THE EMOTIONAL IMPACT OF CONCUSSION: EXPLORING THE RISKS AND EXPERIENCES OF DEPRESSION IN YOUTH RECOVERING FROM

CONCUSSION

THE EMOTIONAL IMPACT OF CONCUSSION: EXPLORING THE RISKS AND EXPERIENCES OF DEPRESSION IN YOUTH RECOVERING FROM CONCUSSION

By

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# Abstract

Children and youth who suffer a mild traumatic brain injury or concussion are at risk for a number of negative outcomes. The symptoms of concussion and the management of these symptoms can be disruptive to the child’s everyday activities, especially if they are prolonged. Depression can result and may complicate the course of recovery.

Depression has overlapping symptoms with concussion and is thought to lengthen the recovery period. There has been much research done in populations of mixed severities of brain injury but very little addresses children with concussion. Knowledge in this area is crucial due to depression’s impact on all aspects of functioning as well as the potential alteration of the child’s developmental trajectory.

The purpose of this research was to examine the risks and predictors of depression following concussion in youth and to explore the experiences of a subsample of youth and their families with prolonged recovery from concussion, complicated by depression.

Chapter One provides a review of the current literature setting the context for the research within what is known about concussion in youth, what is known about depression in youth and because of the early stages of this type of research, what is known about depression as an outcome of concussion in all age groups.

Chapter Two presents a study highlighting the tangible risk for depression in a sample of children being followed in a tertiary care clinic (N=92). Significant predictors of depressive symptomatology were found to be the need for hospital admission and high symptom scores in the first few days and weeks after injury, which may be valuable

information for prevention, early identification and treatment of youth at risk for depression after concussion.

Chapter Three provides an in-depth exploration of the experiences of youth and families who have gone through prolonged recovery from concussion with significant depressive symptomatology. A phenomenological approach was used with six participants and their families who were interviewed and their responses analyzed. A trajectory of recovery was identified; common themes within each of four key stages of the trajectory were discussed and illustrated using direct quotes from the participants.

Chapter Four outlines the important implications of these two studies for health care professionals; particularly in raising awareness of the mental health outcomes of concussion. Knowledge of the impact of debilitating symptoms, activity restrictions and depression can inform discussions early after a concussion to prepare and possibly prevent some of the losses experienced by youth that can lead to depression.

# 

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# Chapter One: Introduction

Concussion or mild traumatic brain injury (mTBI) in children is a mounting public health concern. The increasing incidence, due in part to the widespread participation in competitive sports at younger ages, has contributed to a growing urgency in research to understand the short and long term effects of this injury (Schatz & Moser, 2011). Depression is one of the secondary sequelae following traumatic brain injury of all severities and has multiple causes (Lange, Iverson, & Rose, 2011). The complexity of the interaction between the physiological aspects of the head injury, the psychological aspects of the trauma and the subsequent loss of normal activities and routines all may play a role in the onset of depression. Understanding more about depression following concussion is important due to the potentially poor psychosocial outcomes that include behavioral, psychological and psychiatric consequences and a resultant impact on individual and family functioning (Keightley et al., 2014).

Research into the psychosocial impact of concussion in children is advancing rapidly. Recent studies have reported on a higher likelihood for future depression (Chrisman & Richardson, 2014; Tsai et al., 2014), conduct disorder, bullying and adverse psychosocial outcomes (Ilie et al., 2014) in children when there is a past history of concussion. Much less is known about whether depression complicates and possibly lengthens recovery from concussion when it occurs shortly after injury. Some of the unanswered questions include: How common is it for children to have significant depressive symptoms?; What influences depression?; How does depression manifest after concussion?; and Who may be at risk? Research in this area is needed to guide prevention and early identification efforts in order to decrease the morbidity subsequent to the onset of depression. To that end, this dissertation will focus on understanding more about the extent of this mental health problem and what may help explain or predict those children who develop symptoms of depression in the course of their recovery from concussion.

This thesis presents two manuscripts; the first manuscript (Chapter Two) reports the results of a study of depression assessed in a cohort of post-concussive youth followed at a tertiary care centre. The second manuscript (Chapter Three) examines the experience of children and families who are living with prolonged recovery from concussion with depressive symptoms.

This introductory chapter will provide the background and literature that helped to formulate the research questions. An overview of our current understanding of concussion and of childhood depression is provided along with a discussion of the theoretical rationale and the current evidence addressing depression that occurs post-concussion.

# Concussion

Concussion, or mild traumatic brain injury (mTBI), results in a complex pathophysiological response from a force to the body that transmits to the head or from a direct blow to the head which results in impairment of neurological function that resolves spontaneously (McCrory et al., 2013; Toledo et al., 2012). The diagnosis and determination of the effects of concussion on the brain are difficult, as common imaging techniques often show no signs of injury since it is considered a functional disturbance rather than a structural injury (Halstead & Walter, 2010). A neurometabolic cascade has been described that occurs as axons are stretched and misfire and cells are clogged with calcium (Giza & Hovda, 2001). The energy crisis that results causes decreased cerebral blood flow and results in symptoms of headache, dizziness, poor balance, fogginess, and difficulty with memory, sensory sensitivities and fatigue among many others (Giza & Hovda, 2001). The most current and straightforward definition of concussion from the Zurich Consensus guidelines consists of a Glasgow Coma Scale score between 13 and 15, with or without loss of consciousness; altered mental status or disorientation; plus the presence of one or more of the common symptoms mentioned previously (McCrory et al., 2013). Symptoms may be apparent immediately after the injury, but sometimes do not appear for several hours or days.

## Recovery from Concussion

Healing after concussion generally occurs rapidly and spontaneously with full recovery in days to weeks; however some patients experience persistent negative symptoms (Berrigan, Marshall, Velikonja, & Bayley, 2011). Studies report anywhere from 25% to 50% of children experiencing symptoms one month post injury (Blume et al., 2012; Eisenberg, Andrea, Meehan, & Mannix, 2014). Eleven to 30% of children have symptoms after three months (Babcock et al., 2013; Barlow et al., 2010). Protracted symptoms over many weeks and the resultant loss of activity can lead to secondary symptoms of depression and anxiety (Silverberg & Iverson, 2013). Appropriate management of concussion recovery is believed to prevent some of the secondary symptoms or poor outcomes (Daneshvar et al., 2011; Shrey, Griesbach, & Giza, 2011).

The basis for management of concussion recovery is rest and a graded return to activity (DeMatteo et al., 2014; McCrory et al., 2013). When symptomatic, children are advised to rest both physically and cognitively which includes no screens or smart phones, reading or homework; however there is no rigorous research defining exactly how much rest is necessary (Silverberg & Iverson, 2013). There is controversy, therefore, about the amount of prescribed rest as a management tool in concussion. Prolonged rest can lead to social isolation, depression and deconditioning (Leddy et al., 2010); however, going back to activity too soon can exacerbate symptoms or cause symptom return and lengthens time to recovery (Brown et al., 2014; Guskiewicz et al., 2003; Moser, Glatts, & Schatz, 2012). An evidence-based and balanced approach to managing this complex issue has been advocated as the most practical and guidelines for return to activity (DeMatteo et al., 2014) and return to school (DeMatteo et al., 2015) have now been developed.

Appropriate management of concussion is key in preventing further injury. Having a head injury is a risk factor for sustaining another similar injury within a year (Guskiewicz et al., 2003; Swaine et al., 2007). Multiple injuries have also been identified as a risk factor for increased symptom reporting, prolonged recovery, neurocognitive changes and depression (Corwin et al., 2014a; Mannix et al., 2014). The implication for appropriate education and management of concussion is, therefore, crucial in preventing poor long-term outcomes, which may include more head injuries, extended recovery periods and secondary mental health sequelae.

## Incidence of Concussion in Children

Children have the highest incidence of all those sustaining traumatic brain injuries (TBI) through sports, falls, motor vehicle accidents and non-accidental injuries (Laker, 2011; Wing & James, 2013). An accurate figure representing the incidence of concussion in children is difficult to obtain due to the under-reported nature of this injury and the lack of a consistency in diagnosis. Awareness and recognition, however, is growing and has resulted in a sharp rise in those with concussion presenting to emergency departments (Colvin et al., 2013; Macpherson et al., 2014). Recent figures from sports injuries alone show that the prevalence of concussions that are recognized has doubled in the 8-19 year-old age group (Moser et al., 2012). In Ontario in 2010 14,886 children with concussion were treated in local emergency departments (ED) or by family physicians (Macpherson et al., 2014). Even if a small proportion of these children suffer persistent negative outcomes, such as the 11 – 30% previously cited as having prolonged recoveries, then this is a serious public health problem (Yeates & Taylor, 2005).

## Outcomes of Concussion

Concussion, and particularly repeated concussion, can lead to long term outcomes that include: 1) changes in neurocognitive functioning including processing speed, memory and concentration (Lau, Collins, & Lovell, 2012); 2) psychiatric illness such as mood disorders, post-traumatic stress disorder, anxiety and obsessive compulsive disorder (Bryant et al., 2010); 3) behavioural changes that can include difficulties with attention, initiation, impulse control and organizational skills (Daneshvar et al., 2011; McKinlay, Dalrymple-Alford, Horwood, & Fergusson, 2002) and 4) post-concussive syndrome or protracted symptoms of at least 3 months (Daneshvar et al., 2011). These outcomes often result in functional difficulties that include decreased participation, school performance difficulties and decreased quality of life (DeMatteo et al., 2014; Parsons, Bay, & Valovich-McLeod, 2013).

Post-concussive syndrome. A discussion of Post-Concussive Syndrome (PCS) as one of the possible negative outcomes from concussion is central to understanding the dilemma of disentangling the prolonged symptoms that occur post-concussion from clinical depression: this is the focus of much debate in the literature (Iverson, Brooks, Collins, & Lovell, 2006; Lange et al., 2011; Leddy, Sandhu, Sodhi, Baker, & Willer, 2012). Persistent negative symptoms of concussion are, in fact, diagnostic criteria for PCS that were described in both the International Classification of Diseases-10 (ICD-10; World Health Organization, 1992) and Diagnostic and Statistical Manual-IV-Revised (DSM IV-R, (American Psychiatric Association, 2000). These definitions of PCS involve the presence of persistent cognitive, somatic and behavioural symptoms leading to deficits in functioning (Daneshvar et al., 2011). The more recent DSM-5 has subsumed PCS under the heading Neurocognitive Disorders and it is now called “minor neurocognitive disorder due to traumatic brain injury” (American Psychiatric Association, 2013). A decline in abilities in at least one of the following cognitive processes are needed to meet diagnostic criteria: complex attention, executive function, learning, memory, language or social difficulties confirmed by a family member, clinician or from a deterioration in neurocognitive testing (American Psychiatric Association, 2013). Symptoms of the brain injury must persist past the acute post-injury phase, usually defined as a period of three months. The ensuing cognitive deficits do not necessarily have to interfere with everyday independence to qualify for this diagnosis. This diagnostic category, with its tighter definition of persistent cognitive symptoms, may make it easier to discern the difference between depression and minor cognitive disorder due to traumatic brain injury. However, because most of the literature reviewed here uses this terminology, minor neurocognitive disorder due to brain injury will continue to be referred to as PCS in this thesis.

Current PCS research. Research directed at predicting PCS or determining the underlying cause has shown that both premorbid and injury factors have a role in determining who experiences protracted symptoms. Ponsford et al. (2012) examined predictors in adults with concussion in a prospective cohort with trauma controls and found that premorbid physical and psychiatric problems as well as concurrent anxiety had more influence on persistent symptoms than the injury itself. Studies conducted with children found that 29.3% of those presenting to emergency rooms with concussion had PCS at three months. Predictors of PCS, although limited by the available variables collected on presentation to ED, included headache and hospital admission (Babcock et al., 2013). Other predictors in children that have been documented in the literature include initial symptom presentations of dizziness, headache or amnesia (Babcock et al., 2013; Lau, Kontos, Collins, Mucha, & Lovell, 2011) as well as having a history of more than one concussion, having learning difficulties and the presence of family stressors or psychological problems (Heidi K Blume, Lucas, & Bell, 2011; Ponsford et al., 2012).

The consequences of PCS have been reported as functional deficits; subtle cognitive differences that require educational supports 12 months after injury (Yeates et al., 2012), behavioural impairments (McKinlay et al., 2009); and reduced quality of life (QOL; DeMatteo et al., 2014). In a pilot study of 25 adolescents who had symptoms beyond three months, patients reported their QOL to be at the same level as peers who were undergoing chemotherapy. Investigators found that symptom reporting quadrupled in adolescents with a history of more than one concussion (Duffy, 2012). Increased symptom reporting has also been associated with the development of depression (Rao et al., 2010). PCS significantly impacts children’s relationships, school performance, sport, leisure and social activities and can be a heavy burden on both the child and family (Eisenberg, Meehan, & Mannix, 2014; Ganesalingam et al., 2008) Strong positive relationships between PCS and depression scores have been found in adult literature (Mooney, Speed, & Sheppard, 2005) but this has not yet been extended to children.

# Depression in Children

Depression is a highly complex diagnosis or label of an affective state that overwhelms the individual with helplessness and hopeless emotions (Robertson, 2006). It results in a decline in function affecting occupational or school performance, relationships and can lead to suicidal behavior, substance abuse, physical illness and exposure to negative life events (Children’s Mental Health, 2001). Unipolar major depressive disorder across age groups is ranked as the fourth leading reason for disease burden and is the world’s leading cause of disability (Patten, 2010).

## Epidemiology

Prevalence of depressive disorders is difficult to determine as there is confusion about definitions. Clinical depression or major depressive disorder in the general population is reported to be 2 – 4% in childhood, 4 – 8% in adolescence (approaching adult rates in late adolescence) and 17% in adults (Ahmoi & Petermann, 1999; Kessler, Avenevoli, & Merikangas, 2001). Many studies report on depressive symptoms rather than diagnosis (Horowitz & Garber, 2006) and report that 10 -17% of children have a moderate to severe level of depressive symptoms (Abela & Hankin, 2008; Nolen-Hoeksema, Girgus, & Seligman, 1992). Adolescents who score high on depressive measures, but do not meet criteria for a clinical depression demonstrate equivalent psychosocial dysfunction as those who were diagnosed with depression (Twenge & Nolen-Hoeksema, 2002). In community epidemiological surveys 20% to 50% of adolescents self-report significant sub-threshold levels of depression (Kessler et al., 2001). Sub-threshold depressive symptoms put adolescents at elevated risk for later major depression and suicidal behaviours (Fergusson, Horwood, Ridder, & Beautrais, 2005). One study has shown sub-threshold depressive disorder escalates to full syndrome depressive disorder in 67% of cases within the following ten years (Klein, Shankman, Lewinsohn, & Seeley, 2009). At about 12 to 13 years of age, girls begin to report more depression than boys and this sex difference becomes a 2:1 ratio in later adolescence and adulthood (Abela & Hankin, 2008). Depression is more common among clinical populations (Carr, 2008; Hankin & Abela, 2005). While the literature has reported rising rates of depression in the pediatric population (Abela & Hankin, 2008), a recent systematic review investigating whether adolescent mental health problems are actually increasing identified that the rates of internalizing and externalizing problems remain stable other than for recent cohorts of adolescent girls who have significantly more internalizing symptoms (Bor, Dean, Najman, & Hayatbakhsh, 2014). These disturbing trends are important as clinical depression or sub-threshold depression after concussion may set youth up for further episodes of depression throughout their lifespan (Kessler et al., 2001; Rivas Rodríguez, Nuevo, Chatterji, & Ayuso-Mateos, 2012).

