time period, I was aware and able to reflect on common stressors that accompanied adolescent daily life (e.g., maturation; academic stressors; parental pressures; peer interactions; sporting endeavours, etc.). A drastic shift in one’s independence

also occurs during adolescence, making it a particularly tumultuous transition period – especially when met with an uprooting injury like a concussion with prolonged symptoms.

During my time working on this research project, I decided to concurrently complete a compressed B.ScN. degree at the University of Toronto. With this experience, I was met with the discourse of health and well-being largely from the biomedical perspective. However, along with learning the traditional biomedical and hands-on tasks of nursing, I found a new voice through this educational opportunity. Nursing has taught me about the importance of listening to patient perspectives, considering situational variables and advocating for patient needs. I felt compelled to dive further into my concussion research project, incorporating these perspectives. It became clear to me that there was a large gap in the research literature surrounding concussion recovery directly from the patient (or participant) perspective. I wanted to hear first-person accounts of recovery directly from adolescents who had sustained a concussion. I was particularly interested in the experience of female adolescents, because their accounts of recovery are underrepresented in the research to date (Emmonds et al., 2019). As such, I conducted a case study to examine the accounts of female adolescents recovering from concussion, and the methods of photoelicitation complimented by interviews and focus groups were selected as a means to afford adolescents the opportunity to tell their stories.

1.4 Research Sites

This project was conducted with the support of the Fowler Kennedy Sport Medicine Clinic (FKSMC) as well as the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) within the Thames Valley Children's Centre. FKSMC is a leading centre for sport and exercise medicine in London, Ontario – providing diagnosis, treatment and rehabilitation to athletes of all levels. The centre aims to provide high quality, timely, comprehensive and

compassionate care. With the support and collaboration of Western University and the London Health Sciences Centre, FKSMC strives toward achieving their vision of “setting the standard of excellence in sport and exercise medicine.” There is a specific concussion treatment program within the FKSMC, where sport medicine physicians and physiotherapists work in conjunction with the patient in order to provide comprehensive assessment and treatment programs, and well as injury prevention.

PABICOP, on the other hand, was developed out of the Thames Valley Children’s Centre in London, Ontario. PABICOP is an outreach program for young people who have sustained an acquired brain injury as well as their accompanying families. It is a family-centered, culturally sensitive service that aims to provide single-point access for case management and coordination. It aims to support children and adolescents who are facing social, academic, medical or emotional issues; and it assists families in gaining the knowledge and skills that are necessary for accessing the services needed. PABICOP was established to bridge the gap between rehabilitation services available through the Thames Valley Children’s Centre and medical insight available at the London Health Sciences Children’s Hospital of Southwestern Ontario. In terms of concussion, PABICOP aims to provide a continuum of care model for children and adolescents diagnosed with a concussion, scoping the domains of academic (cognitive), sport (physical), social and community reintegration (Gillett, 2004; McDougall et al., 2006).

1.5 Dissertation Structure

This document is organized in monograph format. Chapter 2 outlines the background review of the literature. I start by broadly outlining the concussion landscape and move towards the specifics of concussion recovery within the adolescent female population. Key topics such as second impact syndrome, subconcussion, rest and return to activity profiles are discussed as they

pertain to the complexity of concussion recovery for the adolescent population. Chapter 3 outlines a scoping review which explores the reported recovery experiences and perspectives of adolescents who have sustained a concussion through sport participation. There is also a discussion of my preconceptions of concussion recovery, which is presented as a preliminary conceptual framework.

Chapter 4 outlines the methodological positioning that frames the project. There is a discussion of the research philosophy behind the project and what resources were used according to the research intentions. Chapter 5 outlines the theoretical perspective of interest that has guided my inquiry into (and interpretation of) concussion recovery, namely the Occupational Risk Factors theoretical perspective (i.e., occupational deprivation; occupational imbalance; and occupational alienation). This perspective is, therefore, discussed in terms of concussion recovery and participation in meaningful activity. Chapter 6 outlines the methods used, and Chapter 7 outlines the results and analysis. Finally, in Chapter 8, I discuss the study results in the context of the existing literature, and present conclusions, a final conceptual framework and recommendations for practice.

Chapter 2: BACKGROUND

2.1 Introduction to Concussion

The incidence of concussion is reportedly reaching epidemic proportions. The Institute for Clinical Evaluative Sciences analyzed provincially-collected data and found that there were 148,710 diagnosed concussions in Ontario in 2013 (Bayley & Langer, 2016). In line with the vast number of concussions being identified, the volume of research is also growing quickly within the literature. It has been stated that the research produced on concussions over the past 15 years surpasses all previous information produced, in both volume and scope (Bailes, Petraglia, Omalu, Nauman, & Talavage, 2013). It is now known that concussions are more common than once thought, and that they are more detrimental to the individual in the weeks and possibly months following the injury as well as in the long-term (Breedlove et al., 2012; Broglio et al., 2011; Halstead & Walter, 2010; Jotwani & Harmon, 2010; Makdissi, Cantu, Johnston, McCrory, & Meeuwisse, 2013; Master & Grady, 2012a). As such, timely identification and appropriate management according to current recommendations, is imperative to prevent avoidable complications (e.g., Post-concussion Syndrome; cumulative effects of multiple brain injuries; Second Impact Syndrome).

2.2 Concussion and Related Definitions

There have been several working definitions of concussion introduced over the past several years. Concussion is used broadly as a diagnostic term to describe a multifaceted brain injury (Bayley, 2013; Grace, 2013; Lovell, 2014; Lueke, 2011; West & Marion, 2013). For the purposes of this project, the focus will be the accepted clinical definition of concussion, which was developed in 2008 and redefined and augmented in the 2012 Zurich Consensus Statement on Concussion in Sport, as well as the 2016 Berlin Statement. The Berlin expert panel outlined

sport related concussion as “a traumatic brain injury induced by biomechanical forces” (McCrory et al., 2017). Several common features that may be utilized in clinically defining the nature of a concussive head injury is that a sport-related concussion: i) “may be caused either by a direct blow to the head, face, neck or elsewhere on the body with an impulsive force transmitted to the head;” ii) “typically results in the rapid onset of short-lived impairment of neurological function that resolves spontaneously, however, in some cases, signs and symptoms can evolve over a number of minutes to hours;” iii) “may result in neuropathological changes, but the acute clinical signs and symptoms largely reflect a functional disturbance rather than a structural injury and, as such, no abnormality is seen on standard structural neuroimaging studies”; iv) “results in a range of clinical signs and symptoms that may or may not involve loss of consciousness;” v) “resolution of clinical and cognitive features typically follows a sequential course, however in some cases symptoms may be prolonged” (McCrory et al., 2017, p. 839).

Traditional diagnostic neuroimaging methods, such as magnetic resonance imaging and computed-tomography scans often show no structural damage. Consequently, a concussion may be conceptualized as a “disruption” in brain connectivity and ability to function fluently (Chamard et al., 2012). Considering its functional nature, some suggest that the term concussion may be too vague to be used clinically, due to the variability of post-traumatic symptoms and recovery experiences. Instead, a classification system that grades concussion severity using neuropsychological symptoms may be more useful (Sharp & Jenkins, 2015).

Symptoms can be experienced in one or all of four broad domains: physical, cognitive, emotional and sleep (see Table 2.1; Gioia & Collins, 2010; Halstead & Walter, 2010; Marsh, Fraser, & Marsh, 2013; Master & Grady, 2012b; McCrory, Meeuwisse, Aubry, Cantu, Dvořák, et al., 2013). The most commonly reported symptoms include headache, dizziness, balance

disturbances, disorientation and difficulty concentrating and remembering (Elleberg, Henry, Macciocchi, Guskiewicz, & Broglio, 2009; Hunt & Trombley, 2010; Makdissi et al., 2010; Sharp & Jenkins, 2015). More recently it has been suggested that neuropsychiatric symptoms including depression, anxiety, apathy and emotional lability are often present in concussed individuals (Elleberg et al., 2009; Master & Grady, 2012b).

Table 2.1. Common signs and symptoms of concussion.

Physical	Cognitive	Emotional	Sleep
Headache	Fogginess	Irritability	Increased sleep
Nausea	Feeling slowed down	Sadness	Decreased sleep
Balance issues	Difficulty concentrating	Emotional lability	Difficulty falling asleep
Dizziness	Difficulty remembering	Nervousness	Difficulty staying asleep
Visual disturbances	Memory issues	Anxiousness	Fragmented sleep
Fatigue	Confusion	Moodiness	Restlessness
Noise sensitivity	Responding slowly	Frustration	
Light sensitivity	Forgetfulness	Sense of loss	
Head and/or neck pain	Decision making issues		

2.3 Sport-related Concussion

A concussion sustained through sport participation is a subset of concussion diagnoses with unique situational factors that make diagnosis and management particularly important and sometimes complex. A sports-related concussion is the same brain injury described above; however, it is sustained by an athlete engaging in sporting activity – either recreational, elite, or professional. Individuals with a suspected concussion are to be removed from the sporting activity immediately and should seek follow up medical attention in a timely manner for diagnosis and treatment options. The complexity of sport-related concussion often lies in the social pressures that accompany identification, diagnosis and management – from the individual athlete themselves, teammates, coaches and/or caregivers. Masking concussion symptoms and returning to play prematurely may result in additional injuries and longer-term complications

(e.g., Post-concussion Syndrome; cumulative effects of multiple brain injuries; Second Impact Syndrome).

A sport practice and/or game setting is a difficult situation for proper and unbiased concussion reporting. Concussion perceptions and judgements are often clouded by “game time” feelings of arousal as well as living in the moment of the game, which promotes returning to activity over rest (Clacy, Sharman, & Lovell, 2013; Kissick & Johnston, 2005). Staying in-play or returning to play after a suspected concussion is a disservice to the health of the athlete and complicates the condition in the long-term. It has been suggested that, unless a loss of consciousness occurs, concussions are underreported (Register-Mihalik et al., 2013). The management of concussion is further complicated by the reluctance of athletes to report symptoms of injury, while maintaining a “toughing it out” mentality common within sporting culture. However, the old mantra “if you can walk, you can play” is slowly being replaced by a push for athletes, coaches and parents to be significantly more conservative when identifying potential concussion – expressing the new mantra, “when in doubt, sit them out” (Roy-Bornstein, 2012). As a more streamlined approach, consensus recommendations suggest that the Sport Concussion Assessment Tool 5 be used on sidelines to identify concussion symptoms (see 2.4.1 for more information).

2.3.1 Second Impact Syndrome

Sport-related concussion has become a significant problem in recent years, with frequent news headlines reporting the consequences of returning to play too soon as well as the long-term effects of the injury. A condition known as Second Impact Syndrome (SIS) has had particular media attention. Although it is only seen on rare occasions, the consequences are particularly severe (McCrory & Berkovic, 1998). The overall incidence and prevalence of SIS remains

unknown. SIS occurs when an individual suffers a symptomatic concussion, then sustains a second impact before recovering, resulting in altered mental status within seconds to minutes of the second impact (Bowen, 2003). The second impact does not have to be of the same severity as the first, and often a lesser hit triggers the symptoms. The time between the first and second injuries is debatable in the literature, but SIS can occur if a subsequent head injury is sustained within minutes and up to four weeks after the first injury (McLendon, Kralik, Grayson, & Golomb, 2016).

Upon second impact, individuals experience diffuse cerebral edema with midline shift as well as possible herniation, subdural hematomas and subarachnoid hemorrhage. Outcomes are often severe, ranging from permanent disability (e.g., cognitive, sensory and motor deficits; hemiplegia) to death. More research is needed in this area, but it has been suggested that the mechanism of this secondary injury may be disrupted autoregulation of the vasculature and/or amplified axonal shearing in the brain following the second impact (McLendon et al., 2016). Participation in sport, particularly contact sport, puts individuals at higher risk for SIS due to the higher occurrence of body contact and impact with the physical environment – especially boxing, football and hockey. Two other notable risk factors for SIS are being male, and age (adolescents aged 14-19 years are particularly at risk; McCrory, Davis, & Makdissi, 2012).

2.3.2 Subconcussion

A subconcussive blow is one that does not meet the criteria for clinical diagnosis of concussion yet is hypothesized to have an adverse long-term effect in some individuals, particularly with repetitive occurrences (Belanger, Vanderploeg, & McAllister, 2016). Subconcussion is a term used to describe a state in which clinical symptoms associated with a concussion diagnosis are not displayed, yet abnormal neurocognitive performance (i.e., memory

and attention) and altered biochemical and activation changes are seen in the brain (Bailes et al., 2013). Abnormal neurological performance is typically detected through traditional concussion diagnostic methods such as functional magnetic resonance imaging and neuropsychological testing. There is also insight into mood and behaviour disturbances later in life as a result of these repeated blows.

Subconcussion has its greatest effect with repetitive occurrences, whereby cumulative impact exposure becomes detrimental, rather than one single event (e.g., repetitive contacts at the line of scrimmage in football). Data collected in football helmet accelerometer studies have shown that football players may experience a wide range of head impacts, from 100 to over 1000 during the course of one season – and whether an impact results in a formal diagnosis, or is subconcussive, each impact places the athlete at risk for neurocognitive sequelae (Broglio et al, 2010; Breedlove et al, 2012). The repetitive impacts mentioned above are part of regulation play for many sports, such as: body-contact in hockey, heading of the ball in soccer, boxing manoeuvres, and tackling in football. Although more research is needed in this area, some experts suggest reserving full body contact for game settings and limiting body contact in practice settings as a means of minimizing overall injury burden.

2.3.3 Post-concussion Syndrome

Most athletes experience a full spontaneous recovery from concussion. However, about 5-30% of concussed patients will experience Post-concussion Syndrome (PCS; Lovell, 2009; Parachute, 2017). PCS represents a complex constellation of symptoms that persists beyond the regular recovery timeframe following the concussive injury, with traditional diagnostic testing (i.e., computed tomography and magnetic resonance imaging) remaining normal. Where the normal course of symptom resolution in a concussion should end and where PCS begins is

variably defined in the literature – suggestions range anywhere from four weeks to three months of continuous post-concussion symptoms for a PCS diagnosis. However, what can be agreed upon is that PCS remains a clinical diagnosis arrived at after careful review of a patient's history, and preinjury psychiatric and medical status (Jotwani & Harmon, 2010). PCS may be considered after symptoms have lasted longer than two weeks for adults or four weeks for children and adolescents (Southern et al., 2019).

There isn't a clear consensus as to the cause of PCS in the literature, however the following (or a combination of the following) are suggested as predictors: i) pre-existing psychiatric illness; ii) stress of injury resulting in mood disorder or psychiatric illness (e.g., depression; anxiety; posttraumatic stress disorder); iii) persistent pain during recovery (i.e., concussion migraine); iv) poor coping mechanisms; and/or v) biomechanical forces on the brainstem, forebrain and temporal lobe. Interestingly, a longitudinal study carried out with children found that PCS can result for different reasons in different patients, and thus, each case should be evaluated independently (Yeates et al., 2009). Lishman (1988) also proposed a theoretical framework called Physiogenesis versus Psychogenesis. This framework proposes that during the early stages of concussion recovery, symptoms are largely organic in origin. Then over the weeks and months following the concussion there is a shift wherein neurobiological factors subside and psychological factors emerge to maintain PCS (Lishman, 1988). This theoretical framework emphasises that spontaneous neurobiological recovery occurs fairly rapidly in most people, but symptomatic and functional recovery could be hampered by psychological problems. More recently, some researchers suggest this framework should be updated to include neurobiological and psychological factors which may play a causal role in PCS from the outset (Silverberg & Iverson, 2011).

At present, a useful strategy for tackling PCS in athletes would be to identify risk factors at the time of the concussion diagnosis and provide individualized care in an attempt at prevention (Jotwani & Harmon, 2010). A review of predictors and risk factors found the following may be potential risk factors for prolonged concussion recovery: i) loss of consciousness or amnesia upon injury; ii) pre- or post-injury migraine headaches; iii) noise and light sensitivity in the first week of recovery; iv) prior concussion diagnosis; v) female; vi) pre-existing mood disorder or psychiatric illness (e.g., anxiety; depression; compulsive, histrionic and narcissistic personality disorders); vii) family history of mood disorders, psychiatric illnesses and/or migraines; viii) medically prescribed excessive cognitive and physical rest; and ix) certain personality characteristics (e.g., perfectionism; egocentrism; narcissistic; etc.; Broshek, De Marco, & Freeman, 2015; Morgan et al., 2015; Nelson, Tarima, et al., 2016; Silverberg & Iverson, 2011; Zemek et al., 2016). The primary goal of treatment and rehabilitation for those who have PCS and comorbidities is to reduce symptom burden and improve functioning by providing individualized treatment.

2.4 Concussion Identification and Diagnosis

2.4.1 Initial Identification

The potential for a concussion is greatest during activities where bodily impact can occur, such as sport practices or games, motor vehicle accidents, playground play or school-based sports activities. Identification may be made by a family member, coach, trainer, teacher or peer (Faure, 2010). However, athletic trainers are commonly the first professionals available onsite to identify and evaluate injuries (Broglia et al., 2014). It is often difficult for the individual athlete to self-detect their injury status due to the cognitive symptom sequelae. Concussion suspicions commonly arise when cognitive or physical changes are noticed in an individual, immediately

following a blow to the head or body (Parachute, 2017). Early identification is important to protect the individual from further injury (i.e., SIS) and so appropriate management options can be pursued.

In the past, there has been significant discrepancy in the identification of a possible concussion at or around the time of the incident (Broglia & Guskiewicz, 2009). Concussions have been said to be one of the most complex injuries to identify, especially in the sport and recreation setting (McCrory et al., 2017). This is likely due to that fact that it is an evolving injury in the acute phase, with rapidly changing clinical signs and symptoms. There are over 47 concussion diagnostic tools (plus 10 sport-specific tools) in North America that can be used to identify a probable concussion (Broglia & Guskiewicz, 2009; McCrory, Meeuwisse, Aubry, Cantu, Dvorak, et al., 2013). However, with the introduction of the 2016 Consensus Statement on Concussion in Sport Guidelines and the 2017 Canadian Guideline on Concussion in Sport, it is now recommended that removal from the activity or situation, followed by neuropsychological test batteries that assess attention and memory function, is both practical and effective – specifically, the Sport Concussion Assessment Tool 5, Concussion Recognition Tool 5 and Standardised Assessment of Concussion (McCrory et al., 2017; Parachute, 2017).

The Sport Concussion Assessment Tool (SCAT) was developed at the second Concussion Consensus in Sport Conference in 2004, to assist medical providers in evaluating sport-related concussion. Now on its fourth revision, the SCAT5 is a tool used in the identification and evaluation of a suspected concussion for those 13 years of age and older. There is also a Child SCAT5 available for those 5 to 12 years of age. The SCAT5 is a multicomponent assessment approach for concussion and has demonstrated value for detecting post-concussion changes in the domains of physical, cognitive and postural stability. It is the

recommended tool for sideline and in-office assessment for concussion within the first three days post-injury – after which its diagnostic utility decreases significantly (Echemendia et al., 2017; McCrory et al., 2009). The SCAT5 identification tool is open access to the public through the Parachute Canada website, however it was developed for use by medical professionals (Southern et al., 2019).

It is well known that healthcare professionals are not present at most athletic events, particularly within youth or recreational sporting leagues. Therefore, the Pocket Sport Concussion Assessment Tool 2 (Pocket SCAT2) was developed following the 2009 Concussion Consensus Conference as a tool for laypeople to recognize the signs and symptoms of concussion and to provide guidance for removing an athlete from play (Echemendia et al., 2017a). The Pocket SCAT2 was renamed the Pocket Concussion Recognition Tool (Pocket CRT) after the 2012 Concussion Consensus Conference, and even more recently was updated as the Concussion Recognition Tool 5 (CRT5) following the 2016 Concussion Consensus Conference (McCrory, Meeuwisse, Aubry, Cantu, Dvorak, et al., 2013; McCrory et al., 2017). The CRT5 remains an identification tool (not diagnostic tool) with the goal being to “recognize and remove.” It also aims to improve consistency with the SCAT5 in terms of visible signs and symptoms. According to the 2016 Canadian Guideline on Concussion in Sport, a concussion should be suspected in any athlete who sustains a significant impact to the head, face, neck, or body and demonstrates any visual signs of a suspected concussion or reports any symptoms as detailed in the CRT5 (Parachute, 2017). The CRT5 identification tool is open access to the public through the Parachute Canada website.

2.4.2 Professional Diagnosis

When a concussion is suspected, the individual should be directed to a health care professional for a timely consult. Typically, a nurse practitioner or medical doctor is responsible for diagnosing concussion in an office-based or emergency medicine setting. However, diagnosis can also occur during sideline evaluation if a nurse practitioner or medical doctor is present. A review by Solomon and Eady (2012), which included health care professionals who diagnose concussions, found that there are small gaps in knowledge of diagnosis and large gaps in initial management. Several Ontario- and Canadian-wide initiatives have been put in place to make streamlined concussion care a priority, with progression continuing in this area (e.g., Parachute Canada; Ontario Neurotrauma Foundation).

2.5 Concussion Management

Management recommendations for concussion have developed commensurately with the increase in concussion research over the past decade. Unfortunately, there continue to be misconceptions in regards to general knowledge of concussion and particularly concussion management (Bloodgood et al., 2013; Cusimano, 2009; McKinlay, Bishop, & McLellan, 2011). These misconceptions can potentially lead to serious health consequences – especially if the concussion is not treated and managed effectively. For example, many patients and families: i) believe that a concussion affects the head but not the brain; ii) are unaware of the adequate amount of time for physical and cognitive rest required for recovery; iii) do not realize the overall seriousness of the injury or the long-term consequences that can occur ; iv) do not recognize the signs and symptoms of concussion, and in turn do not remove themselves from play, or suggest the removal of others; and v) are unaware of the available return-to-school and return-to-sport protocols that facilitate recovery (Bernstein, 2010; McKinlay et al., 2011; Moser,

Schatz, Glenn, Kollias, & Iverson, 2015). The above knowledge gaps can and should be addressed, and several initiatives are in place to do so (e.g., Canadian Guideline on Concussion in Sport; Ontario Provincial Policy Mandate 158) – information that can be used by athletes, coaches, school nurses, teachers, and of course both nurse practitioners and medical doctors to inform and educate the public (Halstead et al., 2013; Master & Grady, 2012b; Ministry of Education, 2014; Parachute, 2017; Saunders, Burdette, Metzler, Joyner, & Buckley, 2013).

A good way to gather multiple informant input on symptom presentation and track symptom recovery, is to use the Post-concussion Symptom Inventory (PCSI; Gioia, Vaughan, & Maegan, 2012). This 22-item symptom scale was originally developed as a self-report measure for adults and adolescents (age 13-18 years) but it has also been adapted for use as a parent and teacher reporting measure, as well as a self-report measure for younger preadolescent children depending upon age (age 5-7 years and 8-12 years, respectively; Sady, Vaughan, & Gioia, 2014). The PCSI form asks for both a retrospective preinjury baseline report of symptoms and a postinjury report of symptoms observed over the past day. This is the recommended tool for managing and tracking concussion symptoms over the course of clinical recovery.

2.5.1 Rest

It is clear that there are metabolic changes in the brain that occur after a concussion (Chamard et al., 2012; Grady, Master, & Gioia, 2012). For days, weeks or even months after a concussion, the focus of the body's energy is directed to the sites of diffuse injury (Grace, 2013). This results in reduced energy available for the typical physical and cognitive demands associated with activities of daily living. Recommendations for rest have been introduced to lessen the demands on the brain during recovery, as well as to limit the possibility of reinjury if one was to return to sport and recreation prematurely. In the acute phase after the concussion,

cognitive and physical activity as well sensory stimulation can worsen symptom levels (Halstead & Walter, 2010; Master & Grady, 2012b). This phase differs for each individual, depending on the severity of the insult, the nature of the injury, as well as personal characteristics (Mayers, 2012). Difficulty has ensued as there has been significant debate over the parameters of rest recommendations. Expert consensus rest recommendations are available, but the literature supporting the guidelines of rest are still mixed and limited. There is more work to be done, particularly in regard to the exact amount and duration of rest (DiFazio, Silverberg, Kirkwood, Bernier, & Iverson, 2016a).

Rest after a concussion refers to the limitation or removal of physical, cognitive, social activity in addition to sensory stimulation (particularly visual, tactile and auditory sensations). Cognitive rest represents a state of avoiding activities that require attention or concentration (e.g., work and school activities, watching television, computer use, playing video games, reading and text messaging; Scorza et al., 2012). Physical rest suggests avoiding bodily movements and functioning that increases heart rate and/or induces perspiration (e.g., aerobic exercise, lifting weights, household chores and sexual activity; Halstead & Walter, 2010). The goal of rest is to keep brain activity below the symptom-exacerbation threshold, or the level of activity that triggers or worsens symptoms (Leddy, Sandhu, Sodhi, Baker, & Willer, 2012).

Recommendations for rest have been a source of particular debate over recent years and have changed significantly from the first expert Concussion Consensus Statement in 2001, to the fifth and most recent Concussion Statement in 2016. Initially it was believed that individuals with concussion should rest until they are completely asymptomatic, then proceed with the return to activities gradually (Aubry et al., 2002). While the majority of individuals return to their regular activities of daily living within 5 to 10 days post-concussion, the problem lies with those

individuals who follow a more sporadic and prolonged recovery trajectory (Belanger & Vanderploeg, 2005; Broglio & Puetz, 2008; Silverberg & Iverson, 2013). The practice of waiting until the individual is completely asymptomatic, has resulted in many individuals resting for weeks or months – at which point rest and removal from activity is less helpful and perhaps even harmful (Grool et al., 2016). As the research in the area of rest continues, the current recommended consensus from the Berlin Statement is: “a brief period of rest during the acute phase of recovery (24-48 hours), followed by a gradual and progressive increase in activity while staying below one’s cognitive and physical symptom-exacerbation threshold” (McCroory et al., 2017).

A period of rest is hypothesized to facilitate the restoration of the acute neurometabolic disturbance following injury and prevent harm associated with excessive neurometabolic demands as well as reinjury during this restoration period (DiFazio et al., 2016a). Returning to activities prematurely, when the individual is not cognitively or physically ready, can exacerbate an already complicated condition (Brown et al., 2014; Norton, Feltz, Brocker, & Granitto, 2013). This may result in amplified short-term symptoms, prolonged symptoms, permanent impairments, subsequent concussion (e.g., SIS), and later-in-life issues (e.g., earlier onset memory impairments; mild cognitive impairment; chronic traumatic encephalopathy; Alzheimer’s disease; Parkinson’s disease; etc.). It has also been suggested that neuropsychiatric symptoms including depression, anxiety, apathy and emotional liability often emerge, with increased probabilities in those who return to activity prematurely or those who have sustained multiple concussions (Lear & Hoang, 2012).

However, as the literature stands currently, rest has been found to be a double-edged sword – suggesting that “strict rest” as well as rest lasting more than five days can slow recovery

and result in more reported symptoms overall (Thomas, Apps, Hoffmann, McCrea, & Hammeke, 2015). It has also been noted that social needs should be considered when making decisions surrounding rest, as the removal of meaningful activity and social interactions may lead to deleterious effects on an individual's mental health and well-being (Halstead et al., 2017). As part of earlier expert Consensus Statement on Concussion in Sport (namely the 2001, 2005, and 2009 versions), health professionals were advised to suggest that patients engage in no activity and complete rest until symptoms resolved. The discouragement of exercise and cognitively challenging activities for weeks, months or even longer (especially in children and adolescents), has had notable consequences on the functional lives of athletes (DiFazio et al., 2016a). Management plans that suggest extended rest cause an individual to feel stressed, anxious and/or depressed about falling behind in his or her regular activities. Also complicating the situation is that symptoms of depression and anxiety often mimic concussion symptoms, which can create an even bigger challenge for healthcare professionals to sort out which symptoms are from the concussion, and which are resulting from underlying anxiety or depression (Halstead et al., 2017).

A systematic review conducted, concluded that the effect of rest as a treatment following sport-related concussion is sparse, and there is a strong need for high level human studies evaluating the effects of rest as a treatment following a concussion (Schneider et al., 2013). There has only been one clinical trial involving complete bed rest following a mild traumatic brain injury in adults recruited from an emergency department, and this trial did not support the use of six days of bed rest as a management strategy (De Kruijk, Leffers, Meerhoff, Rutten, & Twijnstra, 2002). A second randomized control trial focusing on adolescents specifically, found that five days of strict rest did not result in better symptom, cognitive, or balance outcomes at

three days or ten days following injury (Thomas, Apps, Hoffmann, McCrea, & Hammeke, 2015). Interestingly, the same study found that adolescents in the strict rest condition actually reported more post concussive symptoms overall. From these studies, rest lasting five or six days is not beneficial. The current 2016 Consensus Statement on Concussion in Sport Guidelines suggest rest for 24 to 48 hours following a concussion (McCrory et al., 2017).

2.5.2 Return to Activity Protocols

At present, the primary treatment that is recommended to alleviate symptoms of concussion is cast within a return-to-school and/or a return-to-sport framework (Esquivel, Haque, Keating, Marsh, & Lemos, 2013; Mayers, 2012; Mellifont et al., 2013; L Purcell, 2009). These protocols facilitate recovery through avoidance of cognitive, physical, or sensory stimulation for 24-48 hours, followed by a gradual reintegration with pre-concussion activities that allow the person to stay below the symptom exacerbation threshold (Littleton & Guskiewicz, 2013). It is recommended that upon diagnosis, the treating nurse practitioner or medical doctor prescribe return-to-school and/or return-to-sport protocols. In Ontario, Provincial Policy Mandate 158 requires that all school boards must have a concussion policy in place – and part of this mandate is to require individuals with a concussion to have the explicit written permission of a physician or nurse practitioner before returning to school (Ministry of Education, 2014). Further to this, individuals with a concussion diagnosis may require physician documentation for individual accommodations in school, work, and/or sport settings during the symptomatic period and use of treatment protocols (Master et al, 2010).

The process of recovery and return to sport participation follows a stepwise return-to-sport rehabilitation strategy, which has been progressively modified at each 2001 to 2016 Consensus Statement on Concussion in Sport (see Table 2.2 below). The 2016 recommendations

suggest that after a brief period of rest (24-48 hours), symptom-limited activity can begin while staying below the symptom exacerbation threshold (McCrorry et al., 2017). Once concussion-related symptoms have resolved, the individual should continue to proceed to the next level of activity if he/she meets the criteria without recurring symptoms. Individuals should give each step of the return-to-sport protocol 24 hours, resulting in a total recovery period of one week minimum. It is important to note that if any symptoms re-emerge during protocol use, the individual should drop back to the previous asymptomatic level and attempt to progress again after being free from symptoms for a further 24-hour period at the lower level. Return-to-school protocols follow much of the same progression (see Table 2.3). Although individuals are encouraged to return to activity levels that don't exacerbate symptoms, it is also suggested that adolescents successfully return to school before they return to sport (McCrorry et al., 2017).

Table 2.2. Graded return-to-sport protocol.

Stage	Activity	Examples
1	Symptom-limited activity	School, work
2	Light aerobic exercise	Walking, stationary bike
3	Moderate aerobic exercise	Running, skating, resistance training
4	Non-contact practice	Drills
5	Full-contact practice	Scrimmage
6	Full game play	

Table 2.3. Graded return-to-school protocol.

Stage	Activity	Examples
1	Home activities	Reading, writing, drawing, screen time, texting
2	School activities	Homework
3	Part-time school	Schoolwork, some school attendance
4	Full-time school	Full school attendance

According to the Canadian Guideline on Concussion in Sport, when an athlete has been diagnosed with a concussion, they should be provided with a standardized Medical Assessment

Letter. This outlines to the athlete, caregiver(s) and/or spouse that the individual has been diagnosed with a concussion and that they may not return to those activities which may risk a subsequent concussion, until medically cleared to do so by a nurse practitioner or medical doctor (Parachute, 2017). This document can be used to communicate the situation to the athlete's coach(es), teacher(s) and/or employer(s). Once the individual has progressed through their return-to-school and return-to-sport protocols and are deemed as clinically recovered by the nurse practitioner or medical doctor, a Medical Clearance Letter can be issued and a full return to regular sporting activities can be presumed.

2.6 Concussion in Adolescents

Statistics that raise particular concern are those that involve young people. According to the Ontario Neurotrauma Foundation's annual report, the highest rates of concussion in Ontario are found among individuals less than 18 years of age, as documented from visits to emergency departments and physician offices (Munro et al., 2015). A recent study also found that when looking at five Ontario children's hospitals between January 2009 and August 2016, there were 12,159 children and youth treated in emergency departments for suspected concussions and 8935 diagnosed with concussions – diagnosed concussions accounted for 5.4% of injury-related visits (Matveev, Sergio, Fraser-Thomas, & Macpherson, 2018).

When looking more broadly at North American statistics, similar trends are apparent in regard to the impact of concussions on young people. Best estimates by the Centres for Disease Control and Prevention suggest that 65% of concussions are thought to occur in children and adolescents (Norton, Feltz, Brocker, & Granitto, 2013). Additionally, an American study looking at high school students estimated that 136,000 concussions occur per academic year (Gessel, Fields, Collins, Dick, & Comstock, 2007). Nationally, concussions are among the most

common pediatric injuries (McCrory, Meeuwisse, Aubry, Cantu, Dvořák, et al., 2013). These statistics suggest that a significant number of adolescents are affected by concussion, both in Ontario and the surrounding area.

2.6.1 Adolescent Definition and Profile

The adolescent population can be defined as those 13 to 18 years of age. It is clear that there are distinct biological and physiological changes that occur with concussion in individuals 18 years of age and younger, as compared to the effects of this injury within the adult population (Kissick & Johnson, 2005). Adolescents are more vulnerable to concussion for several reasons, including the fact that they are in a critical period for physical and cognitive development, which affects postural stability and also decision making about risk-taking behavior (McKeever & Schatz, 2003; Snyder & Bauer, 2014). Additionally, there is a unique developmental progression occurring in this group of individuals. Of all life-stages, adolescence is arguably the one most marked by rapid and potentially tumultuous transitions – not only in terms of physical development, but in terms of cognitive and psychosocial maturity (Byrne, Davenport, & Mazanov, 2007). Thus, the restrictions to meaningful activities that accompany a concussion may overtax the capacity of many young people to cope.

Most concussion research has been conducted within the adult population and simply applied as a broad overlay to the adolescent population. However, within the last five years, there seems to be more of a push for concussion research for adolescents, likely due to the finding that younger individuals, particularly youth athletes, often have a greater incidence of concussion compared to their adult counterparts. Adolescents represent a unique group, requiring their own body of research specifically targeted to their age and developmental level. There is a clear need for research in this area, and this project can provide a preliminary

representation of the overall recovery that adolescents are experiencing. The adolescent population will be the focus for the remainder of this dissertation.

2.6.2 Identification, Diagnosis, Management

Currently, identification of a concussion in an adolescent is done in much the same way as identification of concussion among adults – definitive neuroimaging findings are usually absent, the SCAT5 is used as an evaluation tool, and PCSI is used to track symptom recovery (Echemendia et al., 2017; Gioia et al., 2012). However, recent updates to the PCSI now allows for completion by the individual adolescent as well as their parents and/or teachers. It tends to be useful to have multiple perspectives of recovery available when tracking symptoms in adolescents. Studies have found that parents often report the presence of symptoms that younger individuals denied, perhaps because they were directly observable by an adult but not internally identifiable by an adolescent (e.g., fatigue; Gioia, Schneider, Vaughan, & Isquith, 2009).

Significant research has focused on early recognition and individualized assessment of signs of symptoms. Developments have been made in this area, however much work remains to be done – especially in regards to presence of unique adolescent-specific symptoms, duration of symptoms, and predictors of prolonged symptoms (McCrory et al., 2017). However, it has been suggested that adolescents commonly have worsening symptoms in the first 24-48hours after injury, especially if cognitive and physical rest are not initiated (Briskin & Weiss Kelly, 2012; Master & Grady, 2012b). There have also been findings that suggest that children and adolescents typically experience acute symptoms for longer than adults – the time range is thought to be less than four weeks for children and adolescents, as compared to less than 10 to 14 days for adults (Nelson, Guskiewicz, et al., 2016). This longer duration of symptoms hints that conservative management recommendations are beneficial for adolescents.

Although return-to-school and return-to-sport protocols are important, they should be individualized, and developmentally appropriate – as should the nature and extent of the initial physical and cognitive rest. Adolescents may require more explicit teaching and instruction in terms of activities to avoid in the period of rest (e.g., no homework; no reading; no texting; no video games; etc.), as well as the monitoring of symptoms during activity reintegration. For these reasons, involvement of caregivers as well as various disciplines (e.g., physician; physiotherapy; occupational therapy; social work; psychologist; etc.) to contribute to evaluation may be beneficial. Collaboration among professionals, as well as seeking out specialist rehabilitation services may more fully address the broad range of complexities and current unknowns in this population (Gioia et al., 2012).

2.6.3 Recovery

Not only is the adolescent population at higher risk for sustaining a concussion, but they may also be more sensitive to post-concussion effects – possibly due to their developmental stage. Therefore, it is not surprising that these individuals show protracted recovery times as compared to adults, as well as greater long-term neurobehavioural impairment. Recovery within this section, refers to “clinical recovery,” which is the span of time from injury to return to regular activities (i.e., school; work; sport). With typical adult recovery being 5-10 days, typical adolescent recovery has been found to be upwards of two to four weeks (Belanger & Vanderploeg, 2005; Laura Purcell, Harvey, & Seabrook, 2016). Currently, recovery is considered to be prolonged in adolescents if symptoms persist more than four weeks – delaying full return to pre-injury activities, and requiring different treatment and management modalities as compared to those experiencing typical recovery (McCrorry et al., 2017). With approximately one-third of adolescents experiencing prolonged recovery, there has been a recent interest in the

predictors of such recovery as a method of more accurate expectations of prognosis as well as the development of tools to enable clinicians to identify those at risk for PCS (McCrea et al., 2013; Zemek et al., 2016).

General consensus has found that the most reliable predictor of a recovery period lasting longer than four weeks was the presence of a greater number of symptoms as well as more severe symptoms in the first three days following the injury (Howell, O'Brien, Beasley, Mannix, & Meehan, 2016; Meehan, Mannix, Stracciolini, Elbin, & Collins, 2013). To a lesser extent, the presence of the following symptoms at the time of injury may also contribute to a longer recovery: sensitivity to noise; fatigue; abnormal tandem stance; abnormal oculomotor exam; and loss of consciousness (Corwin et al., 2014; Grady et al., 2012; Merritt, Rabinowitz, & Arnett, 2015; Zemek et al., 2016). It has also been stated that adolescents who have sustained previous concussions, took twice as long to recover – typically 24 days, as compared to 12 days for those with no history of concussion (Norton, 2013). Additionally, pre-existing presence of migraines has been found to be a predictor of prolonged recovery, especially in girls and women (Terry et al., 2019). The presence of pre-existing mood concerns (e.g., anxiety; depression) can also contribute to protracted recovery and poor overall adjustment (Plourde, Yeates, & Brooks, 2018). Finally, the presence of pre-existing learning disabilities and/or attention deficit hyperactivity disorder increase one's risk for the development of PCS (Zemek et al., 2016).

Quality of life (QOL) has emerged as an important consideration for individuals with a diagnosed concussion. Advantages of considering QOL are to assess the “hidden morbidity” or more subtle consequences of medical conditions or injuries on patient functioning that may not be captured otherwise (Russell et al., 2017). This may be particularly important for adolescents who are experiencing an “invisible injury” like a concussion which cannot not be seen by

outsiders. There have been several studies assessing the Health-Related Quality of Life (HRQOL) in adolescents recovering from a concussion – which is a specific outcome measure that can be used clinically to assess QOL and one’s physical, mental and social functioning. HRQOL is suggested to be temporarily lower for those with a concussion as compared to more overt injuries (e.g., fracture) – improving after receiving physician-documented clinical recovery (Russell, Selci, Black, & Ellis, 2019). It has also been suggested that adolescents with a prolonged recovery demonstrated lower HRQOL post-injury as compared those with more typical recovery trajectories, particularly in regards to physical and school functioning, fatigue and headache (McLeod, Curtis Bay, Lam, & Valier, 2019).