## Symptoms

Depression presents quite differently in children than in adults. Developmental issues make the expression of symptoms different with younger children while adolescents and older children may experience symptoms similar to adults (Carr, 2008; Children’s Mental Health, 2001). Younger children are more likely to show:

* Separation anxiety
* Irritability, accompanying tantrums or behavioural problems
* Lack of co-operation
* Somatic complaints (headache, stomach ache)
* Withdrawal from friends and family
* Apathy and disinterest, loss of interest in play

Unlike adolescents and adults, younger children are less likely to make serious suicide attempts. In adolescence, depression is experienced more with the following symptoms:

* Sleep and appetite disturbances
* Weight loss or gain
* School refusal or decline in academic performance
* Suicidal thoughts feelings and attempts

## Causes of Depression

Depression commonly develops subsequent to life stresses and chronic health conditions (Dejean, Giacomini, Vanstone, & Brundisini, 2013; Hankin, 2006). Not everyone who is exposed to stress will go on to develop depression. Development of depression is widely accepted as being influenced by genetic, environmental and neurobiological factors (Caspi & Moffitt, 2006; Hankin, 2006). This understanding is congruent with vulnerability-stress models that explain the development of psychopathology. Hypotheses based on these models have been researched with a variety of mental illnesses including depression (Monroe & Simons, 1991).

In vulnerability-stress theory the vulnerability is a latent trait that only becomes relevant when it interacts with enough stress to bring about psychopathology (Ingram, 2010). If significant life stressors are not experienced, there is no interaction and, thus, no trigger that would cause the vulnerability to produce depression. Conversely, stress alone is not able to induce the condition without the presence of the vulnerability. Vulnerabilities can be biological, social or cognitive in nature. An expansion of the vulnerability-stress model proposes that individuals who are more susceptible to adverse conditions are also more readily influenced by enriched developmentally enhancing environments (Belsky, 1997; Ellis, Boyce, Belsky, Bakermans-Kranenburg, & van Ijzendoorn, 2011). This differential susceptibility to the environment (Boyce & Ellis, 2005) may prove to be a very useful concept in explaining the onset of depression after concussion and some of the variable recovery patterns. There is a growing body of evidence that children who have had a concussion are at increased risk of being diagnosed with depression during the recovery period or up to 5 years post injury (Chrisman & Richardson, 2014; Luis & Mittenberg, 2002; Max et al., 2012; Tsai et al., 2014). Pre-injury stress, post-injury stress, social factors and neurobiological mechanisms have all been implicated as contributing to a depression outcome after concussion (Kirkwood et al., 2000; Lange et al., 2011; Luis & Mittenberg, 2002). Children with vulnerability traits plus concussion may have more susceptibilities making them more vulnerable to environmental influence after the injury.

## Diagnosis of Depression

Diagnosing depression can be complex as many options for diagnostic categories exist. Major depressive disorder, synonymous with clinical depression is rigorously defined by the DSM-V (American Psychiatric Association, 2013) Mild or moderate depression is often referred to as sub-threshold depression (Rivas Rodríguez et al., 2012). Adjustment disorder is another diagnostic category found under Trauma and Stressor Related Disorders in the DSM-V: sometimes referred to as situational or reactive depression, it requires exposure to trauma or a stressful event (American Psychiatric Association, 2013). Self-report measures of symptoms detect possible cases of depression, but cannot yield a diagnosis. The duration of symptoms, the type of symptoms and the functional deficits required for diagnosis require clinical judgment based on a variety of sources (Kovacs, 2011).

Diagnosis of depression is a complex decision-making process that uses information from a variety of sources and assessment procedures. An increasing focus and reliance on evidence-based systematic evaluation is being recommended in the practice of child and adolescent psychiatry (D’Angelo & Augenstein, 2012). The early detection of depression in childhood is vital to provide timely intervention and prevent the accompanying negative outcomes, recurrence, chronicity and comorbid mental disorders (Fruhe et al., 2011). Nevertheless, depressive disorders often remain undiagnosed. A study of pediatric clinics showed that only 22% of 51 adolescents who actually had mood disorders were detected (Richardson, Russo, Lozano, McCauley, & Katon, 2010). One of the major barriers to screening for depression in clinical populations is the overlap of physical symptoms of disease processes with depression (Dejean et al., 2013). Clinicians often attribute depressive symptoms to part of the chronic disease process and, therefore, depression as a distinct condition is not always recognized by patients or health care professionals (Dejean et al., 2013). Primary care physicians also often rely on a clinical unstructured interview, which has low levels of agreement between clinicians (D’Angelo & Augenstein, 2012). Structured interviews have been perceived as the gold standard; however, these are extensive and time consuming and not usually practiced outside of research settings. Semi-structured interviews and rating scales, when used together, can enhance the diagnosis of depression and provide more evidence-based evaluation (D’Angelo & Augenstein, 2012). Typically, child self-report measures are considered to have greater sensitivity than parent-rating forms, although having a variety of sources and assessment procedures increases confidence in the diagnosis (D’Angelo & Augenstein, 2012). An example of a self-report child measure is the Childhood Depression Inventory (CDI; Kovacs, 2011) which a well-researched measure of depression. It has been shown to have a moderate relationship to independent psychiatric ratings (Twenge & Nolen-Hoeksema, 2002). The CDI is a measure of psychosocial distress rather than depression alone because it measures a subclinical level of depressive symptomatology and it does not discriminate well between depression and anxiety (Twenge & Nolen-Hoeksema, 2002). This screening tool takes only a few minutes to complete and has been validated for use with medically ill children (Allgaier et al., 2012). For screening tools to be used in busy clinical settings, the brevity of the instrument and high criterion validity are important (Fruhe et al., 2011).

# Depression and Brain Injury

Emotional symptoms, irritability and depressed mood are common in recovering from a brain injury (Corwin et al., 2014b; Eisenberg, Meehan, et al., 2014). Sixty percent of children have been reported to be more emotional and 58% to be more irritable one month following the injury (Barlow et al., 2010). Kontos and collegues (2012) investigated depressive and neurocognitive symptoms in 129 high school and collegiate athletes following concussion and found that, in comparison with baseline scores obtained at two days post-injury, increased depression scores were experienced up to 14 days after injury. Eisenberg (2014) recently found that emotional symptoms, which developed in the follow up period during recovery from concussion, lasted the longest from 7 – 23 days on average. If these symptoms are a typical part of brain injury recovery, a question still remains about how does one distinguish when children’s emotional health is most at risk?

## Contributions from Adult Studies

A review of the literature indicates that evidence from adult studies, which are more abundant, may provide a basis for further exploration of depression in children. A recent Canadian national population health study of neurological conditions in all ages found that 38.3% of those with TBI reported mood and anxiety disorders compared to 8.6% without a neurological condition (Ministry of Health,Canada, 2014). Other studies in adult populations with acquired brain injury report incidences up to 77% (Seel et al., 2003). Some of these studies have been criticized for using self-report measures of depression, having different definitions of depression, using retrospective methodologies and for the variation in follow up time, sometimes up to ten years after injury. Even fewer studies have been conducted with the population of individuals who have had a concussion or mTBI. Rapoport,et al. (2003) specifically examined depression after concussion in a cross-sectional study of 170 adults and found that 15.3% met criteria for major depression after a mean of 48 days post-injury. Depression was associated with increased post concussive symptoms and greater psychological and psychosocial distress. Another prospective study that followed a cohort of 43 adults with concussion found depression in 18% of patients up to a year after injury (Rao et al., 2010). These studies addressed the problem of inconsistent diagnosis and definition of depression by using the Structured Clinical Interview for DSM-IV disorders (First, Spitzer, Gibbon, & Williams, 2002) which is considered to be the gold standard for diagnosis of depression. Both investigators excluded those individuals with histories of psychiatric or mood disorder to focus on new-onset depression. Rao and colleagues (2010) also excluded those with prior concussion. This may be an important omission, as there is evidence that multiple concussions are associated with the likelihood of being diagnosed with depression (Guskiewicz et al., 2007). A dose-response relationship was found between the number of concussions and the odds of depression in retired NFL football players: those with a history of three or more concussions were three times more likely to have a diagnosis of depression and those with one to two concussions were 1.5 times more likely than those with no history of concussion to have a clinical diagnosis of depression (Guskiewicz et al., 2007).

## Contributions from Pediatric Studies

Research specific to the pediatric population addressing questions of psychiatric sequelae after TBI is sparse. Kirkwood et al. (2000) prospectively studied 189 children with moderate to severe TBI (6 – 12 years of age) and examined the prevalence and clinical correlates of depression. Baseline testing was completed using, self-report measures of depression, family environment and neurocognitive testing. These measures were repeated at 6 and 12 months. A slightly elevated prevalence of depressive symptoms was found. Fifteen percent of the sample had a T score on the Children’s Depression Inventory (CDI) of ≥ 60 six months after their injury and nine percent at 12 months post injury. A T score of 65 on the CDI is suggested to be indicative of clinical depression (Kovacs, 2011); therefore, the children who had a T score of >60 in Kirkwood’s (2000) study may have had a sub-threshold depressive disorder. Depressive symptoms were associated with socioeconomic status in children with brain injuries as well as in a control group of those with orthopedic injury. Missing data may affect the results of both prevalence and any associated relationships.

Similar findings regarding incidence were reported in a well conducted longitudinal prospective cohort study of 177 children 5 – 14 years of age and controls (Max et al., 2012). Participants were children hospitalized after TBI with 50% of the sample having had a mild injury. Results indicate that 11% were subsequently diagnosed with a new depressive disorder. Predictors of depression in this cohort were older age, traumatic lesions in left parietal and left inferior gyrus, as well as a family history of anxiety. Children 12 years of age and older had a five-fold increased risk of having depression in comparison with younger children. In contrast, Luis & Mittenberg (2002) in another prospective cohort found, a 38% rate of mood and anxiety disorders in a group of 6-15 year olds admitted to hospital with mild (N=42) and moderate/severe (N=19) brain injury six months post injury compared to 14%t in the orthopedic controls; 26% of the mood disorders were depression related. The significant predictors in this study were post-injury stress and severity of TBI. Finally in a weaker cross-sectional design study of children with concussion (only 5% of whom were admitted to hospital) demonstrated a much lower rate of 3% with depression 1 – 3 years after injury (Smyth et al., 2014).

These studies highlight the need for continued research in this area as differing populations (hospitalized versus non-hospitalized), varying length of follow up times (6 months – 3 years), different measures for outcome and divergent ages (younger children only or adolescents included) make it difficult to compare the clinical populations who served as participants. Studies to date have been more focused on the prevalence and prediction of post-concussive syndrome rather than on the psychosocial outcomes. No prospective long-term studies of depression specific to concussion in children have been conducted; however, the literature suggests an increased prevalence of depression after concussion that is greater than that reported in the general community and that occurs relatively early after injury. Depression after childhood concussion requires more empirical study to determine the extent of the problem and to answer questions about who may be vulnerable to this outcome.

## The Relationship Between Post-Concussion Syndrome and Depression

Associations between prolonged recovery and depression have not been systematically studied. Investigators have reported that differential diagnosis of PCS and depression is not straightforward (Baker, Freitas, Leddy, Kozlowski, & Willer, 2012; Willer & Leddy, 2006). Increased symptom reporting, however, has been found to predict the development of depression (Rapoport et al., 2003) and those who are diagnosed with depression after mTBI endorse more post concussive symptoms (Lange et al., 2011). PCS is known also to exacerbate pre-existing depression (Daneshvar et al., 2011). There continue to be many unanswered questions about the underlying causes of either of these outcomes. Chen,and collegues (2008) investigated the neural substrates of depression and prolonged symptoms after concussion with 56 young adult male athletes who had a concussion in the previous year. Functional magnetic resonance imaging (fMRI) has demonstrated differences between those experiencing depression versus those experiencing persistent negative symptoms and concluded that there is an organic basis to PCS that is different from that seen in depression.

Depression and prolonged symptoms of concussion are similar with some overlapping symptoms particularly sleep disturbance, concentration and memory difficulties, fatigue and emotional symptoms such as irritability and sadness. Research is needed to advance our understanding about both of these outcomes and led to the research questions that form the basis of this thesis.

# Research Objectives

The purpose of this research is to examine depression in children who have experienced a concussive injury and to identify the factors associated with the development of depression. The research questions guiding this study are:

1. Do children being followed for concussion at a local Children’s Hospital Acquired Brain Injury clinic develop depression during recovery, and at what point?
2. What factors contribute to depression after concussion in the pediatric population?
   * 1. To what extent do *injury-related factors*: a) recovery time; b) mechanism of injury; c) number of injuries; and d) number and type of symptoms predict the presence of depressive symptoms 3 – 12 months after concussion in children 8 – 18 years of age?
     2. To what extent do *non-injury related* factors: a) age; b) sex; and

c) premorbid diagnosis, learning and behavioural difficulties; predict the presence of depressive symptoms 3 – 12 months after concussion?

1. What are the experiences of families living with their child’s prolonged recovery and depressive symptoms after concussion?

Two different research methodologies are needed to answer these questions. A quantitative approach analyzing data collected from the Acquired Brain Injury database of the McMaster Children’s Hospital was utilized to address Questions 1 and 2 regarding any association between injury and non-injury variables and the development of depression in a child after concussion. Incidence and predictors of self-reported depression were also examined. These results are presented in Chapter Two. In order to address Question 3, a qualitative phenomenological study was conducted using face-to-face in-depth interviews of six children and their families in order to explore their lived experience of prolonged recovery from concussion when the child had significant depressive symptoms. The results of this study are presented in Chapter Three. The ultimate aim is to provide a more systematic approach to identifying children who may be experiencing depression during recovery from concussion. The results of the two studies are integrated and discussed in Chapter Four and clinical implications are described. It is anticipated that this study will lead to improved early identification and health care delivery for families and for the silent minority of children experiencing post-concussive depression.

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# Chapter Two

# Title of Paper: Depression in Children Recovering from Concussion: Correlates and Predictors

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To be submitted to: *Brain Injury*

# Abstract

*Objectives:* Although depression can be a serious consequence of concussion, little is known about the factors that predict depression and concussion recovery outcomes in children. The purpose of this study was to explore the risk and possible predictors of developing significant depressive symptoms in children recovering from concussion.

*Methods:* A prospective cohort study was conducted in a pediatric tertiary care clinic. Depression data was collected on 92 children using the Children’s Depression Inventory-2 (CDI-2) screening tool. Correlations, t-tests and logistic regression were used to examine the associations between depression scores and demographic as well as injury-related factors.

*Results:* Depressive symptoms were found in 22% of the children (T score on CDI-2 > 65). Children with evidence of depressive symptomatology had significantly higher mean post- concussive symptom inventory (PCSI) scores in recovery (p=0.004) than children who were not depressed. i) Sex; ii) hospital admission; iii) number of head injuries; iv) post-concussion symptom score and v) experience of prolonged symptoms were predictive of clinically significant CDI T scores, explaining 36% of the variation in the binary logistic model.

*Conclusion:* Depression is commonly reported in this subset of children. High post-concussive symptom scores and hospital admission were strong predictors of depression. Screening for depression should be standard practice in concussion management in children and youth.

In the United States, the incidence of concussion is reported to be between 1.7 and 3.8 million individuals per year; more than half are children [1]. Recent figures from sports injuries alone show that the prevalence of concussions doubled in the 8-19 year old age group from 1997 to 2007 [2]. Children are a vulnerable group and have the potential for many injuries over their lifespan especially given that concussion is a predictor of future concussions [3, 4].

Recovery trajectories for children post-concussion are varied [5, 6] and are currently described on the basis of the length of symptom presentation; under one month, between 1 – 3 months and over 3 months. Symptoms of concussion are categorized as somatic (e.g., headache and balance issues), emotional (e.g., irritability and anxiety), cognitive (e.g., difficulty concentrating and remembering) and sleep symptoms [7]. Childhood concussive injuries typically resolve in days or weeks but some of these “mild” injuries can have serious and prolonged health consequences [8,9]. When symptoms last more than 3 months they can significantly affect the child’s everyday life and may intensify emotional or depressive symptoms [10]. Children and adolescents are at higher risk for prolonged symptoms after concussion with 11- 30% of children report ongoing symptoms at 3 months post injury [11,12].

While there are frequent references to the risk of developing depression after mild traumatic brain injury (mTBI) otherwise known as concussion,[[1]](#footnote-1) there is little evidence specifically about this result in children. Psychosocial outcomes after childhood concussion are beginning to receive more attention, as depression in young people profoundly affects their participation in school, social and physical activities as well as putting youth at risk for suicidal behavior, substance abuse and negative life trajectories [13,14]. The prevalence for depression in the general population is reported to be 1- 2% in children and 4-8% in adolescents [14,15]. Girls report depression more than boys beginning at 12 years of age and increasing to a 2:1 ratio in later adolescence and adulthood [16]. Injury or illness increases the susceptibility to depression [17,18]. Within the first year after concussion adults demonstrate rates of 15 – 18% of new onset depression [19, 20].

Recent studies investigating depression after concussion in children fall into two categories: 1) those investigating the risk of depression based on exposure to concussion and 2) those that are investigating depression that occurs shortly after injury, complicating the recovery from concussion. Consistent results from the former studies show an increased likelihood of becoming depressed when there is a history of concussion or traumatic brain injury (TBI) [21, 22]. However studies exploring depression that occurs during recovery from concussion are less conclusive in determining prevalence. Two prospective studies found an 11% and 21.4% incidence of new onset of depression/anxiety in children within 6 months after their injury [23, 24]. Both of these studies drew their samples from children who were hospitalized for mild injuries, which potentially introduces selection bias as more severe cases are hospitalized. A recent cross-sectional study of post-concussive children 7 – 17 years old examined them 1 – 3 years post injury for depression and post-concussion symptoms [25]. Depression was found to be uncommon and was experienced by only 3% of their sample [25]. Differences in sample selection and inclusion criteria, definitions of concussion, follow up time and additional methodological issues make it difficult to draw substantive conclusions about the incidence of depression in children recovering from concussion. More studies are needed to close the gaps in knowledge or to confirm and add to some of these preliminary conflicting findings. Investigations specifically representing children with concussion need replication. Studies also need to focus on the period of recovery from concussion and to span both childhood and adolescence if we are to realize the magnitude of the problem.

Research studies examining the association between depression and concussion have identified factors that may predict the incidence of depression after concussion. Many non injury-related factors are reported to be associated with the onset of depression after concussion: older child, family history of anxiety [23], lower socioeconomic status [26], and post-injury stress [24]. In addition, many injury-related factors in the adult population have been identified as risk factors for depression, including; multiple brain injuries, number and severity of symptoms, mechanism of injury, hospitalization and imaging abnormalities [27, 29]. To date, there have been very few studies conducted with children. One pediatric prospective cohort with orthopedic controls demonstrated that the severity of injury and post-injury stress predicted the onset of depression [24].

Research determining both the incidence of depression and the factors that predict risk for depression after concussion is in the early stages. More work needs to be done to understand the incidence of depression in children recovering from concussion and to highlight factors that predict depression in children who are still in recovery from concussion. Determining the factors that increase risk for depression post-concussion can lead to strategies for effective prevention and early intervention.

The purpose of this study is to explore the risk of depression in a cohort of children and youth recovering from concussion, and to identify predictors of depression during the recovery period. It was hypothesized that depression would be associated with prolonged recovery from concussion. It was also hypothesized that there would be gender and age differences in depression, with higher rates among adolescent girls. Finally, it was hypothesized that injury related factors (i.e. number of head injuries, symptom scores and hospitalization) would increase the risk of developing depression.

# Methods

A prospective cohort study was conducted with children recovering from concussion through the acquired brain injury (ABI) clinic (n=477) at a tertiary care Children’s Hospital. This tertiary care centre, located in south-western Ontario, serves a region of approximately 2.3 million people. Approximately 45% of referrals to this clinic are received from the emergency department and hospital wards and 55% are received from community physicians and outlying hospitals. This provides a mixture of children who have had both acute and complex care needs.

## Sample

Due to the interest in depression, a protocol of screening for depression was implemented as a pilot project in the ABI clinic from April-June 2013 with full implementation to all consecutive patients from August to December 2013. Thus a prospective cohort of 92 consecutive children who were newly referred or had follow up appointments scheduled were administered the CDI if they were between the ages of 8 and 18 years. Data of those who met the following inclusion criteria were included for analysis:

1. a diagnosis of mTBI/concussion
2. completion of a Children’s Depression Inventory Screen - 2 [30]
3. completion of one or more Post-Concussion Symptom Inventory [7] checklists

Participants were not excluded if they required hospitalization or had intracranial lesions or skull fractures.

The Hamilton Integrated Research Ethics Board approved the prospective collection of data from the clinical Acquired Brain Injury database. Consent was covered through this process.

## Procedures

Every visit to the ABI follow-up clinic includes a review of the medical history and a physical examination. Parents and children each independently completed a Post Concussion Symptom Inventory (PCSI) [7] and the Children’s Depression Inventory-2 (Short version) (CDI-2S) [30] at the appointment. The PCSI was completed at each clinic appointment with data available for a maximum of three evaluations; time 3, therefore, would be the most current follow up score. The scores from the CDI-2S were obtained every three months, if children were being followed long term, however it was decided to use only those CDI scores from the first administration as there were very few children with more than 1 set of scores. Demographic and other injury information are also compiled as part of the health record and database. Data collection occurred over a period of eight months in 2013.

## Measures

The Children’s Depression Inventory-2 (CDI-2) is both a self-report and parent-report measure of the extent and severity of depressive symptoms [30]. The screening tool (CDI-2S) consists of 12 questions and requires one of three response options: the child chooses the statement that best describes their feelings or moods in the past two weeks. Statements represent the range of severity of the symptom from 0 (none) to 2 (definite). Scores are totaled and raw scores are converted to T scores. A T score of 65 (1.5 SD above the mean) is generally considered to indicate a clinically significant level of depressive symptomatology. This screening tool has a high correlation with the full-length self rated form (r=.95, p<.001) and has been validated for use with medically ill children [31]. There are 3 questions dealing with depressed mood and irritability, 3 questions regarding physical symptoms, 1 about diminished pleasure, 1 dealing with cognitive symptoms and the rest are about feelings of low self esteem, worthlessness and hopelessness.

The parent measure is a parallel questionnaire that includes 17 questions with scores that are grouped into emotional, functional and total score domains. Again, parents are asked to consider the child’s moods and feelings in the past two weeks.

The Post-Concussion Symptom scale [7] is a symptom inventory derived from the original sideline assessment developed by the Pittsburgh Steelers of the National Football League [32]. This clinically driven tool has many variants and has been adopted and standardized into such tools as the Acute Concussion Evaluation [7], the Sport Concussion Assessment Tool [33] and the Immediate Post-Concussion and Cognitve Test [34], which is commonly used to make return to sport decisions. Most of the variants have a 7-point likert scale to measure intensity of symptoms and others have a yes/no dichotomous scale [35]. It is a quick and clinically useful way of tracking symptom resolution through serial administration over days or weeks. The Post Concussive Symptom Inventory (PCSI) [7] is one of the variations and lists 22 concussion symptoms in the domains of physical, cognitive, emotional and sleep and has a yes/no dichotomous scale [35]. Both children and parents fill in this checklist independently, answering yes (1) or no (0) to whether the child has experienced each symptom in the past three days. The “yes” scores are added for a total score out of 22. The scales are valid in measuring change in symptoms over time, however; psychometric evidence is stronger for adolescents than younger children [36].

Symptoms of depression and post concussive symptoms are known to overlap; however, these measures actually have only two items that are worded similarly; irritability and fatigue. Sadness and decision-making are also asked about in both measures but are worded quite differently.

## Data Analysis

Our sample size of 92 is adequate to provide a valid model to estimate risk in logistic regression analyses. The value of 10 events per variable and higher is recommended by Peduzzi et al. for both proportional hazards and logistic regression analyses [37]. Below this the statistical model may not be valid. We will have 1 primary outcome (depressive symptoms indicated by a T score > 65 on CDI-2S) with 5 predictors.

For analysis, children were categorized based on the CDI T-score of ≥ 65 (n=20) indicating depression or < 65 (n=72) indicating no depression. Initially, to test for group differences chi-square and student t-tests were conducted on demographic variables and clinical characteristics. As this was an exploratory study, significance was two tailed and set at p≤.05. Much of the data of interest was not normally distributed, not uncommon in brain injury research, so a decision was made to use non-parametric statistics for correlations and regression. Correlations between depression and injury and non-injury related variables were determined using Spearman’s Rho.Logistic regression was used to model the predictor variables of interest with the primary binary outcome: a clinically significant level of depressive symptoms either present (“yes” T score ≥ 65; coded 1) or not present (“no” T score < 65; coded 0). Predictor variables were selected based on our hypotheses, results from descriptive statistics and univariate analysis using binary logistic regression. The selected variables were subjected to linear regression analysis to test for collinearity. The data did not violate the multicollinearity assumption with variance inflation factors well below the cut off of 10 (range from 1.29 – 2.36). A combination of forward and backward selection was used for model fitting using the most significant candidate covariates and then eliminating those with p values over 0.6 [37]. All data analysis was done using IBM SPSS Statistics for Windows, Version 22.0 [38].

# Results

The study sample examined of 92 children aged 7 – 18 years included 56 girls and 36 boys with a mean age of 15 years ± 2.5. Depression screens were administered a mean of 6.8 months (2 weeks-35 months) after injury (see Table 1). PCSI scores were obtained a mean of 9.2 weeks for Time 1, 5.6 months for Time 2 and 8.5 months for time 3. Information on demographic and clinical characteristics by outcomes is presented in Table 2. The study sample of 92 children differed from the larger dataset of 477 children followed in the ABI clinic in a few ways: there were more girls in our subset (64% compared with 44%); the PCSI means were higher in girls (9.91 vs 8.26) and 70% of the 92 children had symptoms for 3 months or more compared to only 52% in the larger dataset.

<< insert Table 1 about here >>

## Non-Injury Related Factors

In comparing children classified as depressed versus non-depressed (Chi-Square analysis; χ2), there were no significant differences in age (p=0.85), sex (p=0.79), premorbid history of learning issues (p=0.61), or pre-morbid history of mental health issues (p=0.90). Significant differences, however, were noted in decreased academic standing after concussion (χ2=4.6, *df*=1, p=0.03) as well as in persistence of concussion symptoms (>3 months duration) (χ2=6.3, *df*=1, p=0.01). Children with depression were less likely to be succeeding in school after concussion. Prior to their injury 7.6% of children had documented learning issues whereas, after injury, 53% reported a decrease in school performance. This decrease in academic standing was identified by clinical interview with child and parent and was defined as those school difficulties noted post-concussive injury (e.g., decreased academic marks by more than 10%, reduced academic workload or clinician documented symptoms of decreased concentration, difficulty coding and decoding, reading or studying for increased periods of time).

Correlational analysis using spearman rho for categorical variables (see Table 3) showed strong positive associations between depression scores (yes/no) and persistence of concussion symptoms (yes/no) over 3 months (r=0.483, p<0.01), and between depression scores and decrease in academic standing (r=0.431, p< 0.01).

>>Insert Table 2 about here<<

## Injury Related Factors

In comparing children classified as depressed versus not depressed, chi square analysis showed no significant differences in reports of multiple head injuries (p=0.46), cause of injury (p=0.35), computerized tomography abnormalities (p=0.67) or hospital admissions (p=0.67). Significant differences were, however, found in the number of concussion symptoms as reported on the PSCI. Children with depression had higher initial clinic PCSI mean scores (p=0.004) and higher PSCI scores reported on the third clinic visit (p=0.041). Length of hospital stay was also found to be significantly higher in children who were subsequently classified as depressed (T-score > 65 on the CDI-2-S) (p=0.003).

Correlational analysis showed significant positive associations between depression scores and the number of concussion symptoms reported on the PCSI-time 1 (r=0.442, p< 0.01) and time 3 (r=0.602, p< 0.01) indicating a linear relationship.

<< insert Table 3 about here >>

Logistic regression results***.*** The results of the logistic regression analysis show that the full model using the 5 independent variables of gender, number of concussions, admission to hospital, PCSI Time 1 score and experiencing symptoms over 3 months was significant (Χ2 (5)= 18.55, n=71, p< 0.002). This means that the odds for children to have a positive depression score at a mean time of 6 months after concussion is associated with these 5 variables (see Table 3). The model correctly classifies 81.7% of cases. The Nagelkerke R squared value of .357 indicates the model fits the data well. Table 3 presents the standardized coefficient Beta, Wald statistic and significance as well as the odds ratios (OR) and 95% confidence intervals for the variables in the model. The strongest predictors in the model were high PCSI scores (standardized coefficient beta= 0 .278, p=0.009) and admission to hospital (standardized coefficient beta= 2.464, p=0.030). Admission to hospital with an OR of 11.75 means that the odds that a child had a high depression score (T≥65) increased by a factor of 11 if the child was admitted to hospital compared to those who were not admitted. The odds ratio for early PCSI is 1.32, which indicates that for every one point increase in symptom scores (1 additional symptom) the odds of being depressed increase by a factor of 1.32.

Length of hospital stay was a variable that could not be used in the multivariate model because of the potential for over-fitting due to the small sample as only 24 children had a stay over 24 hours. We did a univariate analysis using length of hospital stay to predict depression and found it to be significant Χ2 =8.06, p<0.005 (standardized coefficient Beta=0.447, p= 0.033). This single variable increased classification accuracy by 17% and has an OR of 1.56 indicating that for every extra day of stay in hospital the likelihood of depression increased by a factor of 1.5.

<< insert Table 4 about here >>

# Discussion

In this prospective cohort of children and youth with concussion, we found the incidence of depression to be above that found in community samples cited in the literature and in standardized tests, which report a prevalence of 8% in this age group [39-41]. Twenty-two percent of children self-reported significant depressive symptomatology an average of 6 months following their injury. Youth in our study did report some premorbid histories of headache/migraine (9%), learning issues (7%) and mental health issues (7.5%); yet, none of these were significantly associated with ratings of post-concussion depression. Five predictors, sex, number of concussions, admission to hospital, PCSI score and experiencing prolonged symptoms explained 36% of the variance in depression scores.