Capturing patient perspectives of concussion recovery experiences provides an honest report of symptoms and perceived areas of concern. Studies focusing on the patient perspective is a new area of research, and HRQOL seems to be a good outcome measure to objectively capture QOL on a preliminary level. However, a deeper exploration is needed to get a better picture of the recovering adolescent as a whole, and gain understanding of underlying feelings, opinions and perspectives accompanying recovery from a largely invisible injury. This project aims to use qualitative methodologies to capture subjective and first-hand reports of adolescent perspectives of concussion recovery.

2.6.4 Adolescent Females

A further subgroup of interest is adolescent females – seemingly unique for how they experience a concussion, their symptoms, and the duration of their recovery period. Most of the studies reported within the literature have been conducted within an adult or collegiate population, whereas younger populations are largely missing from the literature (Merritt, Padgett, & Jak, 2019). Adolescent females may be more vulnerable to concussion as compared

to their male counterparts, with some estimates suggesting that they may be at twice the risk of injury, as compared to males (Baker et al., 2016a; Dick, 2009; Lincoln et al., 2011). Several ideas have been suggested as reasons for why more concussions are seen in females, which are listed here: i) decreased head-neck segment mass and overall weaker neck; and ii) increased likelihood to report concussion injury and symptoms (Broshek et al., 2005; Gessel et al., 2007).

Gender differences in symptoms have also been outlined in the literature. Preliminary support exists in regards to females and males experiencing different types of concussion symptoms – females reporting more neurobehavioural and physical symptoms (e.g., drowsiness; sensitivity to noise), whereas males reported more cognitive symptoms (e.g., amnesia; disorientation; Frommer et al., 2011). A systematic review and meta-analysis also found that at both baseline and post-concussion, females had significantly higher total symptom scores on the SCAT5 (Brown, Elsass, Miller, Reed, & Reneker, 2015). Symptom intensity has been documented as higher for females as compared to males, a finding that is consistent across both parent- and self-ratings, with differences being most pronounced among adolescents (Brown et al., 2015; Covassin & Elbin, 2011). Lastly, a longer duration of recovery has also been suggested for young female athletes aged 9-17 years of age as compared to males at the same age (Berz et al., 2013). The presence of gender differences needs further investigation, and raises questions of whether personality styles, neurobiological effects, or mechanics of injury are at play.

2.7 Research Justification

It has been said that concussions are a silent epidemic. Injury reports are particularly high within the adolescent population, defined as those between 13 and 18 years of age. This age group experiences an inevitable period of rapid and potentially tumultuous transitions in the

domains of physical, cognitive and psychosocial functioning. Sustaining a concussion during this time period may further complicate this transition, and perhaps stimulate extra stress and poor coping. The HRQOL clinical measure has recently been introduced to quantitatively assess the patient perspective of one's physical, mental and social functioning while experiencing a health condition or injury. This has been a good starting point for assessing QOL while recovering with a concussion, however a more in-depth exploration is needed, especially due to the complexity of the adolescent time-period. This study aims to use a qualitative methodology to address these complexities using rich descriptions of first-hand experiences in this regard.

A further subgroup of particular importance is adolescent females, as this population has been under-evaluated within the present research literature. This is particularly troubling due to the sheer number of concussions occurring in the adolescent female population – reportedly occurring at twice the frequency of adolescent males (Baker et al., 2016a). Further, from the limited available research, recovery is not as straightforward for adolescent females as compared to males – with higher symptom burden, longer overall recovery and perhaps worse long term outcomes (Berz et al., 2013; Brown et al., 2015; Covassin & Elbin, 2011; Zemek et al., 2016). As such, it becomes even more critical to ensure that females have an equitable opportunity for experiencing an efficient recovery, safe return to daily activity and avoiding complications associated with prolonged recovery. This study aims to address adolescent females and how they experience concussion recovery.

As the research stands, there have been huge developments in identifying and diagnosing a concussion, however what is largely left out is an understanding of the time spent in the recovery period and how it is experienced from the patient perspective. This study aims to start at the ground up as a means of addressing the complex nature of the concussion recovery

experiences. The intention is ultimately identifying care, services protocols and support that promotes adolescent female recovery. Preliminary evidence from the published literature suggests that collaboration among professionals, and the development of specialist services, may more fully address the broad range of complexities and current unknowns in this population (Gioia et al., 2012). Our hypothesis currently falls in line with these recommendations; however, the qualitative exploration aims to address the facilitators and barriers of recovery as a means of delving deeper into the adolescent female experience and building upon current research surrounding clinical risk assessment for PCS at the time of concussion diagnosis (Zemek et al., 2016).

Chapter 3: SCOPING REVIEW¹

3.1 Introduction

Sport-related concussion within the adolescent population (defined as individuals aged 13 to 18 years) is an important public health concern. According to the Ontario Neurotrauma Foundation's annual report, the highest rates of concussion in Ontario are found among individuals less than 18 years of age (Munro et al., 2015). Additionally, an American study looking at high school students estimated that 136,000 concussions occur per academic year (Gessel et al., 2007). Nationally, concussive injuries are said to be among the most common pediatric injuries (McCrory, Meeuwisse, Aubry, Cantu, Dvořák, et al., 2013). The concern not only lies in the vast number of adolescents affected by concussion, but also in the complexity of the recovery progression within this particular population.

Adolescents are said to be more sensitive to post-concussion effects (as compared to adults), likely due to a combination of interacting factors. Most notably, of all life-stages, adolescence is arguably the one most marked by rapid and potentially tumultuous transition – not only in terms of physical development, but in terms of cognitive and psychosocial maturity (Byrne et al., 2007). The academic, social, and sporting activities common within adolescence are often fast-paced and bounded by the high school environment. Adjustment difficulties can result from the requirements for “time off” and activity modifications according to concussion management protocols (i.e., return-to-school; return-to-sport). Feelings of stress, anxiousness, and depression over missing out on regular activities (including falling behind in school) may add to the perceived severity of post-concussion symptoms.

¹ A version of this chapter will be submitted to the *Open Journal of Occupational Therapy* for publication, as follows: Tichenoff, A., Sanderson, N.M., Johnson, A.M. A scoping review: Adolescent recovery experiences and perspectives following a concussion sustained through sport participation.

Post-concussion symptoms typically fall within the domains of physical, cognitive, emotional and sleep (e.g., headache; dizziness; difficulty concentrating; irritability; restlessness). Timely identification, treatment and management is imperative to prevent avoidable complications (e.g., Post-concussion Syndrome; cumulative effects of multiple brain injuries; Second Impact Syndrome). As such, the focus of the vast majority of currently available research surrounding adolescent sport-related concussion focuses on acute identification and evaluation of symptoms. Little is known about the longer-term recovery and reintegration experiences of these individuals, and the impact that the injury has on daily life. Commonly used recovery monitoring scales, like the Post Concussion Symptom Scale (PCSS), do not fully address the complexity of adolescent recovery and reintegration (the PCSS focuses on symptom severity). A more in-depth investigation of recovery experiences from the patient's (adolescent's) perspective is needed.

Although it has been suggested that adolescents with sport-related concussion may require more specialized treatment and management modalities as compared to those experiencing typical recovery, very little is known about their recovery experiences (McCrorry et al., 2017). Assimilating current research surrounding the individual perspective of adolescent recovery would help clinicians guide current treatment practices and direct care needs in a more holistic manner. Therefore, the purpose of this scoping review is to *explore the reported recovery experiences and perspectives of adolescents who have sustained a concussion through sport participation*.

3.2 Materials and Methods

The broader research project that followed this scoping review (see Chapter 6) was framed with an interpretive intent (see Section 4.3.2), and as such we aim to understand if/how

theories relating to the Occupational Risk Factors theoretical perspective (see Chapter 5) relate to adolescent concussion recovery experiences. It was our hope that a preliminary conceptual framework would be constructed from both this scoping review and ideas from the Occupational Risk Factor's theoretical perspective, representing the current understanding of reported recovery perspectives from the literature. After data collection and analysis within the broader project, there were modifications to the preliminary framework which represented our final understandings of concussion recovery (see Section 8.3).

This scoping review was based on the methods outlined by Arksey and O'Malley (2005), and followed five iterative steps: 1) identifying the research question; 2) searching for relevant studies; 3) selecting the studies; 4) charting the data; and 5) collating, summarizing, and reporting the results (Arksey & O'Malley, 2005). A scoping review methodology was selected as a means of examining a collection of peer reviewed materials to map key ideas and develop greater clarity on a conceptual topic. The aim was to analyze a potential knowledge gap in the literature – namely, the consideration of concussion recovery from the perspective of the recovering individual on a holistic level.

Four databases were searched: PubMed, CINAHL, Medline and Scopus. The search terms were “concussion,” “recovery,” “sport” and “adolescents.” Synonyms and Boolean operators were used in the search strategy (see Table 3.1). Included studies were primary full-text articles, written in English and published between 2005 and 2019. The adolescent age range of 13 to 18 years suggested by the Consensus Statement on Concussion in Sport Guidelines was loosened slightly to incorporate varying definitions of adolescence (McCrory et al., 2017).

Table 3.1. Scoping review search terms.

	AND		AND		AND
((mild N traumatic N brain N injur*) OR (mild N2 traumatic N2 brain N2 injur*) OR mTBI OR concuss* OR (brain N injur*) OR (head N injur*) OR (brain N contus*) OR (brain N2 injur*) OR (head N2 contus*)))		((lived N2 experience*) OR (lived N experience*) OR (lived N3 experience*) OR (report* AND N experience*) OR (report* AND N2 experience*) OR (report* AND N3 experience*) OR (daily N life) OR (daily N2 life) OR (daily N3 life) OR (activit* AND N of N daily N living) OR (activit* AND N2 of N2 daily N2 living) OR (activit* AND N3 of N3 daily N3 living) OR (recover* AND N experience*) OR (recover* AND N2 experience*) OR (recover* AND N3 experience*) OR (rehab* AND N experience*) OR (rehab* AND N2 experience*) OR (rehab* AND N3 experience*) OR (reintegrat* AND N experience*) OR (reintegrat* AND N2 experience*) OR (reintegrat* AND N3 experience*) OR reintegrat* OR rehab* OR recover* OR experienc*))		((student N2 athlete*) OR (student N3 athlete*) OR (athlet*) OR (sport*) OR (compet*) OR (train*))	((adolescen* OR teen* OR youth OR (high N school) OR (middle N school)))

The first author of this project (AT) conducted the search and completed the first pass of the articles (i.e., screening titles and abstracts for relevance). Articles were screened with a focus on the following keywords: *lived experience*, *patient perspective* and *reported experience*. At this stage it became obvious that our search strategy resulted in the identification of a large number of irrelevant studies. Among them were articles not related to the keywords or population of interest – these were the main limiters. Terms referring to concussion and mild traumatic brain injury were abundant and varied. In addition, the keywords were largely generic. It was a challenge to choose precise search terms and keywords without the exclusion of relevant studies. This resulted screening 1048 articles and excluding 1032 articles.

The second pass (i.e., assessing full-text articles for eligibility) was completed by the first (AT) and second (NS) authors. Bibliography screening was conducted for all articles that passed the initial screening phase. Any disagreements between reviewers were resolved by consensus. After articles were selected for inclusion, thematic analysis using NVivo software was undertaken to establish themes that were present. Grouping article information into themes has been suggested to be a beneficial approach to synthesizing data within scoping reviews (Levac, Colquhoun, & O'Brien, 2010).

3.3 Results

The PRISMA flow diagram is shown in Figure 3.1. The final number of studies included was four and the summary of extracted data is provided in Table 3.2. All studies were conducted in the United States and were published between 2013 and 2017. Two studies were qualitative interviews, one quantitative questionnaire with self-report data and one quantitative test assessment with self-report data. The mean age of inclusion ranged from 14.8 ± 2.16 to 15.7 ± 1.7 , with both males and females were included in each study. One study included parental interview data in addition to the adolescent interview data, but interviews were conducted separately as to not influence adolescent reporting.

The scoping review identified four main themes of reported lived experiences and/or perceptions of concussion recovery, which are outlined as follows: symptoms, changes in activities, effect on relationships and feelings of frustration. All four articles noted the significance of symptoms, and three discussed changes in activities, effect on relationships and feelings of frustration. However, when considering adolescent recovery experiences as a whole, it made sense to consider the themes within two broad categories, as there was some overlap between the four main themes: i) symptom burden; and ii) activity and occupational restrictions

(described in the sections below). Below is a summary of the patterns of recovery outlined within the four articles included in this scoping review.

Figure 3.1. Scoping review PRISMA 2009 flow diagram.

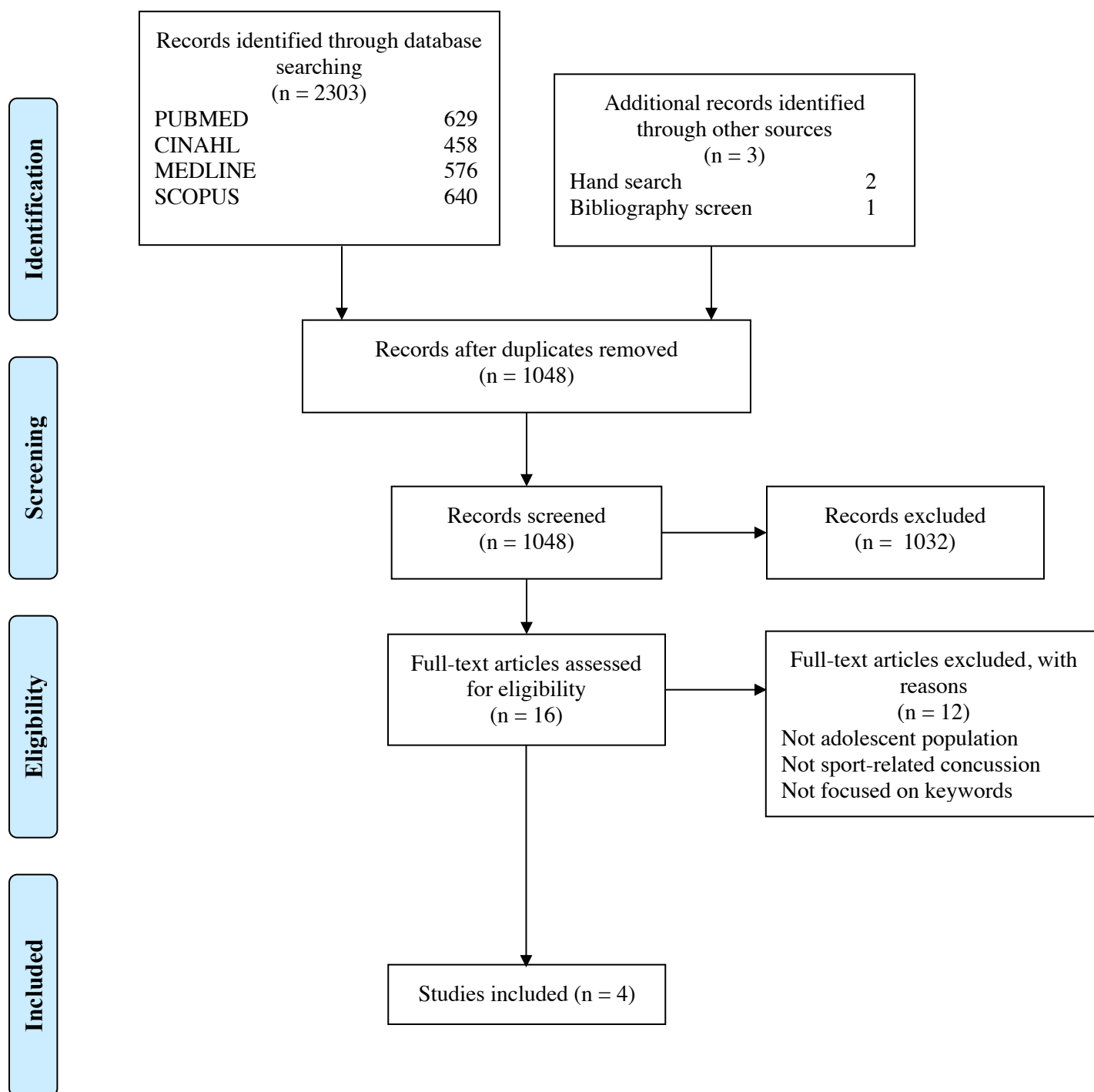


Table 3.2. Extracted data from studies included in the scoping review.

Title	Author	Year	Country	Setting	Sample Size	Age	Purpose	Design	Data Collection	Findings
Young athletes' concerns about sport-related concussion: The patient's perspective.	(Stein et al.)	2016	United States	Sports Medicine Clinic	121 <i>67 males</i> <i>54 females</i>	8 to 18 M=14.8 SD=2.16	To explore which factors are most troubling to young athletes recovering from concussion.	Cross-sectional survey of athletes who were evaluated for a new sport-related concussion.	Questionnaire (multiple choice, rating scales, free responses)	Two themes identified: 1. 57.9% cited symptoms; 2. 56.2% reported loss of activity; and 3. 17% cited both.
Qualitative examination of adolescent health-related quality of life at 1 year postconcussion.	(Iadevaia, Roiger, & Zwart)	2015	United States	Secondary School	7 athlete-parent dyads <i>2 males</i> <i>5 females</i>	12 to 16 M=14.14 SD=1.35	To evaluate athlete and parent perspectives of the effects of a single concussion on the concussed adolescent's HRQOL at 1 year postdiagnosis.	Qualitative interview of athlete (concussion within past year) and primary caregiver.	Semi-structured face-to-face student (n=7) and parent (n=7) interviews.	Four themes identified: 1. significant effect of symptoms; 2. feelings of frustration; 3. influence on school attendance and activities; and 4. nature of interpersonal and team relationships.
The relationship of symptoms and neurocognitive performance to perceived recovery from sports-related concussion among adolescent athletes.	(Sandel, Lovell, Kegel, Collins, & Kontos)	2013	United States	Sports Medicine Concussion Program	101 <i>62 males</i> <i>39 females</i>	12 to 18 M=14.75 SD=1.76	To explore the role of symptoms and neurocognitive performance on adolescent athletes' perceptions of recovery from sports-related concussion.	Pearson product-moment correlations and multiple regression analysis for neurocognitive performance and symptom scores.	Self-report of "percent back to normal," ImPACT neurocognitive test, and PCSS symptom report	<ul style="list-style-type: none"> perceptions of recovery may be influenced more by reported symptoms, rather than objective neurocognitive performance. athletes may not perceive cognitive deficits (e.g., fogginess; difficulty remembering; poor concentration; slowed reaction time) as well as physical symptoms (e.g., headache; vomiting; visual disturbance).
Lived experiences of adolescent athletes following sport-related concussion.	(Valovich McLeod, Wagner, & Bacon)	2017	United States	Secondary School	12 <i>8 males</i> <i>4 females</i>	13 to 18 M=15.7 SD=1.7)	To explore adolescent athlete perceptions regarding psychosocial aspects of sport-related concussion.	Qualitative case series interviews of athletes who sustained a sport-related concussion and was removed from activity 10 days or more.	Semi-structured face-to-face interviews within in the first 15-30 days after concussion	Five themes identified: 1. Effect of symptoms; 2. Impact on emotions; 3. Effect on school role; 4. Effect on societal/social role; and 5. Minimizing/masking symptoms.

3.3.1 *Symptom Burden*

All four articles stated that symptoms affected the adolescent's perceived lived experiences. Symptoms were reported within the domains of physical, cognitive, emotional and sleep. Headaches were the most commonly reported symptom. Other frequently reported symptoms were dizziness, sensitivity to light and sound, visual disturbances, balance deficits, fatigue, nausea, trouble sleeping, difficulty concentrating and feeling foggy. Adolescents seemed to be particularly bothered by physical symptoms (as compared to cognitive symptoms). One article suggested that adolescents may not perceive their cognitive deficits as well as they perceive their physical symptoms – perhaps because physical symptoms are easier for the adolescent and those around them to observe (Sandel et al., 2013).

Multiple post-concussion symptoms were common in the recovering individuals, and reportedly increased or decreased in relation to various demands present in adolescent day-to-day life (e.g., tests/exams; increased sensory stimulation; stressful experiences; lack of sleep; etc.). Some individuals continued to experience symptoms up to one year or longer after sustaining their concussion (Iadevaia et al., 2015). It was apparent that the symptoms experienced were closely tied to one's ability to function and participate in meaningful activity – most notably school, completion of daily tasks, and interacting with others. During times of limited involvement in activities, individuals experienced feelings of distress, isolation, frustration and boredom – especially for those experiencing prolonged symptoms.

In the article that discussed the experience of recovery at one year, concurrent emotional symptoms tended to develop later in the course of recovery when prolonged symptoms were present (Stein et al., 2016). Given the timeline, it is likely that prolonged discomfort, fatigue, and activity restrictions may lead to or exacerbate emotional symptoms (e.g., anxiousness;

feelings of depression; frustration; irritability). Considering adolescence is one of the most common age groups to experience prolonged symptoms, there is utility in highlighting the complexity of the adolescent time period. Sustaining a concussion during an already tumultuous developmental transition can stimulate additional stress and poor coping in the recovering individual – potentially lengthening recovery and leading to additional psychosocial sequelae.

3.3.2 Activity and Occupational Restrictions

In addition to symptom burden, a significant number of adolescents cited loss of participation in activities as the worst part about sustaining a concussion (Stein et al., 2016). The restriction of activities due to symptoms caused disruptions in the adolescent's daily life – most notably academic involvement, social interaction and sport participation. All three articles which discussed activity and occupation restrictions noted that adolescents maintained a desire and willingness to maintain pre-injury activities and routines. Unfortunately, this mindset resulted in adolescents moving through a series of drastic ups and downs in regard to activity involvement and subsequent functioning, instead of following a steady progression of reintegration into activity suggested by treatment protocols. The adolescents discussed the idea of “crashing” and needing extra rest after a period of full activity involvement at the level of pre-injury functioning.

School, social and sport-related participation were the most commonly reported activities missed by recovering adolescents after sustaining a concussion. There was a pattern of maintaining a balance between one's engagement in activity and exacerbating of concussion symptoms. Some activities had to be routinely prioritized over others – with most individuals participating in productive activities (i.e., school-related) over more personally meaningful activities (i.e., socialization). Many adolescents revealed their feelings of concern and stress about falling behind in their regular productive activities. One study also outlined that some

participants described lower levels of self-esteem because they were not able to fulfill their roles as student, friend, and/or teammate (Valovich McLeod, Wagner, & Bacon, 2017).

The adolescent's school role was discussed in-depth within the articles – understandably as the main occupation during the adolescent years is typically “student.” Most individuals experienced a time period where they fell behind in school and had a decline in grades to some degree. The adolescents reported the necessity for attending partial days at school (i.e., starting later or leaving early) to prevent the re-emergence or worsening of symptoms. Cognitive symptoms such as concentration difficulties, confusion and forgetfulness made full participation in one's school role particularly difficult. Extra time and effort put towards schoolwork were reportedly necessary post-concussion (e.g., studying longer; increased conscious focus during class). Many received academic accommodations from teachers and administrators, which were mostly positive and productive experiences.

The impact on social activity after sustaining a concussion was also well described in the articles. Many adolescents reported feeling like an “outsider” or “distant,” as friends and teammates seemed to have a lack of understanding regarding the seriousness of a concussion and the importance of recovery guidelines (Valovich McLeod, Wagner, & Bacon, 2017). There were also perceptions of teachers, friends and teammates referring to the concussed adolescents as “faking” their symptoms – likely do to the invisible nature of concussion symptoms to onlookers. However, other individuals noted that social interactions remained largely unchanged. Family functioning was only outlined in one study and suggested that interactions with immediate family members produced feelings of irritability and frustration – with both parents as well as siblings.

3.4 Discussion

As expected, the number of studies available on the topic of sport-related concussion recovery experiences within adolescence were very limited in quantity. The articles considered relevant to this scoping review question were all published in the last five years, suggesting there is a new interest in the individual perspectives of recovery – a promising shift when considering more holistic treatment options for adolescents who have sustained a concussion during sport. However, there is more work to be done in this area, especially considering that clinicians currently treating adolescents may not be fully aware of the impact that symptom burden and restrictions to meaningful activities have on daily life. It is interesting to note that commonly used concussion recovery monitoring scales (e.g., PCSS) do not fully address the complexity of adolescent recovery and reintegration as they focus only on symptom severity.

Overall, this scoping review identified a knowledge gap regarding the reported experiences of adolescent recovery from a sport-related concussion – more research is needed in this area. There seemed to be a good description and understanding of the concussion symptoms according to physical, cognitive, emotional and sleep domains, but more is needed to understand how these symptoms impact the daily functioning of those experiencing them. For example, it is clear that adolescents often experience headaches, however what is not well articulated in the literature is how an individual's participation in daily experiences may change due to headaches and what the long-term recovery may look like. Of course, each individual will vary in their experiences of recovery and daily functioning, however it would be useful to explore the possibility of common themes that may be present in this area.

As discussed, four main themes of reported lived experiences and/or perceptions of concussion recovery (symptoms, changes in activities, effect on relationships and feelings of

frustration) where collapsed into the two main categories of symptom burden as well as activity and occupational restrictions. It would be helpful to further explore the theme of frustration and other associated feelings that may be accompanying recovery in relation to psychosocial functioning (preliminary examples may be loss, invisibility, isolation and growth). Symptoms and activity restrictions have been more readily apparent in this review, whereas the less tangible themes surrounding feelings and psychosocial aspects of recovery are lacking. It is our plan to explore these aspects in more detail in the broader research study outlined in Chapter 6.

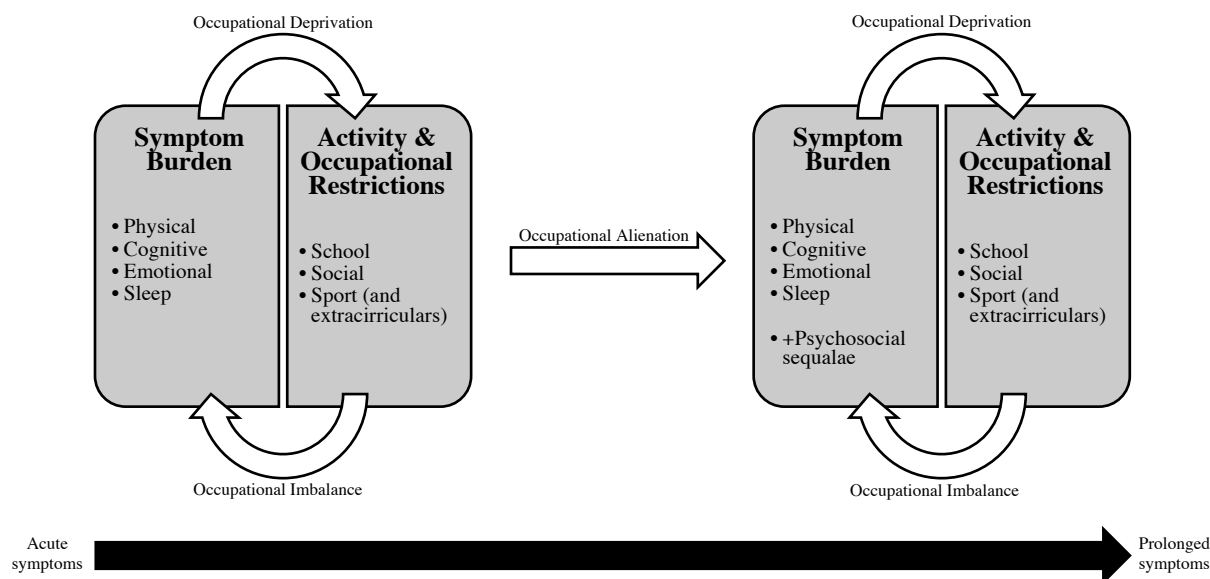
3.4.1 Interactional Nature of Concussion Recovery

A particularly important finding was that there seemed to be a symptom-exacerbation threshold that adolescents functioned within during concussion recovery. This has been previously documented in the literature, and is described as the level of activity that triggers or worsens symptoms (Leddy et al., 2012; Paul McCrory et al., 2017). This phenomenon denotes the close interrelatedness and perhaps cyclic nature of the two broad thematic categories we identified in this scoping review – symptom burden as well as activity and occupational restrictions. Namely, concussion symptoms seem to fluctuate according to one's activity and occupational engagement.

There may be utility in considering adolescent concussion recovery according to an occupational perspective. The foundation of participation and engagement in meaningful occupations aligns well with the 2016 Consensus Statement on Concussion in Sport which emphasizes a symptom-limited approach for return to activities – where an activity is terminated if symptoms are worsened significantly (Finn, 2019; McCrory et al., 2017). Wilcock's Occupational Risk Factors theoretical perspective is particularly relevant as it outlines the possible hinderances to meaningful activity and occupational functioning after sustaining an

injury (Wilcock, 1999). The central premise of the perspective is that engaging in meaningful occupation, and in turn developing one's occupations, is essential to overall health and psychosocial well-being (Kosma, Bryant, & Wilson, 2013; Wilcock, 2005).

Figure 3.2. Framework for concussion recovery in adolescent athletes.



When considering the ideas of concussion recovery in this manner, it was understood that there was a cyclical relationship between the categories (see Figure 3.2). The interactional nature of concussion recovery is shown graphically in Figure 3.2. The acute symptom burden following a concussive injury, creates a temporary state of *occupational deprivation* – a state of preclusion from engagement in occupations of necessity and meaning (Whiteford, 2001). Activity and occupational restrictions result directly due to the symptoms being experienced and indirectly due to the prescribed treatment protocols (e.g., return-to-school; return-to-sport). Limitations in activities creates a temporary state of *occupational imbalance* – a loss of balance between the occupations we chose and those in which we are obliged to engage in (Wilcock,

2005). One's productive activities (as oppose to personally meaningful activities) may be prioritized, as individuals have a reduced amount of energy before reaching their symptom-exacerbation threshold. Occupational deprivation may or may not progress to occupational imbalance, depending on the extent of deprivation as well as the individual's personal resources and supports.

The majority of adolescents clinically recover from a concussion over the course of two to four weeks, creating fewer issues in daily functioning and participation. However, more permanent states of occupational deprivation and imbalance may occur as individuals continue to cycle further between symptom burden and activity restrictions – specifically the one-third of adolescents who experience prolonged recovery (McCrea et al., 2013; Lovell, 2009; Parachute, 2017; Zemek et al., 2016) . Prolonged symptoms and an accompanying diagnosis of Post-concussion Syndrome (PCS) can necessitate significant alterations in daily life for an extended period of time (weeks, months, and sometimes years) – resulting in additional and more chronic feelings of stress, anxiousness and depression about falling behind and missing out in regular activities.

Although more research is needed in this area, there seems to be a period of time when the symptom burden becomes less specific to concussion and more specific to the lack of engagement (i.e., depression, social isolation, anxiety, apathy, emotional liability). At this point there is the addition of *occupational alienation* into the cycle, with associated symptoms of psychosocial sequelae increasing the initial symptom burden. Occupational alienation is defined as a loss of meaning and purpose, resulting in a loss of control, and the development of uncertainty as to how to proceed in life (Wilcock, 2005). Individuals seem to get “stuck” in the

cycle of symptom burden and activity restrictions and will need more specialized concussion treatment and management modalities as compared to those experiencing typical recovery.

3.5 Limitations

Something that seemed to be left out of the reviewed studies, was a delineation of the recovery timeline (or time out of regular activity) for the adolescent participants and how this may impact recovery experiences. There was no demarcation of regular concussion recovery as compared to those who follow a more sporadic and prolonged recovery trajectory. While the majority of adolescents return to their regular activities of daily living within four weeks post-concussion, some individuals experience prolonged recovery profiles with symptoms lasting much longer – months or even years. We would expect that the reported recovery experiences would look quite different for an individual experiencing prolonged recovery (as compared to more normative recovery). More research is needed within the area of the reported recovery experiences of adolescents who have sustained a concussion through sport participation, focusing on those experiencing prolonged symptoms and/or have a diagnosis of PCS.

3.6 Conclusion

Developmental transitions within the adolescent time period are rapid and complex. When a concussion is sustained during this tumultuous time, non-normative concussion recovery profiles are more likely. More involved concussion care from the outset of injury may be necessary for those within the adolescent population. In particular, care modalities extending beyond the current biomedical model (i.e., physician and physiotherapist), such as occupational therapy, may aid in addressing the recovery experiences of symptom burden and activity restrictions more holistically. The aim would be to break the cycle of occupational deprivation

and imbalance as a means of preventing a more chronic state of occupational alienation and associated psychosocial sequelae (e.g., anxiety, depression, isolation).

Chapter 4: METHODOLOGICAL POSITIONING

“What the emerging discipline of health science requires is not a faithful commitment to a single philosophical foundation, but rather the capacity to engage in ongoing dialogues within its epistemic community, to deepen the philosophical discourse, and to embrace epistemological pluralism which is inclusive of knowledge claims informed by difference philosophical traditions...Rather than arguing for one perspective over the other, a generative avenue might be to explore the relative merits and limitations to knowledge generation that each one offers to scholarship in the field” (Kinsella, 2012, pg. 77).

4.1 Qualitative Research

Qualitative research can be defined as a formal process of inquiry, often conducted within a natural setting and characterized by a flexible, yet emerging design (Dempsey & Dempsey, 2000). Data provides an understanding of meaningful experiences, happenings, and phenomena from the participant’s perspective (Stake, 1995). The participants are viewed as emic (insiders) and masters of their own experiences and culture, whereas researchers are seen as etic (outsiders) and retrieve important insights from emic experiences through collaboration and interaction. A qualitative researcher may also be referred to as a “bricoleur.” A bricoleur is a creative “maker or quilts” who, like a quilt maker uses tools of their individual trade to deploy a wide range of theories, methodologies, methods, and general strategies that suit the specific area of research. There is an intimate relationship between the researcher and what is studied, as well as the situational constraints that shape the study.

As a practice, qualitative research has a multi-disciplinary history with competing tensions and contradictions in accordance with the project itself (Dempsey & Dempsey, 2000).

There is a complex, interconnected family of concepts and perspectives used that locate the research within the broad scope of qualitative study. Qualitative researchers must locate themselves within this theoretical web of understandings in order to carry out their research. The value-laden nature of inquiry, in conjunction with a qualitative researcher's drive for the answers to questions, stresses "how" social experiences are created and given meaning (Dempsey & Dempsey, 2000). Below is an outline of this project's philosophical underpinnings, methodology and methods in order to theoretically unpack the research project.

4.2 Philosophical Underpinnings

After careful consideration, we decided that the research questions for this project would be best answered from a post-positivist perspective. A post-positive perspective argues that reality can never be fully apprehended – only approximated (Guba, 1990). There is a reliance on multiple methods of data collection as a way of capturing as much of the reality as possible. This is consistent with the multiple methods that have been purposefully selected for this study (i.e., photoelicitation, interviews, and focus groups). This project's aim is to uncover the recovery experiences of adolescent females who have sustained a concussion during sport participation (i.e., practice, game or recreational setting) and are experiencing prolonged symptoms. The project investigates the facilitators and barriers of recovery, the impact of the concussion on participants' occupation(s), as well as one's experience with return-to-activity protocols.

Sir Karl Popper (1902-1994) was a proponent of post-positivist inquiry, rejecting the classic intuitivist views of the scientific method (Popper, 2002). Popper was interested in the philosophical and political implications of genuinely scientific work (Crotty, 1998). At the heart of Popper's theory lies the idea that no theory can ever be accepted as definitively true (Willis,

2007). He proposed that scientists proceed with their study by engaging in a continual process of conjecture and falsification (Crotty, 1998). It is a matter of scientists making a guess and then finding themselves unable to prove the guess wrong. Popper stated that a researcher can never be completely sure if a subsequent research study may be the one that shows one's theory to be wrong (Popper, 2002). Thus, according to Popper, there is never enough research to permit an elimination of all doubt about a researcher's theory.

Popper suggested a hypothetico-deductive process to research, which ran contrary to the traditional positivist paradigm. The positivist paradigm relies on the assumption that knowledge is derived solely from mathematical and logical treatments leading to one valid truth (Gasson, 2003). This is a very law-driven view of science – verifying data as empirical evidence. Post-positivist study on the contrary, relies on a scientific method which is guided by the following: a) scientific theories are proposed hypothetically; b) propositions are deduced from these theories; and c) the propositions are then tested with an effort to prove them false (Crotty, 1998). For this specific study, the case, issues, and research questions are outlined as a starting point for the post-positivist scientific method. The methodology and methods for this project have been chosen as a means to addressing ideas about the recovery experiences of female adolescents who have encountered a concussion through sport participation.

4.3 Case Study Methodology

4.3.1 Case Study

Case study research is a type of qualitative research practice (Merriam, 1998, 2009). It allows for the exploration of a complex phenomenon while using a variety of data collection methods (Yin, 2003). It is a detailed, intensive study of a particular contextual, and bounded, phenomenon that is undertaken in real life situations (Luck, Jackson, & Usher, 2006). Case

studies allow for contextual issues to be viewed through a variety of lenses, allowing for multiple facets of the phenomenon to be revealed and understood (Flyvbjerg, 2006). Many researchers write about qualitative case study research, but the main contributors within the health and rehabilitation domain, are Robert Stake, Robert Yin and Sharon Merriam (Merriam, 2009; Stake, 2000; Yin, 2013).

Case study research has been defined as a process (Yin, 2013), end product (Merriam, 1998, 2009), or unit of study (Stake, 1995, 2000). Yin (2013) talks about a case study by way of a stepwise process or series of actions that are used to investigate a phenomenon within a real-life context. Merriam (1998, 2009) focuses more on the single instance or phenomenon at hand, and its intensive description and analysis. The methodologist whose definition most aligns with this project, however, is Stake (1995, 2000), who interprets the case study as a means of pinpointing and exploring a case as an integrated system. The current research project aims to address female adolescents' experiences of concussion recovery, and to examine how adolescents navigate the current standard for treatment recommendations as suggested by the 2016 Consensus Statement on Concussion in Sport Guidelines (i.e., return-to-school and return-to-sport protocols). This course of recovery occurs in a bound context, which Stake (2000) highlights as important to delineate in a case study (Luck et al., 2006). It is understood that concussion recovery is a complex phenomenon that requires researchers to address situated contextual understandings of adolescent daily experiences, while considering interactions with the environment. It is proposed that case study methodology is well positioned to advance this aim.

4.3.2 *Research Intent*

There are multiple research intents associated with each specific case study research project – the main three intents are descriptive, interpretive, and evaluative (Merriam, 1998, 2009). Intents define why or how a researcher intends to carry out their particular study (Merriam, 1998). They are selected by the researcher and take into consideration the case, findings in the literature, research experiences (i.e., information learned through conferences, colleagues, etc.), and possibly personal life experiences (Hancock & Algozzine, 2011). A *descriptive intent* is traditionally undertaken when an area of research is new and little literature is available to describe the phenomena (Merriam, 1998). A detailed account of the phenomena is the focus, and the study is not informed or guided by a theory. Rich description, or an explanation of behaviour and its surrounding context (i.e., environmental, social, emotional, etc.), is the defining feature associated with descriptive intent (Geertz, 1973; Houghton, Casey, Shaw, & Murphy, 2013). This in-depth description makes the participant experiences more meaningful to the reader (Hancock & Algozzine, 2011).

An *interpretive intent* in case study research is similar to a descriptive intent in that rich description is also provided of the phenomenon of interest; however, theory is also brought into the study within the analysis phase. The collected data is used to develop conceptual categories as well as to illustrate, support, or challenge theoretical assumptions held prior to gathering data (Merriam, 1998, 2009). The present study will be framed with an interpretive intent as a means to understand if/how the theoretical perspective of Occupational Risk Factors (namely occupational imbalance, occupational deprivation and occupational alienation) relates to adolescent concussion recovery experiences, as described within Chapter 5.

Lastly, Merriam (1998, 2009) discusses *evaluative intent*, which involves description, explanation, and judgment. Typically, this type of intent is only suitable when addressing the success of a program or intervention that has previously been developed and implemented within a selected population. However, since this particular project is not associated with a program or intervention, evaluative intent is not applicable. Guba (1981) suggests that a case study is one of the best types of program reporting processes due to the inclusion of both rich and thick description and analysis.

4.3.3 *Strengths and Limitations*

Similar to other qualitative (and quantitative) methodologies, case study research has strengths and limitations associated with its design. The main strength seems to revolve around the idea that case study research captures complex social phenomena in a detailed manner (Houghton et al., 2013). There is an in-depth and holistic description that illuminates experiential meaning to the reader, in turn expanding the reader's experience. Many qualitative researchers suggest that this strength alone outweighs all associated limitations (Flyvbjerg, 2006; Houghton et al., 2013).

The main weaknesses associated with case study research seem to be in line with other qualitative methodologies. Specifically, qualitative case study research is a costly process – both in regards to time and money (Merriam, 1998). Additionally, the research product (i.e., dissertation, research article, etc.) is lengthy in depicting the detailed experiences of participants, which may lead to researchers oversimplifying or exaggerating findings as a result of page constraints (Merriam, 2009; Morrow, 2005). Qualitative research also relies on the researcher as the primary instrument of data collection, and so this research is limited by the sensitivity, as well as integrity of the investigators involved in the project (Baxter & Jack, 2008; Tashakkori &

Teddle, 1998; Travers, 2001). This could prove to be difficult for a novice case study researcher, because they may not have the experience associated with in-depth data collection and analysis (i.e., through interviews or other methods of data collection). In all, many of the above limitations are not specific to case study research alone, and were adequately accommodated for, throughout the research process (see Chapter 6).

4.3.4 *Types of Case Studies*

Stake's (1995) interpretation of case study research has been chosen and adapted for this study and is supplemented with further developments made by Yin (2003) and Merriam (1998, 2009) in the domain of collective case studies (or multiple case studies). At a general level, a *case study* is a detailed, intensive study of a particular contextual phenomenon that is undertaken in a bounded real life situation (Luck et al., 2006; Yin, 2013). Stake (1995) presents a disciplined, yet interpretive method of study. The use of naturalistic and holistic descriptive practices provides an encompassing framework to guide adolescent participants to share personal experiences about their life following a sport-related concussive injury.

Stake (2000) proposed that three different categories of case studies exist; intrinsic, instrumental, and collective, and this categorisation reflects the potential variation of the case(s) studied within the research project.

- i. *Intrinsic case study*: used to study one specific case of interest. The case illustrates a condition in terms of particularity or consistency when relating to practice or the literature.
- ii. *Instrumental case study*: used to study one specific case of interest. The case is explored as a means to refine a theory; therefore, the case is of secondary interest to the researcher.

- iii. *Collective case study*: used to study multiple cases that surround one condition or phenomenon of interest. The researcher may explore differences within and between the cases.

For this particular research project, a *collective case study* methodology is applied.

4.3.5 *Collective Case Study*

A *collective case study* is a study consisting of several cases, that is undertaken in order to examine a phenomenon, population, or general condition (Stake, 2000). It aims to explore the commonalities and differences both within and between cases. Collective case study researchers seek both what is common and what is particular about the case (Stouffer, 1941). The intention is to study both the commonalities (i.e., generalizations) as well as the ideographic nature (i.e., particularization) of the post-injury recovery experiences of female adolescents living with a concussion. In terms of this project, a belief is held that it is important to acknowledge that each case has important unique features, happenings, relationships, and situations; however, an encompassing view of the cases is also necessary so conclusions can be used to inform others (i.e., organizations with an interest in preventing or managing concussion, individuals who have sustained a concussion, etc.) and inform current concussion management recommendations.

Phenomena are intricately related throughout many coincidental actions, and making sense of them requires a wide array of contexts – such as personal, social, academic, athletic (Stake, 1995). The aim is to address research issues by using the selected methods to create situations in which insightful and meaningful data can be extracted (e.g., photoelicitation, interviews, focus groups). Consistency of case conditions (i.e., female adolescents who have sustained a concussion through sport participation) will be maintained by selecting participant cases from the Fowler Kennedy Sport Medicine Clinic (FKSMC) as well as the Thames Valley

Children's Centre (TVCC) Paediatric Acquired Brain Injury Outreach Program (PABICOP) – these centres represent the primary treatment areas for pediatric concussion for London, Ontario and immediate surrounding area. FKSMC represents the referral centre for acute sport-related concussion, whereas TVCC represents the referral centre for multidisciplinary rehabilitation for more persistent concussion symptoms. Participants were recruited from both centres, with the inclusion criteria of experiencing prolonged concussion symptoms (i.e., symptoms lasting longer than four weeks).

4.3.6 The “Case”

The *case* is a single specific phenomenon that occurs in a bound context (Baxter & Jack, 2008; Creswell, 2003). The case is the process of inquiry as well as the product of inquiry (Stake, 2000). The explicit boundaries (i.e., time, place, event, activity) outlined by the researcher frame the case as a “system,” which assists in focusing data collection (Yin, 2003). The boundaries for this study are informed by the literature outlined in Chapter 2 as well as the implicit boundaries of time and place. The case can be outlined as: *the reported recovery experiences of female adolescents from two treatment centres in Southwestern Ontario, following a sport-related concussive injury when returning to school, returning to sport and returning to occupation(s)*.

4.3.7 The “Issues”

A case study outlines a small number of conceptual *issues* that determine the scope of the study (Stake, 1995). Sometimes compared with hypotheses in quantitative studies, issues guide data collection and researcher-participant interactions. Issues are complex, situated, problematic relationships that set the foundation for data collection. Four issues have been identified, which stem collectively from the literature, the research team's personal experiences with concussion

management, and first-hand reports from individuals who have sustained a concussion (Stake, 1995, 2000). The issues are as follows:

- i) When a female adolescent is diagnosed with a concussion, the treating healthcare professional will prescribe a return-to-activity protocol(s) or general activity modifications;*
- ii) Recovering adolescents may experience a period of withdrawal from activities (e.g., sensory, cognitive, physical, social, psychological, etc.), followed by a reintegration period;*
- iii) The meaningful occupations of each adolescent may be restricted during the recovery period;*
- iv) How each adolescent interprets what is asked of them in terms of a return-to-activity protocol(s) or activity modifications may be understood on an individual basis;*
- v) Female adolescents in Southwestern Ontario identify with, and gain support from, acute and rehabilitation treatment options to enhance recovery.*

These issues were identified to guide the study by developing thematic lines for researcher attention.

4.3.8 Conceptual Framework

In the literature, conceptual frameworks are referred to as the anchor of case study research (Stake, 2000; Yin, 2006). According to Miles and Huberman (1994), the conceptual framework serves to: a) identify and describe relationships that may be present based on participant-described experiences, and b) provide the researcher with the opportunity to assimilate participant constructs into categorical “bins.” The framework develops throughout the study and relationships between constructs begin to emerge (Miles & Huberman, 1994). After

data collection is complete, a progressively developed framework can be used for data interpretation (Baxter & Jack, 2008). There is a possibility that this project's case study approach will lead to the development of a conceptual framework, which can then be used to guide additional research projects in the future – within the research laboratory and within the neighbouring research communities (i.e., FKSMC; TVCC).

4.4 Methods

Arguably, one of the key strengths of case study research is the ability for researchers to use multiple data collection methods (Luck et al., 2006; Yin, 2003). The flexibility to select multiple methods of data collection underlines the importance of holistic and intensive description in case study research. Methods are specifically chosen in accordance with the particular research case and issues (Dempsey & Dempsey, 2000). Additionally, Luck et al. (2006) suggests that a wide array of methods, both qualitative and quantitative, can be applied to case study research – and this depends upon the research question(s), case, and issues. This enables a rich emic description of each case of interest and contributes to a coherent picture of the recovery experience seen from the participant's point of view (Geertz, 1973).

Using multiple methods for data collection enables a comprehensive understanding of how adolescents diagnosed with a concussion experience their recovery. Methodological rigour can be established by using measures already accepted for the specific methods that are selected. The most common method used in case study research is the interview – however, other methods may be selected in addition to, or instead of interviews (Travers, 2001; Yin, 2013). For this study, photoelicitation was the main data collection method, complemented by one-on-one semi-structured interviews and small focus groups.

4.4.1 Photoelicitation

Photoelicitation as a method is based on the idea of incorporating photographs into researcher interactions with participants (i.e., during interview or focus group sessions; Harper, 2002). Participants were asked to take photographs of their experiences while living with a concussion and bring the photographs to interviews and focus group sessions. During participant-researcher interactions, the visual photographs (non-verbal) complemented the verbal discussion, which together elicited deeper levels of experiences, perceptions and consciousness, compared to verbal information alone (Clark-Ibanez, 2004; Harper, 2002). Photographs acted as a language bridge, allowing adolescent participants to more clearly articulate their experiences and perceptions.

Photoelicitation is often confused with photovoice in qualitative research. However, each are distinct – photovoice is a *methodology*, which frames and grounds a study, whereas photoelicitation is a *method* or an approach used to capture data. Further, photovoice was developed as a means of “giving voice” to those who are oppressed in community or political settings (Aubeeluck & Buchanan, 2006; Wang & Redwood-Jones, 2001). It was first used with a participant group consisting of women and children living in a poverty-stricken African society – as a means to bring awareness to the experiences and living situations these individuals were facing on a daily basis. Photoelicitation on the other hand, is used to elicit a deeper understanding of a topic within populations that may benefit from expressing their experiences in visual form, as opposed to verbal form.

Although photoelicitation is a relatively new research method, it is frequently used within the health domain, and has even been used by participants with brain-related injuries and conditions as it relates to this project. For example, photoelicitation has been used to study the

experiences of adults with acquired brain injuries and various other cognitive conditions (e.g., Huntington's disease, Alzheimer's disease). Additionally, it has effectively been used in populations with broad developmental abilities, ranging from preschool-aged children to palliative adults (Lorenz, 2011; Pyle, 2013). This study is the first to use photoelicitation to study the adolescent concussion recovery experiences. Photo elicitation was useful in moving the participant and researcher towards a common understanding of the process of concussion recovery, by eliciting deeper dialogue from adolescents as well as providing verification for the researcher. Additionally, given the symptoms experienced during concussion recovery, some individuals need support outside of verbal articulation in order to talk about and explain their experiences – the visual method facilitated participants' ability to describe their experiences more vividly.

Another reason for choosing to use photoelicitation is due to anecdotal reports from the PABICOP service and healthcare providers. During group programming sessions prior to the implementation of the research, the female adolescent support group self-initiated a project that involved constructing photographic collages to depict their experiences of concussion, as well as a second collage to represent where they see themselves, six months into the future. This intrinsic interest in sharing personal concussion meaning and values through pictorial representations suggested that female adolescent participants would be willing (and perhaps eager) to take part in a visual research project.

4.4.2 Interviews

The main method of uncovering multiple participants' recovery experiences is the interview (Stake, 1995). A semi-structured line of questioning took place on a one-to-one basis (i.e., between one participant and the principal researcher), however some parents were also

present during the interviews. A short, planned list of “issue-oriented questions” were prepared in advance and in accordance to Stanley Payne’s *Art of Asking Questions* (1951). The questions were shared with both the advisory committee and research team and revised accordingly. The revised questions were used to loosely guide the direction of conversation in a semi-structured manner (Payne, 1951). The principal researcher and one other member of the research team also completed a written facsimile during interviews to capture and outline key ideas and episodes within the interview.

According to Stake (1995), a recording device is not necessary in participant-researcher interactions, as the meaning of participant experiences taken from participant conversation is more important than the words themselves. However, the research team decided it would be best to include an audio recording of interviews for back-up analyses purposes. The interview consisted of the principal researcher listening, taking notes (along with one other member of the research team), and asking for clarification where needed. Interviews ran for 30 to 60 minutes and were conducted in a private room on the Western University campus.

4.4.3 Focus Groups

A focus group is a method that allows the researcher to examine the points of view for a number of individuals who share certain opinions and concerns about a topic (Dempsey & Dempsey, 2000). A focus group consists of a small number of individuals who share a common bond – in this project, the bond could be represented as the female adolescent experience of sustaining a concussion during sport participation. The moderator (or principal researcher) directed the inquiry and interaction among participants in an unstructured manner. Focus groups were to be conducted with three to five young women from the same recruitment centre (i.e., one focus group including individuals from FKSMC and one with those from TVCC). These small-

scale focus groups aimed to achieve in-depth discussions, compared to larger focus groups, which generally gather surface content data (Fern, 2001). However, one focus group ended up having four participants, and the second focus group only had two participants.

An advantage for using focus groups with adolescents who have sustained a concussion, is that individuals have the opportunity to join others in sharing experiences who are moving through the same diagnosis and subsequent recovery. The belief is that the focus groups provide participants with a chance to open up and identify with others through sharing their recovery experiences. It was informative for researchers, in that participants talked through and identified shared experiences, thus creating shared understandings used to construct the final conceptual framework. Complimenting traditional interviews with focus groups, allows for new and collective understandings of participant experiences. As in the interviews described above, observations and interpretations were collected in notebooks by the principal researcher as well as one additional members of the research team. Interviews were also audio recorded for back up analysis if needed. Each focus group ran for 60 to 90 minutes.

These focus groups were unique, in that each participant had a chance to share personal photographs they had captured, with the group. The photographs elicited rich discussion among individuals, and the moderator guided interactions to elicit participants' perspectives on their recovery experiences. The four participants in the TVCC focus group had also been part of the PABICOP social group programming. Therefore, they had met before and were familiar with each other (many considered themselves to be friends prior to this study). This trust and cohesion of participants helped uncover a rich and thick description of recovery experiences that these individuals encountered after their sport-related concussion.

Chapter 5: THEORETICAL PERSPECTIVE²

This research project is framed with an interpretive intent – meaning that the collected data is used to illustrate, support and/or challenge theoretical assumptions prior to gathering data (see Section 4.3.2). Based on the scoping review presented in Chapter 3, I made the a priori determination that a focus on the Occupational Risk Factors offered a novel and appropriate way to address and frame my reflections on adolescent concussion recovery. A theoretical perspective focused on Occupational Risk Factors was particularly useful in considering the impact of prolonged periods of disengagement from meaningful activity – either due to treatment recommendations for strict and/or prolonged rest, or self-limiting coping mechanisms occurring alongside Post-concussion Syndrome (PCS). Although the literature connecting occupation and concussion has grown in the past five years, it is still limited. This chapter aims to outline the current landscape of an occupational perspective within concussion management practices as well as to consider the implications for Occupational Risk Factors (namely occupational deprivation, occupational imbalance and occupational alienation).

5.1 Occupational Perspective

An occupational perspective involves studying the things people need, want, or are obliged to do (Hocking & Clair, 2011). Humans are innately occupational beings and are tied closely to the occupational roles fulfilled throughout day-to-day activities (Yerxa, 1998; Yerxa et al., 1990). Yerxa (1998) suggests that occupation is a self-initiated activity, following a specific pattern or routine – often holding practical or symbolic significance for the individual fulfilling the occupation. Individuals often identify themselves by their occupation(s), leading to the

² A version of this chapter will be submitted to the *Open Journal of Occupational Therapy*, as follows: Tichenoff, A., Holmes, J.D., Johnson, A.M. Occupational Risk Factors theoretical perspective: The importance of considering meaningful activity throughout concussion recovery.

occupation being held close to one's core identity (Christiansen & Matuska, 2006). Wilcock (1991) goes so far as to say, "we are what we do" (e.g., student; athlete; artist; musician; etc.). Occupation can be understood broadly and inclusively as the productive and meaningful activities performed by an individual (e.g., school, work, sport, social involvement, leisure, cultural activity; Hammell, 2001). Often, activities that are meaningful to an individual (as compared to strict productive activities) are more fulfilling, and foster sustained well-being (Hammell, 2004).

Individuals create, maintain and develop a sense of meaningfulness and productivity by engaging in personally distinct occupational activities (Wilcock, 1998; Yerxa 1993; Fieldhouse, 2000). By disengaging or abruptly changing the activities tied to one's occupation, an individual may hinder the maintenance and development of personal well-being (Wilcock & Hocking, 2015). For example, prolonged withdrawal from personally meaningful activities is detrimental to individuals, and interferes with living a meaningful, productive and quality life (Martin, Sadlo, & Stew, 2012; Whiteford, 2000). Additionally, disruptive experiences (i.e., injury; illness) will be followed by a process of adjustment and reconstruction of daily life activities. Inability to perform valued everyday occupations may lead to a loss of certain aspects of self, such as perceptions of competence, self-worth and identity (Corbin & Strauss, 1987).

Wilcock's scholarly work examines the fundamental importance of the human occupational perspective when considering one's health. She argues that engaging in meaningful occupation and in turn developing one's occupations, is essential to overall health and psychosocial well-being (Kosma et al., 2013; Wilcock, 2005). Applying an occupational perspective improves a researcher's or healthcare professional's understanding of an individual's health and well-being, by considering individuals as occupationally productive beings (i.e.,

people who can do, be and become; Hitch, Pépin, & Stagnitti, 2014; Wilcock, 1999). *Doing* represents the mechanism for social interaction, societal development and growth, as well as forming the foundation of a community. An individual engages in occupation to be a part of something – to feel as though their contributions make an impact, and matter to society. *Being* is an individual's view of the self – one's nature or essence. Being is derived from deeply rooted personal beliefs and exists in the present. Lastly, *becoming* occurs as a continual and dynamic process over a longer-term period. While fulfilling the principles associated with doing and being through engaging in meaningful occupation, individuals uncover what is personally important and meaningful. Throughout the lifespan, occupational experiences provide a sense of purpose, and in turn engage individuals in the process of working toward a goal and further developing their life.

5.2 Occupational Perspective in Concussion Care

An occupational perspective is not a new frame of thought within healthcare, however it is often overlooked due to the dominance of the biomedical model (Wilcock, 2005; Wilcock & Hocking, 2015). Healthcare professionals can and should incorporate an occupational perspective within concussion care, as it can work well alongside the biomedical model. The foundation of participation and engagement in meaningful occupations aligns well with the most recent 2016 Consensus Statement on Concussion in Sport Guideline that emphasizes gradual participation in regular activities 24-48 hours after injury (McCrory et al., 2017). Therefore, it makes sense that prolonged disengagement from activities during recovery (e.g., strict rest; prolonged rest; self-limiting behavior; etc.) can have deleterious effects on the recovering individual. The utility of an occupational perspective becomes even more apparent when considering the 10-30% of individuals who experience prolonged symptoms and develop PCS,

as psychosocial impairments (e.g., depression; anxiety) develop and become intertwined with concussion symptoms (Scopaz & Hatzenbuehler, 2013; Southern et al., 2019).

An occupational perspective and implications on health, have been previously applied to a number of health- and rehabilitation-related areas, including health promotion, occupational therapy and social justice (Kosma et al., 2013). At present, however, consideration of an occupational perspective within concussion research is limited. The main contributors within this area are Dr. Reed and Dr. Finn – both occupational therapists who have written several position papers as a means to gain recognition for the consideration of occupation within the treatment of concussion. Reed (2011) argues that occupational performance is hindered when an adolescent sustains a concussion, and that a consideration of an occupational perspective is important to appreciate the delicate balance between rest and meaningful activity reintegration. His focus is on the delivery of an occupational perspective through occupational therapists providing holistic, client-centered approach enabling occupations both on and off the playing field (Reed, 2011a). Finn (2019) proposed a novel occupation-based, client-centered framework for the management of concussion. She suggests the importance of healthcare providers considering the physical and cognitive sequelae associated with concussion, but in the context of engagement in meaningful occupation – particularly for individuals with prolonged symptoms. Like Reed's recommendations, this is specific to occupational therapists carrying out treatment.

A variety of health professions can provide care using an occupational perspective, or at least consider the fundamental idea of occupation, but not surprisingly, the most occupationally relevant care provider is the Occupational Therapist. An occupational perspective and occupational therapy are similar in that they both focus on occupation. They differ, however, in that an occupational perspective frames an academic discipline, while occupational therapy is a

profession (Schell, Gillian, Scaffa, & Cohn, 2014). Occupational therapists traditionally work with clients to develop, recover and/or maintain skills as a means to encourage participation in daily activity. A client's goals are at the center of care, and occupational therapists work to allow and to promote participation in personally meaningful activity (e.g., adapt skills or environments).

Occupational therapists are seldom involved in the care of individuals with concussion, especially within the acute phase of recovery (Reed, 2011a). This is likely due to the rapid natural resolution of symptoms expected with uncomplicated concussions (Salisbury, Kolessar, Callender, & Bennett, 2017). Occupational therapists are most frequently involved in concussion care when concussion symptoms are prolonged, or when PCS is present (Boussard et al., 2014). A troubling finding is that occupational therapists scored lower on a concussion knowledge assessment as compared to their peers in other professions (i.e., psychologist; medical doctor; athletic trainer). Therefore, this project proposes that an occupational perspective should be considered throughout concussion recovery by whomever is in the patient's circle of care – both acutely and in the longer term if prolonged symptoms develop. The hope is that theories of Occupational Risk Factors theoretical perspective (outlined below) will further an understanding of what an occupational perspective can contribute throughout concussion recovery, and perhaps provide Occupational Therapists and other health care practitioners with a framework to organize concussion knowledge.

5.3 Occupational Justice

At the root of a theoretical perspective focused on Occupational Risk Factors, is the concept of occupational justice, defined as: recognizing and providing for the occupational needs of individuals and community as part of a fair and empowering society (Wilcock & Townsend,

2000). Townsend and Wilcock (2004) identified four occupational rights that all people should be entitled to. All people deserve: a) to experience meaning and enrichment in their occupations; b) to participate in a range of occupations; c) to make choices and to share decision-making power in daily life; and d) to receive equal privileges for diverse participation in occupations (Townsend & Wilcock, 2004). Occupational rights are outlined to provide equity among individuals, contributing to optimal health, well-being and higher HRQOL.

Prior to the 2016 Consensus Statement on Concussion in Sport, the recommended concussion recovery guidelines between 2001 and 2009 focused on complete physical, cognitive and sensory rest until the individual was symptom free (Aubry et al., 2002; McCrory et al., 2005, 2009, 2013). Due to the change in lifestyle that these concussion treatments necessitated (i.e., complete physical, cognitive, and sensory rest), individuals experienced a loss of harmony between their occupational needs and capacities, and the actual activities in which they engaged. It was not uncommon for individuals to be removed from meaningful activities for an extended period of time – days, months and sometimes longer especially for children and adolescents.

Management plans that suggest extended rest cause an individual to feel stressed, anxious and/or depressed about falling behind and missing out in his or her regular activities (Halstead et al., 2017). Trends towards poor psychosocial health were also apparent for these individuals, or those adhering to strict or prolonged rest recommendations – with anxiety and depression becoming intertwined with concussion symptoms (Broshek et al., 2015; Plourde et al., 2018). Within the literature, this scenario has been called the “activity restriction cascade,” where prescribed rest and activity restriction results in deconditioning, mood changes, stress, and anxiety related to activity withdrawal (DiFazio, Silverberg, Kirkwood, Bernier, & Iverson, 2016). As a result, further rest is often recommended since it is difficult for healthcare providers

to differentiate between the concussion symptoms and psychosocial sequelae – continued and worsened symptoms frequently follow.

The most recent 2016 Concussion Guideline suggests a “brief period of rest during the acute phase of recovery (24-48 hours), followed by a gradual and progressive increase in activity while staying below their cognitive and physical symptom-exacerbation thresholds” (McCrory et al., 2017). These guidelines call for a symptom-limited approach for return to activity – where the activity is terminated if symptoms are worsened significantly. The benefits of these guidelines are clear in that complete rest, and in turn abstaining from meaningful activity, is limited to a brief period of time. However, occupational justice (i.e., a) to experience meaning and enrichment in their occupations; b) to participate in a range of occupations; c) to make choices and to share decision-making power in daily life; and d) to receive equal privileges for diverse participation in occupations) is not achieved, and the injustice that continues is that this guideline is not adequately individualized for the adolescent population aged 13 to 18 years.

The adolescent age group arguably experiences one of the most rapid and potentially tumultuous life transitions (i.e., transition from childhood to adolescence) – not only in terms of physical development, but in terms of cognitive and psychosocial maturity (Byrne et al., 2007). “Normal” concussion recovery for adolescents is four weeks as compared to five to ten days for their adult counterparts. This longer recovery span likely results in a prolonged period of restricted participation in meaningful occupations. Although the symptom-limited approach for return to activity is promoted in the current Consensus Statement on Concussion in Sport Guidelines, four weeks of experiencing some level of concussion symptoms and subsequent restricted activities, in a time of rapid development, is likely to have an impact on psychosocial health and well-being.

The concussion symptoms and changes to meaningful activities that are suggested by current treatment guidelines may overtax ability to cope for many adolescents. Within the four-week period of recovery, adolescents have the potential to be significantly set back in their school, sport, social circle, etc. – creating a state of increased stress, isolation, anxiousness, and depressive thoughts. Additionally, adolescents recovering from a concussion may begin to engage in further self-limiting behaviour due to: a) fear of worsening symptoms; b) decreased perceived satisfaction with occupational performance; c) or a last-ditch effort to exert control over their situation (Finn, 2019). Individuals will choose to limit their engagement in previously enjoyed activities, and the aforementioned activity restriction cascade often surfaces. Therefore, it is not surprising that adolescents are more likely to experience prolonged symptoms, a diagnosis of PCS and/or anxiety and depression, for months to years following the injury – consequences that could potentially be minimized with specialized care. Adolescents are not being afforded their four occupational rights outlined by Townsend and Wilcock (2004), and the health-related consequences are clear.

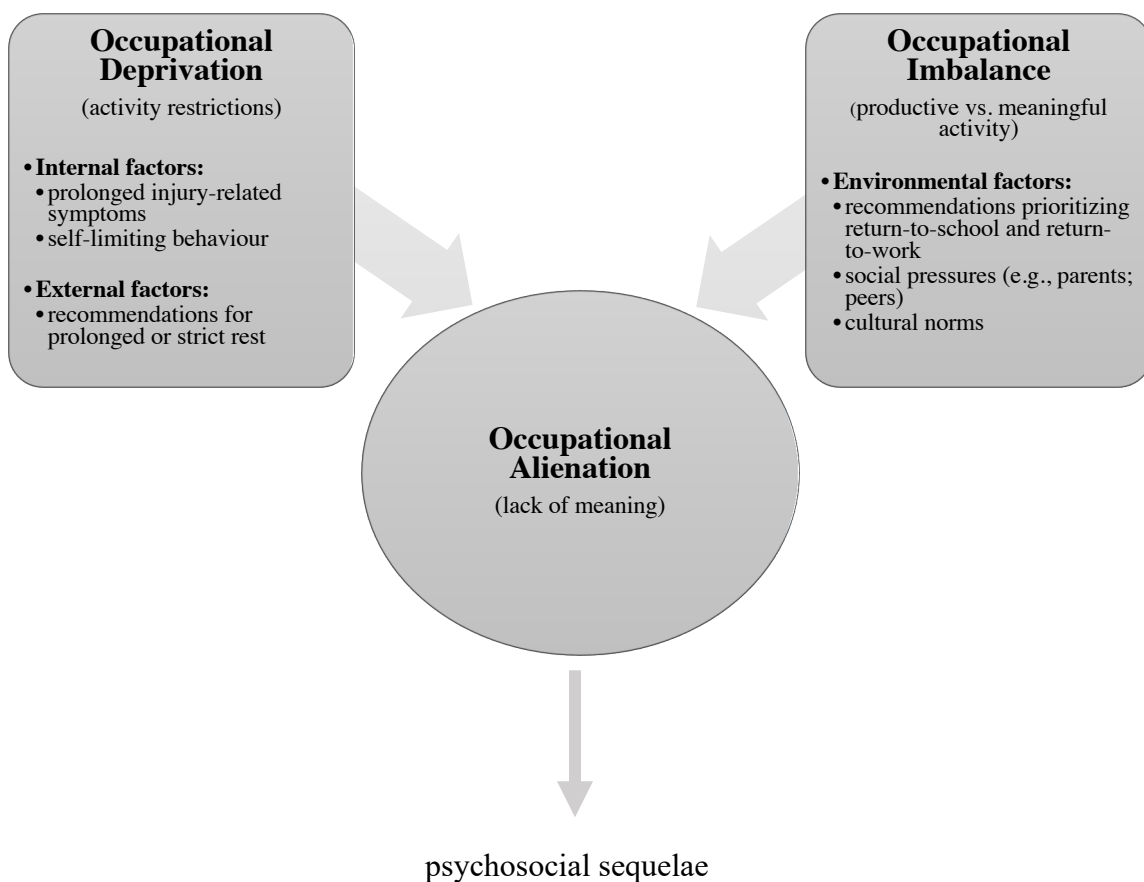
As a method of maintaining optimal health, well-being and health related quality of life (HRQOL), an occupational perspective is important to incorporate into current concussion management practices – especially for adolescent individuals aged 13 to 18 years of age. This may be in the form of a multi-disciplinary management approach. Current recommendations suggest that multi-disciplinary or specialized concussion care is not needed until symptoms become prolonged (extending beyond four weeks for adolescents), however adolescents may benefit from these additional services from the beginning of the treatment period (DiFazio, Silverberg, Kirkwood, Bernier, & Iverson, 2016). Healthcare providers specializing in occupational perspectives, can help adolescents to: i) understand activity changes; ii) prioritize

activity involvement; and iii) provide environmental adaptations. The goal is for adolescents to develop self-efficacy and satisfaction with occupational engagement as well as overall improved HRQOL.

5.4 Occupational Risk Factors Theoretical Perspective

The potential outcomes of occupational injustice are known as “Occupational Risk Factors” and were first identified by Wilcock: i) occupational deprivation; ii) occupational imbalance; and iii) occupational alienation (Kosma et al., 2013; Townsend & Wilcock, 2004). The three occupational risk factors are presented here as a means of framing the project with an interpretive intent (see Figure 5.1 below).

Figure 5.1. Occupational Risk Factors following a concussion.



5.4.1 Occupational Deprivation: Activity Restrictions

Wilcock initially identified the first occupational risk factor known as occupational deprivation, and Whiteford worked to develop the theory further. Occupational deprivation is currently defined as “a state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside immediate control of the individual” (Whiteford, 2000, 2011). The opportunity to perform occupations that have social, cultural and personal relevance is difficult if not impossible for individuals experiencing occupational deprivation (Wilcock, 1999). Occupational deprivation can result from inequity, lack of available services, discrimination, and disability (Whiteford, 2011; Whiteford & Hocking, 2012). Those who have been identified to be particularly vulnerable to occupational deprivation are individuals of minority groups (i.e., ethnic, cultural, religious), prisoners, those who are chronically unemployed, individuals with mental health issues, women and children (Whiteford, 2000).

When considering concussion treatment, occupational deprivation can result from factors that are internal and/or external to the recovering individual (see Figure 5.1). Internal factors may be in the form of the symptoms experienced, or in the initiation of self-limiting behaviours. Symptoms such as headache, blurred vision, balance disturbances, photophobia, difficulty concentrating, issues with decision making, and fatigue, can dramatically limit one’s ability to tolerate school, sport, social and extracurricular activities. Although the majority of individuals experience a rapid natural resolution of concussion symptoms, younger individuals and those diagnosed with PCS can experience symptoms for much longer periods of time. Weeks, months or even years experiencing some level of concussion symptoms and inability to participate in regular activities will have an impact on psychosocial health and well-being.

Prolonged disengagement from activities is especially apparent for the 10-30% of individuals with a concussion who develop prolonged symptoms and PCS (Lovell, 2009; Parachute, 2017). Individuals with PCS may begin to engage in self-limiting behaviours in addition to their concussion symptoms, due to: a) fear of worsening symptoms; b) decreased perceived satisfaction with occupational performance; or c) a last-ditch effort to exert control over their situation (Finn, 2019). Individuals may choose to limit their engagement in previously enjoyed activities. Those with PCS are at further risk for progressing from a state of occupational deprivation to occupational imbalance due to the extent of symptoms as well as the complexity of behaviours.

External factors leading to occupational deprivation, come in the form of recommendations for prolonged and/or strict rest by healthcare providers. Prior to the release of the current 2016 Consensus Statement on Concussion in Sport, the 2001 to 2009 versions suggested complete physical, cognitive and sensory rest until individuals were symptom free (Aubry et al., 2002; McCrory et al., 2005, 2009, 2013). Repercussions of this recommendation are well documented in the literature as the “activity restriction cascade,” where prescribed rest and activity restrictions result in deconditioning, mood changes, stress, and anxiety related to activity withdrawal (DiFazio et al., 2016a). Further rest is often recommended as it is difficult for healthcare providers to differentiate between the concussion symptoms and psychosocial sequelae – and continued and worsened symptoms frequently follow. Unfortunately, some individuals are still dealing with the repercussions of these guidelines in their daily life, however it is reassuring that the updated 2016 Consensus Statement on Concussion in Sport is available and in use to guide current concussion treatments (further discussed below).

5.4.2 Occupational Imbalance: Productive vs. Meaningful Activity

Occupational imbalance is “a loss of balance between work, rest, and play, and between the occupations we choose and those in which we are obliged to engage” (Wilcock, 2005).

Given that occupational balance is needed in order to achieve optimal health, occupational deprivation can result in more permanent imbalances in the occupations of daily living.

Prolonged concussion symptoms and self-limiting behaviours result in individuals prioritizing activities that are to be engaged in – most notably productive activities are frequently prioritized over meaningful activities. For those recovering from a concussion, there are environmental factors within the individual’s life that make them more apt to engage in productive activities, which can lead to occupational imbalance. For example, one’s physical, cultural and demographic environments impact how an individual may interpret return-to-activity guidelines.

The current 2016 Consensus Statement on Concussion in Sport suggests *a return to school prior to return to sport* (McCrory et al., 2017). School and work engagement are the prioritized activities for many recovering individuals – these are highly productive ventures on whole. In addition to return-to-activity protocols, there are additional social pressures and cultural norms which often promote the re-integration of productive activity at the expense of personally or culturally meaningful activities. Common social pressures in the form of parental attitudes, that can lead to occupational imbalance are: i) fear of re-injury during participation in sport and extracurriculars; and ii) prioritization of school due to assumption of potential long-term benefits. Peer pressure can also contribute as there is often a misunderstanding of the recovery process due to the invisible nature of concussion symptoms – individuals can push themselves to keep up to others at school, often leaving no energy reserve for activities that bring

joy and meaning. Lastly, cultural norms in Western societies largely promote productive work over “non-productive” (but meaningful) activity.

Although returning to productive activities may appear to have short-term benefits for the individuals recovering from a concussion (e.g., not falling behind in school), reduced attention to skills and roles that were previously maintained through the performance of meaningful activity contributes to occupational imbalance. Most notably, an imbalance occurs when prioritizing activities that are “just” for productivity over meaningful activities. School and work can also be meaningful to individuals; however, the absence of meaningful activity participation is problematic when paired with a dominance of productive activity. The resulting imbalance in occupations contributes to stress – manifesting as mood changes, and/or boredom (Wilcock, 2005). These symptoms may presage more serious psychosocial complications (e.g., anxiety and depression) and lower quality of life. Therefore, it makes sense to adequately distribute one’s available energy reserve between meaningful and productive activities in a way that contributes meaning to one’s life, all while the individual remains below their symptom-exacerbation threshold. The goal is to promote enriching activities and experiences that can improve self-efficacy and satisfaction with occupational engagement as well as overall improved quality of life.

5.4.3 Occupational Alienation: Lack of Meaning

The last, and arguably most severe risk factor, is occupational alienation. It is described as a “separateness from the harmonious, ecological relationship between occupation, health and the environment that our biopsychosocial selves evolved within” (Wilcock, 2005). There is a loss of meaning and purpose, resulting in a loss of control, and the development of uncertainty as how to proceed in life. Occupational alienation can follow a period of occupational deprivation

and imbalance, especially if personal resources and supports are not adequate. Symptoms of occupational alienation may be isolation, powerlessness, frustration, loss of control, and estrangement from society, with progression toward lasting mood disturbances (Kosma et al., 2013).

When considering concussion and PCS recovery, there may be a time when symptoms become less specific to concussion (i.e., headache, dizziness, balance disturbances and disorientation), and more specific to the lack of engagement (i.e., social isolation, anxiety, depression, suicidal ideation). Psychosocial consequences of concussion and PCS are well documented in the rehabilitation literature (Broshek et al., 2015; Emery et al., 2016; Plourde et al., 2018) – with many similarities seen in reference to symptoms of occupational alienation (see Table 5.1 below). Overall, individuals begin experiencing functional limitations. Individuals lose touch with what their life and occupations looked like prior to injury and may have significant difficulty prioritizing meaningful activities as a means of recovering.

Table 5.1. Psychosocial consequences of concussion gathered from the literature.

Psychosocial Consequences
<ul style="list-style-type: none"> • reduced sense of mental well-being • mood disturbances • depression • anxiety • nervousness • psychosocial distress • confusion • concerns about future • minimization and masking injury & condition • high perception of stress • social role changes • social isolation • disrupted social routines • frustration

5.5 Recommendations

Incorporating an occupational perspective into rehabilitation plans may lead to a more holistic approach for the treatment of adolescents who have sustained a concussion and is likely to lead to improved outcomes. Wilcock's theoretical work on Occupational Risk Factors (i.e., occupational deprivation; occupational imbalance, occupational alienation), provides an excellent context for framing rehabilitation efforts – particularly in situations where an individual's gradual return to activity requires a longer period of time (as is the case for adolescents and individuals with PCS). It is likely, given the foregoing discussion of this theoretical perspective, that providing individuals with increased control over the occupations in which they engage, during the return to learn or work process, has the potential to be fruitful, and to produce positive effects on their health and well-being.

At present, personal meaningfulness through occupational engagement is often left out when considering concussion recovery guidelines and reintegration – as a result, individuals are at risk for occupational deprivation, occupational imbalance and occupational alienation. Individuals who are at risk for experiencing prolonged concussion recoveries would benefit from additional resources and supports aimed at occupational engagement, from the outset of concussion diagnosis as a means of mitigating occupational risk factors. A variety of health and social care professions can provide care using an occupational perspective, or at least consider the fundamental idea of occupation – however, one of the most occupationally relevant care disciplines is occupational therapy (Finn, 2019; Finn & Waskiewicz, 2015; Reed, 2011b).

Given the symptom variability seen in adolescent patients, it is imperative that healthcare professionals consider patient-identified changes in daily life activities and occupations in the context of their pre-injury functioning. Disregarding patient roles, and expectations for recovery,

may lead to failed rehabilitation interventions and an overall worsening of function (DiFazio et al., 2016a). Ideally, an occupational perspective should be considered from the outset of injury – especially for those at risk for PCS as well as adolescents who experience longer recovery profiles. We recommend that concussion healthcare providers are enjoined to consider the activity endeavors of each patient from the perspective of the individual, while also considering the need for safety within the recovery period. This consideration will facilitate the development of a client-centered plan of care that works, and makes sense, for each individual. Adolescents and those at risk for or experiencing PCS would undoubtedly benefit from additional support in accordance with an occupational perspective.

The hope is that considering the Occupational Risk Factors and related theories will further the understanding of the occupational perspective throughout concussion recovery and perhaps provide healthcare providers and Occupational Therapists with further concussion treatment knowledge. Careful attention to meaningful occupations may minimize the experience of post-concussion occupational deprivation, occupational imbalance, and occupational alienation. This is distinct from traditional return-to-activity protocols, in which the focus is on resuming productive behaviours (i.e., school and work). Effective pacing strategies will, therefore, involve counseling individuals to consider their occupational engagement from a holistic, occupational perspective.