Our prevalence of 22% is congruent with other published studies that report an increase in depression after mild – moderate TBI ranging from 11 – 26% [22, 23] as well as findings of depression in other chronic medical conditions including chronic pain, post-traumatic stress disorder, epilepsy and soft tissue injuries [15,39, 41]. However, in a recent childhood concussion cross-sectional study conducted by Smyth et al., [25] only 3% of their sample had depression 1 – 3 years after injury. Although this was also a concussion cohort, other dissimilarities such as numbers of children admitted to hospital and length of time to follow up, in addition to the less rigorous study design and methods, may explain the different results.

Other factors frequently hypothesized to be associated with depression including age, sex, cause of injury and the total number of head injuries had no significant relationship individually with depression in this study. These results were curious as sex in the general population of depressed adolescents has distinct differences with a 2:1 ratio of girls to boys [39-41]. Age is similar to this as rates of depression in adolescents have been shown to be double those seen in younger children [15]. Our sample had only twenty children in the 7 – 12 age group, which may have resulted in a type II error with not enough statistical power to show a true difference.

Evidence has also shown an association between multiple head injuries and depression in adult football players [26]. Our data did not reflect these findings in children. This raises the question about whether there may be different types of depression after head injury; one with a quick onset and another that would be triggered by an accumulation of life stresses brought about by multiple injuries [43].

Although the study findings contribute to debate in the literature about the mechanism of the development of post-concussion depression, there are no clear causal relationships. On the one hand, trauma to prefrontal structures, combined with other biological vulnerabilities (inherited traits of learning disabilities, temperament, etc.) is thought to provide a neurobiological susceptibility to depression [44]. On the other hand, stress (loss of meaningful activity, trauma, and family factors) can also influence the development of depression [45]. In our study, admission to hospital and length of stay increased the likelihood of showing elevated depressive symptoms in the first year after a concussive injury. It has been theorized that hospitalized youth may represent a subset of children who have more damage to frontal regions and neural networks that regulate emotions [46], as well, the hospitalization itself is very stressful which may explain the higher rates of depression after concussion found in studies using hospitalized samples [23, 42]. Other factors associated with a high depression score in our data were academic difficulties and experiencing symptoms over three months in duration which both create a great amount of stress in the youth.

One of the most stressful activities post-concussion is return to school [47]. Thirty percent of children post concussion have reported school absence and dropping grades[47,48]. We found a significant relationship between a decrease in academic standing and depression scores. Findings of prolonged school absence and declining academic performance may indicate that the child is depressed or at risk for becoming depressed. On the other hand depression could very well precede a decrease in academic standing. Clearly school performance is worthy of attention for signaling potential poor outcomes.

Prolonged recovery from concussion was also moderately associated with depression in our sample and in our depression prediction model, a child with symptoms over three months had a 1.2 fold increased odds of being depressed even when accounting for all other variables.

Significant depressive symptoms, can predispose youth to depression in subsequent years and later into adulthood [50]. Once a depressive episode has resolved, deficits in academics and social relationships remain making the developmental cost of depression in childhood and adolescence very high [13].  It is therefore vital to identify those children who may be susceptible to depression early in their recovery post-concussion. Based on our results, we recommend that screening for depression in this vulnerable population should be a regular part of follow up: particularly for those who are admitted to hospital, have high symptom scores, experience protracted symptoms or are experiencing academic failure. Because we were unable to follow all children from inception, timing of depressive symptoms is an unknown. Longitudinal studies have reported depression diagnosis early after injury [18,45]. In our study significant depressive symptoms were reported at a mean of 6 months after injury, which may not represent the natural history of onset. Screening for depression should occur in the first weeks to months post-concussion with further research needed to determine the optimal time period. Early identification might lead to timely provision of management strategies to prevent the effects of depression.

## Limitations

There are several limitations to this study. Our subset of data did differ from the larger dataset as 70% of the sub-sample had symptoms more than three months after their injury compared to 52% in the larger dataset, which suggests that this subset of children seems to have more complex recovery patterns than previously seen. This is most likely a reflection of the increasingly specialized nature of the clinic attracting more complex referrals. Referral bias may also have been introduced due to the tertiary nature of this clinic. Although referrals were from a variety of sources, 50 - 60% were from other hospitals and community physicians, which suggests that these children may have been more chronic in their recovery patterns when referred. However the sample does include the spectrum of concussion recovery trajectories and provided a unique opportunity to examine a protracted symptom group. The clinical nature of the database resulted in some inconsistencies in data collection as children did not return for follow up or information was not obtained which means there was missing data over time. This may have resulted in a lack of power to detect difference between those with depression scores and those without and also may have limited the model building in predicting depression.

## Conclusion

Depression in the first year after childhood concussion is not a rare occurrence. Prevalence of depression during concussion recovery is 4 times that reported for childhood depression in published population data. This study adds to the knowledge regarding the risk of depression in youth recovering from concussion and some of the factors that play a role in increasing that risk. Children with a history including admission to hospital, high initial symptom scores and prolonged symptoms over three months should be followed closely with vigilance for the development of depressive symptoms.

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| --- | --- | --- |
| **Table 1: Time from injury to Depression Screen** | | |
| Time from injury to screen | Total Number  N=84\* (%) | CDI T ≥65  N=19 (%) |
| < 1 month | 18 (21) | 4 (21) |
| 1 – 3 months | 20 (24) | 3 (16) |
| 3 – 6 months | 20 (24) | 5 (26) |
| 6 – 12 months | 7 (8) | 5 (26) |
| > 12 months | 19 (23) | 2 (11) |

\*Hospital records incomplete with some dates of injury

|  |  |  |  |
| --- | --- | --- | --- |
| Table 2: Characteristics of sample by CDI-2 scores | | | |
|  | CDI ≤ 65  Non-depressed  N=72 | CDI ≥ 65  Depressed  N=20 | Test Statistic |
| Age in years mean (sd) | 14.71 (2.6) | 14.59 (2.3) | p=0.85 |
| Gender n (%)  Male  Female | 29 ( 40.3)  43 (59.7) | 7 (35)  13 (65) | χ2=.798, *df*=1,  p=0.44 |
| Premorbid Hx n (%)  Headaches/migraines  Learning issues  Mental health | 6 (6.5)  5 (5.4)  4 (4.3) | 3 (3.2)  2 (2.2)  2 (2.2) | p= 0.90  p=0.61  p=0.66 |
| Months from injury to CDI mean (sd) | 7.1 (8.8) | 6.6 (7.5) | t*(84)*=-.26, p=.79 |
| Referred n (%)  acutely from ED/wards  tertiary care | 23 (32)  33 (46) | 5 (7)  11 (15) | χ2=.562, *df*=2, p=.755 |
| PCSI Scores - mean (sd)  Time 1 (N=90)  Time 2 (N=51)  Time 3 (N=35) | 7.06(5.4)  6.41 (5.4)  6.1 (4.5) | 11.05 (5.3)  8.27 (7.0)  10.11 (6.03) | t89=2.95, p=.004\*\*  t59=1.62, p=.035  t33=2.12, p=.041\* |
| Cause of injury n (%)  Sport related  MVA  Falls/trips  Other | 30 (47)  8 (12.5)  9 (14)  17 (26.5) | 13 (65)  2 (10)  4 (20)  1 (5) | χ2=8.97, *df*=8, p=0.35 |
| Multiple concussions n (%) | 31 (56) | 7 (35) | t(89)=-.738, p=.463 |
| Decrease in Academic Standing n (%) | 29 (37.6) | 12 (15.5) | F=5.71, df=1,  p=0.024\* |
| Admitted to hospital n (%) | 21 (30) | 7 (35) | χ2=.181, df=1, p=0.67 |
| Length of stay in hospital mean (sd) | 1.76 (1.2) | 6.14 (5.2) | t(*22*)=3.33, p=0.003\*\* |

\*significant at the 0.05 level

\*\*significant at the 0.01 level

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Table 3: Correlation matrix for the relationship among non-injury and injury related concussion variables | | | | | | | | | | | | | | |
| VVar | 1  gend | 2  Age | 3  LoFU | 4  LOS | 5  #con | 6  PCSI1 | 7  PCSI2 | 8  PCSI3 | 9  EPS1 | 10  EPS3 | 11  DAS | 12  ChildT | 13  ParT | 14  AdmHosp |
| 1.Gender | 1 | .257\* | .111 | -.237 | -.039 | .173 | .090 | .123 | .079 | -.152 | .212 | .136 | .119 | -.153 |
| 2. Age |  | 1 | -.033 | .131 | .078 | .147 | .081 | .133 | .071 | .145 | .219 | .165 | -.052 | .022 |
| 3. LoFU |  |  | 1 | .333 | .051 | -.004 | .024 | .037 | .081 | .066 | .024 | -.051 | .191 | -.421\*\* |
| 4. LOS |  |  |  | 1 | .422\* | .095 | -.090 | .341 | .262 | .321 | .229 | .269 | .198 | - |
| 5. #con |  |  |  |  | 1 | .078 | .117 | -.198 | .019 | .052 | .108 | .051 | .033 | -.374\*\* |
| 6. PCSI 1 |  |  |  |  |  | 1 | .440\*\* | .171 | .186 | .456\*\* | .382\*\* | .442\*\* | .304\*\* | -.253\* |
| 7. PCSI 2 |  |  |  |  |  |  | 1 | .346\* | -.056 | .365\* | .540\*\* | .200 | .438\*\* | -.255 |
| 8. PCSI 3 |  |  |  |  |  |  |  | 1 | -.244 | .471\* | .325 | .602\*\* | .601\*\* | .034 |
| 9. EPS1 |  |  |  |  |  |  |  |  | 1 | .231 | .187 | .188 | .009 | -.180 |
| 10. EPS3 |  |  |  |  |  |  |  |  |  | 1 | .502\*\* | .483\*\* | .146 | -.062 |
| 11. DAS |  |  |  |  |  |  |  |  |  |  | 1 | .431\* | .406\*\* | -.293\* |
| 12.CDIT-Child |  |  |  |  |  |  |  |  |  |  |  | 1 | .210 | -.068 |
| 13. CDIT-Par |  |  |  |  |  |  |  |  |  |  |  |  | 1 | .077 |
| 14. Adm Hosp |  |  |  |  |  |  |  |  |  |  |  |  |  | 1 |

LoFU=length of follow up, LOS= length of stay in hospital, #con=number of concussions, PCSI=post concussive symptoms inventory score (time 1,2,3), EPS1=experienced prolonged symptoms for 1 month, EPS3=experienced prolonged symptoms for 3 months, DIAS=decrease in academic standing, CDIT-child=CDI T score recorded by child, CDIT-par=CDI T score recorded by parent, Adm Hosp=Admitted to hospital

\* is significant at the .05 level (2 tailed)

\*\* is significant at the .01 level (2 tailed)

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| TabTable 4: Logistic regression predicting likelihood of depression in concussion recovery | | | | | | | | | |
| VARIABLES | | B | S.E. | Wald | df | Sig. | Exp(B) | 95% C.I.for EXP(B) | |
| Lower | Upper |
|  | Symptom score T-1 | .278 | .106 | 6.896 | 1 | .009 | 1.320 | 1.073 | 1.624 |
| Adm to Hosp | 2.464 | 1.136 | 4.705 | 1 | .030 | 11.748 | 1.268 | 108.823 |
| Symptoms > 3 mos | 1.619 | 1.202 | 1.814 | 1 | .178 | 5.050 | .478 | 53.312 |
| # HI | .197 | .290 | .461 | 1 | .497 | 1.217 | .690 | 2.148 |
| Gender (ref male) | -.847 | .825 | 1.054 | 1 | .305 | .429 | .085 | 2.160 |
| Constant | -6.533 | 2.136 | 9.356 | 1 | .002 | .001 |  |  |

-child=CDI T score recorded by child, CDIT-par=CDI T score recorded by parent, Adm Hosp=Admitted to hospital

\* is significant at the .05 level (2 tailed)

\*\* is significant at the .01 level (2 tailed)

# Chapter Three

# Title of Paper: Exploring prolonged recovery and depression in youth after concussion:

# A trajectory of recovery

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# Abstract

Objectives:

The emotional impact of prolonged recovery from concussion can complicate children’s return to full participation in their daily lives. We aim to explore the lived experience of protracted recoveries with significant depressive symptomology from the perspective of youth and their families.

Methods:

A qualitative phenomenological design using semi-structured interviews was employed with six children 11 – 18 years of age who were 4 – 38 (mean=11) months post-injury. Inclusion criteria consisted of a concussion diagnosis and a T score of > 65 on the Childhood Depression Inventory-2. Parents were also interviewed. Data was transcribed, coded and analyzed for themes using NVivo 10 software.

Findings:

For children and their families, recovery from concussion and the associated depression evolved over time in four key stages. Stage one, the initial impact, included the incident causing the concussion, as well as acute symptoms and their management. Stage two, the fallout, included the functional consequences of symptoms and associated depression on their lives. The third stage, putting the pieces back together, described the way children and families begin to cope. The final stage, finding a new or renewed path, occured when children had either taken up their past lives or found meaning and value despite the remaining effects of concussion and/or depression.

Conclusions

Youth recovering from concussion that is complicated by significant depressive symptoms experience a multilayered emotional process of recovery that has home, school, interpersonal/social and health care implications. Understanding this trajectory of recovery provides opportunities to plan and structure services that may ease the burden of suffering for families.

The symptoms of concussion or mild traumatic brain injury can take a long time to resolve and may result in significant long-term difficulties [1-3]. Headaches, fatigue, dizziness, slowed thinking, balance difficulties, emotional dysregulation and sleep disturbances are but a few of the symptoms that can disrupt the daily lives of children and their families [3]. Children are especially vulnerable to post-concussive symptoms and report more significant cognitive symptoms than adults a year after the injury [3].

Sixty-six percent of traumatic brain injuries occur in those under 20 years of age with the most common cause being sport in school-aged children [4]. Incidence data reported from emergency department visits of youth who are participating in organized sports shows a dramatic increase, doubling in the ten years between 1997-2007 [5]. These increasing numbers, along with the well-documented longer recovery time in children, increases the potential for poor health. In a longitudinal study of children with acquired brain injury, quality of life (QOL) was impacted regardless of the severity of injury [6]. In a cohort study of 8 – 15 year old children with mild traumatic brain injury (mTBI). Yeates and colleagues (2012) found that protracted symptoms were associated with significant declines in health-related QOL as well as a 50 percent increase in academic intervention at 3 and 12 months post injury [7]. Children with protracted symptoms after concussion reported a similar QOL as their peers with cancer [8].

Depression after concussion seems to contribute to poorer health outcomes than concussion alone [9]. When a depressive episode occurs during recovery from concussion, it can be difficult to detect due to overlapping symptoms from the concussion. Sleep, emotional and cognitive symptoms, for example, are similar to those of depression. A depression that occurs in the first 3 months following the injury intensifies and prolongs these post-concussive symptoms [10]. The concurrent nature of the symptoms can make it difficult to disentangle depression from the symptoms of concussion in order to identify and treat it appropriately [11].

Ongoing symptoms, whether they are caused by the concussion alone or due to depression, can affect the child’s ability to function. This creates a significant burden on individuals, families and society as the child’s school performance and social function often declines. In addition, physical health problems such as sleep issues, fatigue and pain are more likely [12].

The recommended management of concussion is a balance of rest with gradual return to activities [13,15]. Finding the proper balance, however, can be very difficult. For example, children are advised to rest when they are symptomatic; however, prolonged rest can lengthen the recovery time and contribute to depression [16]. Going back to activity too soon, on the other hand, can exacerbate current symptoms and may even elicit the return of symptoms and lengthen recovery. Pre-injury stress has been shown to contribute to protracted symptoms [17]. Additional stressors associated with prolonged symptoms, including the loss of meaningful activity and disruption to everyday routines, are thought to contribute to the onset of depression [18]. Managing concussion recovery when it is combined with the onset of depression is, therefore, complex.