Chapter 6: METHODS

6.1 Research Design

This research project used a qualitative case study methodology that addresses the reported experiences of adolescent females diagnosed with a sport-related concussion. More specifically, Stake's collective case study framework was adhered to as a way to study multiple cases that surround one condition of interest. The commonalities (i.e., generalizations) as well as the ideographic nature (i.e., particularization) of the post-concussion recovery experiences were addressed by recruiting participants from a sport medicine clinic as well as a paediatric rehabilitation centre (Stake, 1995, 2000). The study was framed with an interpretive intent as a means to understand if/how theories relating to occupational risk factors (namely occupational imbalance, occupational deprivation and occupational alienation) relate to adolescent concussion recovery experiences (Merriam, 1998, 2009).

The case was defined as *the reported recovery experiences of female adolescents from two treatment centres in Southwestern Ontario, following a sport-related concussive injury when returning to school, returning to sport and returning to occupation(s)*. There was a consideration of how adolescents interpret what has been asked of them – from healthcare providers, caregivers, educators and coaches, etcetera. Overall, an identification of the barriers and facilitators that accompany the recovery experience will help to address the specific needs of the members of the adolescent female population who are recovering from a concussion. More on the theoretical positioning of the research design can be found in Chapter 5.

6.2 Research Questions

- i) *How do female adolescents who have sustained a concussion through sport participation (e.g., game, practice or recreational setting) describe their*

recovery experiences of return to school, return to sport and return to occupation?

- ii) What are the barriers and facilitators that accompany one's return to school, return to sport and/or return to occupation(s)?*
- iii) How do female adolescents who have sustained a concussive injury interpret what has been asked of them in terms of return-to-activity protocol(s) or suggested activity modifications?*

6.3 Setting

This project was conducted with the support of the Fowler Kennedy Sport Medicine Clinic (FKSMC) as well as the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). FKSMC is a leading centre for sport and exercise medicine in London, Ontario – providing diagnosis, treatment and rehabilitation to athletes of all levels. The centre aims to provide high quality, timely, comprehensive and compassionate care. With the support and collaboration of Western University and the London Health Sciences Centre, FKSMC strives toward achieving their vision of “setting the standard of excellence in sport and exercise medicine.” There is a specific concussion treatment program within the FKSMC, where sport medicine physicians and physiotherapists work in conjunction with the patient in order to provide comprehensive assessment and treatment programs, and well as injury prevention.

PABICOP on the other hand was developed at the Thames Valley Children's Centre in London, Ontario. PABICOP is an outreach program for young people who have sustained an acquired brain injury as well as their accompanying families. It is a family-centered, culturally sensitive service that aims to provide single-point access for case management and coordination. It aims to support children and adolescents who are facing social, academic, medical or

emotional issues, and it assists families in gaining the knowledge and skills that are necessary for accessing the services needed. PABICOP was established to bridge the gap between rehabilitation services available through the Thames Valley Children's Centre and medical insight available at the London Health Sciences Children's Hospital of Southwestern Ontario. In terms of concussion, PABICOP aims to provide a continuum of care model for children and adolescents diagnosed with a concussion, scoping the domains of academic (cognitive), sport (physical), social and community reintegration (Gillett, 2004; McDougall et al., 2006).

6.4 Participants

Although many young people with a vast array of conditions, illnesses and injuries participate in FKSMC and PABICOP programming, this project specifically focused on female adolescents who have been diagnosed with a concussion as the result of a sport-related activity (i.e., concussion will have to be sustained during a sports game, practice or recreation setting). Considering the research questions, purpose, and resources available, this project included four participants from the PABICOP program and two participants from the FKSMC. A purposive sample was drawn, which allows for a variety of participants to be included and acknowledges opportunities for intensive study of the case at hand (Denzin & Lincoln, 2000). More specifically, criterion sampling was employed. Criterion sampling involves selecting participant cases that meet some predetermined criterion of importance. The criterion of importance for this study is to consider individuals who have shared the life experience of a prolonged recovery from a sport-related concussion and subsequent treatment and management practices (Tashakkori & Teddlie, 1998).

According to Stake's (1995) contributions to case study research, balance and variety in the sample is important in order to consider generalization and particularization respectively.

Therefore, we sought to achieve maximum variation through the use of homogeneous sub-groups sampled from within two very different treatment centres (i.e., PABICOP and FKSMC members). This allows for a wide range of variation of participants from Southwestern Ontario to be included. Both unique and common cases will be explored by hosting two separate focus groups – one for PABICOP members and one for FKSMC members. By bringing individuals together from similar backgrounds and experiences, it simplifies analysis and facilitates group interviewing and focus groups. This project will likely uncover central themes, core elements, and/or shared dimensions.

The sample size of eight females was the initially proposed number of participants based on the collective case study methodological approach, however we achieved six females through our recruitment efforts. Participant recruitment proved to be difficult, especially as the data collection period overlapped with the COVID-19 pandemic. However, participant data proved to be especially rich in description through the photos and reflections shared – therefore sufficient data to make meaningful interpretations (i.e., saturation) was achieved with the six participants that were recruited for the study. The project initially recruited four females from PABICOP in 2017, which began the first set of interviews and focus group one. Data analysis continuously occurred throughout this stage of data collection. The project then recruited two additional females from FKSMC in 2019/2020, forming the second focus group. Despite the diverse recruitment centres, this staged iterative process resulted in saturation (or redundancy) after sampling and evaluating six cases. That is, the sample was large enough in that consistent themes and patterns were seen in the data analysis, and no new concepts emerged through the later interviews, focus groups, and photoelicitation exercises (Stake, 2000). Eight females was

an estimate only, therefore the recruited six were deemed sufficient to draw meaningful conclusions.

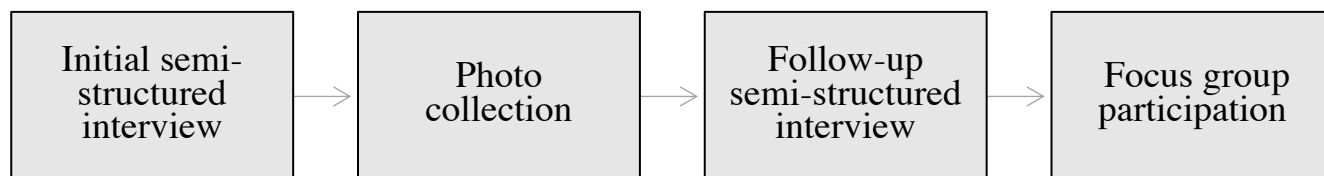
Inclusion criteria for participants were: individuals 13 to 17 years of age; diagnosis of concussion or mild traumatic brain injury by a healthcare professional; concussion encountered through sport participation; recovery lasting longer than four weeks; written consent from participant and parent/caregiver; and possesses the cognitive ability to participate in interviews, photoelicitation activities, and focus groups (e.g., at a stage of recovery in that the participant can tolerate social interaction, group-settings, and a camera flash). Individuals were excluded from this study if they were considered to have had pre-existing cognitive dysfunction prior to their concussion – most particularly if this cognitive dysfunction was considered likely to hinder participation in the photoelicitation activities, semi-structured interviews, and/or focus group discussions. Participants were cleared to participate in regular daily life activities by their nurse practitioner or medical doctor. Prior to study initiation, all procedures and consent documentation were approved by the Health Sciences Research Ethics Board at Western University, as well as the Research Advisory Committee at the Thames Valley Children Centre (see Appendix A and B respectively).

6.5 Data Collection

The sequential phases of this study were as follows: (1) initial semi-structured interview with camera instruction; (2) photo collection; (3) follow-up semi-structured interview; and (4) focus group participation (Figure 6.1 below). This sequence was used in both study phases – once with four participants from PABICOP and again with two participants from FKSMC. Using multiple methods for data collection enabled a more comprehensive consideration of adolescent concussion recovery experiences. All researcher-participant interactions took place

on Western University campus. However, in light of the COVID-19 pandemic, amendments were made to the Health Sciences Research Ethics Board at Western University, and the final focus group used Zoom videoconferencing to ensure the safety of the participants and researchers.

Figure 6.1. Phases of the study.



6.5.1 First Data Collection Session (Initial Interview)

After individuals were recruited by the primary researcher, consent forms and the letter of information were reviewed and signed by the participant and accompanying caregiver (see Appendix C). The primary researcher also discussed photo consent and release forms with the participants. Adolescents were encouraged to take part in the interview individually, however caregivers were permitted to sit in on discussions if the participant felt that she could be transparent with her responses in the presence of the caregiver. This was considered to be important, as caregivers could have influenced what was shared by the adolescent participants, given the extent to which social pressures and support are entwined within the concussion recovery process (as discussed in Chapter 2). Interviews lasted between 30 and 60 minutes. Interviews were recorded electronically by the principal investigator throughout the interaction, and transcribed at a later date in a secure electronic field notebook.

A semi-structured line of questioning took place. Questioning began with introductions

and gathering information regarding the basic demographics of each adolescent (e.g., age, gender, grade in school, postal code, date of injury, etc.). Next, interviews moved toward more open-ended questioning, and focused on concussion recovery experiences and any barriers or facilitators that were encountered during recovery. Open-ended questions were used to guide the interview, depending on the direction of conversation with the participant (e.g., recovery progression, positive and negative aspects of daily life during recovery, use of return-to-school or return-to-sport protocols, formal and informal supports that were made use of, etc; See Figure 6.2).

Figure 6.2. Open-ended questions used during first interview.

1. Tell me about your concussion injury (who, what, where, why, when, how)?
2. What did the days after your concussion look like?
3. Were there any changes in your daily life after the concussion?
4. Was there anything or anyone that supported (or helped in) the recovery process?
5. Were there any barriers that you encountered after your concussion?
6. What was your involvement with FKSMC?
7. What was your involvement with TVCC?
8. Is there anything you'd like to share with others who may have sustained a concussion and are entering recovery?
9. What does your life look like now?

Participants were then asked to take photos of salient experiences that illustrated their experiences of living with, and recovering from, a concussion. Participants were also told that photos can represent barriers and/or facilitators encountered while returning to school, returning to sport, and returning to occupation(s). The participants' cellular phones were used to take the photographs during the photoelicitation portion of this study. To ensure spontaneous photographs were elicited, the photo was to be emailed to the primary researcher right after it

was captured. This ensured that the photos weren't deleted or staged in any manner – and were more spontaneous in nature. Disposable cameras were also considered, however, they were thought to be less convenient as compared to cellular phones, which were carried throughout the day by each participant. Due to the requirement of using electronics and potential exposure to bright lights and camera flashes, participants were required to have physician support for their return to regular activity without reoccurrence of concussion symptoms.

6.5.2 Second Data Collection Session (Photo Collection)

Although participants were encouraged to take as many pictures as they saw fit, the researcher suggested that participants take between five and thirty photographs. Although participants were encouraged to take their own photographs, they were also told that they could ask a friend or family member to capture a photo for them if it was under direct participant direction. Participants were also permitted to select existing photos from their personal collection for inclusion in the study, or take photos of existing photos. If photographs included another individual's face, that individual was required to sign a photo consent and release form which was discussed with the participant at the initial interview (see Appendix D). Participants were allocated a two week period to collect their photographs.

6.5.3 Third Data Collection Session (Follow-up Interviews)

This interview was also conducted by the principal investigator. Individuals were asked to speak about the photos they captured, spending more time on certain photos depending on participant interest and involvement in the discussion. Further probes were used to elicit deeper understanding of the photographs (i.e., “how” statements, “what” statements). The researcher encouraged participants to talk about experiences with regular activities of daily living as well as engagement with reintegration protocols (e.g., return-to-school and return-to-sport protocols).

Member checking by the researcher was also used to “check back” or ask participants to clarify words, categories, or interpretations (Lincoln, 1985; Spradley, 1979).

At the end of the session, individuals were assigned a “homework” exercise that consisted of participants selecting a maximum of five photos from their collection that best illustrated their experiences with their concussion recovery process, and provide a title and/or caption for each photo. Participants were notified at this meeting that they would be discussing the five photos during the focus group session with their peers. Additionally, scheduling information was collected in order to plan focus group meetings. Interviews ran for approximately 20 to 60 minutes. They were recorded electronically, and themes were recorded by the principal investigator in a secure electronic field notebook.

6.5.4 Fourth Data Collection Session (Focus Groups)

The small-scale focus groups aimed to achieve in-depth discussions, compared to larger focus groups, which gather surface content data (Fern, 2001). Again, it was recommended that adolescents participate in these sessions without their caregivers so their experience could be better understood in the absence of parental pressures or expectations. To maintain separation of the data between recruitment centres, there was one focus group per phase – one with the 4 participants from PABICOP and one with the 2 participants from FKSMC. During the focus group sessions, individuals were able to discuss some, or possibly all, of the five photos they had chosen, depending on the direction of conversation that unfolds. Discussion was initiated and continued by probes from the principal researcher, providing time and instances for all individuals to share their thoughts and experiences. Again, as in the one-on-one interview, member checking was used as a means of “checking back” or asking participants to clarify words, categories, or interpretations with the researcher (Lincoln, 1985; Spradley, 1979). Focus

groups were recorded electronically, and notes were taken in a secure electronic field notebook. Focus groups ran from 40 to 90 minutes.

6.6 Data Analysis

Case study research views the data analysis process as taking ideas/data apart and relating it back to the broad picture (or broad case). Specifically, themes were addressed in regards to the case, issues and research questions (as a reminder, these are outlined in Table 6.1). Cases were assessed for themes both within individual cases as well as between multiple case interactions. As noted previously, this project was designed with an interpretive intent – meaning that along with providing a rich description of the case of interest, theory is also brought into the study within the analysis phase (see Chapter 4). This is largely accomplished through a conceptual framework, which is the anchor of case study research (Stake, 2000; Yin, 2006). According to Miles and Huberman (1994), the conceptual framework serves to: a) identify and describe relationships that may be present based on participant described experiences, and b) provide the researcher with the opportunity to assimilate participant constructs into categorical “bins.” The framework acts as a guide initially, but also acts as a tool for data interpretation. A progressively developed framework emerges through the data analysis process, as relationships between constructs become apparent (Miles & Huberman, 1994).

Table 6.1. Case, issues and research questions.

Case	<i>The reported recovery experiences of female adolescents from two treatment centres in Southwestern Ontario, following a sport-related concussive injury (e.g., game, practice or recreational setting) when returning to school, returning to sport and returning to occupation(s).</i>
Issues	<ul style="list-style-type: none"> <i>i) When a female adolescent is diagnosed with a concussion, the treating healthcare professional will prescribe a return-to-activity protocol(s) or general activity modifications;</i> <i>ii) Recovering adolescents may experience a period of withdrawal from activities (e.g., sensory, cognitive, physical, social, psychological, etc.), followed by a reintegration period;</i> <i>iii) The meaningful occupations of each adolescent may be restricted during the recovery period;</i> <i>iv) How each adolescent interprets what is asked of them in terms of a return-to-activity protocol(s) or activity modifications may be understood on an individual basis;</i> <i>v) Female adolescents in Southwestern Ontario identify with, and gain support from acute and rehabilitation treatment options to enhance recovery.</i>
Research Questions	<ul style="list-style-type: none"> <i>i) How do female adolescents who have sustained a concussion through sport participation (e.g., game, practice or recreational setting) describe their recovery experiences of return to school, return to sport and return to occupation?</i> <i>ii) What are the barriers and facilitators that accompany one's return to school, return to sport and/or return to occupation(s)?</i> <i>iii) How do female adolescents who have sustained a concussive injury interpret what has been asked of them in terms of return-to-activity protocol(s) or suggested activity modifications?</i>

6.6.1 Preparing the Conceptual Framework

Analysis began early on during this collective case study process, as certain constructs of interest began to surface during the literature review. The theoretical perspective initially identified for exploration in terms of concussion recovery was an Occupational Risk Factors theoretical perspective – comprised of theoretical constructs of occupational deprivation,

occupational imbalance and occupational alienation (see Chapter 5). This theoretical perspective addressed some of our research questions, as it modeled the psychosocial outcomes resulting from the removal of meaningful activities from one's daily life. We also conducted a scoping review exploring the reported recovery experiences and perspectives of adolescents who have sustained a concussion through sport participation – themes identified were the significance of symptoms, changes in activities, effect on relationships and feelings of frustration (see Chapter 3). This acted as a starting point for the experiences of concussion recovery we were seeking to understand. We ended up seeing some initial relationships between the Occupational Risk Factors and the themes uncovered in the scoping review (see Chapter 3), which lead to the development of a preliminary conceptual framework (see Figure 3.2). This conceptual framework was the starting point for our understanding of concussion recovery experiences, guiding initial coding, and augmented as understandings deepened during data collection and analysis.

6.6.2 Collecting Data and Mind-Mapping

Searching for meaning and patterns continues when researchers begin their interactions with participants. After the initial interaction with each participant, the primary researcher constructed a case-specific mind map of themes which were emerging. Interviews were also re-listened to with a second researcher within the days following each interview – this often resulted in developing ideas further and themes were negotiated through consensual review. We constructed a mind map for each participant interview, and after the first focus group was complete, common themes across participants were identified on a larger collective mind map. In line with collective case study research, the focus remained on the commonalities as well as the ideographic nature of concussion recovery experiences. This iterative process continued

during data collection for the remaining two participants and second focus group. These meetings were used largely as a member-checking opportunity, checking initial themes (initial four participants) against these new recovery experiences (subsequent two participants). Overall, the case-specific and collective mind maps were used as an organizational tool and to identify potential emerging themes.

6.6.3 Data Coding, Interpretation and Aggregation

Audio recordings were transcribed on an ongoing basis as data was collected. This was an opportunity to become fully immersed in the data. The qualitative analysis software, NVivo, was used to organize interview and focus group transcriptions as well as the photographs taken by participants. NVivo was also used to code data and mind map emerging themes. Coding occurred in three phases: 1) deductive coding using the predetermined concepts from Occupational Risk Factors theoretical perspective and the recovery experiences scoping review (see Table 6.2); 2) inductive line-by-line coding to interpret new patterns and meaning; and 3) categorical aggregation of main codes (parent nodes) and relating codes (child nodes).

Table 6.2. Terms coded in phase one.

Occupational Risk Factor Nodes	Recovery Scoping Review Nodes
<ul style="list-style-type: none"> • Occupational deprivation • Occupational imbalance • Occupational alienation 	<ul style="list-style-type: none"> • Significance of symptoms • Changes in activities • Effect on relationships • Feelings of frustration

As a means of reaching new meaning in the data, case study projects generally make use of two strategies: direct interpretation and categorical aggregation (phase 2 and 3 of coding). Direct interpretation occurs when researchers look for a single instance and draw meaning from

it. Ultimately, the new impressions and ideas found in the data were taken apart, and meaning was assigned to these parts by naming thematic nodes in NVivo. Categorical aggregation occurs when researchers cluster complex data into categories to ease the search for meaning – striving for the emergence of issue relevant meanings. This was accomplished in NVivo through mind mapping emerging themes, and relating/assimilating main codes (parent nodes) and relating codes (child nodes). Hierarchy sunburst charts were also used to assess the number of coding references and number of items coded at each thematic node to get a sense of the frequency of themes.

6.6.4 Developing the Conceptual Framework

The conceptual framework acted as a guide to further our understanding of developing meaning and themes. Themes were modified and added during the course of analysis – focusing on the organization of major themes and sub-themes. NVivo was used to assess patterns in the data, using hierarchy charts and comparison diagrams. In this process, potential thematic contenders or “runners” were disconfirmed by the data and removed. A small number of related themes remained. After interpretation and aggregation of different aspects of the data, a new conceptual framework was ultimately constructed building upon ideas from the preliminary conceptual framework (see Figure 8.1).

6.7 Rigour and Quality

6.7.1 Lincoln and Guba's Trustworthiness

Rich rigour is met by providing a complex abundance of data. This project used Lincoln and Guba's (1985) four constructs of “trustworthiness” to ensure rigour i) credibility; ii) transferability; iii) dependability; and iv) confirmability. While the flexible nature of qualitative research should be embraced, strategies to ensure rigour must also be in place to maintain quality

of the study (Houghton et al., 2013). To determine or assess the rigour of case study research, four criteria are proposed by Lincoln and Guba (1985), and are briefly described below:

- i) *Credibility*: Refers to the value and believability of the findings.
- ii) *Dependability*: Refers to how stable the data are (similar to “reliability” in quantitative research).
- iii) *Confirmability*: Refers to the neutrality and accuracy of the data.
- iv) *Transferability*: Refers to whether or not the findings can be transferred

These four constructs were incorporated into Tracy’s eight criteria for excellent research (described further below), to ensure rigour and quality.

6.7.2 Tracy’s Criteria for Excellent Qualitative Research

Tracy’s (2010) eight “big-tent” criteria for excellent qualitative research was used as a guide to help ensure this project’s findings were sufficiently authentic. According to Tracy (2010), the end goal criteria for quality qualitative research are as follows: i) worthy topic; ii) rich rigour; iii) sincerity; iv) credibility; v) resonance; vi) significant contribution; vii) meaningful coherence; and viii) ethical. Although qualitative researchers generally shy away from set universal criteria for assessing legitimacy, this list was found to be particularly useful as a learning tool. Efforts in meeting each of these criteria will be outlined below (complete summary in Table 6.3).

First, good qualitative research with a *worthy topic* is relevant, timely, significant and interesting (Tracy, 2010). The main arguments that present this project’s topic as worthy are largely based on research gaps outlined in previous chapters: a) first-hand accounts of concussion recovery are largely left out of current literature; and b) the female population has been underrepresented within current literature, which is especially troubling considering

adolescent females reportedly experience twice the frequency of concussions as compared to adolescent males (Baker et al., 2016b; Emmonds et al., 2019). The literature review and research justification further outline why this is a worthy topic (see Chapter 2).

Table 6.3. Methods for achieving quality research.

Goal	Efforts to Achieve Quality Research
Worthy Topic	<ul style="list-style-type: none"> • Case, issues and research questions seek to fill gaps in the literature
Rich Rigour	<ul style="list-style-type: none"> • Lincoln and Guba's (1985) credibility, transferability, dependability, confirmability • Variable sampling sites: TVCC, FKSMC • Multiple data sources: interviews, focus groups, photoelicitation • Ample time in field • Audit trail
Sincerity	<ul style="list-style-type: none"> • Lincoln and Guba's (1985) dependability and confirmability • Self-reflexivity • Transparency
Credibility	<ul style="list-style-type: none"> • Lincoln and Guba's (1985) credibility and dependability • Thick description • Triangulation • Member checking
Resonance	<ul style="list-style-type: none"> • Lincoln and Guba's (1985) transferability • Narrative moves the reader through the story of recovery, eliciting emotion
Significant Contribution	<ul style="list-style-type: none"> • Extends knowledge of female concussion recovery experiences • Proposes a novel conceptual framework for conceptualizing health and well-being during concussion recovery • Suggestion for improved practice and care provision
Meaningful Coherence	<ul style="list-style-type: none"> • Connection of literature, research questions and findings by use of a progressively developed conceptual framework
Ethical	<ul style="list-style-type: none"> • Approval from Health Sciences Research Ethics Board at Western University • Approval from Research Advisory Committee at the Thames Valley Children Centre • Sharing research contributions with participants on an ongoing basis

Richness was also generated through a “requisite variety” of sampling, data sources and theoretical constructs (Weick, 2007). The initially proposed sample was eight participants – four from a rehabilitation setting (TVCC) and four from an acute clinic setting (FKSMC). However, a surprising amount of rich and thick data was collected after the first eight interviews and first focus group (four participants recruited from TVCC). The majority of final themes had already emerged, and participants reported consensus among these themes during the focus group by way of member checking. The use of photoelicitation as a visual method, complimented with interviews and focus groups, proved to be effective in probing deep discussion with adolescents. Each of the four interviews ran longer than proposed with the initial TVCC participants, as participants had an abundance of information to share about their experiences.

The aim was to still recruit an additional four participants from the FKSMC to allow for the integration of additional recovery perspectives, however only two additional participants could be recruited, due to recruitment cessation during the COVID-19 pandemic. During initial meetings with the two participants from FKSMC, we found that the reported experiences were largely in line with TVCC participants and no new themes or ideas were emerging from the data. Therefore, saturation was deemed to have been reached. We found that the second focus group (two participants recruited from FKSMC) acted as an opportunity for further member checking of themes, while also making case comparisons between sites.

The project also employed prolonged engagement with the participants to enhance credibility (Denzin & Lincoln, 2000). An extended period of time was spent with participants during the interviews and focus groups, as an attempt to gain a full understanding of the phenomenon of adolescent concussion recovery – and a significantly longer time period will be spent with the data (i.e., transcripts, photos, etc.). The proposed timeframes were 30 to 60

minutes for the interviews and 60 to 90 minutes for the focus groups. However, the primary researcher was open to spending as much time as needed for participants to adequately share their experiences (in order to reach saturation). An absence of new emerging ideas from participants during data collection was evidence that saturation has been achieved and data collection can be brought to a close (Houghton et al., 2013). Several interviews and the first focus group did run over the allocated time estimate.

Rich rigour was also accomplished through an audit trail. An audit trail refers to a systematic process by which the principal researcher records all activities that are related to the investigation so that an outside individual can examine the data and draw independent conclusions (Dempsey & Dempsey, 2000; Morrow, 2005). It can be considered as a dependability and confirmability criteria (Houghton et al., 2013). The audit trail was collected jointly on a secure laptop file as well as in a paper notebook, depending on the data being collected (i.e., audio recording, photographs, mind maps, researcher jot notes, etc.).

Sincerity was met by self-reflexivity and transparency. Reflexivity was undertaken by the primary researcher as a means of pondering the actions or impressions of participants and deliberating recollections in order to relate them back to theory (Denzin & Lincoln, 2000). Reflexivity can be considered to address dependability and confirmability criteria. A reflexive journal was kept throughout data collection and data analysis. This was a tool that allowed the primary researcher to remain critical and self-aware throughout this research process. It was found to be especially critical during the initial data collection phase.

Transparency was also employed to ensure sincerity. Although a semi-structured line of questioning was maintained during interviews, the goal was for the interviewer to remain neutral of personal assumptions, taken-for-granted understandings and motivations in responses and

questioning probes. In my own practice as a nurse, I have had numerous experiences and opportunities to exercise my skill of remaining neutral of preconceived notions during in-person interactions. It is my hope that throughout this document, it is clear to the reader that I have made my best attempt to be as transparent as possible. To explicitly state my transparency, I have added a personal positioning statement (see Section 1.3), methodological positioning chapter (see Chapter 4) and this section on rigour and quality of research (see Section 6.7).

Credibility represents research that readers feel trustworthy enough to act on and make decisions in line with (Tracy, 2010). Lincoln and Guba (1985) suggest that good qualitative research is credible and dependable (see Section 6.7.1). Case study research is known for the inclusion of thick description and analysis – which is outlined in the results section (see Chapter 7). Additionally, triangulation is a credibility criteria that involves comparing data sources and individuals to identify if a single social theme is present (Denzin, 1978). For the purposes of this project, the phenomena to be triangulated was the case (see Table 6.1). Two basic types of triangulation were conducted: a) data triangulation (using a variety of data, including photographic and transcript data); and b) methodological triangulation (use of multiple methods to study a research problem, including photoelicitation, interviews and focus groups; Baxter & Jack, 2008; Houghton et al., 2013).

Another method employed to ensure credibility was member checking. Member checking is arguably the most important credibility check in case study research (Tashakkori & Teddlie, 1998). Like triangulation, member checking is also considered to be addressing rigour through credibility (Houghton et al., 2013). It involves “checking back” or asking participants to clarify words, categories, or interpretations to the researcher (Lincoln & Guba, 1985; Spradley, 1979). This occurred throughout interviews and focus groups as needed. Additionally, as

themes began to emerge after the initial interviews, they were reflected back to subsequent participants to confirm relevancy.

The term *resonance* suggests that the research should move readers through an evocative representation of the findings (Tracy, 2010). The results section begins with an entry vignette, so readers immediately start developing a vicarious experience, and get a feel of the environment of concussion recovery. There are also narrative descriptions to further define the case and context. Descriptive detail, participant photographs and quotations are all included throughout the results section to promote resonance. Also, throughout this document, there has been a summary of understandings and developments about the case and how generalizations about the case changed throughout the research process (i.e., progressive developments of the conceptual framework can be seen through Figure 3.1, Figure 7.3, Figure 7.5, and finally Figure 8.1). The aim was to ensure transferability, by creating a report that invites accessibility so that researchers can intuitively transfer the research into their own action (Tracy, 2010).

Significant contribution can be thought of as the conceptual framework of mental and emotional well-being which was developed throughout this project (see Figure 8.1). This is represented as a novel framework constructed from real-life perspectives of recovery and can be utilized by healthcare providers whom are treating and caring for individuals who have sustained a concussion, to optimize adolescent female well-being. It considers the whole person when approaching concussion treatment, with consideration of an occupational perspective and personally meaningful activity during the reintegration process.

Meaningful coherence is met by achieving what the project purports to be about, and meaningfully interconnecting literature, research questions, findings and interpretations (Tracy, 2010). This dissertation aims to guide the reader through the research process, starting broadly

and becoming more narrowly focused on the case, issues and research questions as each chapter progresses. The scoping review of recovery experiences (Chapter 3) and the occupational perspective (Chapter 5) are ultimately brought together and become progressively more integrated throughout – informing the methods and results. The goal was to organize this dissertation in a way that flows for the reader. By doing so, it will become clear how the conceptual framework for concussion recovery develops throughout the project.

Lastly, *ethical* considerations are imperative in the research process. Procedural ethics were met through organizational approval by the Health Sciences Research Ethics Board at Western University, as well as institutional approval by the Research Advisory Committee at the Thames Valley Children Centre. Exiting ethics were also considered as interviews and focus groups wrapped up, as the research relationship ultimately had to end. However, the primary researcher made sure to explain to the participants (and caregivers) that moving forward, the dissertation, future publications and/or presentations would be openly shared through email. Participants were eager to share their story and have their voice be heard – so they were equally interested in the idea of having access to the research contributions moving forward.

Chapter 7: RESULTS

The purpose of this qualitative case study was to explore the concussion recovery experiences of adolescent female athletes and how they coped in the months following the injury. The focus was to explore issues surrounding returning to activity and occupation following a concussion, when symptoms extend beyond the typical four-week recovery timeframe. The areas of focus included the period of withdrawal from activities (i.e., sensory, cognitive, physical, social and psychological) as well as the reintegration period. The participants were still very much within the reintegration period (had not returned to all pre-injury activities), and they shared reflections of their personal progress ranging between 10 to 18 months into recovery. The names of the six primary participants have been changed to protect their identity, and are as follows: Alice, Natalie, Hannah, Mia, Grace and Sadie. Four participants also had a parent involved in their first and/or second interview.

This chapter offers an in-depth description of the six participants' recoveries, originating from the interview, focus group and photoelicitation data. The three research questions will be answered to gain a better understanding of the first-person reports of recovery experiences and what it is like to reintegrate into activities and occupations. The main themes that emerged from coding will be discussed in detail. Main recovery experience themes were: 1) symptom burden; 2) activity changes and restrictions; and 3) emotional and psychosocial sequelae. Further subthemes of recovery experiences will be unpacked below. Main facilitator themes of recovery were: 1) emotional support; 2) recovery toolkit; 3) energy allocation and pacing; and 4) meaningful activity. The barrier theme of recovery was personality characteristics. Finally, overarching interpretations of reintegration were described through the following themes: 1) loss; 2) trial and error; and 3) invisibility.

7.1 Participant Vignettes

The study participants consisted of six adolescent females (age range 15 to 18 years). Four (Alice, Natalie, Hannah, and Mia) were recruited from a multidisciplinary health team environment, and two (Grace and Sadie) were recruited from a sports medicine clinic. The profiles of the participants are outlined below and summarized in Table 7.1.

Table 7.1. Summary of participants and involvement.

Participant	Age	Pre-injury Sport(s) of Choice	Time Since Concussion Diagnosis	Reintegration Progress	Caregiver Involvement
Alice	16	Two individual sports.	18 months	Part-time school moderate load	-
Natalie	18	Two competitive team sports; competitive individual sport; school-based team sport.	17 months	Part-time school moderate load	Mother at first interview
Hannah	17	Competitive team sport.	17 months	School-type work	Father at first and second interview
Mia	18	Competitive individual sport; school-based team sport.	10 months	Part-time school light load	-
Grace	15	Competitive team sport.	16 months	Part-time school moderate load	Mother at first and second interview
Sadie	15	Competitive team sport; school-based individual sport and team sport.	13 months	Full-time school	Mother at first and second interview

Alice was a 16-year-old involved in two individual sports. She sustained a concussion at school while engaged in recreational activity on the schoolyard. She also identified herself as an art student. She was in second semester of grade 10 at the time of data collection.

Natalie was an 18-year-old member of a competitive sports team. Her three secondary sports of interest were also competitive in nature – two team sports and one individual sport. She presented her experiences with her second concussion, which occurred during her primary sport of interest. She was enrolled in second semester of grade 12, taking a reduced course load. Natalie’s mother was also involved in her first interview.

Hannah was a 17-year-old member of a competitive sports team. She sustained a concussion in a game time setting. Prior to the concussion, she also enjoyed participating in instrumental band where she played the flute. She was taking grade 10 and 11 courses on a part-time basis. Hannah’s father was also involved in her first and second interview.

Mia was an 18-year-old member of an individual sport and a member of a high school sports team. She sustained her concussion during a game-time incident with her primary individual sports team. She was an active member at her sports club, where she coached younger athletes and volunteered her time on a weekly basis. She was enrolled in a grade 11 course.

Grace was a 15-year-old member of a competitive sport who sustained a concussion during a game time incident. She was enrolled in second semester of grade 9 at the time of data collection. Grace’s mother was also involved in her first and second interview.

Sadie was a 15-year-old who engaged in a competitive individual sport. She sustained a concussion during a sport practice setting. She also participated in both a school-based individual sport and team sport prior to the concussion. She was enrolled in second semester of grade 9. Sadie’s mother was also involved in her first and second interview.

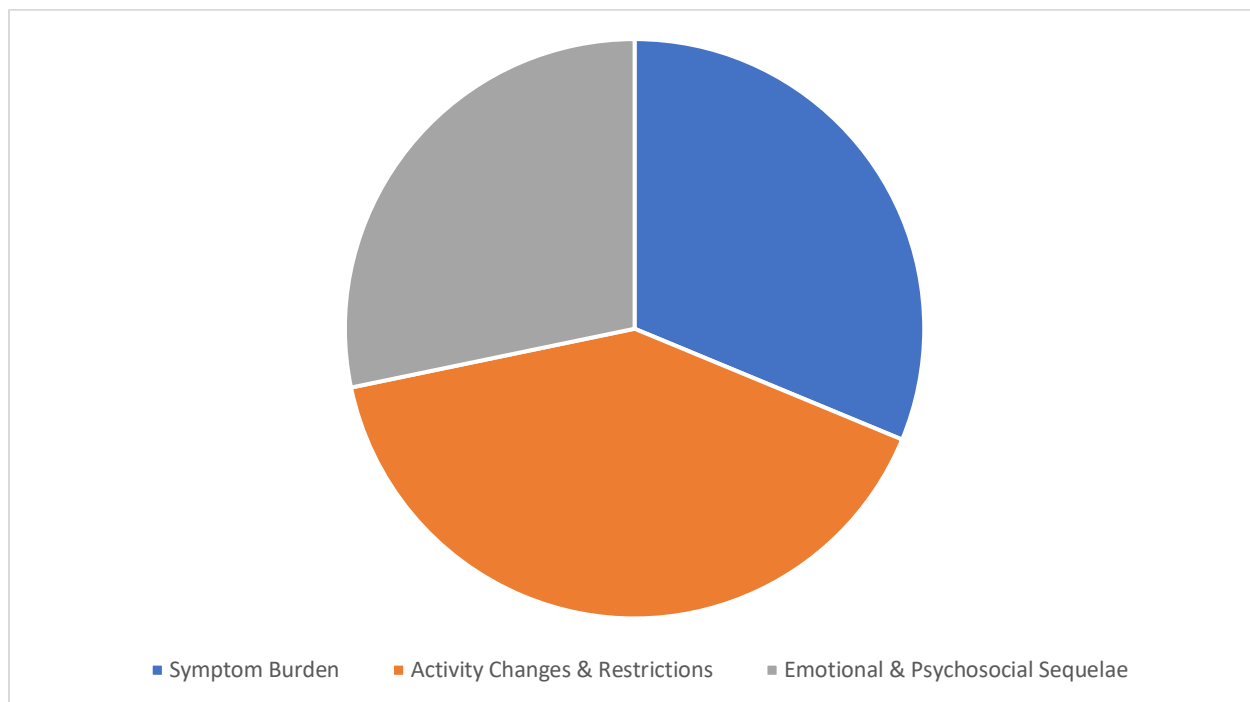
7.2 Research Question One: Recovery Experiences

The first research question asks: *how do female adolescents who have sustained a concussion through sport participation (e.g., game, practice or recreational setting) describe*

their recovery experiences of return to school, return to sport and return to occupation?

Through the analysis of the data collected to address this research question, three main themes emerged: 1) symptom burden; 2) activity changes and restrictions; and 3) emotional and psychosocial sequelae. The frequency of coded themes can be visualized in the sunburst in Figure 7.1. During data analysis, hierarchy sunburst charts (or pie chart graphs) were used to assess the number of coding references and number of items coded at each thematic node to get a sense of the frequency of themes. The visual sunburst allows for a comparison of the amount of coding at each node (i.e., some nodes contain more coding references than others). It allows for a visual representation of the prominent themes in the project. Each theme will be explored within the following sections.

Figure 7.1. Frequency sunburst of recovery experiences themes.



7.2.1 Symptom Burden

All participants perceived that the concussion symptoms they encountered influenced their experiences of regular daily life and how they functioned in day-to-day activities. The subjective prevalence, frequency, and severity of symptoms placed a physiological and psychological burden on patients, and produced negative emotional responses. The main symptom that was collectively experienced by all participants was the presence of headaches. Symptoms outside of headaches were also experienced, but less frequently. Additional symptoms reported by all participants were: impaired proprioception, visual disturbances, and sensitivity to external stimuli (i.e., light, sound, movement). Table 7.1 outlines the hierarchy of symptoms that participants collectively referenced. Symptoms reported to a lesser extent by some participants were: emotional lability, dizziness, nausea, trouble sleeping, difficulty concentrating, memory disturbance and impaired temperature regulation. Headaches, impaired proprioception, visual disturbances, and sensitivity external stimuli will be discussed below.

Table 7.2. Hierarchy of symptoms that participants referenced.

	Symptoms Referenced (from most to least common)
Symptom Burden	<ol style="list-style-type: none"> 1. Headache 2. Impaired proprioception 3. Visual disturbance 4. Sensitivity to external stimuli

First off, headaches were part of the constant reality for participants and were experienced on a daily basis during concussion recovery. The quality of the headache pain was reported as “*pressure.*” The progress in recovery dictated the localization of headache pain – headaches early in recovery were often localized to the front forehead region and with time they became less localized. Alice described the quality of her headaches in the quotation below:

I have excruciating headaches. It almost feels like my skull...like my brain is trying to break through my skull but someone is also drilling into my head. They are mostly in the back and the top of my head. And they don't really change, they're always there. It feels like someone is pulling really hard and there is that added...it feels like your skull is trying to break.

Natalie also describes her headaches:

It just feels like pressure like in my head. Like there's a difference between headache that I may get before [the concussion] from working too much or something like that. A concussion headache is more pressure...but other headaches just hurt a little bit. I don't know it's definitely different it's more pressure. It feels like my brain is like swollen and was pushing on my skull.

The participants also discussed the intensity level of headaches. Varying levels of pain was experienced on a daily basis, but participants reported that headaches were “*always there*” during recovery. Hannah's father described the level of her headaches below:

There are some days that she says her headaches are only 4/10 [on a pain rating scale]. Which for her...is fabulous. I would like to hear 0 but we haven't heard that yet. But 4/10 is a big improvement. Most days she rates from a 6 to 7...that's an operational level. When she gets around 8 that's when we have to start changing plans for the day.