Many questions about the phenomenon of prolonged concussion recovery associated with depressive symptoms remain unanswered. A qualitative study of 13 athletes aged 10 – 13 recovering typically from concussion found that, although no long term impact on school or sport was experienced, higher levels of anger and frustration related to performance post-injury were found [19]. Qualitative studies focused on prolonged recovery after concussion from the family’s perspective are thus far non-existent. This project was undertaken to explore how children and their families experience concussive injury and subsequent recovery as well as the emotional/depressive symptoms that may be a part of the process. Understanding how families make sense of their experiences, their perceptions of the impact on the child and family unit, and determining what is helpful or not during this time can help in planning the types of services and resources needed at various stages to prevent or improve poor outcomes.

# Methods

## Design

A hermeneutic phenomenological approach was employed to examine the lived experience of participants with the phenomenon of prolonged recovery from concussion complicated by depressive symptoms. Hermeneutics is the art and science of interpretation and is described as an attitude or disposition rather than a distinct methodology [20]. In this type of phenomenology, the “hermeneutic circle” is central to understanding and interpretation. The ever-expanding circle between the whole and part of the text and in the dynamic between the researcher and the participant is integral to analysis as “to understand the part, you look to the whole; to understand the whole, you look to the part” [21].

Ethical approval for this study was obtained from the Hamilton Integrated Research Ethics Board overseeing the McMaster University Faculty of Health Sciences. Informed consent was obtained from all parents and assent from the youths was obtained at the time of the interview.

## Sampling

Participants were recruited through the health care team of the Acquired Brain Injury clinic at a tertiary-care children’s hospital serving South-Western Ontario from December 2013 to April 2014. Purposive sampling was employed to generate a group of key informants who experienced similar events. Consequently large numbers of participants were not required to capture meaningful accounts. Children who met the following inclusion criteria were sought: 1) diagnosis of MTBI/concussion; 2) between the ages of 10 – 18 years; 3) post-concussive symptoms present ≥ 3 months post-injury; 4) evidence of depression on both parent and child reports (operationalized as a Child Depression Inventory-2 screen score ≥ 65); 5) child not under psychiatric care in the year prior to concussion. In addition, the parent had to be willing to participate and both the child and family had to be able to communicate in English (for participating in the interviews). Twelve potential recruits were identified, however two were excluded due to other diagnoses, and four declined to participate. The final sample of six participants (four girls and two boys) included five families (since one family had two girls who both met the inclusion criteria). Four of the five families were two-parent families. Two families had both parents participating in the interview, two had mothers only, and one had the father only. Youth were interviewed with their parent/parents, in the family home between March and August of 2014. Table 1 provides characteristics of the sample.

<< insert Table 1 about here >>

## Procedures

In-depth interviews of 45 to 80 minutes in length were conducted by the first author, in the family home. Children chose whether to have parents present during their interview or whether they wished to be interviewed separately. Most interviews were conducted with the parents nearby. In three cases, the process was sequential with children interviewed first and then the parents. In two cases, the parent and child were interviewed together, with each having a turn answering the questions. All interviews were audiotaped and transcribed. Five key open-ended questions guided the interview: Tell me the story of your concussion. Tell me about any mood changes you have experienced since your concussion. What has the impact of this been on you? What has it been like for your family? What are the things that have been helpful or challenging throughout this whole experience? Follow-up probes were used to gather an in-depth understanding of their beliefs and experiences. A second telephone interview was completed with three of six of the participants as a member checking strategy, after they had an opportunity to review a summary of the study findings. Additional sources of data included scores from the depression screening tool that was completed at the time of interview, as well as field notes completed by the first author throughout the process of data collection and analysis.

## Screening tool

The Children’s Depression Inventory-2 (CDI-2S) was used to evaluate the presence of significant depressive symptoms [22]. The CDI-2S is both a self-report and parent-report measure of the extent and severity of depressive symptoms in children 7 – 17 years of age. The screening tool consists of 12 questions and the child chooses the statement that best describes their feelings or moods in the past 2 weeks. Statements represent the range of severity of the symptom from 0 (none) to 2 (definite). There are 3 questions dealing with depressed mood and irritability, 3 questions regarding physical symptoms, 1 about diminished pleasure, 1 dealing with cognitive symptoms and the rest are about feelings of low self esteem, worthlessness and hopelessness. Scores from all questions are totaled and raw scores are converted to T scores. A T score of 65 (1.5 SD above the mean) is considered to indicate a clinically significant level of depressive symptomatology [22]. This screening tool has a high correlation with the full-length self rated form (r=.95, p<.001) and has been validated for use with medically ill children [23].

Children and their parents completed the depression screen independently of each other during follow up for their concussion at the tertiary care clinic. Agreement between the parent and child’s score indicating significant depressive symptoms (T≥65) was used to determine eligibility for this study.

## Data Analysis

Interviews were transcribed word for word and uploaded to NVivo 10 [24] for coding and organization. A hermeneutic iterative process was adopted using a “wholistic approach” and narrowing to selective data to analyze and widening the lens again [21]. Initially, transcripts were read in whole form and re-read to code statements by questioning those data segments of interest and asking “what is going on here?” Codes were grouped into sub categories. Data was also explored using content analysis to expand the lens outward to the whole and confirm sub-categories. Themes came out of a process of writing summary descriptions of each interview/story as these reflected similar concepts over time and meeting with the research team to generate different perspectives and agreement. Once the themes were developed a framework analysis was used to build a matrix of the cases and themes to complete the analysis. Fieldnotes and memoing were used to facilitate researcher reflexivity.

Quality and rigour were addressed using detailed audit trails of project notes, decisions, codes/themes and memos. Member checking was conducted by sending a summary report of the themes to participants who then commented on the extent that the summary captured their own experiences and provided additional examples. Verification of the interpretation was received from three participants and added to the trustworthiness of the study.

# Findings

Participants described their prolonged recovery from concussion and subsequent depression as a trajectory of 4 stages: “the impact”, “the fall-out”, “piecing it back together” and “the new or renewed path” (see figure 1). Each of these stages encompasses a set of common experiences after concussion, including a multilayered emotional process of recovery within the context of home, school, interpersonal relationships and health care. Rich descriptions of functional changes were provided most noticeably in the middle two stages of the fallout and putting the pieces back together. Exemplars are provided by the children and parents and labeled C1-6 for the children and P1-7 for the participating parents.

## The Impact

The first “impact” stage includes the concussive incident, the diagnosis and early management as well as the acute physical and cognitive symptoms associated with the concussion. The themes in this stage are the feelings of shock and the uncertainty of figuring out whether to respond and how to respond to the injury. The concussive injury occurred at school for three of six participants (a fall and gym class collisions). Two of the other injuries occurred in competitive sport and one was the result of a pedestrian motor vehicle accident.

One 18 year-old who has had 6 concussions since she was eleven described her reaction to her concussions like this “The first one is just like a big shock, you don’t really know what to do. Then your second one you’re able to recognize more easily ‘cause you know the symptoms” (C2).

Symptoms commonly progressed to headaches, dizziness, nausea, fatigue and sensory sensitivities. One teenage girl, who received her second concussion in her first basketball game back after her initial injury, described her confusion this way.

I don’t remember blacking out but I remember being very confused and everyone was like; “What’s wrong?” and I just wanted everyone to like shut up so I could figure out what was going on. I remember sitting on the bench during the game and the lights were starting to bother me and the noise and it’s like, I kind of knew that I had gotten another one. (C5)

Variation in the responses to injury depended on how many injuries have been experienced and also those around the child. Coaches, for example, often knew what to do and informed parents immediately whereas some other caregivers seemed to be unaware of the significance of the injury and did not communicate this or mobilize assistance. One 11 year old described the reaction of a caregiver after she fell off of a climbing apparatus:

So when I told her that I had hit my head she said that I would… I would be fine, that I just scared myself. She didn’t do anything for like an hour. Then I kept complaining about it because it really hurt and so finally she put ice on it. (C6)

This same girl’s parents had talked about coming to the recognition about what they were dealing with:

No they didn’t notify us so I just…she’s kind of accident prone, and so I didn’t take her to the doctor immediately because she wasn’t sort of exhibiting any signs so when the next day they called us from school and told us that she wasn’t feeling well and that she wanted to come home so we took her to the doctor and they diagnosed her with a mild concussion. Yeah they said keep her away from straining her eyes, not too much TV or reading or video games and then just keep her home until the end of the weekend (P7).

All youth had received the diagnosis of concussion or had come to the understanding that they were dealing with a significant injury some immediately and others within 24 hours of the incident. Most families did go to their family physician but a couple of the families had professional background knowledge in this area and were able to recognize the concussion and respond with the appropriate activity limitations.

## The Fallout

The fallout describes the stage where the concussion symptoms persist beyond 1 – 2 weeks and the functional impact permeates into all aspects of the day-to-day lives of children and their families. Concussion symptoms and depressive symptoms co-occurred during this stage and were rarely discussed as separate entities. For both the youth and parents, this stage is burdened with multiple losses and the emotions of anger, frustration, sadness and loneliness that signify grief reactions. Emotional sequelae affected functioning at home, at school, and with peers.

*Personal fall-out*  Youth found the activity restrictions inherent in concussion recovery protocols difficult to adhere to and talked about how bored they were or how hard it was to be out of contact with friends. They alluded to resentment or irritation with the restrictions they were given. One 11-year-old girl stated “I wasn’t allowed to read or go on the computer, play video games, watch TV, play my iPod. Basically, I kind of just sat there.” (C6).

Sport/leisure, friendships and school performance were frequently discussed as problematic due to the youth’s inability to participate fully in each of these areas for many weeks to months. Four of 6 described sport and exercise as a lifestyle they had previously adopted to relieve stress or as a potential future career path. The interruption of these activities added stress and uncertainty to their lives. Three of the sport-oriented girls with multiple concussions discussed having to quit their sport (two have done this and one is afraid that the next injury will result in this decision). A 16-year-old girl discussed the multiple losses she experienced of which sport was a significant loss:

One of the hardest parts for me was, like, I had everything. I was good at school, I can do sports, I had lots of friends, everything was set for me and so it was really difficult getting the concussions cause I kind of lost everything right away. So it was really hard losing my sports and I think that was really hard because they have been a part of my life for so long and it’s a way that I like to get rid of stress and anxiety and so I found with my concussions that I had way more anxiety because I didn’t have an outlet for that. (C5)

Social disruptions were also experienced. Missing out on peer group activities, feeling misunderstood or not believed were some of the challenges as well as much more extensive loss as some children experienced a total rejection by their entire peer group. This latter was described by three of the six (2 girls/1boy) with the youngest girl (11) having been bullied prior to her concussion. A 16-year-old girl had this understanding of how concussion contributed to her losing her whole peer group.

They didn’t understand and they just thought like “oh she’s just like being grouchy or she’s just like mad at us, like she’s not talking.” And like it was just too much for me to do school and then the social part; so my friends kind of… they really ditched me. So that was hard because I lost my friend group too in the middle of all that, so I was kind of alone. (C5)

A theme of not being believed was common to participants in the fall-out phase. Several participants described that the invisible nature of their difficulties generated a lack of understanding and support from peers and teachers and sometimes led to feelings of guilt on the part of the injured youth.

School absence and decline in performance was a shared experience in the fall-out after concussion. Four participants were away from school for one to three weeks, and two were off for more than two months. Participants talked about not being able to keep up and were frustrated with the concentration and memory difficulties that made school and homework so much harder.

The personal impact of all of these losses affected the youth’s sense of identity. All of the participants experienced a change in their sense of self due to the physical symptoms, which changed their perceptions of themselves as an athlete, high achieving student or outgoing and fun friend. A 17-year-old boy talked about his changing sense of self and identity.

Yeah and I knew like …I could see myself changing a lot in the way I interacted with people and things I’d say and I became very introverted as a person. (C3)

*Family fall-out* In the context of their home environment, the youth talked about being increasingly irritable, angry and frustrated which led to conflict with parents and siblings. One participant, for example, described ongoing tensions in the family precipitated by her sister’s frustration with her post-concussion limitations.

When she doesn’t get things, then she’ll ask me for help but then she’ll be very frustrated with herself but it comes out towards me. Then I was trying to help her so that makes me frustrated and then my parents get frustrated and then they’re yelling at each other. (C2)

Families mirrored the children’s emotional responses of anger and frustration with prolonged recovery and some families found blame as an outlet. The mother of a grade nine student who lost his school semester and his high level hockey position that he had worked so hard for because of an injury acquired in gym class stated:

And as the shock of realizing how bad things were has worn off, the resentment and anger has come in; this insane outrage with the school, with the teacher, with the kid that did it…(P4)

Parents also expressed much sadness about watching their child suffer through multiple losses. One mother empathizing with her daughter’s pain said:

Yeah we were worried about her state of mind, you know, her loneliness and angry for her that her friends would be so mean. That’s hard to watch (P5).

Many parents described their struggles in knowing how to support their child. They struggled to know how and when to push their child to move forward, and when to hold them back in order to protect them from repercussions of the concussion symptoms. This led to self-doubt regarding their parenting abilities, especially in knowing when to push and when to help. The father of two daughters who both had a history of multiple concussions and mood disorders, talked about parenting being a balancing act.

Stressful, very stressful as a parent, especially with us, the way that we’ve taught you girls “don’t give up on things” and “keep trying’ and “don’t just walk away from…” but when you are trying and you can’t get it-it’s even harder and then we have to find that fine line between “OK relax” or “don’t give up attitude” right? That’s the hardest part for myself has been trying to balance that. (P2)

For both the youth and parents, this stage is fraught with emotions that result from the grieving of losses. Anger and frustration seem to be predominant in this phase of recovery from concussion.

*<<Insert figure 1 about here>>*

## Piecing it Back Together

This stage was a time of struggle to find ways of getting through the fallout, despite the persistence of symptoms and emotional challenges. Families and youth attempted to find resources and strategies to move forward without any predictable time frame for getting better. Anxiety appeared to be the hallmark emotion of this stage as children and parents tried to balance recovery with reengagement in activity.

Personal PiecesMany of the youth (4 of 6) talked about experiencing fear and anxiety with the reintroduction of a stressful activity. Return to school was typically one of the first activities re-established after concussion and seemed to intensify symptoms and causes anxiety due to the student trying to keep up with the curriculum, educator expectations and the youth’s own expectations of themselves and their pre-injury identity. In order to be successful at school, accommodations and supportive relationships with educators were identified as very important. Every participant had some type of accommodation; 2 had IEP’s put in place since their injury, 5 dropped classes and were excused from tests and exams and a few were doing online courses.

In order to resolve some of the losses in social and leisure areas, many youth found engagement in meaningful activity an important part of trying to get their life back on track. Music, faith, coaching and volunteer work with others were some of the strategies that gave individuals a sense of purpose and relieved boredom. One family of a 14 year-old boy dealt with this in a unique way by purchasing snakes for their son to care for.

He was driving me crazy. So actually because of his stress and his boredom and his irritability; because of that we ended up letting him get snakes [pythons] because it was just something that he could deal with. It wasn't too much stimulation and the activity engaged him completely. (P4)

Another teen’s experience with volunteer work was important for her to get through her recovery.