Hannah described the intensity of her worst headaches:

I have really bad days where even the motion of walking...it feels like my head starts pounding and splitting. And then I can't even walk. I have collapsing episodes.

Alice shared a photo titled “The Brain” which she captured to help onlookers understand what it is like to experience concussion headaches (see Photo 7.1). She goes on to discuss how headaches were her most prominent symptom, and that it felt like someone is “*pulling really hard,*” like hair ties would pull on your scalp when they are too tight. She described the varying levels of headaches she experienced:

I put different hair ties because different ones give you different headaches. The coil ones are supposed to be painless but really they are not. So I kind of interpreted that as...well those are my soft headaches. And then the normal ones [hair ties] are like my medium headache. And then there's the elastic elastic ones [hair ties]...like those tiny tiny ones...those are my worst headaches.

Photo 7.1. “The Brain” by Alice.



Headaches were reported to be constant after the injury, fading to a dullness “*in the background*” over time. However, there were also times when severe headaches would resurface – often after a period of overstimulation, engaging in activity (too much or for too long), stress, lack of sleep and sometimes for no identifiable reason at all. There were days when participants reported that the headaches would be so severe, that they would have to resort to a low stimulation environment (dark and quiet) to rest and sleep. On these days, additional symptoms (e.g., nausea, dizziness) may also escalate and/or emerge in addition to the headache pain. Mia talked about her fluctuating headaches below:

Like I always have a constant headache but then I have those days where I’ll have a peak [low headache intensity] where I’m doing better. Like I will still have symptoms and headaches but they are so mild I can just push them back and I don’t think about it. And

then it drops very very low like to the point where I just get so frustrated and don't want to do this anymore.

Headache fluctuations were also described by Hannah:

The headaches are the really the big one...it's just so debilitating, all the pressure in your head. So overall it gets better but definitely changes from day to day. Some days it's much worse and everywhere, and other days it's just really bad and at the front. It also tends to come with stabbing eye pain, and sore eyes and that type of thing.

The second most commonly reported symptom was impaired proprioception – described as the body's ability to perceive its position in space. The participants described this situation collectively using phrases such as “I can't feel my body,” “my perception is off” or “I'm clumsy.”

Mia stated, “I don't feel like I'm in space, but I don't feel like I'm in my body.” Next to

headaches, impaired proprioception was particularly troubling to participants – creating distress.

Natalie described her experience with proprioception issues while handling dishes in the kitchen:

My mom had to buy new glasses. I was not allowed to set the table and I was not allowed to unload the dishwasher because I would always break the glasses or dishes. I would go in reach for it and it would not be where I thought it was and then it would fall. And I wouldn't even...like I would go to reach not even thinking about it and then it would be on the ground. I'm like oh shoot there's another glass broken. It was just stuff like that. My perception was and still is off.

Hannah described her experiences of proprioception, when she walked down a hallway at the multidisciplinary care team clinic:

I had to turn my head and look here, and I had to turn my head there and then walk. I just zigzagged everywhere, and it was a disaster. I was wondering why I was always kind of doing the grapevine to the side when I was walking...all the time. And they [healthcare team] said it was because my brain and my body...like my brain doesn't know where my body is so it just messes up when I'm walking.

Alice shared her experiences of proprioception in her photograph titled “Stairs of Doom” (see Photo 7.2). The following quotation described the photo:

I had a lot of trouble with stairs and keeping my balance. They were kind of my enemy for a long time, so I didn't like to go near them...I despised them. I can't keep my

balance anywhere especially the stairs. (...) I just don't know what my body is doing sometimes. My depth perception is off.

Photo 7.2. “Stairs of Doom” by Alice.



The next symptom, visual disturbances, was also reported by all participants. This was largely described as the eyes “*having difficulty working together*” as well as abnormal eye movements. Two participants, Alice and Mia, also reported losing their peripheral vision, which was identified months after the initial concussion diagnosis. Hannah described her visual disturbance in the following quotation:

Quite often one eye would go off to the side and the other one would stay forward. I looked like a chameleon.

Mia explained the visual disturbance as:

The best way to explain it is that your eyes don't move properly. Like you have to strain your eyes, which is a problem as to why we can't read supposedly. It can be really overwhelming when there's a lot of writing on the page. My eyes become lazy and they don't really work properly.

Natalie discusses the use of prism glasses to help correct her visual disturbance. She captured a

photograph that she titled “New Glasses” to share her experiences with vision changes (see Photo 7.3). She described the role of her prism glasses in the following quotation:

When I was looking at the papers it was blurry because my brain was trying so hard to put the two pictures that my eyes were seeing together. But I couldn't do it. Basically they [glasses] put the two pictures from each eye together. It was just to force my eyes to space out and move apart a little bit. It was like I was crossed eyed. It was like looking at everything cross eyed and I couldn't see anything properly. But then it [glasses] would push my eyes apart and my brain would know it was two pictures and then they [eyes] would work together.

Photo 7.3. “New Glasses” by Natalie.



Finally, sensitivity to external stimuli was a frequently referenced symptom. Certain stimulation in the environment would often overwhelm the senses of participants and create a situation of discomfort and progressed to intolerability if they remained within the high

stimulation environment. Participants experienced light sensitivity, sound sensitivity and motion sensitivity. Light sensitivity occurred when the level of light in the environment was too bright.

Sound sensitivity occurred when the level of noise in the environment was too loud. Motion sensitivity occurred when the level of motion in the environment was too abundant.

Environments with high external stimuli often resulted in increased headaches and the emergence of additional concussion symptoms. Hannah described the light sensitivity she experienced in the following quotation:

It [household lights] seemed too bright and my eyes were really sore. And it just felt better to not look at it. It felt like looking at the sun and I was like I can't look at this at all.

Alice shared a photograph titled “Too Bright” to demonstrate her experience of light sensitivity (see Photo 7.4). She discussed that when she was out in the community, lighting was an obstacle and brought on headaches:

I had a headache and I was sitting there [in a restaurant] and we were finishing our lunch. And I was just like wow my head has gotten worse since I've been sitting here. I looked up and um...there was a really bright light. I don't even have to be looking at it and it bothers me. I was just like wow. This light is really hurting my head. And it's just...the brighter light, the bigger the headache.

The experience of sound sensitivity was also described by Alice:

My head could not handle loud sounds or even like minimal sounds for a very long time. Even people talking annoyed me. Basically, everything annoyed me. I just liked peace and quiet.

Photo 7.4. “Too Bright” by Alice.



Motion sensitivity was often referenced by participants when talking about crowds. The movement of people around the individual was bothersome and resulted in dizziness, increased headaches and sometimes “*panic*.” When a participant with a concussion was moving (i.e., walking) within a moving crowd, the experience of motion sensitivity became even more pronounced. Grace explained how she felt during a period of motion sensitivity:

It’s just a lot of people moving around you all the time. Like I describe places as too “peopley.” It’s bright, it’s loud, there are a lot of people moving. I eat in the hall by my locker because it’s quieter there.

Alice also reported:

I don’t like crowds. I just can’t handle it. The noise too. I am not claustrophobic, but it almost feels like I’m claustrophobic when there are too many people. That started after the concussion.

Overall, the constellation of symptoms experienced by participants were hard to manage and the reduction in occupations was pronounced. All four of the main reported symptoms described by participants were also physical in nature (as compared to cognitive, emotional and

sleep). Due to the persistence of symptoms, individuals were not able to fully participate in their regular activities for many months. Participants were restricted in their engagement in occupations due to their symptom burden. Symptoms had been experienced for 10 to 18 months at the time of data collection, and although progress had been made in terms of symptom reduction, the progress in recovery was slow and symptoms were still apparent and experienced daily. Due to the persistence of symptoms, negative emotional responses (e.g., frustration; stress) were common when discussing recovery.

A lot of discussion took place surrounding how the symptoms in Table 7.1 impacted daily activities. All participants were at the stage of recovery where they had some involvement in school, so that is the activity that was often discussed. Each individual described an eagerness to get back to school and other occupations, but were also faced with a chronicity of debilitating symptoms. Hannah discussed headache symptoms she experienced in relation to her schoolwork:

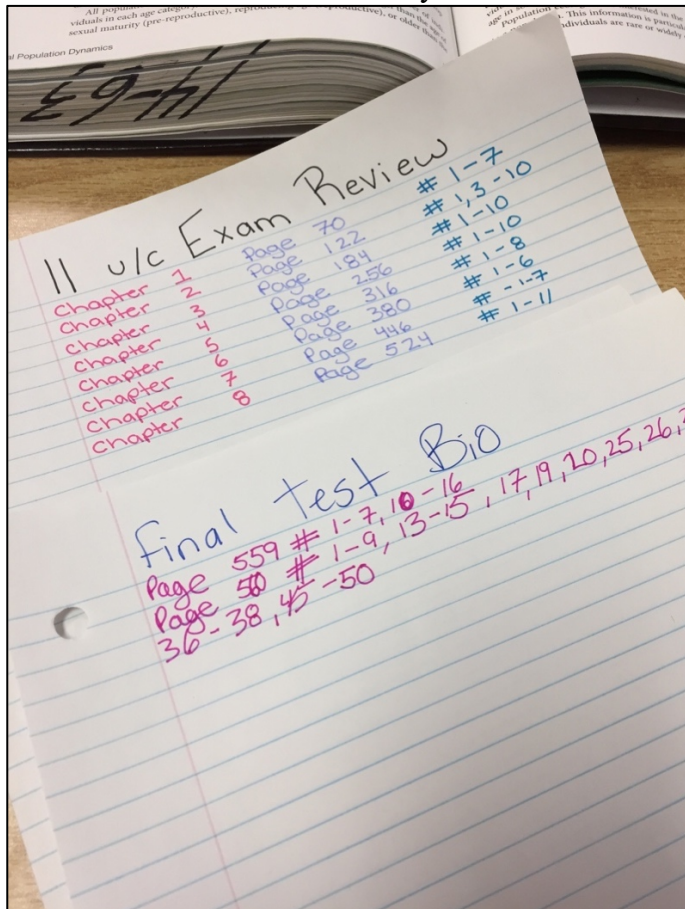
You can't really concentrate on other things as well. Like it's obviously improved since I got my injury but still it's really hard to do schoolwork. It [headaches] sometimes fades into the background but sometimes that is worse...because it tends to get worse and worse and worse when I am doing work. Now I can ignore it a little bit. And then I get to a point where I'm just done for the rest of the day.

Natalie talked about how her headaches would affect her writing, making her work “sloppy,” and she would frequently “mess up” and “miss stuff.” She shared a photo titled “Before and After” which shows the state of organization and neatness of her notes before a headache, as compared to later in the day when she was experiencing a headache (see Photo 7.5):

Some of my notes are printed really neat and nice and the other half will be all messy. It's not that I'm rushing and not that I'm trying to just get it down. It just gets all messed up. That was Math [top writing sample], the period before Biology. But then I had a headache, so I went to Biology to write down the stuff that I was going to miss...like what I needed to do when I went home [bottom writing sample]. So that's the difference between me without headache and with a headache. Every time I have a headache it is

just hard to comprehend. So just looking at it and then going to write it, something gets switched up in my brain. I start messing up and missing stuff at school.

Photo 7.5. “Before and After” by Natalie.



In addition to headaches, impaired proprioception also impacted daily life at school. Maneuvering through the school environment was often a challenge for participants. Natalie discussed the difficulty of maneuvering herself through the hallway at her high school between classes:

My perception was just off. Like I just walked into things. Even like if someone bumped into me...like I'll think I'm getting out of their way, and then they still hit me. I think I'm out of their way, but I'm still bumping into them or walking into the wall. Like my perception is just off. I didn't realize they were there, or they would bump into me and it would be...I don't know how to explain it...but it really...I don't know. I didn't like that very much.

In general, it was reported by participants that the school environment and activities involved in schooling overwhelmed their senses. Light, sound and motion sensitivity were apparent, often occurring simultaneously within the school environment. Mia discussed how the school environment overwhelmed her senses and resulted in “*panic.*” Similar to the experiences of other participants, Mia often had to remove herself from school activities and the school environment:

My eyesight and the loud noises I can't handle...it makes me panic because that's not who I used to be. It becomes hard and noisy and crowded and you don't know where you are. It's really hard to explain...you just feel lost in the sea of people at school. There are days where my body shuts down and says not today.

Alice described her experiences of writing a high school exam, and how light sensitivity escalated her headaches and irritability:

Sitting there in the exam is hard because I'm going to get a really bad headache from concentrating too hard. The lights are going to be way too bright and I'm going to get more of a headache. And I'll probably get irritated because I can't figure out this question because I can't remember anything.

Sound sensitivity was especially apparent in participants who were involved with music class at school. Both Sadie and Hannah reported that after their concussion, they were unable to continue with instrumental band class and clubs. Sadie talked about how sound sensitivity became apparent during her string instrumental music class. She discussed the notion of the sounds being intolerable:

Even music...I was allowed to leave music class. I loved music because they did string instruments. But once I had a concussion, I had to give it up. It just drove me crazy. I had to go to the library where it was quiet. I was off music for the rest of the year.

Finally, motion sensitivity in the crowded classrooms and hallways at school often resulted in negative emotional reactions for the participants. Natalie discussed her inability to go to her sporting centre and school due to her the motion sensitivity she experienced in crowded settings:

I would sometimes be scared to go out...to go to [my sporting centre] or to go to school because of the crowds. I didn't feel like I knew where I was. But just in the moment when everyone was everywhere, and the little touch all of a sudden...I was done, and I was crying. So yeah. That was the worst, crowds were my enemy.

7.2.2 Activity Changes and Restrictions

All participants collectively eluded to the idea that as compared to before their concussion, activity involvement changed and was restricted during their recovery. Participants discussed their activity involvement prior to their concussion, reporting how their schedule used to be full – using language such as “*busy*,” “*very active*” and “*no rest*” to describe day-to-day life. They talked about an eagerness to return to their previous activity level, but how this was largely unattainable given their symptoms and stage of recovery. An interaction between participants within the first focus group outlines the drastic activity changes that take place after a concussion:

- Hannah: *Your life gets derailed basically after a concussion.*
 Natalie: *Yeah, like you see all the happiness that is happening around you...you qualify for [a provincial competition], you are playing [your favourite sport] at competitive level and you love it. And then boom...*
 Hannah: *You can't even get out of bed.*
 Natalie: *Yeah. Your goal is going to be going to one class and maybe being able to stay for even half of it.*
 Mia: *You feel like you're living somebody else's life because life is just not as you remember it.*

All participants referred to a period of rest that preceded activity reintegration. They discussed spending a period of time in a dark room, removed from stimulation and activities (ranging from 1 to 8 weeks). In this time, participants focused on complete rest, avoiding sensory stimulation and daily activities. Hannah shared her experience of rest:

They [treating healthcare provider] just said I was concussed, and I had to go home and rest with no screens. No reading...nothing...just sit in a dark room basically. And rest for a few weeks. And as time went on, they started to lift certain conditions. The rest period was around six weeks...maybe eight. What do you do for eight weeks in a dark room? Basically, you lose your mind.

Mia also discussed her one-month long rest period:

Well at this time, the studies showed that sitting in a dark room doing nothing was the way to recover. So, I sat in the dark hole called my bedroom. Didn't eat...drank a little bit maybe and slept a lot. That's pretty much it honestly for the first month.

Alice described a similar experience:

I sat alone in a dark room...I was just sitting in darkness and that's what it felt like. It was very isolating and not fun at all. Occasionally listening to audiobooks if my head could handle it. And I slept a lot. Then after two weeks my headache lessened, and I was starting to feel little bit better. I just remember being so excited when I could come out of the dark room and into regular spaces. So, I would go out and have minimal time reading. I basically read or just listened to music or drew. And I could only do it for like 20 minutes time and then I have to take a break.

After the period of rest, participants reported how they began trying to reintegrate activities while also managing their symptoms. The participants often talked about how their life “fell apart” or “went to shit” after the injury when referencing the reduction in activities. There was a sense of loss in terms of activity involvement that was felt during recovery. The loss also stemmed from the change in identity that the participants felt after the reduction of their activities (i.e., athlete; student; friend; artist). Alice discussed the collective loss of her pre-concussion activities below:

I couldn't do all the things I wanted to do. I couldn't do [my individual sports] with my mom...we used to do that three times a week. So, I couldn't do that anymore. That was one thing gone. I'm also a vocal student or I was...but that was taken away because it was just horrible for my head. I couldn't do that. Even doing art...I'm actually an art student I guess you could say. I couldn't do that a lot because it was a lot of concentrating. So, my life just kind of fell apart in my mind.

The four main activities that were impacted by all participants during recovery were: academics and school; social involvement; sport and physical activity; and extracurriculars (see Table 7.3).

Each of these four activities will be discussed in detail below.

Table 7.3. Hierarchy of activities that participants referenced.

Activity Changes and Restrictions	Activities Referenced (from most to least common)
	<ol style="list-style-type: none"> 1. Academics and school 2. Social involvement 3. Sport and physical activity 4. Extracurriculars

First, academic and school activities were discussed frequently, likely due to the fact that all participants were in a stage of recovery where they were participating in school to some degree. The return to school in some capacity (i.e., attending school for some part of the day to engage in coursework) occurred within a range of 1 week to 4 months for participants. During recovery, participants attended school for partial days or took a lighter course load. No participants regularly completed coursework in an at-home or online format (aside from homework and days missed). Only one participant, Sadie, attended high school on a full-time basis with a full course load at the time of interviews. In the following quotation, Grace talked about how school participation looked a lot different during her recovery:

School was a lot different. Like when I got to school there was a lot of stuff I had to catch up on. But the teachers were pretty good in the sense that I didn't have to do some of the assignments and stuff like that. But it was a lot different. Just like going in there I thought I could do what I was doing before, but I couldn't.

Mia also discussed how she wasn't able to participate in school to the level she wanted to:

You just feel so alone and then...and everything feels like it's changing and not working. I'm not at school full-time and I'm not handling hard courses like I usually would be.

The participants also discussed how the burden of symptoms would result in inconsistencies in their school schedules as compared to their schedule before the concussion. They would have to miss school days, leave school early, and take breaks from schoolwork in response to the symptoms they experienced. At 17 months into recovery, Hannah discussed how her schooling remained inconsistent:

Right now, I do schoolwork in the resource room. Only like maximum two to three times a week for an hour. And I often miss several weeks because of my symptoms or collapsing or whatever. It's not very consistent at all yet.

Natalie also talked about how changes in symptoms occurred day-to-day, and would impact her ability to engage consistently in school activities:

I'm just trying to get through the day at school. Like some days I don't make it till the end and some days I do. Most days I can make it now.

Taking a break partway through school activities due to symptoms represented an activity change that all participants experienced. Although participants were willing and eager to move forward with schoolwork, they also had to learn to step back frequently and rest. Natalie shared the photograph titled "Taking a Break" (see Photo 7.6) to illustrate the need for breaks, but also to share how it is often difficult to take a break or rest when in the school environment:

If you don't understand something just taking a break, leaving it and then coming back to it. Like if I don't understand something, I'll just go back to it later. When I'm feeling better and maybe I'll do better. It's a lot easier at home to take breaks than at school, just because I can go to my room and take a nap. But at school it's more like me taking myself out of the classroom. I find that hard because I don't want to miss something...that just stresses me out. That's why it's harder for me to take a break or take myself out of the situation at school.

Photo 7.6. “Taking a Break” by Natalie.



In an effort to maintain consistency in school participation, there were often times when participants would “*push through*” their symptoms in an effort to get schoolwork done or maintain activity engagement. This undoubtedly resulted in a rebound of symptoms and poor functioning. Participants would commonly exceed their symptom-exacerbation threshold. Alice talked about her attempt to start back to school full-time after a summer break of reduced symptoms:

I went full in...it [school activity] was non-stop. I didn't take any breaks. About a month in I was not okay, so I got a lot of accommodations. But I went in without telling anyone and I wouldn't take breaks.

Grace's mother also discussed a period of increased engagement at school, and how symptoms resurfaced:

But then it wasn't good. The next couple weeks of school were...and...they were terrible. I think she just...people, fluorescent lights all the time. At that point she was really struggling with all three of her classes and Phys ed [gym class]. So, she's not doing Phys ed now...she has a spare. So now she spends a period in resource which gives her time to work on the other classes.

It is important to note that school was the main focus for energy allocation during recovery. School participation was also the first activity to be reintegrated consistently in the participants' schedules (as compared to the other three activities listed in Table 7.3). There were references and discussions about how participants had “*no choice*” and “*just had to*” in regard to school participation. Prioritization of school over other activities was highlighted by Hannah when asked “*what is your main goal moving forward*” by the interviewer:

Probably going back-to-school. But that's not going to be fun because I'm going to be in a grade lower than I was, with people who are younger than me. So, the courses I'm going to be taking will likely be some grade eleven and some grade ten. My schedule will be very messed up. But I just need to get some credits so I can get through this and move onto university...and have a better life.

Grace and her mother also discussed the idea that school was prioritized over other activities.

When asked by the interviewer, “*what activities do you allocate your energy towards,*” the follow responses were shared:

Grace: *School.*
 Mother: *It's not optional so...I don't know if she chose it so much.*

Within the interactions with the participant that followed this quotation, Grace's mood shifted to annoyance and frustration with her recovery situation. The conversation structure also shifted to one-word answers about how she was not able to comfortably (i.e., without symptoms) participate in the activities in which she wanted to engage (e.g., her sport of choice; hanging out with friends). She said that she “*really didn't have anything else to do*” aside from school.

Social involvement was the second most frequently referenced activity change and restriction. However, unlike school participation, social involvement was only engaged in when the opportunity presented itself and was viewed as less mandatory during recovery. Participants expressed that they definitely wanted to interact in social situations and with friends, but they

had fewer opportunities overall. Sadie discussed how her interactions with friends at her individual sport club reduced after her concussion:

I've been [participating in my sport] with the same girls for...this year would've been nine years. We still talk, but unfortunately, I don't see them as much. We would see each other like three to five times a week and now it's like once a month when I possibly see them.

Participants collectively reported that, since they were not at school or at their sport practices and competitions/games, there were less opportunities for social engagement. Alice discussed how not being at school impacted her social life:

I lost a lot of friends because I wouldn't be at school...and they [friends] would find new people. I had people that stuck by me, but it's hard when you're not there. And I understand where they're coming from because when I'm not there to be their friend it's hard.

The participants also reported that the majority of their friends before the concussion had a lack of understanding for prolonged concussion recovery and Post-concussion Syndrome (PCS). Mia described how many of her old friends didn't understand her condition:

They [interactions with friends] changed a lot. Like because my friends don't really get it. It's hard to explain to anyone...like what's going on with me. I've had a concussion for almost two years...they don't really get that.

Three participants (Natalie, Mia and Sadie) made it clear that male peers in particular, did not understand the magnitude of their condition, and often “called them out,” denying that they were even experiencing symptoms. They would say that the participants were “faking” their symptoms. Natalie discussed an interaction with a male peer at her school:

Some of the guys at my school were just mean. They just always said stuff...well they still do. I remember going home crying one day to my mom. He just did not understand. I think I went to the resource room or something...and I went, and he was there and said I wasn't even allowed to be there. He was saying how messed up I was and all this. And he said this doesn't really happen when you have a concussion. He was like he's had ten concussions and he's fine. And I just went home to cry.

Situations when peers displayed a lack of understanding for concussion recovery experiences, created negative feelings and emotional distress. The source of the lack of understanding by peers was the non-normative prolonged length of recovery associated with PCS.

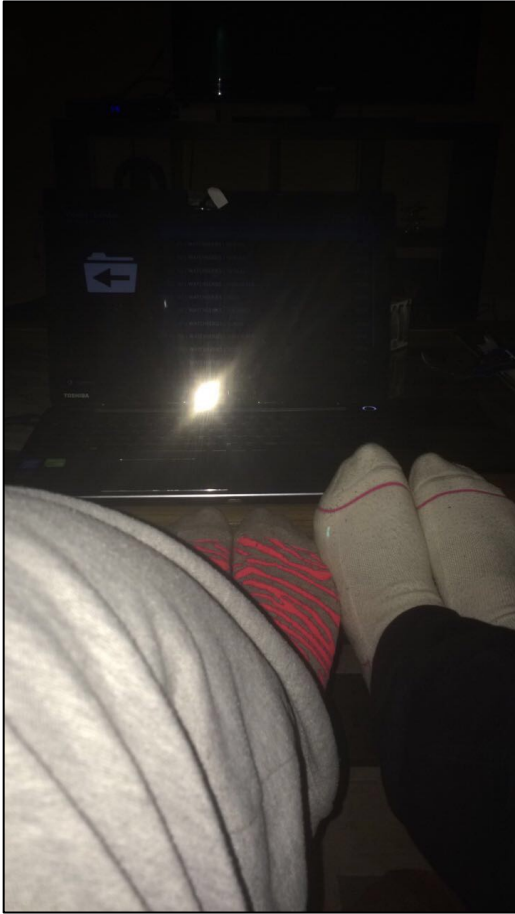
The friends that remained supportive of the participants throughout recovery, were those willing to cater to those with the concussion and make accommodations to the social activities and interactions. But this was not without compromise, as the individual with the concussion also made concessions for the sake of socialization as well. Natalie shared how her friends catered to her needs during a social interaction:

Socially, what I could do changed. Like it wasn't...if I was hanging out with someone it wasn't going out and doing something. It was just coming over and we were just sitting there in the dark room together. But they knew that...they'd say Natalie, I'm not doing anything do you want me to come over? And I'd say yes please. It was different. They'd have to cater to me more. We wouldn't go out for dinner anymore. It would be quieter...just different.

Mia shared a photograph captioned “A Best Friend’s Support,” to demonstrate how her close friend would make accommodations when they spent time together (see Photo 7.7). She discussed the photograph and activity changes in the following quotation:

That's me and one of my best friends. Um I think we are trying to watch the bachelor. You can see that the room is dark, and we are watching off the laptop and not a regular T.V. My friend makes accommodations for me...she's able to turn off the lights and watch on a smaller and less bright screen for me. It's not as preferred to her probably, but she does it. She's been there with me through a lot.

Photo 7.7. “A Best Friend’s Support” by Mia.



Participants also made concessions for the sake of engaging in social activities, but this often resulted in surpassing the symptom-exacerbation threshold. Discomfort due to increased symptoms resulted. Alice described how she occasionally accepted an increased symptom burden in exchange for time socializing with friends:

I will go out with my friends to the mall...which, it is loud there and it's not nice to my head. Or we'll go out to a loud restaurant and get dinner or something. And I know I'm going to regret it, and I know I'm going to have a huge headache, but sometimes it's worth it to be with my friends. I need to get out sometimes.

The next activity that participants referenced collectively as being restricted, was sport and physical activity. None of the participants had returned to their main sport of choice – resulting in a collective sense of loss. There was a sense of loss due to the activity loss but also

the loss to their identity (i.e., athlete). Participants discussed how sport was greatly impacted following the injury. The lowest level of activity engagement was sport and physical activity (as compared to the other three activities listed in Table 7.3). Sadie described how her sporting activities changed and were limited during recovery:

I was always really sporty and active. And always participating in gym class and doing a bunch of different sport activities. And I really had to slow down after that concussion. I wasn't able to do as much stuff. So, like I wasn't able to go skiing with my sisters [recreational physical activity]. That was definitely hard and frustrating. Especially because I had to stop my [main sport of choice].

Photo 7.8. “Collecting Dust” by Hannah.



Hannah captured a photograph which she titled “Collecting Dust” (see Photo 7.8), and described how she was not able to participate in her sport of choice, which was her passion:

I was just trying to show that I don't use it [sports equipment] anymore...and that was my life. It is just put off to the side collecting dust. So yeah it was just showing that it's kind of neglected and I don't have sports or anything anymore. I really miss [my competitive team sport] and being active. It is really upsetting because I wanted to be a really good player and then that got taken away for me. Maybe I could've had a scholarship...it was my dream.

Some participants had progressed to walking on a treadmill or pedaling on a stationary bike for minutes at a time, but none were consistently active to the high level of sport they had engaged in prior to the concussion. Sadie was the only participant who was able to go for a short run comfortably without exceeding the symptom-exacerbation threshold (i.e., with no symptoms during or after running). Natalie discussed her experience with limited physical activity engagement during recovery:

I couldn't do anything [physical activity]. And they [medical providers] were like once your symptoms start to get better you can go on the bike and try it for five to ten minutes. And then I would go on it and I couldn't do it. And that would make me more upset. The feeling of someone saying I could try it...and I would get myself all built-up and excited that I can try it. And then I would go and do it, and I was not able to do it. So, then it just felt like I was taking steps back...which I wasn't...but I just wasn't getting any better. So that was hard.

Hannah also discussed her state of limited physical activity and the inconsistent activity tolerance that she experienced:

They've [medical providers] recommended like going on a bike or something...or even going jogging eventually. But at this point I can't even work up to that from walks consistently. My tolerance changes. I have approximate levels that keep changing so it's hard.

Mia talked about how she started light workouts at a local gym to work at progressively reintegrating physical activity:

I also try to go to the gym a lot. I like to do cardio...so I walk on an incline on the treadmill. And I do biking [stationary]...I'm trying to increase speed because right now I have to go really slow or else I get a headache. So right now, I'm working with my physiotherapist to be able to get my heart rate up without getting a headache. So, I monitor my heart rate and everything. And then I take a break and go upstairs and do

abs for like 20 minutes. Usually I'm at the gym for 45 minutes to an hour and then I'm done.

Despite the presence of a low physical activity tolerance, all participants wanted to get back to higher levels of physical activity. Collectively, participants described how during their recovery they would try to get back to physical activity after a period of “*reduced*” or “*low headaches*,” by going for a run or participating in a previously enjoyed sport. They would try to engage in an amount of physical activity that was not a tolerable level and were met with a rebound period of increased symptoms – brought on immediately and in the following days or weeks. Natalie captured a photograph titled “Sports and Physical Activity” (see Photo 7.9) and discussed the rebound of symptoms she experienced after a short jog:

I was all excited in the summer I hadn't had a headache in a week. I really didn't need to talk to the doctors in the summer. So, I didn't have a headache for week, so I thought I'd go for a jog around the block. That was a bad decision...like I ran, and I was fine, and I was so happy I ran...but then for the next two weeks I was just down. It was not good. All my symptoms were worse. The photo looks happy and I got my new shoes to go running. I'm all excited...and then it didn't turn out very well.

Photo 7.9. “Sports and Physical Activity” by Natalie.



Hannah also discussed her attempt to reintegrate recreational yoga after her injury, and how it resulted in an increased level of symptoms:

Once I did this calisthenic yoga video. And I tried doing it. And I think I only did...not even half of the disc...like maybe a quarter or something. My dad wanted to sign me up for yoga classes and stuff because I miss [my competitive team sport] and being active. But I couldn't even do that...I did like 15 minutes and then I collapsed, and I couldn't move for the rest the day.

Participants reported that prior to the concussion, they were highly active individuals, and they had participated in a wide range of sport and physical activities prior to their injuries. They discussed not being able to participate in their main sport, but also that they were unable to participate in secondary and perhaps more recreational sports. Natalie talked about her attempt to participate in a team sport in gym class within the quotation below:

We were doing [a team sport] and I've been on the [school-based sport team] for three or four years so people ask if they could play me and stuff like that. And then that was probably the gym class I did the most...and that's when I actually broke a sweat. But when I actually did something in the gym class that's when...I had to stop, and I went home.

Sadie also discussed how she was unable to participate in recreational skiing following her concussion. She captured a photo titled “Skiing” (see Figure 7.10) to illustrate her lack of recreational sport engagement, and how skiing had not yet been reintroduced:

That's me and my sisters skiing. I haven't really been able to ski yet. But I guess it was just taken away from me. But I'm going to be able to get back into it soon hopefully.

Photo 7.10. “Skiing” by Sadie.



Finally, the remaining activity that participants collectively discussed was extracurricular activity. Activities such as music (e.g., band; choir), school clubs, volunteering and paid work were all put on a “backburner” during recovery – again school was the priority activity and reintegrated into daily life first. Mia discussed the loss she felt during recovery because she was unable to participate in school clubs:

I used to be in a lot of school clubs and everything. And now because all the clubs take place after school, I’m not a part of them anymore. Because I only have two classes and I have to go home and rest or I will be dead [fatigued] after. It was another way to get involved where you felt active in your community. And I’m not anymore and I’m sad about that. But I’m still part of their group chats...and you see them having fun and see them in the hallway at school. And I just feel left out. That was pretty hard.

Hannah talked about her inability to participate in band, which also led to missing out on travelling experiences:

I really wanted to get back into my music. But I can’t handle instrumental or band because it’s way too loud. And flute hurts your head...like all the blowing. I can’t be in band...and in band you get to go on a lot of trips. They went to Canada’s Wonderland and then Toronto. I was even signed up for a New York trip, but I obviously couldn’t go.

The process of getting a driver's licence was another extracurricular activity that was frequently discussed for those of age (Grace and Sadie weren't yet 16 years old, so they didn't discuss this). Alice, Natalie, Hannah and Mia talked about a delay in being able to write the G1 beginners licencing test. Mia was the only participant who prioritized driver's education and undertaking the G2 in-car test, the remaining participants talked about being unable to write and take the in-car test. Natalie's mother discussed how Natalie was unable to complete the written G1 test:

She couldn't go for her license...all of her friends were getting their drivers licenses and she couldn't. She couldn't sit long enough to write the exam for the beginners and stuff. So, she's kind of behind in that regard. That's the reason why we are driving her here.

Hannah also described her reasoning as to why she didn't get her driver's licence during recovery:

I could've got my license, but I don't want to get it with the collapsing. I don't want to kill someone. I don't think a lot of concussion people really take that into consideration. It's not that I think I can actually kill someone...I just don't want to get an accident. Like you could technically get it but it's not safe. I don't want to learn to drive and then forget other things. I think it'll be easier to drive once I'm ready and healthier...and easier to learn too.

7.2.3 Emotional and Psychosocial Sequelae

Participants discussed varying reports of emotional and psychosocial sequelae throughout recovery. Sequela refers to a symptom or condition which is the consequence of a previous disease or injury (i.e., concussion injury). Ultimately, the concussion injury, prolonged symptoms and activity changes, resulted in the development of additional emotional and psychosocial symptoms. The sequelae were less specific to the concussion symptoms appearing at injury onset (i.e., headache, impaired proprioception, visual disturbance, and sensitivity to external stimuli), and more specific to symptoms resulting due to a prolonged lack of engagement over a period of months (i.e., stress and feelings of frustration, depression and

anxiety). Over the course of months into recovery sequelae became more apparent. Mia talked openly about her mood changes and frustration throughout recovery:

And then it [concussion symptoms] drops very very low [inability to participate] like to the point where I just get so frustrated and don't want to do this anymore. I'm not going to lie I had suicidal thoughts in the past about this. And you feel so left out of life and society. I was stuck in a black room for two months. And after I came out, then they said I shouldn't have been in there for that long, and that's going to slow down your recovery. I think they should've told me that when I first got my injury.

In this quotation, Mia talked about the emotional toll of concussion symptoms, leading to an inability to participate in desired activities, which ultimately lead to emotional upheaval and mood changes. More emotional and psychosocial implications of PCS recovery will be unpacked below. The two major subthemes that will be discussed in this section are: frustration; and stress cascade (see Table 7.4).

Table 7.4. Hierarchy of emotional sequelae that participants referenced.

Emotional & Psychosocial Sequelae	Sequelae Referenced (from most to least common)
	1. Frustration 2. Stress cascade

First, a strong sense of frustration emerged as a commonly reported theme and was apparent throughout recovery. When participants reflected on their recovery, there was frustration surrounding medical treatment recommendations. This was especially the case for participants at their first point of care with the healthcare system. Alice discussed her frustration with the care she received at a pediatric emergency room, where she was diagnosed with a concussion:

So, all the doctors were very indecisive about it. And at the hospital...they didn't really know what they were talking about. And it was confusing because half the doctors said I had a concussion and then the other half said I didn't. So, it was very mixed, and nobody really knew how to guide my recovery.

Hannah reported a similar experience when she sought out a diagnosis and treatment at an urgent care centre – with aspirin being the final treatment recommendation:

I went to urgent care first and that doctor did a very...kind of dismissive diagnosis. I told him I think I'm concussed. And he said okay. So, he made me lift my arms, and tested my legs and arms to make sure I could move them up and down. And then he flashed light in my eyes and that's about it. He told me to take aspirin for the pain and that's it. And to go home.

Grace and her mother also discussed the care she received at the emergency department:

Grace: *They told me I had a minor concussion. But we had to wait a long time. And then we got to see the doctor and he said I had a minor concussion. It [treatment recommendations] was really just like...take it easy. Stay away from the [sport setting]...yeah.*

Mother: *I wasn't entirely impressed with our experience at the hospital. He [physician] played football and he figured he had many concussions over the time he played. And said he was a doctor and he was just fine, and she would be fine too. More telling us about his football stories than really telling us what we should do. We went to see her family doctor the following day and we had a little more direction there.*

The initial diagnosis and treatment recommendations participants received from urgent care or the emergency department created a sense of frustration and prompted participants and their caregivers to seek additional follow-up care to get more direction for treatment recommendations.

All participants received care at the same sports medicine clinic during their recovery. This was facilitated by a referral from a family doctor, or by the participants' parent(s) calling the clinic directly. Frustration also stemmed from treatment at this clinic, but only for half the participants – these participants reported attending a “*concussion clinic*,” whereas the other three participants attended regular clinic appointments. All participants were receiving care from a sport medicine physician/resident, it was just the delivery of care which differed. Alice, Natalie and Mia were the participants who reported frustration arising from the concussion clinic.

Natalie described her experiences with the concussion clinic below:

Every week I went there and filled out the same form and concussion papers [symptom questionnaire]. And then they said, oh no change okay, see you next week. And that's about it. And then they told me I couldn't do anything. Every time I would leave there I would cry in the car. Sometimes I wouldn't even make it to the car. Because they didn't help, and they seriously didn't do anything.

Mia discussed her experiences with the concussion clinic, saying how it was frustrating because she felt like it wasn't helping her long-term concussion symptoms:

They don't know how to take care of long-term concussion patients. Most people last a week or a month max. And we are those 10%...the people who have a long-term concussion. Because there are no standards or anything...they are at the end of their wits. However, they did nothing to learn about it, and they can't tell you if it's going to be a long or short recovery. So, the first time you show up they take good care of you because they think you're going to be cured straightaway. And then they just keep checking in on you after that. But the way they check in on you...they don't do any tests or physicals or anything. It's literally just reading a page full of words [symptom questionnaire].

There was a consensus that the concussion clinic was not a great treatment option for individuals experiencing prolonged symptoms. There were feelings of frustration that stemmed from the prolonged symptoms and activity restrictions, and how medical providers were “*not doing anything to actively improve recovery*” and were simply monitoring symptoms. However, when Alice, Natalie and Mia were referred to a multidisciplinary healthcare team at a children's rehabilitation centre many months into recovery, they were satisfied and encouraged by the care they received.

Another source of frustration that was reported by participants was the experience of prolonged symptoms. The concussion symptoms were lasting months and up over a year, and the individuals had to participate in restricted activities at a lower functional level (as compared to their pre-concussion functional ability) for an extended period of time. Since there was some engagement in school for all participants, they often referenced school when talking about this type of frustration. Natalie captured a picture, titled “Time” to display her frustration (see Photo

7.11). She discussed how it took a long time for her to complete school tasks and also how recovery had been long in general:

This one is like a double meaning. It represents just how long everything takes. It just seems to take a lot longer for me to do things. So like homework...it takes a lot longer to try to understand things or copying notes down. It gets frustrating, especially when we are copying down notes and I'm trying as fast as I can. Before the concussion I was very fast just like everybody else. But now I'm always telling the teacher wait I'm not done. I'm just a lot slower trying to understand what's on the board and putting it onto paper. Everything just seems to take a lot longer. And also, just like how long my concussion recovery has been...that also ticks away like the clock.

Photo 7.11. "Time" by Natalie.



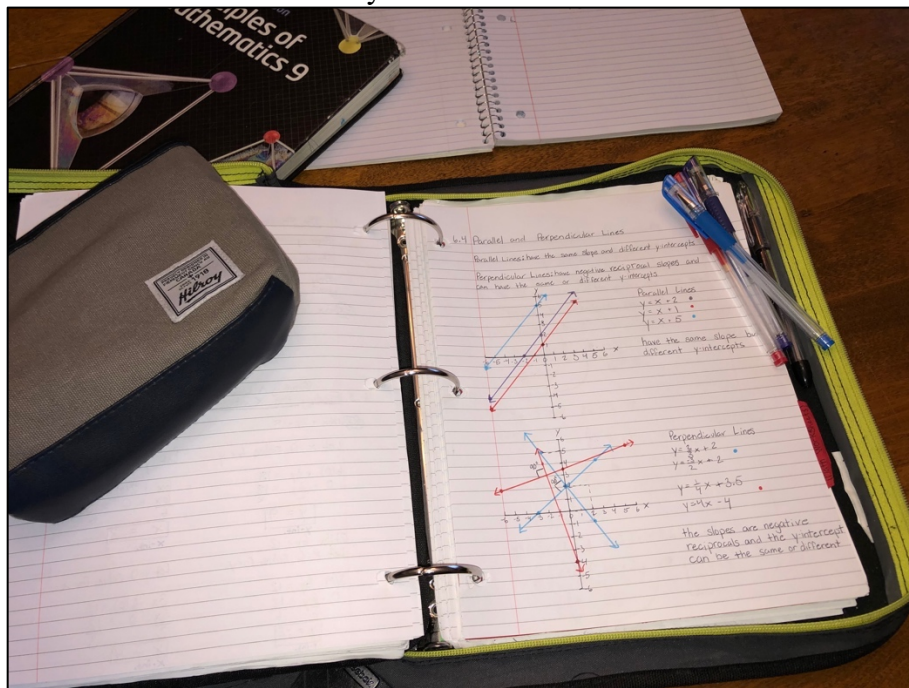
Hannah discussed her frustration with the length of her 17-month recovery and activity restrictions:

I can't make life goals because of my concussion. Like my life goals right now are pretty pathetic...like basically I just go to school and get well so.

Grace also captured a photo titled “Frustration,” (see Photo 7.12) which was complimented by a quotation discussing about how her symptoms dictate school-related activities and how it takes a long time to complete coursework:

That's my schoolwork. School has changed a lot, and the work has changed a lot. Like not only just going into high school but just the way I do my work and stuff. So, I have to work through it in intervals...like I do some of it and then I need to take a break. Even just going to school like I'm so tired after school now and I wasn't before.

Photo 7.12. “Frustration” by Grace.



Participants also reported frustration in regard to others' lack of understanding of their symptoms and activity restrictions. The concussion symptoms were lasting longer than normal concussion recovery trajectories, and comments would arise that would result in distress.

Overall, there was a sense of invisibility – participants used language like, “*they can’t see it*” and “*they don’t understand*” when discussing this type of frustration. A lack of understanding from specifically peers, was the main source of frustration. Mia discussed how many of her peers did not understand PCS recovery and that she felt alone during recovery:

It’s also really stressful when people say oh, I had a concussion and it lasted a week and I’m fine now and you should be fine now too. That gets really stressful because again we are not on the same battlefield. I’m happy that you recovered quickly. I would never wish this on my worst enemy. It absolutely sucks but this is my life, and I need to learn how to deal with it. And people telling me that my life is not challenging and that I’m not going to have these obstacles...it’s just giving me another obstacle that I have to go through. So yeah, it’s definitely stressful. It’s stressful because by the end of the day if you feel like you’re fighting this by yourself. You’re the only one who feels what you’re feeling.

Natalie’s mother also discussed the lack of understanding of those who have not experienced prolonged concussion symptoms and PCS recovery:

You can sit there and tell somebody what you’re going through but unless you’re actually living it...and even as a parent. People ask and think they understand concussion recovery. But until you see what she’s going through and the amount of mood swings, and the pain she’s in...no one really understands. I think we had very little understanding of the potential concussion recovery prior to experiencing this.

Hannah also experienced frustration in regard to her peers at school. Her and her father described how she repeatedly tried to re-connect with friends that were lost during recovery:

Hannah: *No one asked how I was. And my dad heard through my teachers that some of them [peers] thought I was dead. And then I texted a few people and said hey what’s up...and they didn’t answer me. I was like why are you not answering me? I had a hard time making friends in the first place, so I knew I was basically going to lose all of them once I was out [not attending school, my sport and band]. And I even tried texting, and no one cares.*

Father: *I just don’t think the kids understand what’s going on. Like they don’t see anything wrong with her but she’s just seldomly at school. They just don’t know what to do, I think. It is a hidden injury inside the head. A lot of people don’t understand how to respond to that.*

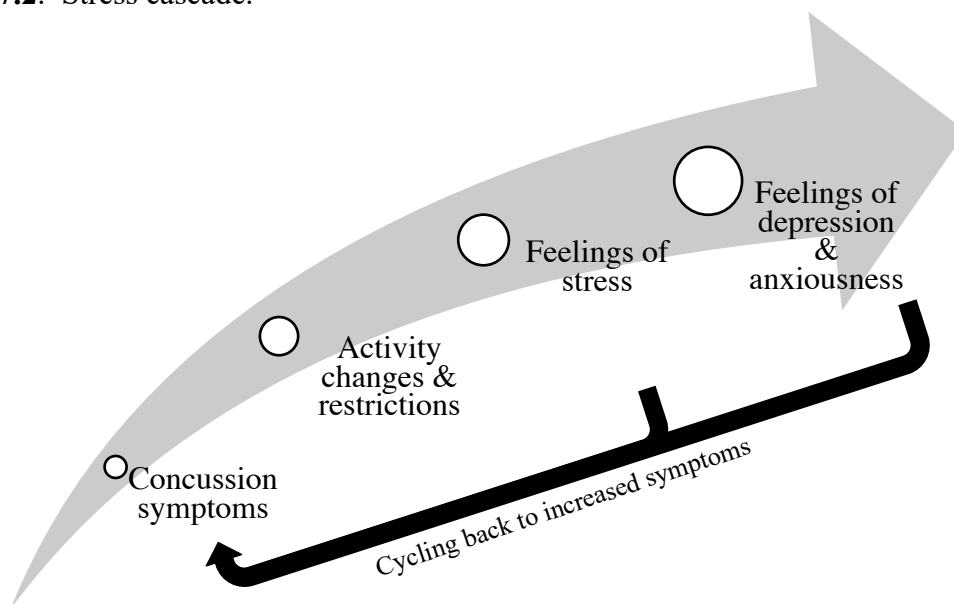
Alice elaborates on the theme of invisibility in the following quotation, saying that it would be easier if her injury could be physically seen by others:

My friend, she recently had to get surgery on her knee. And so, we have two things [injuries] ...so she's in a knee brace and I have a brain injury. It's like people don't see mine so they don't think it's such a big deal. Whereas if you have a knee brace and crutches someone is going to say are you okay do you need anything? It really sucks. I almost feel envious that she has a visible injury.

The second subtheme frequently discussed by participants in regard to emotional and psychosocial sequelae was the stress cascade. This represented a period when chronic concussion symptoms (most notably headache) combined with activity changes and restrictions, produced feelings of stress, which then perpetuated feelings of depression and anxiousness (see Figure 7.2). Consequently, the feelings of depression and anxiousness further increasing concussion headaches. The participants were ultimately overtaxed and described that they were struggling to cope with the situation. Mia discussed the interaction between stress and feelings of anxiousness and depression:

I'm always stressed which makes me depressed. Every little thing just becomes stressful. Like driving isn't supposed to be stressful...but when you think about it even walking is stressful now. So, everything just becomes more stressful because it needs to have more attention after the concussion. There's only so much one can handle, and I know I overthink things, but at the same time all the small worries just get carried out of proportion.

Figure 7.2. Stress cascade.



The prolonged symptoms and disengagement from activities were particularly worrisome for participants, resulting in increased stress. Participants also reported increased stress due to the prolonged recovery and uncertainty about the future. Hannah talked about the stress she felt as a result of being off school for weeks:

Even if you are off for one day sick, there's a lot of work to catch up on. Especially with the semester system you don't have much time. Even when you're going consistently, it is hard to get all your work done. So, I knew missing weeks and weeks and weeks I was going to barely get the credits. And I was obsessed with my marks being eighties and nineties too. I was worried [my grades] were going to drop so much from me being off.

Sadie also discussed the stress and worry she felt in regard to the unknowns associated with a prolonged concussion recovery:

I was just worried if I would ever be able to [participate] the way I used to before I stopped [my competitive individual sport]. Or if I would ever go back to doing things like I used to. It's just any future plans. I was also worried because I was missing so many days [of school] because of bad headaches or being off because of my concussion. I was worried that my grades would drop or not be as good as they are.

Participants discussed how stress lead to additional emotional sequelae. They talked about the multitude of emotions and feelings that surfaced as recovery proceeded. Feelings of anxiousness and depression became apparent with time and were not present within the participant reports of initial concussion symptoms around the time of injury. Alice talked about the feelings of stress and anxiousness she experienced during recovery:

I'm always kind of thinking ahead...and thinking is this really going to be okay? I'm constantly thinking about a million things at once...and I never used to be like that. I used to be able to focus really well, but now I can't focus at all. I kind of just blame everything on my concussion. Um it's probably from other stuff too but the concussion makes it more jumbled. It encourages it almost.

Natalie also talked about her feelings of anxiousness that emerged weeks to months into her recovery, and was largely due to her functional capacity at school:

I get stressed out really easy over little things. And yeah that stresses me out because I'm trying hard. (...) They [medical providers] said I need to stop [worrying]. That's why I was in the concussion support group mostly...because I was trying to deal with stress and find other ways to deal with stuff like that. But it still stresses me out way too much. I feel like I have to do a thousand things and I only have five minutes to do them.

Mia captured a picture titled “Crying” which shows her face with tears and a solemn expression after a stressful day (this photo is not included due to confidentiality reasons). She talked about how she often cries when she feels stressed, which quickly escalates to feelings of anxiousness about her recovery and the future:

Once you start crying it just kind of spirals out of control...because I'm usually crying about one thing and then escalates to thinking about something else. And then you're no longer crying about something small you're crying about the whole picture. Mom always says that I have to break it up and focus on one thing rather than the big picture. She says okay focus on this one thing and get it done today, and tomorrow we will discuss something else. Whereas I'm always looking at the future and can't really focus on the present small steps in between.

Feelings of anxiety and depression were reported by all individuals at some point in their recovery. Most participants talked openly about these feelings, however, it was helpful to have

parents present at some of the interviews, as they were inclined to talk objectively about their child's feelings and mood. Sadie's mother discussed Sadie's depressed mood three to four months into recovery:

She slid a little bit into depression because she couldn't do the things she wanted to do. There were a lot of tears. To walk away from it [competitive individual sport]...it caused depression for her. I had to sit there and watch her go through depression and everything because she couldn't be [there] anymore.

Grace's mother also talked about depression and low mood during Grace's recovery:

I felt that there have been a lot of transitions at an age where...even watching for depression. That goes along with concussion. As a parent, to sort out what is regular 13-year-old behavior and teenage crustiness, and you know...what is depression. We've had some rough, very frustrating days about her limitations post-concussion.

Natalie's mother also referenced how Natalie experienced a depressed mood during recovery:

So, when Natalie was on high, she was on the high and the world was great, but then when she hit a low it was like her siblings would go and hide. So, it was an adjustment, when you live with someone like that. Everyone is involved.

Hannah described her feelings of anxiety and how she used a spray bottle with cool water to calm her body down:

I get really hot...especially with my anxiety. It calms me down if I just spray my face with it [spray bottle]. It's similar to a panic attack. Like if I'm wearing a coat or sweater, I have to get off right away...I start panicking to get it off. And I feel really hot and it won't go away. So, I have to cool myself down immediately.

There were reports from two participants (Mia and Hannah) of pre-existing anxiety and/or depression, and how it worsened or "spiked" during concussion recovery. Mia discussed her pre-existing anxiety and depression, which she had been treating with medication prior to the injury. When asked, "how do you think your anxiety and depression has changed after your concussion," Mia responded with the following quotation:

It totally and completely changed. So before [the concussion], I was already pre-medicated. It's always been an issue. But when I got a concussion...as I said before I'm a very go go go girl...and my head couldn't handle that. So, my head would need me to

stop but my heart would want to keep going. And this made me very anxious as to why I couldn't do [pre-injury activities]. I kept thinking negatively and asking myself why I couldn't do it. And then I get anxious and think oh what if I can't do this later on.

Hannah and her father also discussed a level of pre-existing anxiety. Prior to the concussion, Hannah had received counselling treatment for her anxiety as needed from a therapist – but nothing on an on-going basis. But a few months into recovery, she needed more support for the anxiety, and she was prescribed an anti-depressant medication. Hannah's father described his daughter's anxiety in the following quotation:

She has always had anxiety and she's been seeing a therapist for a number of years for it. But she has never been medicated for it and we never thought we needed that. But once the concussion came...the anxiety and head injury kind of played off each other. The anxiety spiked.

Grace was also prescribed amitriptyline (anti-depressant) several months into her recovery. It was prescribed primarily to treat chronic headaches; however, it would also have a positive effect on anxiety and depression symptoms.

The final result of the stress cascade (see Figure 7.2), was that feelings of stress, depression and anxiety (and diagnosed depression and anxiety) would cycle back and result in increased symptoms (i.e., increased headaches). The resultant headaches started the stress cascade over again and it turned into a cyclical trend. Mia talked about the cyclic nature between anxiety, depression and headache symptoms in the quotation below:

I'm depressed now and I'm anxious for the future...which then gives me a worse headache...and then I get more anxious and depressed. It's just like a vicious circle. And yeah that's huge. It's gotten to the point where my doctors don't know what to tackle first, the headache or the anxiety. Because it is a vicious cycle and they feed off of each other. And with my headaches I get anxiety and then with my anxiety and get headaches. So, it's very hard to figure out what to tackle first.

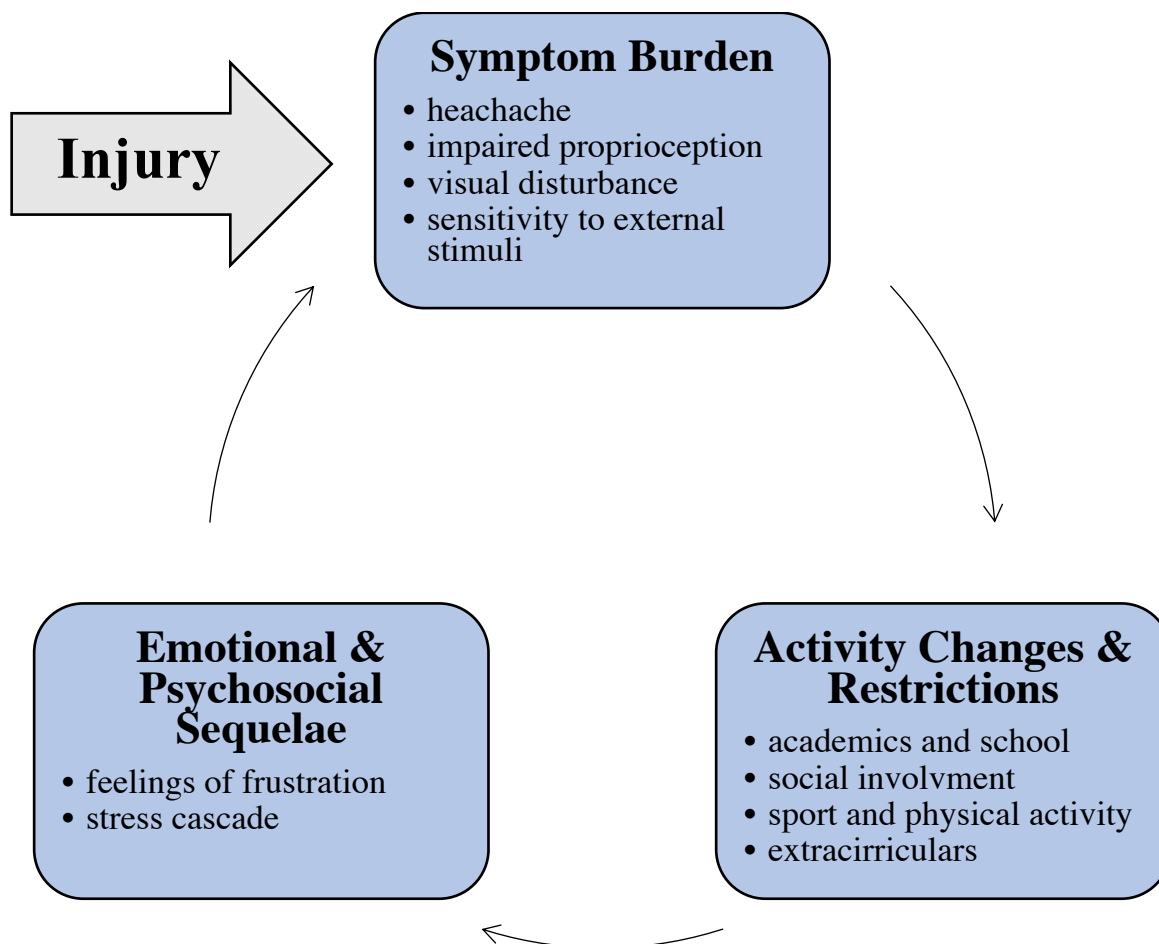
Sadie and her mother also discussed the cyclic nature of stress, anxiousness and headaches. In one instance, Sadie discussed an experience when stress due to the inability to participate in her grade eight graduation trip resulted in a visit to the emergency department:

- Sadie: *I had to miss my trip.*
 Mother: *Oh yes. She had to miss her grade 8 graduation trip. Mhm...that was a doozy.*
 Sadie: *I actually ended up having a really bad headache the day before and had to go to the hospital.*
 Mother: *Yes, I had to take her because her headache was so bad. We ended up right back an emergency.*
 C1: *I had to miss school for a few days.*
 Interviewer: *So, what do you think that headache was from?*
 Mother: *I think it was stress. Yeah it was stress. She had fundraised and paid for that whole trip by herself.*

7.2.4 Interactional Nature of Recovery Experiences

This study found that female adolescents who have sustained a concussion through sport participation describe their recovery experiences of return to learn, return to play and return to occupation in a way that highlighted the themes of: 1) burden of symptoms, 2) activity restrictions and changes; and 3) emotional and psychosocial sequelae. When allowing the conceptual framework (Occupational Risk Factors theoretical perspective) to guide the analysis, it was clear that a cyclical trend between themes was apparent (see Figure 7.3). The three themes identified, interact with each other in a cyclic nature during recovery.

Figure 7.3. Interactional nature of recovery experience themes.



First, the burden of symptoms prevents individuals from taking part in regular activities and occupations. Next, the activity changes and restrictions create an imbalance between meaningful and productive activities. Productive and school activities are prioritized. Then, emotional and psychosocial sequelae become apparent as participants experience a loss of meaning, purpose and identity. The development of feelings of frustration, anxiety and depression (months into recovery), completes the cycle – ultimately adding to the initial symptom burden. Mia discussed how her symptom burden increased in the months following

the initial injury, and how there is an uncertainty as to how to “fix” her condition and proceed in life:

I would say on the daily, the four or five things I deal with most would be headaches, nausea, anxiety and depression. Those would be my four top things that I battle each day. They are little small things that can't be fixed just like that. This has been going on for eight months and it's very stressful. I think the biggest thing would just be the fact that anxiety and depression have also been a huge part of it. And I just noticed new things. It just kind of throws me over the edge. I don't know what it is, but it definitely feeds my anxiety and depression. It's just a vicious cycle. It's a huge problem and I'm still trying figure it out.

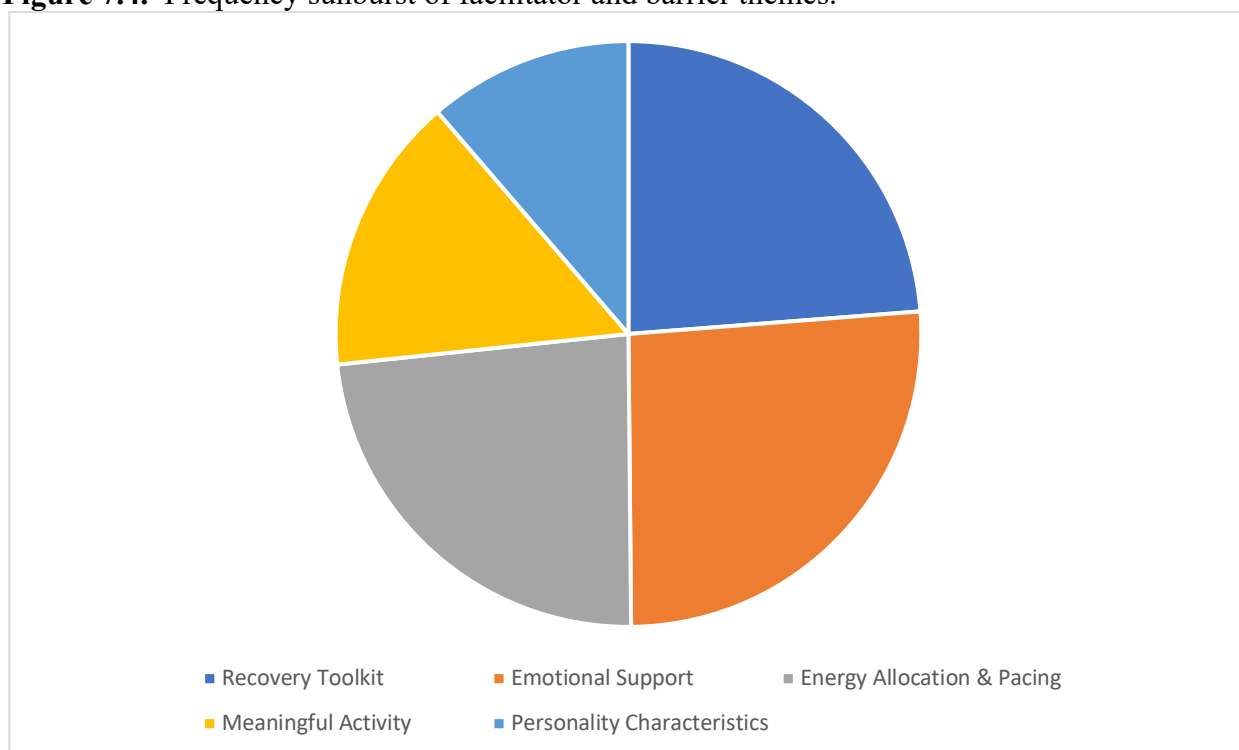
7.3 Research Question Two: Facilitators and Barriers

The second research question asks: *What are the barriers and facilitators that accompany one's return to school, return to sport and/or return to occupation(s)?* Throughout the analysis of data collected to address this research question, four main themes emerged in regards to facilitators: 1) emotional support; 2) recovery toolkit; 3) energy allocation & pacing; and 4) meaningful activity (see Table 7.5). One theme emerged in regards to a barrier: personality characteristics. The frequency of coded themes can be visualized in the sunburst in Figure 7.4. Each theme will be explored in the following sections.

Table 7.5. Hierarchy of facilitators and barriers that participants referenced.

Facilitators	Barriers
1. Emotional support 2. Recovery toolkit 3. Energy allocation & pacing 4. Meaningful activity	1. Personality characteristics

Figure 7.4. Frequency sunburst of facilitator and barrier themes.



7.3.1 Emotional Support

The emotional support that participants received throughout recovery was an important point of emphasis throughout the interviews and focus groups. Emotional support can be described as someone who shows empathy, compassion and genuine concern for the individual recovering from the concussion. This support facilitated feelings of well-being for participants, at a time of uncertainty during prolonged concussion recovery. Mia shared a quotation about the importance of emotional support during her recovery:

To anybody who were to get this [concussion and PCS]...I would say talk to people. Whether they have had a concussion or not. And you will learn who is by your side because it is those people who are helping me survive each day.

There were different sources of emotional support that the participants reported. The most frequently reported were as follows (in order of frequency): i) parental support; ii) concussion

support group; iii) good friends; and iv) pet support. These four sources of emotional support will be discussed further below.

All participants named parental support as their main source of emotional support. Parents were “*always there*” to talk, facilitate activity reintegration and concussion-related appointments. Sadie described her parental support in the following quotation:

They like helped me through everything. They were there through it all. Mom and dad would drive me to all my appointments and stuff.

Grace also discussed how her mother was one of her biggest supports during recovery. She captured a photo which she titled “Parental Support,” to show how her mother improved her well-being during recovery (this photo is not included due to confidentiality reasons). In this photo, Grace and her mother are leaning together and smiling for a photo, while sitting in the front seat of a car. She described the photo in the following quotation:

I put my mom in it because she’s the one who had to put up with me the whole time. Just like she was always with me. She’s the one who took me to all my appointments and stuff.

Natalie also reported that “*my parents...my mom especially,*” were her biggest sources of support during recovery.

Four of the participants were also involved in a concussion support group that was run by a social worker (member of the multidisciplinary care team). This was a 6-week support group where female adolescents with prolonged concussion symptoms would meet one evening a week to connect and share recovery experiences. Those who were involved in the support group found it beneficial during recovery because everyone in the group was going through a similar recovery experience (i.e., prolonged concussion symptoms). Participants described how they could “*easily connect*” and “*relate*” to the other members in the support group. Mia described the members of the concussion support group and how they are very understanding:

They've been a huge part of my life. Just because we can talk about common symptoms. If you want to get support after a tough day when nobody understands your concussion... then you need someone to talk to that can relate to you. And that will be those in the concussion group.

Natalie also talked about the benefits of having someone you can truly relate to in regard to prolonged concussion recovery. She described the role of the support group:

Just like emotional support stuff. And a lot of complaining and comparing between the other girls. But I didn't think it would benefit me at all since I had [the concussion] for a year...like what else can I really be taught kind of thing. I found I learned stuff from the concussion support group. I learned a lot actually. Like I learned how to deal with [recovery] and different coping skills from girls my age.

When the interviewer asked Alice, “what do you think your most effective concussion treatment was,” she responded with the following quotation:

The [multidisciplinary care team] and the concussion support group. (...) I think it really helped. Not just getting over the concussion but just being with people. I could talk to them.

The importance of emotional support from the perspective of someone going through the same experience, was perceived as a facilitator of recovery for the participants.

Having at least one good friend was also reported as a source of emotional support and a facilitator of well-being during recovery. The participants discussed how their friends changed during recovery, resulting in a “handful of good friends.” Some friends’ “true colours” showed, and only supportive friends “stuck” by them throughout the prolonged recovery. Having a few close friends facilitated and improved well-being during recovery. Mia discussed the support she felt from her best friend:

My friend started to come over [to her house] and she would say let's nap together, because she knew I couldn't do anything. So, she was really good. And a big help. And she would fill me in on gossip or tell me about school...just to make sure I didn't lose connection or whatever. She was very patient. Sometimes when I'm crying, I'll say to her you don't even know why am crying. But then she says, yes, I do...it's because of this. And I'll be like oh yeah, you're right, and I'll stop crying and feel supported.

Alice also talked about her best friend, and how simply having a physical presence in the same room helped her to feel supported and have a more positive outlook on recovery. When asked by the interviewer, “*you said that your mom was supporting you, who else tended to support you,*”

Alice responded with the following quotation:

My best friend who I still talk to. He used to come over every day after school if I was up to it. And we would just lay in silence. That’s all I could do but it was really nice.

Hannah discussed how she had always had trouble making friends, and how she lost contact with those few friends following the concussion. During recovery she talked about one friend that remained supportive and understanding:

My one friend from [my competitive sport] team who helped me up when I got my concussion...she’s been checking in and texting me every few months asking how I am. She’s keeping tabs on me and asking how I am and stuff. She is into a lot of sports too, so she understands that I’m injured and miserable and isolated. She’s basically the only one with empathy right now.

Pet support was also a commonly reported facilitator of recovery but was also viewed as a personally meaningful activity (see more about meaningful activity in section 7.3.4). Mia, Natalie and Sadie talked about the emotional support they received from their dogs, and Hannah talked about her parrot. Mia captured three photographs of her dog, sharing stories of how important her dog has been during her recovery. One is included below, which Mia titled “Love of My Life” (see Photo 7.13). A quotation about Mia’s emotional support dog is as follows:

My dog is my life. He’s more than a safety net. I can’t imagine life without him. He’s always been there for me but after this [concussion], even more so. Like my dog knows when I’m not feeling well, and he will guide me to the couch and start to play and I will follow him. Or he will run and hop up on the couch and then I go on the couch. And then I end up feeling really sick or blacking out or just feeling really faint. And when I cry, he licks off my tears. But like he always knows what’s going to happen before it happens. He knows...he knows my limits better than I do. And he’s just always been there for me.

Photo 7.13. “Love of my Life” by Mia.



Natalie also included a photo of her dog (see Photo 7.14). She discussed how the dog comforted her during hard times and provided companionship while she was recovering at home alone. The dog provided a sense of well-being in Natalie. She titled the photo, “My Comforter,” and shared the following quotation:

She [dog] just knows when you're not feeling well or down. She will just come and lay with you and stuff. So that's why I have this picture. Because when I was in the dark room for like a month, she was the only one in the house with me for most of it. So, we just kind of sat there and did nothing together. She knows if I'm going to cry or she knows if I am upset. She will follow me and stuff like that. My dog has been my biggest support, I think.

Photo 7.14. “My Comforter” by Natalie.



7.3.2 Recovery Toolkit

The recovery toolkit refers to a variety of resources, assistive devices, and accommodations which participants learned about and found helpful, throughout their recovery process. The aim of these tools were to facilitate participation and improve functioning for daily life. Over time, participants reported that they developed and aquired a set of strategies and tools that worked to minimize symptoms. The tools were introduced to participants overtime, and by way of many interactions and appointments with a variety of care providers. When participants discussed recovery, they often referred to the process as “*trial and error*,” and that as recovery progressed they found more “*answers*” to symptom- and activity-related challenges. The

consequences of the trial and error approach was outlined well by Hannah's father in the following quotation:

[Treatment recommendations] all kind of compounded [the recovery situation] because you have an adolescent who is being subjected to all these trial and error approaches. She falls further and further behind and becomes more socially isolated...the anxiety level comes up...and depression.

There were frequent references to the idea that not all treatment recommendations by care providers were effective in minimizing symptoms and improving functioning, and that developing their individualized recovery toolkit took several months.

A biomedical approach (i.e., health is biological and treatments aim to eliminate disease, pain or defects) often guided initial treatment strategies, but over time a more holistic or biopsychosocial approach was integrated into recovery patterns. All individuals were taking “a lot” of acetaminophen and/or ibuprofen for symptoms of pain (mainly headaches) during the acute recovery period. However, within the first few weeks and months after the injury, all participants determined that this method of treatment was “*not working.*” Natalie shared a photograph titled “Pain” to represent her shift away from medications during recovery (see Photo 7.15). She described the photograph in the following quotation:

This is just stuff to help me with my headaches. And I did the Advil that was tipped over because [medical professionals] said I should stop taking Advil and start trying to find other ways to manage headaches. And I found this little peppermint oil and it helps so much for headaches and I haven't taken Advil in a very long time. So that's why I put that in there. But the oil facing up because it worked and Advil facing down and empty because it didn't work. You put it [peppermint oil] on your forehead and on your temples and the back of your neck. It's almost like a freezing cold numb feeling and it feels really good. It just takes the headache away.

Photo 7.15. “Pain” by Natalie.



Additional medications were also prescribed to participants once symptoms were identified as being prolonged. Hannah was prescribed an antidepressant for the treatment of anxiety. Grace was prescribed an antidepressant for the treatment of persistent concussion headaches. Both participants reported that these treatments were “*working.*”

Physiotherapy was another first-line treatment for concussion symptoms – all six participants tried physiotherapy in the first few weeks of recovery. Five participants stopped going to physiotherapy after two to five sessions, as they were not seeing any benefits in symptom reduction or functional improvements. Additionally, most participants were unable to participate fully in the suggested strengthening exercises and physical activity suggested by the Physiotherapists. Hannah and her father discussed how trying physiotherapy wasn’t effective during the early months of recovery:

Hannah: *I saw a Physiotherapist...for my neck and balance. But it was too early to see any improvement or really even do the exercises at home. So, we eventually stopped that after a couple months.*

Father: *And we just got to the point where the Physiotherapist would put her in a dark room and put a warm pack around her neck. And she would sit there for over half of it. He would show her exercises she could try but she wasn't able to do them. We just weren't seeing the benefits.*

Some participants also discussed how they had to find a physiotherapy clinic that was accommodating of their condition. The physiotherapy environment at the sports medicine clinic was reported to aggravate and increase symptoms due to the amount of sensory stimulation (i.e., bright lights; noisy; busy gym). Mia talked about seeking out a low-stimulation physiotherapy office in the quotation below:

To get to the office of the concussion clinic...it's at the back of the physio gym...and it's super loud and super busy and crazy. So, my mom said you're absolutely not doing physio here. So, this [new physiotherapy office] is quiet, they work with you one-on-one...and I really like it.

Mia was the only participant who continued physiotherapy throughout recovery. She found it especially beneficial when she was at the stage of recovery which allowed for physical activity integration. She talked about how walking on a treadmill and riding a stationary biking was gradually introduced while monitoring her heartrate and symptom-exacerbation threshold level.

In the following months as the symptoms persisted, a more biopsychosocial approach to health (i.e., health is an interaction between biological, psychological and social components, and treatment planning aims to integrate both the provider's and patient's perspective) was adopted. Participants were introduced and referred to more holistic treatment options (i.e., chiropractor; massage therapy; craniosacral therapy; acupuncture), which were reported to be beneficial for some participants. Four participants were also referred to a pediatric multidisciplinary care team for children and adolescents with acquired brain injuries. The team consisted of a Neurologist, an Occupational Therapist, a Psychologist, a Social Worker and a

School Liason. Natalie described the support she felt and benefits from the initial meeting with the multidisciplinary care team:

The first appointment, um that one helped a lot. They did testing but they already knew what needed to be done, which was good. I got [prescription prism] glasses that day. I got the [weighted] vest which really helped. Yeah I think I support those the most out of everything in recovery...my glasses and that vest. Those two help me the most.

Several months into recovery, participants began to learn about and build a recovery toolkit of strategies and assistive devices that improved their functional level and tolerance for activities. The toolkit largely targeted the symptoms that participants were experiencing, but it was individual to each participant (see Table 7.6).

Table 7.6. Recovery toolkit examples.

Headache	Impaired Proprioception	Visual Disturbance	Sensitivity to External Stimuli
<ul style="list-style-type: none"> • hot/cold pack • essential oils (e.g., peppermint; frankincense) 	<ul style="list-style-type: none"> • weighted vest • compression top 	<ul style="list-style-type: none"> • prescription glasses (e.g., prism) 	<ul style="list-style-type: none"> • sunglasses • prescription glasses (e.g., tinted) • ear plugs

Hannah shared a photograph as an example of the tools she used on a regular daily basis to support her symptoms, which she titled, “The Bare Minimum” (see Photo 7.16). Hannah shared the following description of the photograph:

That is my back pack of all my tools. So there are instant ice packs...so I can just break them and use them [for headaches]. (...) [Musician earplugs for noise reduction], and then spray bottle [for anxiety and temperative regulation] and sunglasses [for light minimization]. I have a headache journal...I use that to write about my headaches. And then an [eyemask for light and motion minimization] and [baseball] hat because sometimes that helps [for light minimization]. So it's just all my stuff. And I carry around a backpack to school and stuff...so it's basically what I need to take with me.

Photo 7.16. “The Bare Minimum” by Hannah.



The breakdown of the main recovery tools that participants made use of are as follows: five used prescription glasses, four participants reported using essential oils, three used compression tops and two used a weighted vest. Hot/cold packs, sunglasses and earplugs were used sporadically by some participants as needed but not by all participants.

A final important part of the recovery toolkit was the accommodations that participants received for school participation. Accommodations are described as an alternation in environment or curriculum format that allows an individual with a concussion to gain access to course content. Participants on a whole were unable to receive accommodations in high school unless they had written documentation from a healthcare provider. Participants reported receiving these accommodations from either a sports medicine physician or through the multidisciplinary care team that they were working with (a process that was facilitated by the School Liason). Individuals receiving their accommodations from a sports medicine physician were provided with a school release form (i.e., when to return to school), and a sport release form (i.e., when to return to sport). Aside from these two release forms, participants did not

report receiving any formal counselling or explicit education for school accommodations, and instead only sporadic suggestions as to which school-related activities to avoid (e.g., avoid school trips; avoid gym). Overall, the focus of these accommodations appeared to be oriented towards reducing the risk of re-injury.

Accommodations from the multidisciplinary health team were facilitated by a School Liason who worked directly with the participant, their families, and their associated school to develop individualized strategies to be used in the school setting. For example, Natalie's mother described how the School Liason helped with individualized accommodations which were assimilated into Natalie's school day:

So right away during our first meeting with them...we started. I think Natalie didn't really realize all of her symptoms until they started talking. Like even just...the one that I can think of the most was probably...the most upsetting for me too...was going through the halls [at school]. So when the bell rang, she would be ducking into a classroom getting all upset and anxious, and then calling me to come and pick her up. But really...she wasn't able to maneuver through the people. So, um, the Occupational Therapist there was the one that had indicated why she was having those issues. And then once that happened it was just as simple as getting out of class before the bell went and not having to maneuver through the halls. You could see night and day improvements when she started meeting with them.

Natalie and her mother also described her accommodations for testing situations at school:

Natalie: *My classes are the same except for tests. Biology is last period and if I have a test in that class I probably won't make it because I'll have a headache by the end of the day...if I do the full day. So I do tests at the beginning of the day during my online peer tutoring class [first period]. So then I don't get there [to Biology class] and then not be able to write. My tests are usually switched or I get them split up sometimes if the test is really big. So I do one part one day and another part another day.*

Mother: *Because just from conversations she was having with the School Liason, they figured out she was the strongest in the morning. So she said why don't you write your tests in the morning? And we were both looking at each other... thinking yeah, why didn't we think of that? It made perfect sense. So she [School Liason] just contacted the school and said either she going to have to have longer time to write the test or it'll need to be in the morning.*

The individualized accommodation plans provided by the pediatric multidisciplinary care team were reported to be beneficial to all four participants who received them, and allowed for increased school participation and the ability to complete course work. These accommodations would put in place for the length of time that participants experienced concussion symptoms.

Two participants required an Individual Education Plan (IEP). Mia had an IEP prior to her concussion, related to an anxiety diagnosis, and she reported that these accommodations continued to be beneficial. Her accommodations became more extensive after her involvement with the multidisciplinary care team. She discussed her combined anxiety- and concussion-related accommodations below:

So now [the IEP accommodations] are a little more extensive. I go in the back room and close the door and shut the lights off. So, I'm allowed to write in the dark. I also have unlimited time. And sometimes I need someone to script for me or work with me one-on-one. I can take as many breaks as I want. I can split the test up into sections. If I can't get through a class, I can just go to the resource room and sit there. It's pretty good.

Hannah acquired an IEP after her concussion. She reported the difficulty she faced when trying to get the accommodations she needed in terms of the concussion diagnosis. Therefore, her new anxiety diagnosis (post-concussion) was used to facilitate the approval of an IEP and receiving the accommodations she needed to participate in school. Hannah's father discussed this difficulty below:

For some reason, in the world of concussion it's a little more challenging to get accommodations. But in the world of anxiety, because they have been dealing with anxiety disorders for so many years, the minute you mention that...oh wow there is a whole new world that opens up for accommodations. So it's kind of the back door way to work around it and get some accommodation for her concussion...by using the anxiety diagnosis. The school just seems very difficult to navigate and rigid with their policies.