I helped out at a retirement home volunteering and that did a world of good for me and it gave me something to look forward to everyday to get out. They were such nice people because they wanted company so that was very helpful for me. It made me learn a lot about myself and it almost gave me a purpose too. (C2)

New activity alternatives were not always found and a couple of the teens chose to risk returning to their sport or exercising as their symptoms began to lessen. One felt this helped her to gradually resolve her symptoms, yet another received another sport concussion a few months after the interview. Efforts to balance re-engaging in activity while remaining symptom free and preventing another concussion appeared to be challenging in the absence of external support.

Family PiecesFamily support was recognized as extremely important in the weeks and months after a concussive injury; both emotional and practical support such as driving to appointments or helping with organizational and life skills. The mother of a teen with multiple concussions reported:

Yeah I took a lot of time. Even just to come pick her up because she couldn’t make it through the day. I did a lot of that, or go make appointments with her school to advocate for her or we had a lot of doctor’s appointments. She was on Amitriptyline every night so she was groggy every morning, so we were driving her to school because she would be late. So there was a lot of just, you know, being there when she needed us. So I took a lot of time; like you know, hours here, hours there. (P5)

A tension remained in family dynamics as parents tried to balance their protectiveness with providing autonomy as the children began to feel better. The fear and risk of another concussion was on the minds of most parents and children. The mother of a 14-year-old boy described her fear reactions.

Yeah and you're scared to let them do anything and I'm like “Oh my God” like you know, he's telling me how he slipped on the driveway and I was immediately overcome with murderous rage and I wanted to yell at my husband like “have you lost your mind, what is wrong with you. Take the trash out, for God's sakes or at least salt the driveway” (chuckles) like, you know “come on he just got over a concussion; what if he slips and falls and hurts himself again”.  So you know, you don't want to wrap them in bubble wrap but that's a very hard impulse to fight…(P4)

Anxiety is the hallmark emotion of this stage as children and parents balance recovery with reengagement.

## New or Renewed Path

This final stage represents the process of children coming to terms with the differences in themselves and their lives. Development of new goals or ways of coping signified moving forward and some resolution of their concussion experience. There is a sense of increased confidence and some optimism, but a grudging acceptance of their new reality is a common theme.

New Personal Path

Most youth recognize a marked change in themselves from before their injury/injuries and have adjusted their goals and expectations to reflect their new sense of self. One or two others felt that that they were able take up their old life as symptoms began to dissipate. One 14-year-old did not feel much had changed but reflected on the impact of the injury on his goals. He stated, “I want a good hockey scholarship into a few colleges. I now know what you need to get there so finding out things that I could have done and now I can't, it's kind of a set back” (C4). One teen 10 months after her injury was beginning to feel some resolution:

Only very recently have I finally got back my energy to like meet new people and go out and do social things. So now I’m kind of starting to just rebuild everything and I can finally run now without getting headaches and so right now I’m kind of just trying to rebuild everything

She is anticipating finishing high school next year talked about her future and the continuing uncertainty, based on her current abilities.

And a part of the concussion is I don’t know if I have the marks for Nursing, so it kind of really depends on this grade 12 year, on how well I do. There is this program in {city}, for fashion management….(C5)

All participants described themselves as still having residual effects from the concussion or depression. Most acknowledged differences in themselves; how they think, behave and interact compared to before their concussions. Uncertainty about whether they will ever feel like before was commonly remarked upon but 4 of the 6 related related a reluctant acceptance that things may always be harder. An 18-year-old girl described how she expects things to be harder.

It’s been 2 years already and a lot of people have said I’m still going to have symptoms until I’m old so I feel university is going to be hard for me. (C2)

Family Path

Parents seemed to reflect back on the time since their child’s injury to try to make meaning and sense out of their experiences. One mother related the positive consequences of going through such a terrible experience.

And every time she sort of got knocked down [with adverse experiences] she sort of just hunkered down and we’d do what we had to do to make sure she was okay. So, I think in a way it’s made us a better family, you know, if you look at it that way. (P5)

Another family theorized about the differences in their child since the concussion and stated “..maybe she was destined down this path anyway and the concussion just sped it up” (P7). It was a way for them to make sense of her anxiety and learning disability diagnosis.

*<<<Insert table 2 about here>>*

## Experiences of Health Care

There were various points along the trajectory when families linked with the health care system. The common element in almost all of the narratives was that there was no map or predictable path to services. One parent stated “I think that that's the worse thing about these things is that you cannot gauge where you're going; there's no end limit in sight, you know- 6 weeks for a cast…”(P4).

In the initial post acute phase the struggle to recognize what they were dealing with was a not easy for some families. This mother of a 16-year-old girl felt unprepared for the repercussions of her daughter’s symptoms.

But I don’t know that we were at all prepared for the side effects, you know? And I almost feel like we stumbled into those thinking, “well why isn’t she getting her schoolwork done? She is an honour student and she is not doing her schoolwork? And we thought…. “Is she goofing off?” We didn’t know that this could just be another side effect. So I almost wonder if a system would be helpful to actually, you know, have someone to talk to about those things rather than just measuring your performance. (P5)

The mother of the two teens with concussions and depression/anxiety had similar thoughts regarding information needs.

I just think it [mental health outcomes] needs to be brought to the forefront at the beginning because I don't think it matters how old you are, you are going to experience some type of psychological effect. And the more parents are made aware of these potential changes, that they can watch for them and try to help out their child the best that they can because I think maybe in some circumstances some kids don't have those resources to talk to their parents (P1)

The emotional and mental health consequences of concussion did not seem to be easily recognized by health care providers. Families related that their concerns were not always heard or addressed. They didn’t always feel believed by health care providers. Parents of a teen girl described their sense of not being heard, particularly around the mental health issues.

He [family physician] knew nothing about the mental health part of it, nothing and so he couldn't help us so finally we get to [a concussion specialist] and he was the one who then started her on the medications and then recommended her to [another specialist] so she saw her and she recommended the [mental health specialists].  But it was just the process to get there was very time consuming and frustrating. Because when we first went to the doctor and they asked "what is your main concern?" Our main concern is the anxiety and the things that she thinks happened when they didn't happen; he just fluffed them off.  It wasn't at the forefront like it was for us. We know concussions take time, really the only medicine is time to heal and rest. We know that, but its the psychological effects after and nobody around here is aware of them. (P1)

This theme of a chain of referrals to get to someone who recognizes the connection between mental health and concussion and can help was recurrent in the stories of families. The father of the two girls with concussion and mental health issues described his cyclical feelings of frustration, anxiety and relief in seeking services that were not readily available:

…just the general doctors not knowing. So we're spending time, effort to go to the physician's to get answers and they don't know so they just keep passing you on to somebody that hopefully knows.  So again the frustration part that "oh I'm going here to get this resolved" and then ok go to the next one and then the time frame for that, and then the next time frame.  The anxiety for everybody is still going on because we still don't get an answer; they just keep passing it off. (P2)

Some parents voiced concern that services seemed to be mostly directed toward assessment and measurement of progress. These parents suggested more opportunities were needed for talking and listening to concerns. In their endless quest for answers and help, many families did end up accessing services not covered in the public domain of health care such as allied health professionals, alternative choices or sports injury clinics. Some families felt that finding the right medication was key especially to manage headache symptoms, restore sleep or reduce anxiety.

# Discussion

This is the first study of its kind to explore the experiences of adolescents going through prolonged concussion recovery complicated by depressive symptoms from the perspective of both the youth and their parents. The main finding was that prolonged recovery from concussion follows a trajectory of four phases, which were labeled as: the impact, the fall-out, piecing it back together and a new or renewed path. This trajectory has key emotional elements that seemed to be commonly experienced in each phase. Similar themes were found in study of military personnel with persistent symptoms after concussion who described their common experiences in terms of the onset, symptom experiences, recovery and acceptance [25].

For youth in our study the experience of prolonged recovery from concussion manifested initially with physical symptoms that were managed with prescribed rest, both physical and cognitive. The resulting losses from this lengthy inactivity due to ongoing symptoms were experienced in both valued activities, and most importantly to children, the loss of social opportunities and relationships. The cognitive and emotional process of coming to terms with these multiple losses resembled a grief response that ran parallel to each phase of our trajectory [26]. Many children described that the intense emotional responses or depressive symptoms occurred within days to several weeks post-injury.

Multiple losses and the intense emotional responses to these have been described in other findings from qualitative studies with adults after traumatic brain injury [27, 28]. It has been argued that depressive symptoms after mTBI/concussion are more frequent than in moderate to severe brain injuries due to awareness of differences in functional consequences in those with milder injuries [29].

A meta-synthesis of qualitative studies of those with TBI found a consistent theme of loss of identity [28]. This theme was also highlighted by youth in our study and has been a key finding in qualitative studies of those with depression alone [30, 31]. Chronic disease literature is also abundant with descriptions of the loss of self and previous self-image [32-34]. Prolonged recovery from concussion with its activity restrictions and subsequent functional deficits could arguably situate itself as a chronic condition with variable symptomology and uncertain outcome. The youth and family’s experience of and their reactions to poor outcomes from concussion can be understood in the context of a theory of chronic illness.

Bury’s social theory of chronic illness as a biographical disruption is very helpful in understanding prolonged recovery from concussion [35]. This framework is described with 3 central premises: 1) that chronic illness disrupts the “taken for granted” structures of daily life and assumptions about the future; 2) it forces a rethinking of the individual’s self-concept and “biography” and 3) it results in a practical response to the disruption of “mobilizing resources” [36]. The onset of the condition or “disruption” parallels the “impact and fall-out” phases of our trajectory where participants experienced a disruption of the physical self and decreased confidence in the body subsequently leading to a loss of confidence in their social interactions or self-identity. As the participant’s symptoms seemed to worsen and result in more loss, they began to perceive stigmatization in their social networks, which resulted in further withdrawal. The coping or adaptation response in Bury’s concept of mobilizing resources is reflective of the latter two stages of our trajectory, “piecing it back together and new or renewed path” where the youth try to maintain meaning or find new meaning in order to redefine themselves in their disrupted lives [37]. These parallel stages and the corresponding emotional responses are depicted in Figure 2. Bury’s theory is particularly relevant in this exploratory study of children and their parents due to the emphasis on the social nature of the disruption and the interruption of family or parental roles.

Parental narratives layered on top of the youth’s experience provided a rich understanding of the meaning of the experience of prolonged recovery from concussion. Parents felt unprepared for the consequences of their child’s concussion. A study looking at specific needs of adolescents and their parents after concussion identified the number one need is for “clear information about the consequences of the injury and the course of recovery” [38]. Health care services were difficult to negotiate given the complexity of both physical and mental health needs of the child. Information and services are more readily available in the acute stage post injury than for the longer term. It was also easier to access information and services for the physical repercussions, more so than for the mental health consequences of concussion. There seemed to be a disconnect between knowledge and practice as mental health impacts from concussion are purported but the mixed responses of health care providers and the lack of awareness from parent perspectives points to a knowledge translation problem. Pediatric guidelines for management of concussion have recently been published online [39]. Making parents aware of resources that lay out the course of clinical care would help them feel more control over the uncertainty that is central in protracted recoveries. Recently, an algorithm for decision-making with mental health issues has been outlined in the Ontario Neurotrauma Foundation guidelines, which is an important resource for front line health care providers [39].

In addition to information and better and more timely access to health care resources, parents also drew attention to their very emotional experiences of watching their children suffer and the self-doubt they experience in relation to their own parenting. They talked about a need for space to be able to discuss these issues with experts who understand and can hear their concerns. Other forms of parent support may be helpful particularly during the fall-out and piecing it back together phases. A psycho-educational stress management program for parents of children with ABI has been shown to decrease parental anxiety and depression [40] and parent-to-parent support groups have been helpful to parents of children with developmental disabilities [41].

## Limitations

There are several study limitations that should be noted. The first is that the sample had only six participants and their families. This did not allow us to achieve full saturation although Guest and collegues reported that basic elements of metathemes are present after 6 interviews [42]. Our sample consisted of only one pre-teen while all others were adolescents and all were middle to upper middle class with five of six having intact families. These factors could explain an appraisal of experiences that are not transferable to a wider range of children with concussion. A broader sample of families that would capture differing levels of family stress such as socioeconomic status and stability as well as different cultural values may have helped ensure some transferability. Although the sample did capture a cross-section of various time points after injury thereby providing insights into the temporal sequence of recovery, prolonged engagement over time would enhance these findings. The study did begin to highlight some important differences that family support may contribute to the children’s experiences of their recovery from concussion and this should be explored in future studies.

## Conclusion

Youth experiencing prolonged recovery from concussion experienced a life-changing event. Emotional responses underpin a trajectory of recovery that mirrors a grief response as the youth learn to cope and adapt to their new realities. Youth cannot be treated in isolation as their parents experience their own emotional distress and need support in balancing their parenting approaches with the recommended concussion management strategies. The trajectory of emotional responses and phases of recovery may indicate a need for specialized services in order to manage the complex physical and emotional needs of families experiencing an unexpected and prolonged course of recovery.

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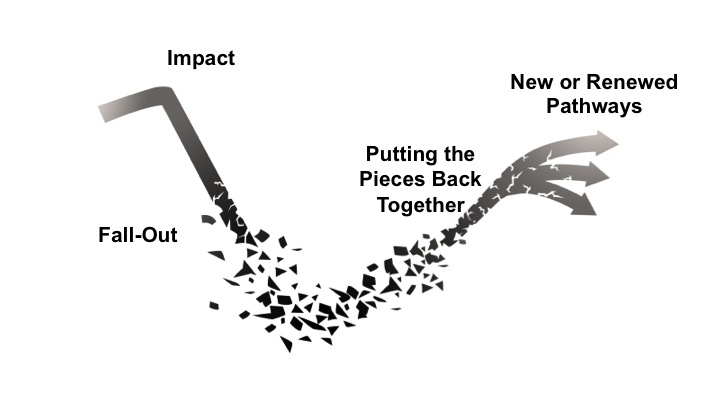
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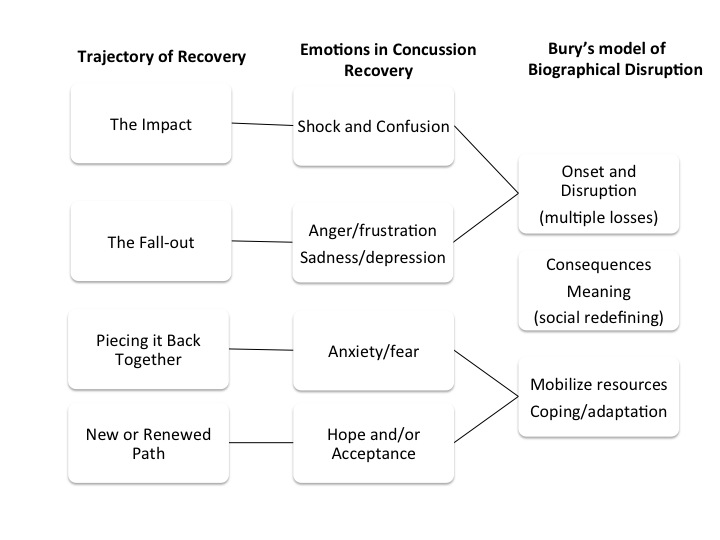
|  |  |
| --- | --- |
| **Table 1: Participant Characteristics** | |
| Mean Age in years (range) | 15 (11-18) |
| Sex (Male/Female) | 2M/4F |
| Injury   * Sport related * Gym class * MVA * Fall | 2  2  1  1 |
| Grade range | 5-12 |
| Months from injury to recruitment | 9 (1-28) |
| Months from injury to interview | 17 (4-39) |
| Diagnosed with new mood disorder | 4 |
| Prior history   * Anxiety * Migraines | 1  3 |
| Multiple head injuries | 4 |

**Figure 1: Trajectory of Prolonged Recovery from Concussion**



**Figure 2: Emotional and social implications along the trajectory of recovery from**

**concussion**



# Chapter Four: Discussion

The purpose of this thesis was to explore the phenomena of depression after concussion in children and youth. A quantitative prospective study was conducted to explore prediction and risk of significant depressive symptoms after concussion and a qualitative phenomenological study was conducted to examine the lived experience in children and families of prolonged recovery from concussion complicated by depressive symptoms. The results of the first study add to our understanding about the risk, correlates and predictors of depression after concussion in this population. The findings from the second study provide a conceptual framework for understanding the trajectory of emotional and functional recovery, based on the perspective of youth and families living with prolonged concussion symptoms and delayed recovery that is complicated by significant depressive symptomatology. This discussion will begin by reviewing the findings from each study in the context of current literature. Research directions are suggested throughout and the chapter concludes by discussing the clinical implications of this research.