7.3.3 Energy Allocation and Pacing

Each participant spent time talking about energy allocation and pacing during the interviews and focus groups. Energy allocation is a strategy for adequately distributing one's available energy reserve between activities, all while remaining below the symptom-exacerbation threshold. Pacing is a strategy for proceeding with activities at a level (i.e., intensity and duration) which maintains symptoms below the symptom-exacerbation threshold. This theme eludes to the idea that the activities participants choose to do, and how long they do them for, impacts the degree of symptoms that participants experience. Ideally, the goal for individuals recovering from concussion is to gradually increase activity tolerance without significantly increasing or crossing the symptom-exacerbation threshold. Participants in the interviews reported that they needed to find the right level of activity whereby their symptoms were eliminated or better controlled. Energy allocation and pacing facilitated recovery, whereas rigidly avoiding activities or chaotically over-engaging in activities acted as a barrier to recovery.

During the interviews, when the interviewer asked participants, "*is there anything you would want to share with someone who has just sustained a concussion,*" five out of the six participants made reference to the importance of energy allocation and pacing. Three quotations in response to the interviewer's question are shared below:

Alice: *Don't push yourself. I know they [individual with a concussion] probably want to go back to their life and just forget it. But you can't ignore the concussion. Returning to activity...you need to go like very slow. If you go headfirst, literally, it's not going to be great. That's my suggestion to everyone. Take it slow.*

Mia: *I would say that you have to work at your own pace. Whether that means schoolwork, actual work or whatever. Taking advice from other people to do this...it will help you. Because everyone's recovery is different. And that's something I learned.*

Natalie: *Don't push yourself. If something doesn't feel right stop. Don't push yourself. That's what I want to share. Something that I don't always follow but it's something that you really should follow.*

All participants discussed energy allocation and pacing in terms of balancing their own activities.

Alice talked about how balancing her activities was important during recovery:

If I'm good to my head the previous day, then the next day I'm going to have more energy. And then if I have a crazy day then then the next day won't be good. It really just depends on the day and activities before.

For all participants, the main activity that was prioritized was productive school activities. Natalie discussed how she had to balance her energy between school, physical activity and work in a way that prioritized school on weekdays:

It's either school or sports. So right now, it's school and not very much activity. On the weekends...like on Saturday, is when I do something a little bit more active. So, like I have this app on my phone, and I'll do a 10-minute circuit or something. But that's about it. On Sunday my activity for the day is work [stocking grocery shelves]. So, if I go to work then I can't really do much after that. So usually I'm at school five days a week, Saturday is my resting day or doing something that I can't do during school, then Sunday is at work.

Hannah and her father discussed the balancing of activities during recovery, and how school was the focus of Hannah's energy:

Hannah: *It is at the point where I always have school to focus on. Like I've tried yoga or going to an activity but I know that will ruin school and I will lose a credit. So I can't do that. And if I'm not in school, then I have to do a vision therapy and I have to put all my energy there.*

Father: *The problem with it was...and this is something we discovered quickly...she only had so much gas [energy] in the gas tank [energy reserve].*

There were also discussions about how “*pushing yourself*” or over-engaging in activities is detrimental and exceeds the symptom-exacerbation threshold (i.e., results in an increase of symptoms). Participants described experiences of how they would frequently “*break-through*” the symptom-exacerbation threshold. Although participants outlined the importance of focusing on energy allocation and pacing, there were also references to the difficulty of

maintaining this focus during a prolonged recovery. Alice described how pushing herself in school resulted in increased symptoms:

If I push myself too hard in school...like especially in school, if I'm like, I'll do all these five projects this week and get them all done. Then I can't go to school for the following week.

Mia described an experience of pushing herself and not pacing her reintegration of physical activity:

I went on a run after a week of staying in bed. And I was just like...you know what, screw this, I'm going for a run. I blacked out and puked everywhere. I was out. I completely fainted. I made it home and stepped through the door and just fainted.

Natalie described her experience of pacing and how it became problematic when there was a rush to return to activities:

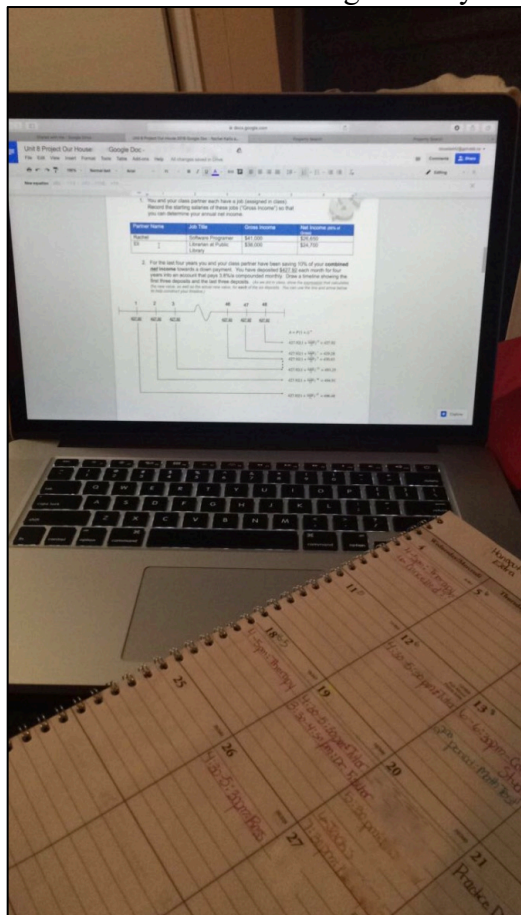
Yeah you can't jump into it. Like when you're sitting there completely in the dark room doing nothing...I think I was in there for three weeks. Then I finally was going back to school and the first day I made it to the full day of school. And I was like yep I'm going to go to [my sport of choice] and I'm going to run too. And I knew I felt like crap after the full day. And then I had a few other instances like that. I thought oh I'm better I haven't had headache in a few days I may as well try running...yeah it really doesn't work out that well.

When there was a period of over-engagement in activities, there was a spike in symptoms and a period when participants had to allocate more time in rest. Ultimately, this was a setback in the activity reintegration process, and a barrier to recovery.

There was also discussion about how planning was closely tied to energy allocation and pacing. Participants would spend time planning with calendars and reminders. This was a way to organize and balance their activities, while being mindful of scheduling time for rest each day. Mia captured a photo that she titled, "The Planning Life," to depict how she used her monthly planner to organize daily activities (see Photo 7.17). She discussed planning in the following quotation, and how rest was a big part of her days:

In the bottom right corner is my planner. You can see it's colour-coded. And I prefer to see a full month on a planner, so then I can see everything. I normally try to put everything in my planner. So every month I have it filled out. It helps me. My free time is usually just spent for rest...there seems to be a lot of sitting down and resting that has to be scheduled too.

Photo 7.17. “The Planning Life” by Mia.



Hannah also discussed her use of calendars and reminders set on her phone to plan time for activities and rest:

We have a white board at home with times and dates on it. And I have one on my room. And you block off rest times. You can put reminders in your phone about it so you don't forget.

7.3.4 Meaningful Activity

Meaningful activities, or activities that are tailored to an individual's needs or preferences, were also viewed by the participant as important in facilitating recovery.

Meaningful activity added purpose and enjoyment to the participants' lives, resulting in improved mood and emotional well-being. As mentioned previously, school-related activities were prioritized for all participants (over meaningful activities) during the activity reintegration process. Some participants discussed how engaging in schoolwork was in fact meaningful to them, however the imbalance that resulted due to high level productive ventures and limited or absent meaningful activity was problematic. However, participants enjoyed meaningful activities "*whenever they could.*" All six participants discussed how meaningful activity was important to their well-being and increased feelings of positivity. However, they also wished they were able to participate in these meaningful activities on a more regular basis. Meaningful activities were very personal in nature, but examples of some of the meaningful activities that participants engaged in (and were tolerated without exceeding the symptom-exacerbation threshold) are included in Table 7.7.

Table 7.7. Examples of meaningful activities during recovery.

Participant	Meaningful Activity
Alice	Graphic art, drama and acting, socialization
Natalie	Socialization, line dancing, pet care
Hannah	Pet care, school work
Mia	Learning to drive, pet care, socialization
Grace	Photography, drawing, painting, socialization
Sadie	Car racing, socialization

Sadie talked a lot about meaningful activities and how they brought her a sense of happiness and purpose during recovery. After her concussion, she was unable to return to her competitive individual sport – her sport of choice. However, she tried to stay involved with the sporting community by coaching younger children. She also became involved in car racing after

her injury. She described car racing as “a new sport and something new to try.” Sadie’s mother also reported that:

She kind of glows when she talks about it. She used to have that glow with [her previous sport of choice]...but now it's all car racing.

Sadie shared a photo titled, “My New Sport, My New Adventure,” to highlight the importance of meaningful activity (see Photo 7.18). She described the photo in the discussion below:

That is my racecar. So because of my concussion I had to stop [my competitive individual sport] and so I had always kinda thought about driving a racecar or something. But after I fell and got a concussion it kind of pushed me to try it. So I went out and tried driving that car around the track and it was fun. And a few weeks later we ended up buying the car. So now I'm trying something completely different, driving that car around this summer. So yeah my new summer adventure.

Photo 7.18. “My New Sport, My New Adventure” by Sadie.



Grace also discussed meaningful activity and how the initial period of recovery with limited meaningful activity engagement was difficult and she experienced feelings of depression. She was unable to participate in her sport of choice and spent a period of time engaged in “just

school.” However, over several months she was able to integrate previously enjoyed activities, and they became more prominent in her life (i.e., photography; drawing; painting). Six out of the nine photographs she submitted represented the personally meaningful activities that she participated in – representing a new identity she found during recovery. One photo of Grace’s meaningful activity engagement is shared below (see Photo 7.19). She captured a photo titled, “Travelling, Exploring and Different Places,” and discussed how photography became an important activity during recovery. Grace and her mother shared how photography was an opportunity to take photos, but it was also a chance to enjoy the outdoors and travelling experiences:

- Grace: *I like taking pictures. I took a lot of pictures [during a recent trip]. Like even on my phone too.*
- Mother: *The time outside has been good for you. You weren’t really interested in going for a big walk but if you can take the camera out, you stay out for a long time just wandering. And looking at things. Laying on a log, to get the right shot.*
- Grace: *Yeah I wanted to get it just right.*

Photo 7.19. “Travelling, Exploring and Different Places” by Grace.



Natalie talked about the difficulty of integrating meaningful socialization back into her daily life at the beginning her recovery. But, with time she was able to find a way to include socialization into her daily life on occasion. Her initial absence from school and other sporting activities resulted in a drastic decrease in the time and connections she had with friends. She mentioned that the majority of her friends prior to the concussion, she connected with through school and her sport of choice. She described how returning to school part-time was great for reconnecting with some friends, however she often felt “*left out*” and “*bored*” at home as her recovery necessitated increased time for rest. Natalie shared a photograph which she titled, “Changes in Socialization” to show how she was able to occasionally engage in socialization after the injury (see Photo 7.20). A quotation to describe the photo is presented below:

Yogen fruz is really good. Yes it's one of my favorites. So I took the picture of that... just because it symbolizes something I enjoy and I do it with my friends. And just that we found ways to do stuff with [friends] that still catered to my symptoms. It was really hard at the beginning of [the recovery]... just not being there and stuff. But we definitely... I found ways to manage it and fix it a little bit.

Photo 7.20. “Changes in Socialization” by Natalie.

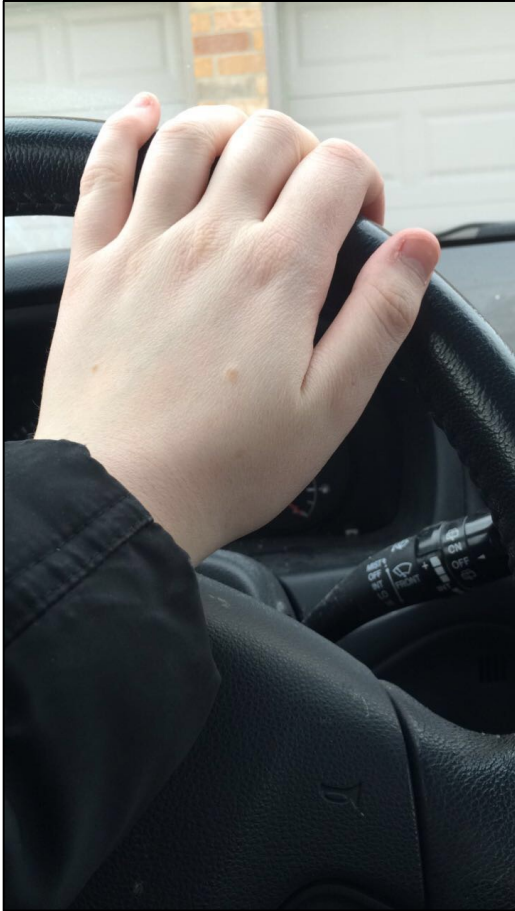


Mia was able to integrate driver's education and the completion of her G2 in-car driving test during recovery. She discussed how it was hard to set long-term goals during recovery, but she set the short-term goal of learning to drive and it worked out favourably. She enjoyed driving, and it was a time to focus on something other than school and the prolonged recovery she was experiencing. She found meaning which surfaced from the freedom that driving independantly, as she often “*felt trapped*” and “*stuck*” at home during recovery. She captured a

photograph titled, “Wheel of Fortune” (see Photo 7.21) and described the positivity that surfaced after she learned to drive and was able to take her mom’s car out independently:

Sometimes I just like to drive...it uses a lot of gas, but I just drive. It just helps me calm down and have a little freedom. You can't access social media because you're not going to text or call while driving. I just love it. You don't have time to think about school or anything that's going on in your life because you have to focus on the road. You're not thinking about problems, you're just driving. I called [the photo] Wheel of Fortune because...although this [concussion] has been the total opposite of fortunate and it sucks and there so much pain through it. I see myself always seeing the positive side [learning to drive].

Photo 7.21. “Wheel of Fortune” by Mia.



Overall, the participants felt a sense of satisfaction and emotional well-being when they were able to participate in activities they personally selected and found enjoyable. Participants identified themselves by their activities and occupations, leading to the occupations being help

close to one's core identity. These meaningful activities helped the participants to develop their occupations, outside of the prioritized productive activities during recovery (i.e., academics and school).

7.3.5 Personality Characteristics

There were common themes in accordance with personality traits that all six participants displayed. When describing themselves, the participants used language such as “*perfectionist*,” “*driven*,” “*neat freak*,” “*competitive*” and “*stubborn*.” These traits largely lined up with the description of a Type A personality – individuals who are ambitious, rigidly organized, anxious, like control, impatient, and concerned with time management. Individuals with Type A personalities are often high-achieving and driven (which was the case for all six participants).

Mia described her personality in the quotation below:

I'm a perfectionist and I like things to be done a certain way and at a certain time. As an athlete and a [competitive sport participant], you push yourself...it's always go. If you fall, you get up and you do it again. You do it and you do it and you do it until you get it.

Type A personality traits in regard to rigid organization, was also noted in Sadie's interviews:

My friend...she makes fun of me because my notes are so neat and colourful. Like everything is colour coded. And I always say it's just...that's how I work, and I always have. Some people's notes are a mess and it drives me insane.

Hannah also described her ambition and drive for high marks at school:

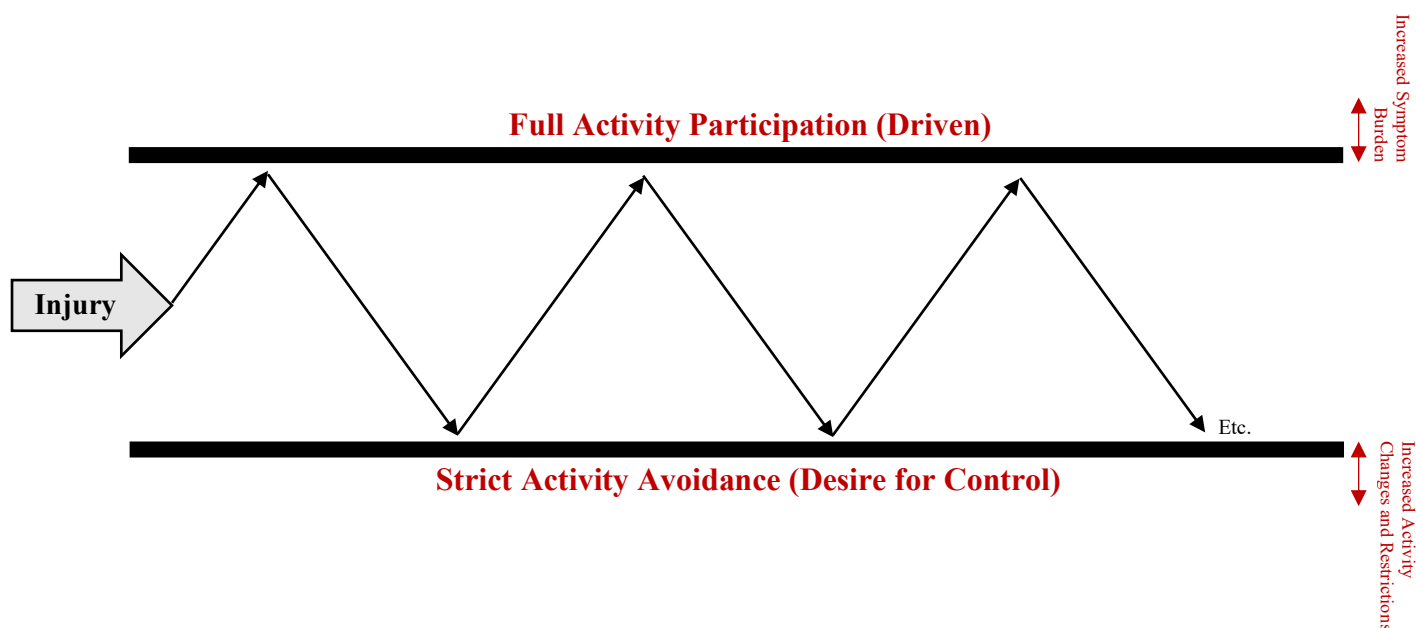
I was obsessed with my marks being eighties and nineties too. I was worried they were going to drop so much from me being off.

All six individuals portrayed Type A personality characteristics within interviews and focus groups.

Type A personality traits were a barrier to concussion recovery when participants were met with the requirement to allocate energy and pace activities. During recovery, participants had a lower energy reserve and had to engage in fewer activities and at a lower intensity than

what they were used to prior to the concussion. Therefore, participants didn't have the previous stamina for engaging in activities in their regular Type A personality fashion. During the early months of recovery, a pattern of participation emerged due to personality, and participants would either: a) adhere to strict activity avoidance through rest; or b) participate in excessive over-participation in activity (see Figure 7.5). Once the individual entered recovery, the desire to control and minimize symptoms (through activity avoidance) was met with the drive to participate in regular pre-concussion activities (through full activity participation). Participants seemed to get stuck in an all-or-nothing mindset when approaching activity reintegration during recovery, and flexible pacing and planning was difficult. When the participants would engage in full activity participation, there would be an increased symptom burden (shown to the upper right in Figure 7.5). Alternatively, when the participants would engage in strict activity avoidance, there would be increased activity changes and restrictions (shown to the lower right in Figure 7.5).

Figure 7.5. All-or-nothing pattern of activity during recovery.



Hannah's father discussed the barrier of Hannah's personality in the following quotation:

I think personality has a huge impact on recovery...I really do. I mean a much less driven student might not be encountering some of the issues that Hannah is encountering. And that seems to be holding up recovery right now. So not that that's a bad thing...I don't want her to think that. Personality traits are good things. It's just that sometimes that is working against us when we are injured. She has two speeds...stop and go. There is no gearing in between.

There was frustration felt by participants in regard to activity modifications and pacing. Their personality characteristics made it difficult to participate in activities “halfway.” They wanted desperately to participate in their pre-concussion activities, but symptoms would repeatedly get in the way of this level of participation whenever an attempt was made – they were performing at a lower functional level. When symptoms would return, they would revert to a state of strict rest (i.e., removal from all activities and sensory stimulation). This back and forth pattern between full participation and activity avoidance is shown in Figure 7.5. Natalie discussed an experience at school when she pushed herself in gym during fitness testing:

For fitness testing I thought I could maybe do some of that. So, [the teachers] said if I feel like I needed to stop I should. But with me being competitive, I don't want to stop so that is what's hard too. I don't want to stop or not do something. So, if I say I'll try it, I'm probably going to finish it. But then I'll have more headaches and more symptoms because I did it and I overdid myself. Like I'm still trying to know [and learn] when to stop. That's what's hard. Trying to figure out when I need to stop or stuff like that...especially with sports and stuff.

Over many months, participants learned how to “slow down” and “pace” themselves during activities. Participants reported that two strategies for pacing that they learned were: i) to have pre-planned periods of rest on their calendars; and ii) alternating frequently between activity and rest during demanding/fatiguing activities (e.g., homework; studying). But these were skills that needed extra instruction and practice. Hannah's father discussed the dilemma of pacing and how Hannah continues to struggle 17 months into recovery:

[Pacing] is something that she struggles with because it annoys her, and it doesn't suit her personality. Like if there's a task in front of her she wants to slam right through it and get it done. If it's due next week is going to be done tonight all in one go. And she needs to learn how to pace better than that...with everything...activities, studying. It doesn't matter she needs to pace better.

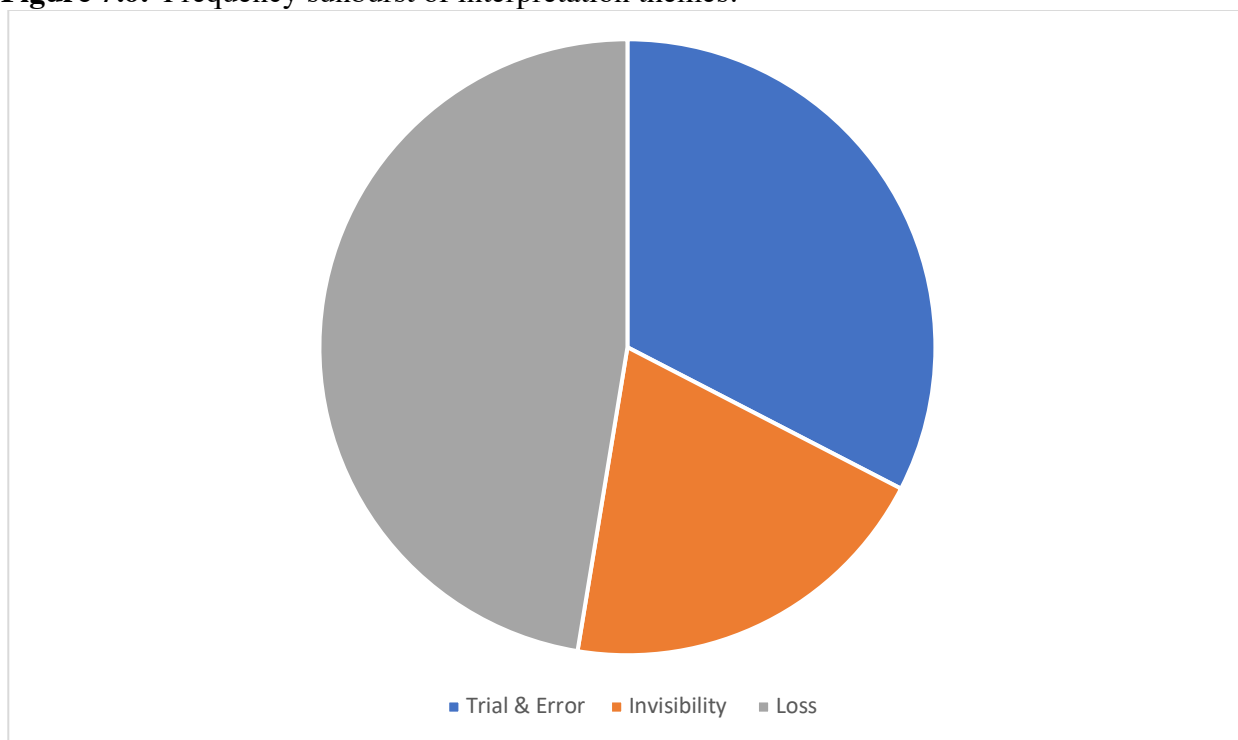
Mia also talked about the barrier of her personality, but how she is learning to adjust her expectations while learning how to effectively reintegrate activities:

I'm so stubborn...it's bad. Like it's one of the worst things for me...so that was a huge barrier. Once I'm determined that something is going to happen, it's going to happen. But now I know that it is not realistic and I'm going to have to set different goals. I'm getting better and better [at pacing].

7.4 Research Question Three: Interpretations of Activity Modifications

The third research question asks: *how do female adolescents who have sustained a concussive injury interpret what has been asked of them in terms of return-to-activity protocol(s) or suggested activity modifications?* This question has largely been answered throughout the previous two sections (see 7.2 and 7.3). The treatment recommendation of rest was addressed in section 7.2.2. and return to activity reintegration recommendations and accommodations were addressed in sections 7.3.3 and 7.3.2 respectively. However, three themes that were briefly discussed in section 7.2 and 7.3, and are pertinent to research question three, will be unpacked more below. The interpretations of activity modifications and reintegration throughout recovery that were perceived by the participants as follows: 1) loss; 2) trial and error; and 3) invisibility. The frequency of coded themes can be visualized in the sunburst in Figure 7.6. These overarching themes will be discussed below.

Figure 7.6. Frequency sunburst of interpretation themes.



7.4.1 Loss

Loss can be thought of as the process of losing something or someone. In terms of prolonged concussion recovery, the interpretation of loss was abrupt at the time of the injury and it remained to some degree throughout the months and years during recovery. The participant's previously enjoyed activities and social involvement had been drastically decreased throughout recovery. There was an imbalance between what an individual wanted to do and what they were required to do in accordance with activity modifications. Feelings of frustration were commonly reported in addition to the interpretation of loss. Mia discussed how life during recovery was not as she remembered it prior to the concussive injury:

Socially and academically I have taken a step back and am taking it slowly. Life is not how I remember it. I feel as if I'm a newborn put into a teenager's body. I had to relearn everything...how to walk, talk, think, write, read...all of that. I had to reteach myself. And everything...everything just got taken away from me. I'm not going to where

I thought I would go. I thought I was going to graduate this year and go to university next year. Now I'm staying back a year to do a full year [of high school]. And after that I have to do another year because I changed my career path because of this concussion.

None of the participants were able to go back to their sport of choice, and those who engaged in contact sports were advised by medical professionals to not go back at all. This was interpreted as a loss of identity, as participants had been participating in their primary sport since they were young children – it was a big part of their daily lives and who they were. Natalie discussed the loss she felt when sports were not part of her life anymore:

Sports...that's part of who I am, and I can't really do that. That was probably the hardest thing, I think. I had played [my competitive team sport] forever. Also, [my competitive individual sport] since grade 10. I enjoyed that. That was the thing, when I first got my concussion, I remember sitting in the hospital thinking that [the provincial competition] was supposed to be the next week. I was just lying there thinking if I can't [participate] in [the provincial competition] then life is going to be over. Like that is what I really wanted to do. And I couldn't [participate] and that was hard. It really sucked. But yeah sports were really hard to deal with.

Sadie also interpreted a sense of loss when she was unable to be involved in her individual competitive sport at the level she had participated at prior to the concussion. She shared a picture which was titled with the name of her individual competitive sport, to capture the loss of identity she felt during recovery (removed over concerns regarding anonymity). Sadie discussed the photo below:

That [sport] is what I always used to do. [It] was like what I did in the past and how I ended up with my concussion. Like I...everything was [that sport] for me. It got to the point where I was [playing that sport] five days a week. But yeah...I loved [it]. But like now I can't.

Additional results regarding the theme of loss can be found integrated in section 7.2.2.

7.4.2 Trial and Error

Trial and error is the process of finding out the best way to reach a desired result.

Individuals try out one or more ways or methods, then note and eliminate the aspects that do not

contribute to the desired result. In terms of concussion recovery, participants felt as though there wasn't one simple solution for their prolonged symptoms. Healthcare providers would suggest ideas and refer participants to different resources, but overall, participants would have to try different treatment modalities in order to find what worked best for them personally. Hannah discussed trialing many different options to minimize her symptoms, and how she eventually found options that worked for her. She shared a photograph titled, "Pain" (see Photo 7.24), to share what worked to manage symptoms, which she described below:

I just came up with this stuff that really helped me. It is all the different tools I have to use to feel decent and cope with my injury. So, there's a heating pack for neck pain. An ice pack for my head. And an eye mask for darkness. And then the spray bottle for temperature regulation. So, it is showing all the different things you need to feel decent with a concussion.

Photo 7.24. "Pain" by Hannah.



Participants also discussed the different healthcare providers they met with during recovery and the multitude of appointments they attended. They reported how each healthcare

professional and/or appointment helped a little bit or with one aspect of improved function.

Grace's mother discussed the trial and error approach in the quotation below:

Honestly, I think nothing was really the solution. But everything we did helped a little bit or with one piece of it. We are still chasing a little bit.

Mia talked about the trial and error approach to treatment, and how she often became frustrated and overwhelmed with the lack of direction during recovery. Her perspective is included below:

And so, it just gets stressful when each doctor has a different view as to how I should treat my body and how I should recover. So, it's very hard to choose what to listen to and what not to. Everyone's recovery is different. And that's something I learned. Stuff that helps me hasn't really helped my friends and vice versa. So yeah, trial and error is helpful.

Some examples of treatments, diagnostics and therapies reportedly trialed by participants are listed in Table 7.8. Participants reported the efficacy of various treatments to varying degrees. Additional results regarding the theme of trial and error can be found in section 7.3.2.

7.4.3 Invisibility

Invisibility is described as a situation when individuals feel unseen by onlookers.

Participants implied that the necessary activity modifications for prolonged concussion recovery were met by a lack of understanding by peers. There were discussions about how peers who had sustained a prior concussion or those who had not experienced concussion first-hand, assumed recovery would take a week or two and then a return to regular activity could ensue. However, prolonged recovery did not follow the normative concussion recovery trajectory, and participants experienced months and up over a year of symptoms and activity restrictions. As a result, participants interpreted this as invisibility throughout recovery. Mia shared a quotation about the complexity of prolonged concussion recovery and the lack of understanding by onlookers:

I just get so irritated so easily, especially because some people think they know what's best for us. So, people will say just taking an easy course load, just wear your glasses, just shut off the lights...blah, blah, blah. Doctors, classmates, family, friends, everyone

thinks they have a solution to this...and it gets annoying. They really don't know what I'm going through. It's not like just taking a magic medicine...or putting a cast on a broken bone. No, it doesn't work that way. People think there is medicine for everything and solutions for everything. There isn't for this. I'm not going to wear a cast around my brain.

Table 7.8. Examples of treatment and management options trialed during recovery.

Care Provider	Trialed Treatment, Diagnostic Technique or Therapy
Emergency Medicine Physician	<ul style="list-style-type: none"> • Acetaminophen • Ibuprofen • Rest
Sports Medicine Physician	<ul style="list-style-type: none"> • Anti-depressant • Magnetic resonance imaging • Referrals • School release form • Sport release form
Family Physician	<ul style="list-style-type: none"> • Anti-depressant
Otolaryngologist	<ul style="list-style-type: none"> • Nasal endoscope • Nasal spray (i.e., inflammation)
Neurologist	<ul style="list-style-type: none"> • Magnetic resonance imaging • Referrals
Cardiologist	<ul style="list-style-type: none"> • Sodium Chloride Tablets
Psychiatrist	<ul style="list-style-type: none"> • Anti-depressant
Optometrist	<ul style="list-style-type: none"> • Prescription glasses (i.e., prism; tinted) • Vision therapy
Physiotherapist	<ul style="list-style-type: none"> • Strength and mobility exercises • Return to physical activity education • Acupuncture
Occupational Therapist	<ul style="list-style-type: none"> • Return to school activity education • Weighted vest • Compression top
Speech-Language Pathologist	<ul style="list-style-type: none"> • Return to school activity education
Psychologist	<ul style="list-style-type: none"> • Counselling
Social Worker	<ul style="list-style-type: none"> • Liaison with school
Chiropractor	<ul style="list-style-type: none"> • Manipulation and adjustment
Massage Therapist	<ul style="list-style-type: none"> • Massage
Osteopath	<ul style="list-style-type: none"> • Craniosacral Therapy

Alice also reported a lack of understanding and the invisibility she felt during recovery:

[Peers] would tell me I was getting free rides because of this thing with my head. They would say I wasn't even injured and its fake. And I would say it's not fake, you just can't see it. And I think that's the issue with concussions...you can't see it but, you can feel them.

Overall, the non-normative recovery progression (and associated activity modifications) associated with prolonged concussion recovery lead to feelings of invisibility. Additional results regarding the theme of invisibility can be found in section 7.2.3.

Chapter 8: DISCUSSION

This dissertation presents a qualitative case study investigation that explores the recovery experiences of adolescent females who have sustained a concussion through sport participation and are facing Post-concussion Syndrome (PCS). An interactional conceptual framework for concussion recovery was developed, which shows the relationship of themes that emerged during analysis. Recovery is conceptualized in terms of the themes of symptom burden, activity changes and restrictions, and both emotional and psychosocial sequelae. The risk of long-term consequences was explored in the context of pre-injury susceptibility (i.e., personality characteristics) and post-injury resilience (i.e., energy allocation and pacing; meaningful activity; recovery toolkit; emotional support). Conclusions drawn from themes will be explored below, followed by an explanation of the final conceptual framework, and recommendations for practice.

8.1 Conclusions Drawn from Recovery Experience Themes

8.1.1 Symptom Burden

This study found that symptoms affected the adolescent's perceived recovery experiences. The four most frequently reported symptoms were: a) headache; b) impaired proprioception; c) visual disturbance; and d) sensitivity to external stimuli. Although concussion symptoms generally fall within the domains of physical, cognitive, emotional and sleep, the most frequently reported symptoms by participants were physical symptoms. Therefore, participants were particularly bothered by physical symptoms, as compared to cognitive, emotional and sleep symptoms. This is consistent with a previous study which suggested that adolescents may not perceive their cognitive deficits as well as they perceive their physical symptoms (Sandel et al., 2013). Further, participants frequently reported a feeling of invisibility during recovery, sharing

that onlookers did not understand their hidden brain injury and symptoms (as compared to an observable injury such as a broken leg with a cast). Therefore, reporting physical symptoms would make it easier for the adolescent and those around them to perceive and notice the burden of their injury.

Participants continued to experience symptoms at 10 to 18 months into their recovery. This falls within the PCS classification, as the literature notes that the duration of PCS symptoms varies from months to years (Lovell, 2009; Parachute, 2017). Post-concussion symptoms were experienced daily, and reportedly increased or decreased in relation to various demands present in the adolescent's day-to-day life (e.g., tests/exams; increased sensory stimulation; stressful experiences; lack of sleep; etc.). All participants discussed that the symptoms impacted their pre-concussion activities and their ability to participate in daily life. The initial symptom burden was reported as the primary reason for the activity changes and restrictions during recovery. These findings are similar to reports in previous studies which found that the concussion symptoms experienced during recovery were closely tied to one's ability to function and participate in activities (Iadevaia et al., 2015; Sandel et al., 2013; Stein et al., 2016; Valovich McLeod, Wagner, & Bacon, 2017).

8.1.2 Activity Changes and Restrictions

Disruptions in the participant's daily life were found most frequently within the following areas: a) academics and school; b) social involvement; c) sport and physical activity; and d) extracurriculars. Similar to previous findings in the literature, adolescents experienced a sense of loss as a result of these activity changes (Iadevaia et al., 2015; Stein et al., 2016). The abrupt, unexpected and drastic reduction of participation and associated identity change was the source of loss for participants. Adolescents were unable to fully participate in productive activities such

as school, and meaningful activities such as social involvement, sport and physical activity and extracurriculars were also limited. Loss of identity had been reported previously – one study found that adolescents with a concussion described lower levels of self-esteem because they were not able to fulfill their pre-injury roles such as student, friend, teammate (Valovich McLeod, Wagner, & Bacon, 2017).

A pattern of activity was noted during reintegration, as all participants prioritized academics and school activities over all other activities during recovery. Participants reported that they did not have a choice about returning to school. The exact source of this lack of choice was unclear but was likely due to various social pressures and cultural norms (i.e., personal; parental; societal), which favour productive work over non-productive (but meaningful) activity. However, it was detrimental to the recovering adolescents when school was prioritized over other meaningful activities – the imbalance and lack of engagement in meaningful activity added to the sense of loss. Social involvement and extracurriculars were found to be enjoyable, but largely neglected, as they were viewed as less mandatory as compared to school. Physical activity was also drastically reduced following the injury, and none of the participants had returned to their main pre-injury sport of choice. This has been documented in the wider literature, where prolonged withdrawal from personally meaningful activities interferes with individuals living a meaningful, productive and quality life (Martin et al., 2012; Whiteford, 2000).

8.1.3 Emotional and Psychosocial Sequelae

Participants discussed that months into recovery, emotional and psychosocial sequelae became apparent (i.e., feelings of frustration, stress, anxiousness and depression) and added to the initial symptom burden. These findings of emotional symptoms that emerged in female

athletes during a protracted concussion recovery are consistent with previous reports in the literature (Andre-Morin, Caron, & Bloom, 2017). The sequelae were less specific to the concussion symptoms appearing at injury onset and more specific to symptoms resulting due to a prolonged lack of engagement over an extended period of time. While discussing the recovery progression, sequelae became more apparent in participant discussions within several months following the injury (very few emotional symptoms were reported around the time of injury). This finding was similar to a previous study that explored adolescent concussion recovery experiences at one year post-injury, where concurrent emotional symptoms tended to develop later in the course of recovery when prolonged concussion symptoms were present (Stein et al., 2016).

The two sub-themes of emotional and psychosocial sequelae that emerged were: a) feelings of frustration; and b) the stress cascade. Frustration was largely related to the prolonged symptoms and activity changes; however, it was also reported as a result of interpersonal relationships where peers did not understand how concussion symptoms could potentially last for months (as compared to normative adolescent concussion recovery lasting one to four weeks). Many peers would claim that the adolescent females were faking their injury and that it wasn't real. There were discussions about how PCS is a largely invisible injury, and as a result the adolescents were not able to relate to many of their peers after the injury. Many friendships faded overtime and were lost during recovery. These findings are largely consistent with previous studies which suggest that sources of frustration stem from various sources, such as longevity of physical symptoms, time missed from activities and interpersonal relationships (Iadevaia et al., 2015; Limond, Dorris, & McMillan, 2009).

Frustration was also reported in relation to perceived limitations and inconsistencies in treatment recommendations by healthcare providers. Participants reported how a trial and error approach was assumed during recovery, which resulted in many failed attempts at symptom management and activity reintegration. There were many emotional let downs while trialing the various treatments participants received, causing frustration, but overtime the treatment recommendations that were effective were pieced and used together to improve well-being (i.e., recovery toolkit). The assistive devices, planning techniques, and environmental accommodations that were effective treatment recommendations are described below in section 8.2.4. Frustration stemming from healthcare providers and the trial and error approach for PCS treatment has not been reported previously in the literature.

The second subtheme of emotional and psychosocial sequelae was the pattern of sequelae that developed through the stress cascade. Chronic stress developing into feelings of anxiousness and depression (and for some, diagnosed anxiety and/or depression) was seen as a pattern of recovery progression. Stress was reported in relation to the emotional pressures such as being off school, missing activities, functional ability, and the future. It is not surprising that PCS recovery leads to chronic stress, as there are continuous and prolonged interferences in one's ability to function within various domains of life. Stress during PCS recovery has been previously explored and eludes to the emotional toll of prolonged symptoms and activity restrictions (Iadevaia et al., 2015).

The stress experienced by adolescents during recovery is likely to result at least partially due to situational factors (as oppose to biological or injury-related factors; DiFazio, Silverberg, Kirkwood, Bernier, & Iverson, 2016). The literature also suggests that individuals who experience chronic situational stress during recovery from a mild to moderate brain injury, also

report an increase in psychological symptoms and psychiatric illness (Bay & De-Leon, 2011). This was the case with adolescent females in this study. Feelings of anxiousness and depression were experienced by each participant at some point during recovery and was understood to contribute to chronic stress. Psychiatric illness was noted in two participants – one reported worsening of pre-existing depression and anxiety (needing increased support and treatments), and a second participant received a diagnosis of anxiety during recovery.

Therefore, postconcussion emotional sequelae are not uncommon during concussion recovery, especially for adolescent females. Ultimately feelings of stress, anxiousness and depression cascaded and increased concussion symptoms, especially headaches. It is well accepted in the literature that psychological stress can trigger headaches. Interestingly, there are no symptoms that distinguish trauma-triggered migraines from a concussion, as headache is the most common complaint for both conditions (Lords & Greene, 2014). When reviewing the literature on migraine headaches, the predominating cause of headaches is thought to pertain to emotional stress or tension (Salleh, 2008). Overall, symptoms of the concussion and inability to participate in desired activities led to varying degrees of post-concussion emotional upheaval and stress overtime, with many similarities in terms of the stress reaction mirrored in the current literature of migraine sufferers.

8.2 Conclusions Drawn from Facilitator and Barrier Themes

8.2.1 Personality Characteristics

Throughout recovery, participants maintained the desire and drive to return to pre-injury activities and routines, which seemed to be tied to personality characteristics and the way individuals approached recovery. In particular, Type A personality characteristics were apparent in all participants (i.e., high achieving; perfectionism; rigid organization; impatient; driven;

desire for control). Limited information about how personality type impacts concussion recovery is available in the literature, however, one paper suggests that pre-injury personality factors such as being a perfectionist and driven, have been found to be strong predictors of severity and course of PCS when considering concussion from a biopsychosocial perspective (Silverberg & Iverson, 2011). Additionally, those experiencing chronic headaches due to migraines are also noted to have Type A personality characteristics (e.g., perfectionist; ambitious; rigid; overly; excessively competitive; Huber & Henrich, 2003).

This study found that Type A personality characteristics contributed to adolescents moving through a series of drastic ups and downs in regard to activity involvement and subsequent functioning, instead of following the recommended steady progression of reintegration suggested by the 2016 Consensus Statement on Concussion in Sport Guidelines. During recovery, the desire to control and minimize symptoms (through strict activity avoidance) was met with the drive to participate in regular pre-concussion activities (through full activity participation). However, strict activity avoidance resulted in further activity changes and restrictions (i.e., limited activity participation), and full activity participation resulted in participants exceeding the symptom-exacerbation threshold and subsequently increasing the symptom burden experienced (see Figure 7.5). Participants seemed to get stuck in an all-or-nothing pattern of activity reintegration during recovery, and flexible pacing and planning was difficult.

8.2.2 Energy Allocation and Pacing

Participants discussed how energy allocation and pacing facilitated recovery, whereas both strict avoidance of activities or over-engaging in activities acted as barriers to recovery.

Energy allocation and pacing rests on the idea that structural damage to the brain after a concussion disrupts the cognitive system, resulting in an inefficiency in processing (Wylie & Flashman, 2017). During concussion recovery the brain is working harder than normal and has reduced functional capacity. Therefore, individuals do not tolerate either of the extremes of complete rest (for more than a day or two following the injury) or full pre-injury activity participation. The aim of energy allocation and pacing is to balance one's energy between activity engagement and rest, so the symptom-exacerbation threshold is not surpassed. Ideally, participants keep track of their energy expenditure during the day – spreading the energy out between activities and taking scheduled breaks during activity participation.

This facilitator of recovery is supported in the literature for cognitive-based activities (school reintegration) as well as physical-based activities (sport reintegration; McCrory et al., 2017). Energy allocation and pacing also outlines the inefficacy of complete rest or full activity participation. The literature suggest that complete rest and the avoidance of sensory stimulation lasting more than five days can slow recovery and result in more reported symptoms overall (Thomas et al., 2015). Additionally, both observational and experimental laboratory studies have demonstrated that bouts of intense physical or mental activity can exacerbate symptoms in concussed athletes (Schneider et al., 2017). Therefore, functioning within the middle ground between rest and full activity participation is ideal for recovering individuals.

8.2.3 Meaningful Activity

Increasingly it had been recognized that participation in personally meaningful activities has a direct relationship on an individual's perceived quality of life following a traumatic brain injury (McLean, Jarus, Hubley, & Jongbloed, 2014). The International Classification of Functioning, Disability and Health has allowed for a broader perspective of health and well-

being, which considers how the inclusion of meaningful activity can enrich an individual's life and improve well-being, however it remains limited for use within current considerations for concussion care and recovery (Reed, 2011a). The argument here is that personally meaningful activities should be prioritized and integrated into energy allocation and pacing strategies. The adolescents in this study described how taking part in enjoyable activities such as socialization, time with a pet, and photography, produced feelings of well-being and improved mood. However, they had limited opportunities for meaningful activities as they persistently prioritized productive work such as academics and school. Although school was important to participants, the imbalance that resulted due to high time and energy commitments to school over meaningful participation in extracurriculars, hobbies and cultural activities was problematic and reduced feelings of well-being during recovery.

Participants in this study discussed the loss they felt in regard to the imbalance between their productive activities (i.e., academics and school), as compared to their non-productive (but meaningful) activities. They were largely unable participate in activities outside of academics and school (i.e., relationships; employment; leisure; and recreation), because all their available energy reserve had to be allocated to school. Participants discussed how being able to resume some meaningful activities post-injury should be a primary focus during recovery because they enjoyed those activities and missed them greatly. Overall, more research is needed in terms of the specific impact of meaningful activity involvement during concussion recovery, but this study does elude to the idea that engaging in meaningful activity and related occupational functioning after sustaining an injury can allow individuals to improve overall health and psychosocial well-being (Kosma et al., 2013; Wilcock, 2005).

8.2.4 *Recovery Toolkit*

The recovery toolkit represents various strategies used by individuals with a concussion in order to minimize symptoms and facilitate activity reintegration. The main toolkit items recommended by participants were: i) prescription glasses; ii) weighted vest or compression top; iii) activity and headache monitoring; and iv) academic accommodations. These strategies were acknowledged by participants as facilitators of recovery. It is interesting that the toolkit items suggested by participants all lie within the scope of practice of Occupational Therapists (OT). Assistive devices, planning techniques, and environmental accommodations all help individuals improve optimal functioning within daily life. However, at current, the consideration of concussion care within the occupational perspective is limited, and OTs are seldom involved in the care of individuals with concussion (Finn, 2019; Reed, 2011a). However, due to the significant activity changes and restrictions that accompany concussion recovery, there is utility in including an OT – for the facilitation of the recovery toolkit, as well as appreciating the delicate balance between rest and meaningful activity.

8.2.5 *Emotional Support*

Another facilitator of concussion recovery that emerged from the data was that supportive and informed individuals such as parents, good friends and members of a concussion support group made recovery progress smoother. This was consistent with findings in the literature that suggest adolescents who maintain positive social connections during PCS recovery, described fewer persistent social and emotional issues (Davies, Bernstein, & Daprano, 2020). Another recent study looking at adolescent female lived experience, found that fostering social support during recovery from a key group of providers (i.e., close friends; youth with a personal history of concussion; and parents) mitigate different challenges of concussion recovery (Kita et al.,

2020). The providers listed were consistent with the providers we found in our study, with the addition of pet support. Participation in a multitude of pre-injury activities (i.e., school; sport; social life; extracurriculars), followed by the removal from those activities following a concussion have significant emotional implications particularly for adolescents (Valovich McLeod, Wagner, Parsons, & Bacon, 2017). Having support and connections with people who know about the non-normative PCS recovery progression have a role in supporting mental and emotional well-being during recovery.

Emotional support pets were also mentioned frequently by participants, helping to improve mood and prevent loneliness in the adolescent females. Participants discussed how especially in the initial days of acute symptom recovery; family dogs would provide accompaniment during periods of rest when no other activities were tolerable and both family and friends were not available. Pets are a common type of emotional support noted in the wider traumatic brain injury literature with benefits such as increased motivation and improved satisfaction with recovery, however it has not been explored within the area of concussion and PCS recovery (Hediger, Thommen, Wagner, Gaab, & Hund-Georgiadis, 2019).

8.3 Conceptual Framework for Concussion Recovery

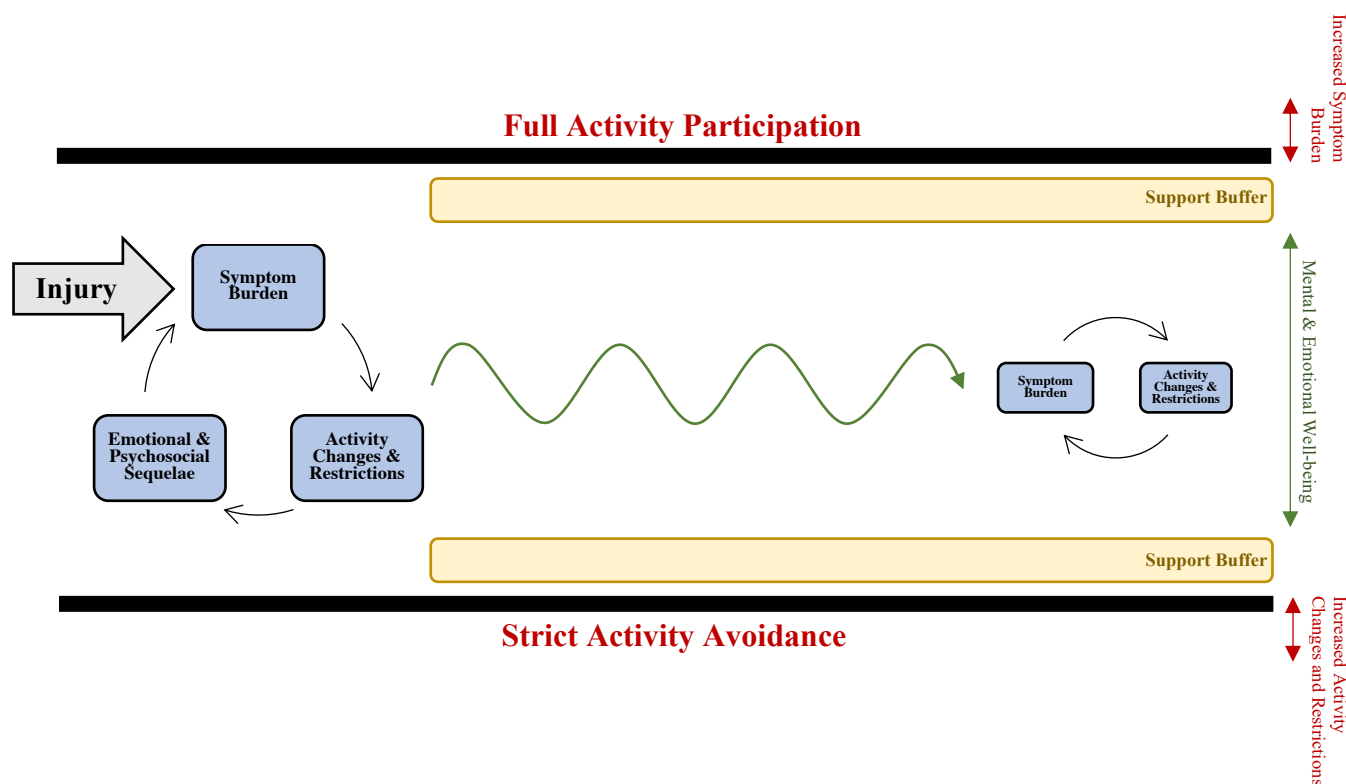
A final conceptual framework for mental and emotional well-being during recovery is presented, incorporating and relating the themes of recovery outlined above (Figure 8.1). It shows how both strict avoidance of activity as well as full activity patterns associated with Type A personality characteristics can be minimized by way of healthcare providers providing a “support buffer.” The buffer will serve to minimize (or prevent) the recovering adolescent’s tendency to proceed with activity reintegration efforts in an all-or-nothing pattern. Ideally individuals will participate in the activity reintegration process while being supported by

facilitators of recovery (i.e., energy allocation and pacing; meaningful activity; recovery toolkit; emotional support). The overall goal is to break the PCS recovery cycle, by reducing both the activity changes and restrictions and possibly eliminating emotional and psychosocial sequelae altogether.

8.3.1 Strict Activity Avoidance versus Full Activity Participation

A pattern of activity involvement was observed where adolescents recovering from PCS would either: a) participate in strict activity avoidance; or b) participate in full pre-injury activity levels (see Figure 7.5). This recovery pattern is thought to be largely due to Type A personality characteristics. High achieving, rigidly organized, and highly active adolescents would sustain a concussion, and have difficulty with energy allocation and pacing due to their pre-injury tendencies and a high stamina for activity. Individuals seemed to get stuck in an all-or-nothing participation pattern when approaching activity reintegration, and flexible pacing and planning was difficult. The desire to control and minimize symptoms (through activity avoidance) was met with the drive to participate in regular pre-concussion activities (through full activity participation). However, rigid activity avoidance resulted in further activity changes and restrictions, and chaotic full activity participation resulted in an increased symptom burden.

Figure 8.1. Conceptual framework for mental and emotional well-being during recovery.



8.3.2 Support Buffer

Both strict activity avoidance and full activity participation need to be avoided in order to improve mental and emotional well-being in recovering adolescents. Therefore, the possibility of “support buffers” are introduced to prevent the recovering individual from experiencing an all-or-nothing pattern of participation, and to ultimately facilitate post-injury resilience. The role of healthcare providers is presented as the “support buffer” during recovery. Ideally, OTs will be included on the care team, as they appear to be particularly well-suited to educate and enable the following facilitators: i) energy allocation and pacing; ii) meaningful activity; iii) a recovery toolkit; and iv) emotional support. By providing adolescents with education and support according to an occupational perspective, adolescents will be better prepared to approach recovery with a reintegration mindset that focuses on gradual pacing and balance of both

productive and meaningful activity. The goal is for mental and emotional well-being to be maximized through use of “support buffers.”

8.3.3 Recovery Cycle Mitigation

With time, the possibility of the mitigation of the PCS recovery cycle may be possible. Preventing all-or-nothing patterns of activity (i.e., strict activity avoidance or full activity participation), will result in fewer activity restrictions and changes as well as a reduced symptom burden within the recovery cycle. Adequate support from healthcare providers according to an occupational perspective (ideally including OTs), has the possibility to fully eliminate the emotional and psychosocial sequelae that result due to frustration and the stress cascade. Adolescents will have the opportunity to maintain meaningful activity throughout the gradual activity reintegration process, and feelings of frustration, stress, anxiety and depression may not surface months into recovery as concussion care currently stands. Therefore, the recovery cycle will be mitigated, and adolescents will have improved mental and emotional well-being when adequately supported during recovery.

8.4 Recommendations for Practice

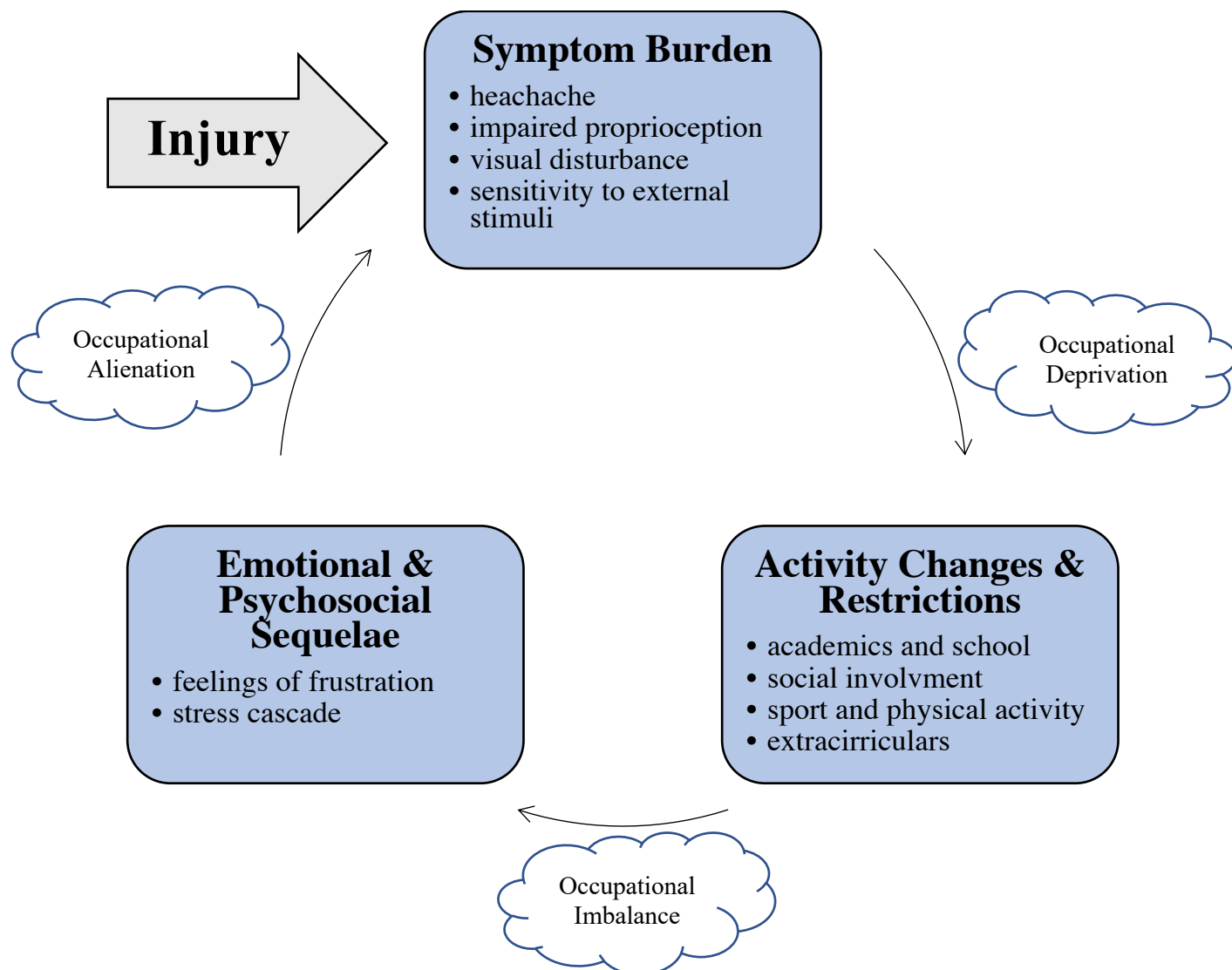
8.4.1 Occupational Risk Factors Theoretical Perspective

Considering adolescence is one of the most common age groups to experience prolonged concussion symptoms, there is utility in highlighting the complexity of the adolescent time period. The Occupational Risk Factors theoretical perspective allowed for the consideration of this complexity as recovery themes emerged in an integrated fashion. For an adolescent who sustains a concussion during an already tumultuous developmental transition, additional stress and poor coping can be triggered due to the nature of PCS recovery, leading to the chronicity and cyclical nature recovery experiences. When considering the ideas of concussion recovery in this

manner, the final understanding that was gathered from this study was that there was a cyclical relationship between the risk factors of occupational deprivation, occupational imbalance and occupational alienation (see Figure 8.2).

The acute symptom burden following a concussive injury creates a temporary state of occupational deprivation – a state of preclusion from engagement in occupations of necessity and meaning (Whiteford, 2001). Activity and occupational restrictions result directly due to the symptoms being experienced. Limitations in activities creates a temporary state of occupational imbalance – a loss of balance between the occupations we chose and those in which we are obliged to engage in (Wilcock, 2005). One's productive activities (as oppose to meaningful activities) may be prioritized, as individuals have a reduced amount of energy before reaching their symptom-exacerbation threshold. Occupational deprivation may or may not progress to occupational imbalance, depending on the extent of deprivation as well as the individual's personal resources and supports. The last, and arguably most severe risk factor, is occupational alienation. There is a loss of meaning and purpose, resulting in a loss of control, and the development of uncertainty as how to proceed in life. Occupational alienation can follow a period of occupational deprivation and imbalance, especially if personal resources and supports are not adequate.

Figure 8.2. Interactional nature of recovery themes and occupational risk factors.



The Occupational Risk Factors theoretical perspective underlines the importance of an adolescent's personal resources and supports. There is a need for an adequate "support buffer" for adolescents who have sustained a concussion as they are already experiencing a tumultuous developmental transition. It is imperative that healthcare professionals consider patient-identified changes in daily life activities and occupations in the context of their pre-injury functioning. Disregarding patient roles, and expectations for recovery, may lead to failed

rehabilitation interventions and an overall worsening of function (DiFazio et al., 2016a). This is distinct from traditional return-to-activity protocols, in which the focus is on resuming productive behaviours (i.e., school and work). Effective pacing strategies will, therefore, involve counseling individuals to consider their occupations from a holistic, occupational perspective. The hope is that this study and the Occupational Risk Factors theoretical perspective will further the understanding of the occupational perspective throughout concussion recovery and perhaps provide healthcare providers (especially OTs) with further adolescent concussion treatment knowledge.

8.4.2 Occupational Perspective

An occupational perspective is not a new frame of thought within healthcare, however it is often overlooked due to the dominance of the biomedical model (Wilcock, 2005). The foundation of participation and engagement in meaningful occupations aligns well with the most recent 2016 Consensus Statement on Concussion in Sport Guideline that emphasizes gradual participation in regular activities 24-48 hours after injury, with a symptom-limited approach for return to activities – where an activity is terminated if symptoms are worsened significantly (McCrory et al., 2017). Therefore, it makes sense that both strict activity avoidance and periods full activity participation described in this study (i.e., all-or-nothing activity participation), can have deleterious effects on the recovering individual. The utility of an occupational perspective becomes even more apparent when considering the one-third of adolescents who experience prolonged symptoms and PCS, as emotional and psychosocial sequelae (e.g., frustration; stress; depression; anxiety) can develop and become intertwined with concussion symptoms (Scopaz & Hatzenbuehler, 2013; Southern et al., 2019; Zemek et al., 2016).

At present, the consideration of an occupational perspective within concussion research remains limited largely to position papers (Finn & Waskiewicz, 2015; Reed, 2011a). However, one recent study outlined that the addition of an OT to an interdisciplinary concussion care team improved identification of functional impairments (e.g., activity performance) in individuals 12 to 24 years, which ultimately optimized patient care (Harris et al., 2019). The results from this study adds further recognition to the benefits of an occupational perspective and OT within the treatment of concussion. A variety of health and social care professions can provide care using an occupational perspective, or at least consider the fundamental idea of occupation – however, not surprisingly, one of the most occupationally relevant care disciplines is occupational therapy. OTs traditionally work with clients to develop, recover and/or maintain skills as a means of encouraging participation in daily activities. A client’s goals are at the center of care, and OTs work to allow and to promote participation in personally meaningful activity through the adaptation of skills or environments.

The participants in this study discussed themes that facilitated recovery and promoted post-injury resilience (i.e., energy allocation and pacing; meaningful activity; recovery toolkit; and emotional support). It was interesting that these are largely in line with the occupational perspective and each lies within an OT’s scope of practice. Assistive devices, planning techniques, and environmental accommodations are customarily used by OTs to help individuals improve optimal functioning within daily life. Participants learned about the facilitators of recovery from a variety of healthcare providers which are listed below: sports medicine physician; neurologist; optometrist; physiotherapist; speech-language pathologist; and occupational therapist. However, it may be the most efficient for adolescents experiencing prolonged symptoms to avoid the trial and error treatment approach reported by participants in

this study (resulting in increased frustration) and seek an OT early on in their recovery process. Therefore, healthcare professionals can and should incorporate an occupational perspective within concussion care, as it can work well alongside the biomedical model.

The importance of an occupational perspective and OTs within concussion care may be especially important for female adolescents. Recovery is not as straightforward for adolescent females as compared to males – with higher symptom burden, longer overall recovery and perhaps worse long term outcomes (Berz et al., 2013; Brown et al., 2015; Covassin & Elbin, 2011). As such, it becomes even more critical to ensure that females have an equitable opportunity for experiencing an efficient recovery, safe return to daily activity and avoiding complications associated with prolonged recovery. Ideally an OT will be included in the circle of care promptly, and especially after a PCS diagnosis is made (i.e., PCS consideration after concussion symptoms lasting longer than 4 weeks for adolescents). The OT will work collaboratively with the individual while educating and facilitating the following: i) energy allocation and pacing; ii) meaningful activity; iii) recovery toolkit; and iv) emotional support. The inclusion of an occupational perspective in adolescent female concussion care will serve as a “support buffer” during recovery.

8.5 Limitations

Limitations for this study include sample size, size of the second focus group, and sample characteristics. At six adolescents and four parents, the sample size was small and did not reach the proposed sample size of eight adolescents. Collaborations with two concussion care settings were made, but the primary researcher only received the contact information for eight potential participants who were interested. Fortunately, saturation was approached after the first focus group of four participants, and the remaining two participants acted as a member checking

opportunity. A second limitation was the size of the second focus group – only two participants. This created a focus group that was more of a back and forth between the participants instead of a larger conversation.

An unforeseen sample characteristic that was noted, was that three participants experienced their concussion in elementary school whereas the other three sustained their concussion in highschool. It was noted that there were drastic differences in the supports received in elementary school as compared to highschool. For example, in elementary school participants reported more freedom for academic accommodations with no impacts on their grades (i.e., simply sitting out of certain classes). However, when they entered highschool and for those who sustained their concussion in highschool, there wasn't an opportunity to sit out of classes because there would be repercussions on their grades. There were more academic requirements of participants who sustained their concussion in highschool or were in highschool, which made energy allocation and pacing especially difficult. This ultimately produced a more stressful situation for recovering adolescents in highschool (as compared to elementary school).

A final limitation was the sample characteristic that parents were involved at some interviews and not others. Although parents whom sat in on the interviews were asked to allow for space for their child to share their experiences from the individual perspective, some information was shared from the parent perspective. However, the use of photoelicitation allowed adolescents to share personal photos of their recovery, giving the adolescents power and choice in how they represented their recovery experiences. Additionally, the focus groups were free from parental involvement, allowing for honest and candid discussions between adolescents.

8.6 Future Directions

It would be useful to explore the recovery experiences of adolescent male athletes within the same study guidelines. Namely, exploring the reported experiences of recovery from the male perspective, and seeing how their recovery is similar and/or different from adolescent females. Additionally, addressing the presence and implications of A-type personality characteristics in adolescent athletes recovering from PCS would be an interesting future project. A-type personality characteristics as a barrier to PCS recovery was a novel finding from this study – more research is needed to explore this barrier to recovery. Self-descriptors used by participants such as “perfectionist,” “driven,” “neat freak,” “competitive” and “stubborn,” could be expanded on further and explored more in-depth. The last suggestion for future research relates to the theme of “trial and error” and which management techniques or treatments within the “recovery toolkit” are beneficial to the large majority of adolescent athletes recovering from PCS. It was found that frustration was common regarding the trailing of many therapies and treatments during recovery, and that there was “no straightforward path” to find beneficial treatments. It would be interesting to gain consensus from experts in regard to the common and beneficial treatment strategies prescribed for those recovering from PCS.

8.7 Summary

The purpose of this study was to explore the recovery experiences of adolescent females who have sustained a concussion through sport participants and experienced prolonged recovery profiles. Facilitators and barriers to recovery were also considered. The themes that emerged from the data provided insights into the experiences of adolescent females who were recovering from prolonged concussion recovery and PCS. Participants reported that they experienced concussion symptoms which influenced their experiences of daily life. Specifically, the

symptoms lead participants to miss out on academics and school, social involvement, sport and physical activity, and extracurriculars. During the activity reintegration process, there was an imbalance between the activities that individuals “needed” to do as compared to those they “wanted” to engage in. Productive academic and school related activities were consistently prioritized, while meaningful activities remained limited. However, when there was an opportunity for meaningful activity engagement, individuals experienced a sense of mental and emotional well-being.

Over the course of months of experiencing chronic symptoms and limited meaningful activity, individuals experienced the emergence of emotional and psychosocial sequelae (i.e., feelings of frustration; stress; anxiousness; and depression), and a sense of loss and uncertainty as to how to proceed with recovery. In addition, one participant reported worsening of pre-existing anxiety and depression diagnoses and one participant reported receiving an anxiety diagnosis. The feelings of frustration, anxiousness and depression as well as both anxiety and depression diagnoses lead to an increase in the initial concussion symptom burden, and the PCS recovery cycle continued (see Figure 8.2). The risk of long-term consequences was explored in the context of pre-injury susceptibility (i.e., personality characteristics) and post-injury resilience (i.e., energy allocation and pacing; meaningful activity; recovery toolkit; emotional support).

The findings from this study illustrate the importance of taking the time to listen to adolescent females who have sustained a concussion. This will act as a method for proactively monitoring those at risk for developing prolonged concussion symptom (possibly females adolescents with A type personality traits). Additionally for those already experiencing prolonged symptoms, listening will act as the starting point for individualized patient care. The themes of loss, invisibility, and trial and error for those who are experiencing non-normative

concussion recovery experiences, create a situation of frustration during concussion recovery. Ideally, adolescent females should be closely monitored for emotional and psychosocial sequelae. The knowledge gained from this study can be applied to the larger body of knowledge that aims to guide healthcare providers in providing the best care possible for individuals experiencing concussion and PCS. Further research is necessary to explore the benefits of including the occupational perspective and occupation therapy within the circle of care for adolescent females who have sustained a concussion and are experiencing prolonged symptoms.

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APPENDIX A

Ethics Approval from Health Sciences Research Ethics Board



Date: 11 October 2019

To: Andrew Johnson

Project ID: 105697

Study Title: Capturing the experience of sport-related concussions

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

REB Meeting Date: 15/Oct/2019

Date Approval Issued: 11/Oct/2019

REB Approval Expiry Date: 04/Nov/2020

Dear Andrew Johnson,

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

Western University REB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The REB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Daniel Wyzynski, Research Ethics Coordinator, on behalf of Dr. Joseph Gilbert, HSREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

APPENDIX B

Ethics Approval from the Research Advisory Committee



31 March 2014

Dr. Andrew Johnson
School of Health Studies
Graduate Program in Health and Rehabilitation Sciences

Re: The Lived Experience of Concussion Treatment and Management: Return-to-Learn & Return-to-Play

Dear Dr. Johnson,

On March 31 2014, Thames Valley Children's Centre's (TVCC) Research Advisory Committee (RAC) reviewed and conditionally approved the above-named project. The Committee felt the study was clearly relevant for clinical practice.

Your study will receive full acceptance once a copy of the ethics approval from Western University's Health Sciences Research Ethics Board (HSREB) is received by Kathryn Hayman, TVCC's Research Officer.

The Committee had some feedback on your application that they would like me to pass onto you.

Members of the Committee were not sure if additional questions would be used to probe for further information from participants. They suggested that investigators include probes.

Letter of Information: The Committee felt that the Letter of Information was overly complex and the language could be simplified. The Committee wondered if it was acceptable to retain electronic data indefinitely. The Committee also wondered if the \$2 gift card was a typographical error.

The Committee hopes that you find their feedback helpful.

At the completion of your study, we look forward to the presentation of your findings to TVCC staff members through a "Discovery Series" presentation and an easy-to-read "Facts to Go" summary page. Please forward details of any future presentations and publications that arise from the study directly to Kathryn Hayman. Kathryn can also help to facilitate the "Discovery Series" presentation.

If you have any questions, please do not hesitate to contact me.

The Committee extends their best wishes for a successful project once the approval from the HSREB has been provided!



Yours sincerely, _____

Janette McDougall, Ph.D.
Researcher, Research Program
Chair, Research Advisory Committee
Thames Valley Children's Centre

Cc: Karen Lowry, Director, QM
Linda Bolack, Director, CTSS
Sara Somers, Social Worker, PABICOP
Janice Gray, Psychometrist, PABICOP

APPENDIX C

Letter of Information and Consent Form



Capturing the experience of sport-related concussions

PRINCIPAL INVESTIGATOR:

Dr. Andrew M. Johnson, PhD

CO-INVESTIGATORS:

Dr. Janette McDougall, PhD

Dr. Lisa Fischer, MD, BScPT, CCFP(SEM)

Annalise M. Tichenoff, BHSc, BScN

You are invited to participate in a research project looking at the adolescent experience of concussion recovery. We are interested in your daily life experiences – whether it is a facilitator or barrier in your recovery progression, changes in your school routine or extracurricular activities, or meaningful experiences with supports (e.g., an individual, treatment option, aid or modification, service, etc.). Your interpretation of how these people, places, and things affect your experience with concussion is what we are looking for. To accomplish this, we will ask you to take photographs that represent things that affect your day-to-day experiences with concussion treatment and management.

Study Description

The study will progress as follows: an informal interview; a period of time where you capture photographs at home, school, sport-based setting; a meeting to review the photos you have captured; and a group-based session in which you can share your photos with peers. After your second meeting with the research team, you will have the chance to select the 5 most representative or most meaningful photos to share during the group meeting. Throughout this study, we will work together and attempt to identify common themes within the photos that you and the other participants have captured.

We plan to speak with a total of 20 adolescents diagnosed with a concussion. All individuals will have been diagnosed with a concussion – sustained through sport participation, either during play or practice. In order to be eligible for participation, you must be fluent in English, you must be capable of taking photographs with a digital camera (or cellular device), and you must be capable of discussing the photographs that you take in both an individual and group setting. Individuals between 12 and 19 years of age are welcome to take part in this study. Also, parents or caregivers can sit in on all meetings, although they are not required to.

Benefits of Participation

Although you will not experience any direct benefits from participating in this research, it is our hope that this study will help us understand the aspects of concussion recovery that are most challenging to you. We intend to develop treatment and management options that address the specific needs of adolescents who have, like you, also sustained a concussion. We also hope to address the usefulness and practicality of return-to-learn

and/or return to play guidelines (i.e., physical and cognitive rest followed by gradual reintegration to activities). The information we will collect during this study will be shared with youth who have sustained a concussion and those who play sports and may encounter a concussion in the future.

Study Procedures

We will ask you to come to the Qualitative Research Lab in the Faculty of Health Sciences, at Elborn College, on three separate occasions:

1. To review this letter of information, to gather basic demographic information, and to discuss the process by which you will capture photos of the aspects of your environment that are relevant to your experience of living with and recovering from a concussion;
2. To speak with the investigators about the photos that you have taken, and to discuss your thought process in choosing to take these photos;
3. To speak with a small group of youth similar to yourself who have also sustained a sport-related concussion, and share experiences and photographs as a means of identifying common themes.

In between the first and second visit to the university, we will ask you to take photos of aspects of your environment that are relevant to your experience of living with and recovering from a concussion. We would like you to email us the photos. This email address will only be accessible by members of the research team, for the duration of the study, and all members will have access to the photos that you send. Should you wish to delete any photos, please let us know, either via email or by phone, and we will do so immediately. We will be audio recording both the interviews (during visit #1 and #2) and the interactions during the discussion group (visit #3). If you do not want to be audio recorded, you should not participate in this study. One of the researchers will also take notes on a computer during all three meetings. Visit #1 is expected to take approximately 30 to 40 minutes, and visits #2 and #3 are expected to take 40 to 60 minutes.

Voluntary Participation and Protection of Information

Your participation in this research project is voluntary. You may refuse to participate, refuse to answer any questions, and you may withdraw your participation at any time with no effect on your future participation in university-sponsored activities, on your academic status (if applicable), or your future medical care. If you withdraw your participation in the study before the conclusion of data collection, your data will be destroyed. Although we cannot guarantee full confidentiality within the study, owing to the fact that this study involves the use of focus groups, no identifying information will be attached to the data collected in this study. The only record of your name that will be retained will be on the attached consent form, and this information will be stored in a locked file cabinet, within a locked room, that is (in turn) inside Dr. Johnson's research laboratory (a room that is locked at all times). If the results of this study are published, your name will not be used, and no information that discloses your identity will be released or published without your explicit consent to the disclosure. Data collected during the course of this study will be retained for a period of five years after the last manuscript to result from the study has been published.

As a token of our appreciation for the time you spend completing this study, at the end of visit #3 we will provide you with a \$20 gift certificate redeemable at your choice of the following vendors: Starbucks, Chapters, and Tim Horton's. If you choose to discontinue your participation in the study, please let the principal investigator know, and we will arrange for you to receive the gift certificate prior to the end of visit #3. If you drove to the experiment today, we will provide you with a parking voucher for your vehicle.

Representatives of Western University's Health Sciences Research Ethics Board may contact you, or require access to your study-related records to monitor the conduct of the research.

Further Questions

If you have any questions about this research project, please contact the principal investigator, Dr. Andrew Johnson. If you have any questions about your rights as a research participant, or the conduct of this study, you may contact the Office of Research Ethics. You are not waiving any legal rights by signing the attached consent form. This letter is yours to keep.

Capturing the experience of sport-related concussions

Please sign this form to indicate that you agree with the following statement:

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

Participant (Printed Name):

Participant (Signature):

Date: _____

Caregiver or guardian (Printed Name):

Caregiver or guardian (Signature):

Date: _____

Person Obtaining Informed Consent (Printed Name):

Person Obtaining Informed Consent (Signature):

Date: _____

APPENDIX D

Photo Consent and Release Form



Capturing the experience of sport-related concussions

PRINCIPAL INVESTIGATOR:

Dr. Andrew M. Johnson, PhD

CO-INVESTIGATORS:

Dr. Janette McDougall, PhD

Dr. Lisa Fischer, MD, BScPT, CCFP(SEM)

Annalise M. Tichenoff, BHSc, BScN

I grant _____ (participant name) the right to take photograph(s) of me and my property in connection with this research study. I agree that the above investigators may use such photographs for research and study purposes. I understand that my name will not be used and all faces will be blurred in the photographs.

I have read and understand the above:

Photographed Individual (Printed Name):

Photographed Individual (Signature):

Date: _____

CURRICULUM VITAE

Name: Annalise Michelle Tichenoff

Post-secondary Education and Degrees:

Western University
London, Ontario, Canada
2008-2012 B.HSc.

University of Toronto
Toronto, Ontario, Canada
2014-2016 B.ScN. (R.N.)

Western University
London, Ontario, Canada
2013-2020 Ph.D.

Honours and Awards:

Entrance Scholarship
School of Health Sciences, Western University
2008

Gold Medal
School of Health Sciences, Western University
2012

Seymour Schulich Scholarship in Nursing
Seymour Schulich, University of Toronto
2014

Ontario Graduate Scholarship
School of Health & Rehabilitation Sciences, Western University
2014

Julia Alice Saddingham Memorial Award in Nursing
Saddingham Family, University of Toronto
2015

Related Work Experience:

Teaching Assistant
The University of Western Ontario
2013, 2016, 2017

Registered Nurse
London Health Sciences Centre
2016-2019

Publications:

Tichenoff, A., Holmes, J.D., Klapak, H., Lemmon, J., Picanco, M., Torrieri, A., Johnson, A.M. (2013). Nonpharmacological methods for reducing falls risk among individuals living with progressive supranuclear palsy. *Journal of Current Clinical Care*, 4(July), 1-7.

Echlin, P.S., Johnson, A.M., Holmes, J.D., **Tichenoff, A.**, Gray, S., Gatavackas, H., Walsh, J., Middlebro, T., Blignaut, A., MacIntyre, M., Anderson, C., Fredman, E., Mayinger, M., Skopelja, E., Sasaki, T., Bouix, S., Pasternak, O., Helmer, K.G., Koerte, I., Shenton, M.E., Forwell, L.A. (2014). The Sport Concussion Education Project: A brief report on an educational initiative. *Journal of Neurosurgery*, 121(6), 1331-1336.