In the first study (Chapter Two), a prospective cohort of children who were being followed after a concussive injury demonstrated an increased risk of developing depression within the first year after their injury. Significant depressive symptomatology was found during routine screening at regular follow-up appointments. The rate of depression in this population was two to four times greater than expected in the general population. Those who experience hospital admission and many post-concussion symptoms are significantly more likely to have elevated depressive symptoms when controlling for age, number of head injuries and delayed symptom recovery.

The binary logistic regression model included five variables: sex, symptom scores, hospital admission, prolonged symptoms over 3 months and multiple head injuries. This model accounted for 36% of the variance in the outcome. High symptom scores have been implicated in studies that have predicted protracted recoveries (Grubenhoff et al., 2014; Meehan, Mannix, Stracciolini, Elbin, & Collins, 2013). Symptom scores were also found to be a predictor of depression in studies with adults with concussion (Rao et al., 2010). Clearly, increased symptom reporting predicts poor outcomes but may not help discern between protracted recoveries and the onset of depression. Whether or not a child had been admitted to hospital was also a significant predictor in this study. The majority of admissions were just overnight but perhaps indicate a more serious injury clinically and, therefore, suggest that there may be underlying neurobiological processes that could trigger a depression. Alternatively, hospital admission could also reflect a more stressful experience from the child’s perspective triggering more anxiety and depression from environmental factors.

Although some of the factors associated with the development of depression in children being followed for a concussive injury were examined, they provide an increased understanding of who may be at risk but do not answer the question of the causal mechanism of depression.

The second study (Chapter Three) found that children and family’s experience with prolonged recovery from concussion and depression moved along multiple stages in a trajectory of recovery. This trajectory highlights the functional impact of activity disruptions not only on the child’s performance at school and in extra-curricular activities, but on the child’s identity, self-worth and perceptions of competence. The loss of social connections, meaningful activities and dreams for the future had a profound impact on many of the participants. The trajectory also highlighted the emotional sequelae associated with functional changes, moving from an initial stage of shock and confusion to the fall-out stage of anger, frustration and sadness, and then to fear and anxiety about re-engaging in activities and, finally, to some sense of acceptance of a different life path. The trajectory highlighted not only how the process impacts children, but also how it impacts on their families. The struggles that parents experienced throughout the process, including fears for their child, uncertainty about how best to support them, and frustration with the healthcare system are a number of key issues to consider in the recovery process.

Although there are studies in the literature that highlight functional changes that children experience in terms of disruption to school performance and performance in instrumental activities of daily living, little attention has been paid to the evolution of participation over time. One study looking at the effects of concussion on leisure activities a year after injury has shown a statistically significant reduction in instrumental daily activities as well as social, physical and cultural activities (Jonsson & Andersson, 2012). In terms of school performance, a study conducted in a tertiary care sports medicine clinic found that 61% of children reported a decline in grades, 69% needed school accommodations and this increased to 87% when the youth were depressed (Corwin et al., 2014). Findings from our study highlight how disruption or change in meaningful activities has the potential to strongly influence the youth’s developmental trajectory. Activity disruptions can lead to poorer psychosocial outcomes in the short term, but can also lead to long-term resiliency through adapting activities and building a new sense of self. While grieving and depression were identified as key emotional responses to the multiple losses, the youth in our study eventually engaged in new activities to help them cope and “restore a sense of value and purpose to life” (Hammell, 2004), despite ongoing depressive symptoms. This is a positive message of hope that children and their families may need as they struggle through the early stages of uncertainty and grief. It also points to the importance of engagement in meaningful activities in the process of recovery.

In terms of the emotional impact of prolonged recovery from depression, the study findings are consistent with other studies in the literature that have explored the emotional changes associated with the onset of illness and disability. For example, links were made to the theory of biographical disruption, which explains how the “sufferer” tries to recreate meaning through “repairing ruptures between body, self and society” disrupted by illness and uncertainty (Williams, 2000). In addition, the response of children and their families could be conceptualized as a process of grieving. Grief is a natural response to loss and is distinct from depression although accumulated losses and stress in grieving youth can increase the risk of depression (Ferszt & Leveillee, 2009). This study has provided unique insights into the emotional trajectory that is linked to activity disruptions following concussion associated with depression.

As reviewed earlier, differentiating the emotional sequelae of concussion from depression can be difficult as there are similarities in symptoms. The CDI-2 screening test chosen for use in this study has only two items that overlap with the PCSI - irritability and fatigue – so it could assist in discerning between the emotional sequelae of concussion and depression. Research has demonstrated that emotional symptoms occur early in recovery, from 1 – 3 weeks (Eisenberg, Meehan, & Mannix, 2014; Kontos, Covassin, Elbin, & Parker, 2012) which makes time a factor to consider; the further away from the injury, the more concerning emotional symptoms may be. A persistent view of the self as worthless, disconnecting from social supports and experiencing overwhelming emotions that impede function are also strong indicators of a concerning depressive episode outside of the emotional and grief responses to injury (Boelen, Van De Schoot, Van Den Hout, De Keijser, & Van Den Bout, 2010; Ferszt & Leveillee, 2009)

Disentangling the symptoms of depression from prolonged recovery after concussion is difficult to do clinically, particularly if the depression is mild. Grief and mild depression are just a few of the potential overlapping emotional responses to concussive injury and the recovery period. These conditions may be one threshold of a dimension of emotional responses that may not require pharmacological treatment, but may instead respond well to other types of interventions, including occupational therapy, psychotherapy and family based interventions (Hankin, 2006; Zuckerbrot, Cheung, Jensen, Stein, & Laraque, 2007).

## Integrating the Studies

The advantage of conducting a quantitative and a qualitative study with a similar population was to be able to elucidate the stories or potential explanations behind some of the numbers. The point at which depression occurs for children after a concussion was not identified in the quantitative analysis, as it was not an inception cohort. Mean time from injury to depression, however, was approximately 6 months (range 2 weeks – 35 months). Participants in the qualitative study revealed that the onset of depressive symptoms occurred within 3 months of their injury. There is evidence of both early and late onset depression after mild to moderate TBI with specific symptomatology differentiating the two (Bay & Covassin, 2012). Early onset depression (within days) is characterized by somatic and anxiety-like symptoms whereas late onset depression is described as having more psychological symptoms and cognitive difficulties (Bay & Covassin, 2012). Participants in the qualitative study described both early and late onset depression. Causal mechanisms of depression after concussion are complex and can be obscured by directionality of the associated relationships. For example, is it the prolonged symptoms causing depression or is it the depression that leads to prolonged symptoms? Similarly, decreased academic standing and depression were also significantly correlated in our findings. Accounts from participants in the qualitative study described times when the stressful activity of return to school triggered anxiety and depression and times when the depression was experienced within days of the injury and affected their motivation to go to school and their performance. Longitudinal research with a large sample including a comparison group is needed to clarify risks and predictors.

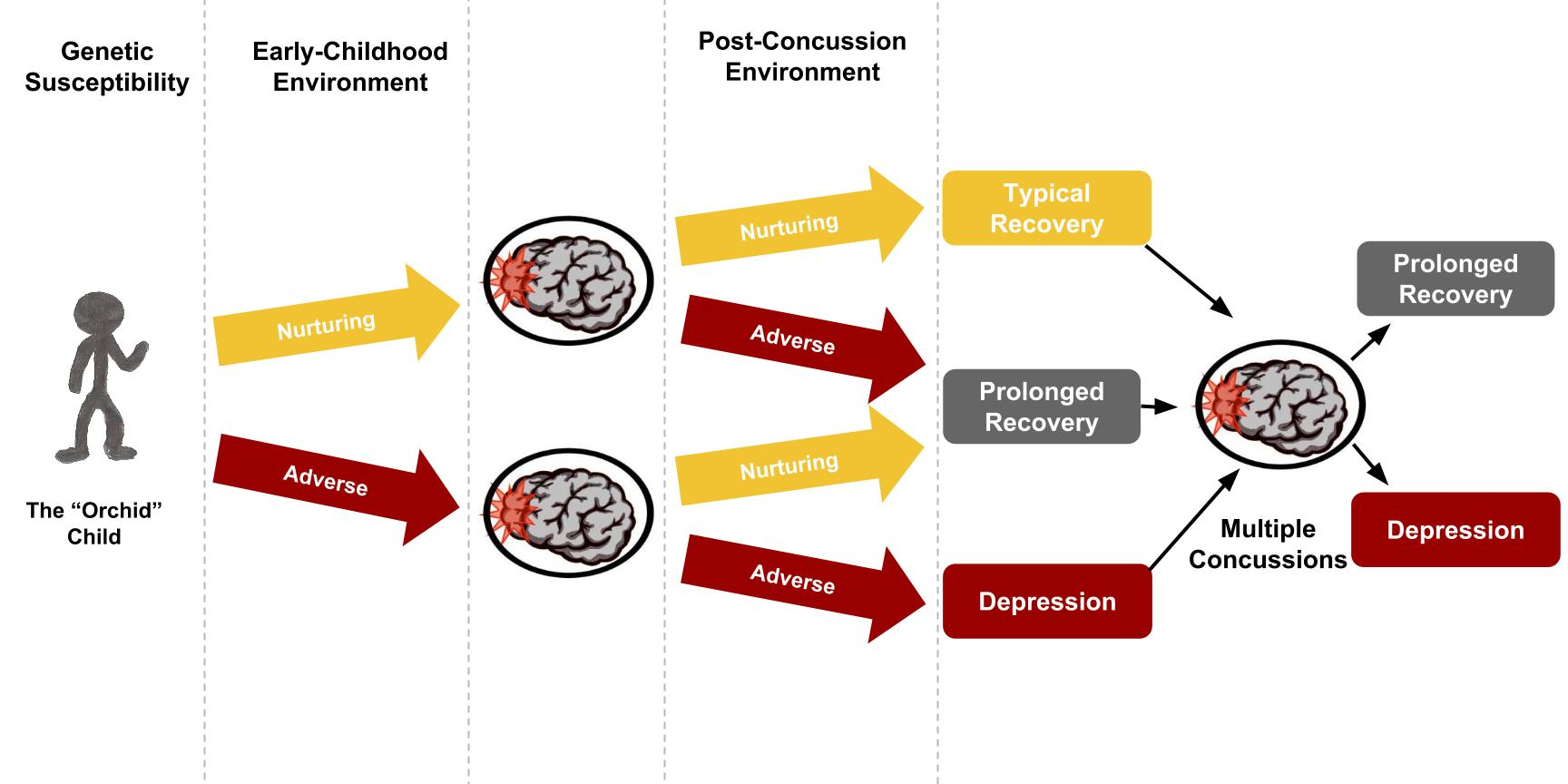
Theory is necessary to guide research. Vulnerability stress theory was introduced in Chapter One as one way of thinking about the onset of depression (Ingram, 2010). Given the current findings, it would seem that the outcomes from concussion might also be considered from a differential susceptibility framework (Ellis, Boyce, Belsky, Bakermans-Kranenburg, & van Ijzendoorn, 2011). A model using the concepts of the differential susceptibility theory to explain differing outcomes of concussion has been developed (see Figure 1). This model considers the outcome of children to be highly dependent on their environment: both early childhood experiences and the context around the concussive incident that includes the child’s resources and support or conversely their stress during healing from concussion. Multiple concussions are hypothesized to lead to poorer outcomes, including both prolonged recovery and depression. Validating this framework, which emphasizes both environmental stressors and vulnerabilities both to the concussion and from the injury itself, would require further hypothesis-driven studies.

## Implications for Clinical Practice

There are many emotional and practical implications of the findings concerning post-concussive risk of depression as well as the trajectory of recovery that could inform resource and service planning. In the acute stage of symptom management, the development of a clinical pathway that projects potential recovery patterns and check-in points regarding when and how to access health care would be very helpful for families. Families were frustrated with the lack of

**Figure 1: Model explaining childhood concussion outcomes based on the differential**

**susceptibility framework**



\* Adapted from the Differential Susceptibility Theory (Ellis, Boyce, Belsky, Bakermans-Kranenburg & Van Ijzendoorm, 2011)

recognition of the mental health consequences of concussion as well as what they perceived to be a dearth of available services or effective interventions for the ongoing symptoms of concussion. Families were looking for guidance from the health care system and reassurance that service providers were knowledgeable about their child’s condition. A clinical pathway could inform frontline service providers as well as families. This pathway could recommended weekly or monthly check ups, depending on presentation and length of recovery. Decision-making practices about assessments, transition supports and services that should be sought at various points along the trajectory could be outlined. Some of this work has already begun in that recovery patterns are guiding the new return to activity protocols (DeMatteo et al., 2014) and practice guidelines for managing pediatric concussion have been developed (Zemek, Duval, & DeMatteo, 2014). Although this knowledge has been synthesized and made available (DeMatteo, 2013), it has not yet been fully adopted by frontline providers. Adapting guidelines to a local community context may result in increased uptake by service providers; for example, decision-making algorithms could list local services and specialists when referrals are recommended.

Another clinical implication in the acute stage, when children and families are first introduced to concussion management protocols that advocate a graduated return to all activity, is that health care providers need to be aware of the emotional impact of implementing activity restrictions. Discussion with families about finding ways that the youth can remain socially connected and maintain a sense of self through valued activities may help prevent some of the loss of self experienced by the youth who go through prolonged recoveries.

This work also highlights that the treatment of youth should not occur in isolation of their families. Parental uncertainty and distress affects the family and parents can be overly cautious and protective or, conversely, question the need for concussion management strategies. Parents of children with concussion experience psychological distress and are at increased risk for anxiety and depression themselves (Ganesalingam et al., 2008; Wade, Carey, & Wolfe, 2006). Educational intervention directly after concussion has been shown to affect outcomes; however, application to those later in the recovery process has not been researched (Snell, Surgenor, Hay-Smith, & Siegert, 2009). Other resources such as family therapy, parent-to- parent support or online support have shown promise in TBI and other special needs populations (Singer, Ethridge, & Aldana, 2007; Wade et al., 2006).

A further clinical implication rising from this research is the need to develop consistent monitoring of significant depressive symptoms in children and youth who have had a concussion, in order to provide intervention to affected youth and their families. Screening is known to improve health outcomes when linked to effective follow-up and treatment (Macmillan, Patterson, & Wathen, 2005). Targeted screening in high-risk patients has been a highly recommended approach to identify patients with depression (Sharp & Lipsky, 2002) but has rarely been implemented with children who have had a concussion. A self-report measure of depressive symptoms can be built into concussion follow-up protocols. This study, conducted in a busy concussion clinic, showed that elevated symptoms reported on the CDI-2 screen were not always disclosed during the general interview. Concussion increases the risk for elevated depressive symptoms and other indicators could be identified that are known to multiply the risk such as a first-degree relative with history of depression, chronic pain (e.g., backache, headache), impoverished home environment, experiencing major life changes, fatigue or sleep disturbance (Macmillan et al., 2005). The timing of the onset of depression is not yet clear; this study would suggest that an initial screening should occur between one and three months post-injury and could facilitate discussion with the youth of the functional implications of their concussion and their feelings.

Intervention for depression has been well researched but often with unclear results (Merry et al., 2011; Nordheim, Ekeland, Hagen, & Heian, 2009); treatment for prolonged recovery from concussion has even more limited research (Leddy, Sandhu, Sodhi, Baker, & Willer, 2012). The families interviewed did not experience the phenomena of concussion and of depression as two distinct conditions; therefore, there may have been an expectation that provision of services would align and treat these together. Symptoms of concussion and depression overlap, yet both result in decreased engagement in meaningful activities. An approach to intervention directed at the combination of these conditions might be more effective than treating the depression in isolation and may lead to earlier recovery and re-engagement in daily life. An intervention study examining this question with an active rehabilitation approach is another highly needed area of research and a multi-site trial is currently underway across Canada.

# Conclusion

The goal of this research was to understand more about depression after concussion in youth and how it may complicate their recoveries. This thesis confirms and adds to the growing body of evidence that there is a tangible risk of depression in youth after concussion. Predictors of elevated symptoms of depression included high post-concussive symptom scores and admission to hospital. Exploring the lives of children and families as they experienced the challenges of activity restrictions, emotional symptoms and their interactions with health care provided insight into how health care providers might better support children and families during recovery from concussion.

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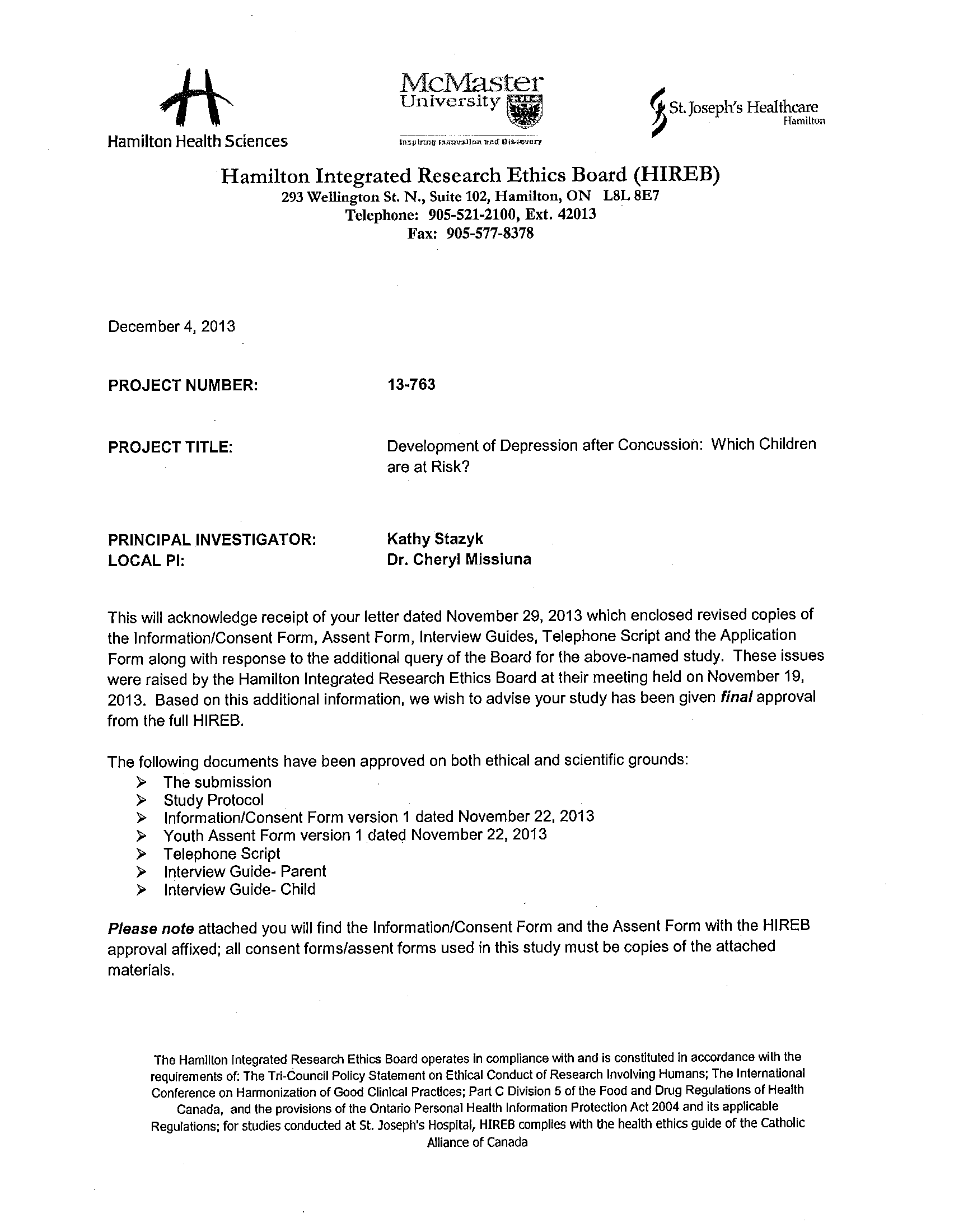
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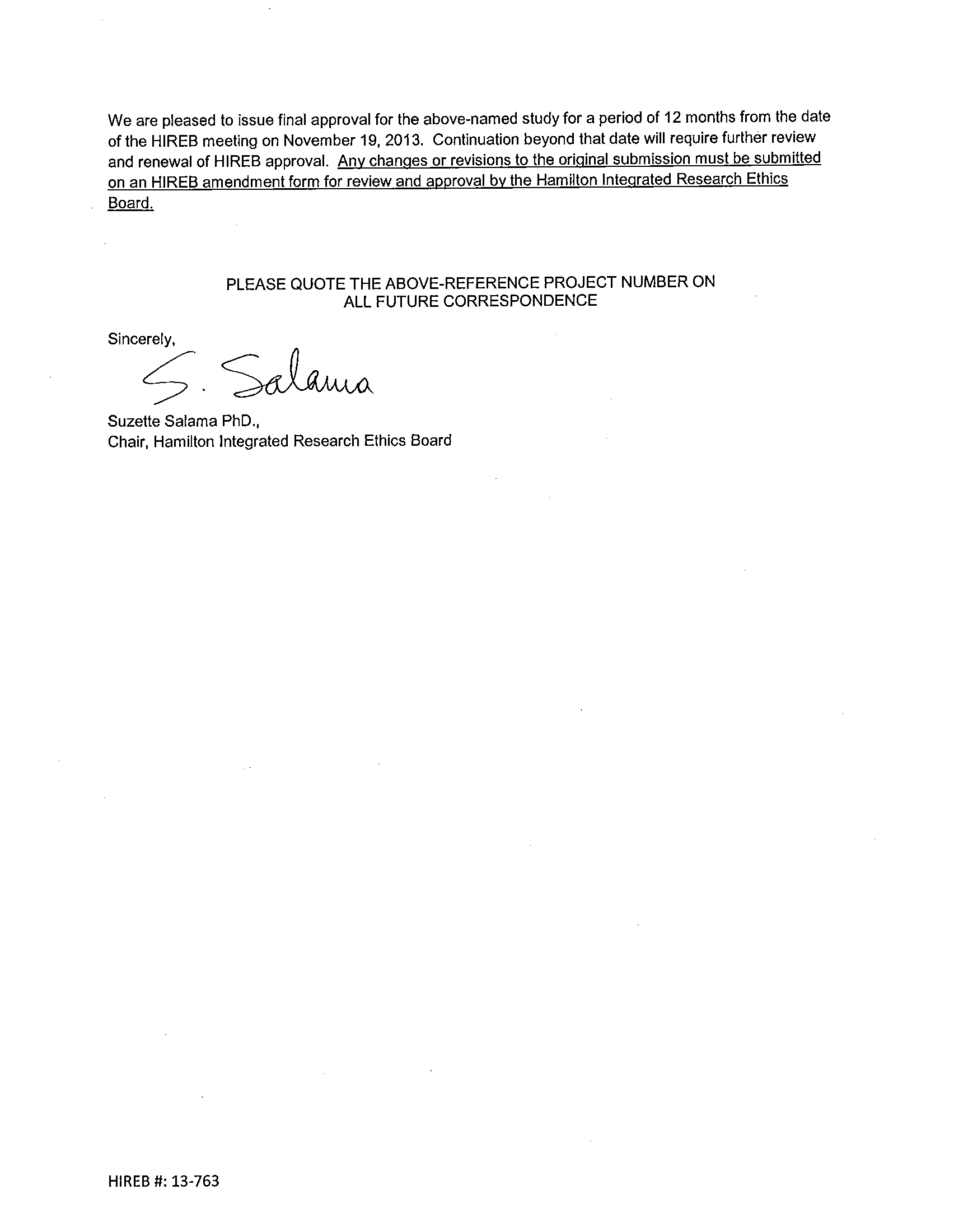
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**Appendix A-Approval Letter**





**Appendix B- Parent Consent Form**



**Information and Consent Form: Development of Depression after Concussion:**

**Which Children are at Risk?**

Principal Investigator: Kathy Stazyk, BHScOTReg(Ont), McMaster University

Supervisor: Dr. Cheryl Missiuna, Ph.D., OTReg(Ont), McMaster University

Dear Parents/Guardians:

We would like to invite you to take part in a study to understand changes in mood in children who are recovering from concussion.

**WHY ARE WE DOING THIS STUDY?**

Mood changes or depressive symptoms can develop after life stresses and injuries. These changes are thought to be more frequent after brain injury and can often prevent a child from returning to school and sports. We need a better understanding about mood changes after concussion so that we can intervene early to prevent or lessen the impact of this on participation.

**WHAT BENEFIT IS THIS TO YOU AND YOUR CHILD?**

There are no direct benefits from participating; however, the information shared by your family helps us to understand the strengths and challenges that are experienced when a child is recovering from concussion and the added impact of changes in mood and emotions.

**WHAT RISKS ARE INVOLVED IN THIS STUDY?**

The risk of participating in interviews is low, although it may be stressful to talk about the experiences that families and children have had since the concussion occurred.

**WHAT DO YOU NEED TO DO?**

If you choose to take part in this study you will be contacted to set up an interview which will be scheduled at your convenience at your home if you like, or an agreed upon location that is comfortable for you sharing personal information. You will need to sign these consent forms and give them to the investigator before the interview begins. The interview will take about an hour and can include yourself and your child together or separately with their assent. The questions will ask about the impact of concussion and mood changes on your family and on your son/daughter, what things have been helpful and what has been most challenging in this recovery period. The interview will be audio recorded to help with collecting and analyzing the information. At this appointment you will also be asked to complete a brief questionnaire about your child’s moods and feelings over the previous two weeks.

**IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?**

Even if you agree to participate in the study, you and your child's participation is voluntary and you may withdraw from the study at any time. There is no obligation for you or your child to answer any questions or to participate in any aspect of this project.

**WILL MY INFORMATION BE KEPT CONFIDENTIAL?**

All personal data will be kept strictly confidential and all information will be coded so that your name is not associated with your answers. Only the researchers will have access to the data. No personal information regarding your child or family will be identified in publication of the results of this study.

**WHAT ELSE DO YOU NEED TO KNOW?**

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). The REB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, Hamilton Integrated Research Ethics Board (HIREB) at 905.521.2100 x 42013.

If you would like to receive more information about the study please contact Kathy Stazyk at 289-208-1139 or by email: [stazyk@mcmaster.ca](mailto:stazyk@mcmaster.ca) or Dr. Cheryl Missiuna at 905-525-9140 ext 27842 or by email: [missiuna@mcmaster.ca](mailto:missiuna@mcmaster.ca).

**Thank you for your participation!**

Kathy Stazyk Cheryl Missiuna

McMaster University McMaster University

**INFORMED CONSENT – Depressive Symptoms after Concussion**

Parental/Guardian Statement:

I am the parent or legal guardian of the child named below, who is under the age of 18 years

**Parent’s Consent and Signature**

**❑ Yes please sign us up!**

I give my personal consent and give consent for my child, \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_, to take part in this study where an occupational therapist will interview myself and my child (with their assent) about their experiences with recovery from concussion.

**❑No, thank-you.**

Signature of Parent/Guardian: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Print name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

I have explained this study and believe that it has been understood and the participant is voluntarily and knowlingly giving informed consent.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature Date

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

Person obtaining consent

**Appendix C- Youth Assent Form**



**YOUTH ASSENT FORM: Development of Depression after Concussion: Which children are at risk?**

UNDERSTANDING KIDS LIKE YOU!

**WHY ARE WE DOING THIS STUDY?**

We are doing this research study to find out more about kids moods and feelings after they have had a concussion injury. We are asking kids who are having long lasting symptoms and may be very sad or depressed about this to tell us more about their everyday lives.

**If I AM IN THE STUDY, WHAT WILL HAPPEN TO ME?**

The person reading this with you will want to ask you questions about your feelings after concussion and what it has been like for you. We are also talking to your parents about these things too. You will also be asked to answer a short questionnaire about your moods and feelings for the past 2 weeks.

**Will I BE HURT IF I AM IN THE STUDY?**

Many children like to tell their story, however if at any point you feel uncomfortable, all you have to do is say that you would like to stop.

**WHAT IF I DON’T WANT TO ANSWER ONE OF THE QUESTIONS?**

You can skip any of the questions that make you uncomfortable. If you don’t understand a question, you can ask the person from the study to explain it to you.

**HOW WILL THE STUDY HELP ME?**

The information you share with us helps us understand more about how kids your age feel after having a concussion and about getting better from it. It helps us to help kids like you to have positive experiences in the future.

**DO I HAVE TO BE IN THIS STUDY?**

You don’t have to be in this study if you don’t want to. People take part in studies like this one because they want to –they think it is interesting and important. Nobody will make you be a part of a study if you don’t want to and you can leave the study if you decide you no longer want to take part.

**WHAT HAPPENS AFTER THE STUDY?**

When we are finished this study we will write a report about what was learned. This report will not include your name or that you were in the study.

**WHAT IF I HAVE QUESTIONS?**

You can ask questions if you do not understand the study. You can also call or email us if you have questions later:

Kathy Stazyk,

Person in charge of the study……………….email:stazyk@mcmaster.ca tel: 289-208-1139

**ASSENT**

If you would like to be in this study, please print/write your name. If you decide that you don’t want to be in the study, even after you have started, all you have to do is let someone know.

I,\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(Print your name) would like to be in this research study.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Date of assent)

I have explained this study and believe that \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ has understood it.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(Name of person who obtained assent)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Signature and Date)

**Appendix D- Interview Guide**

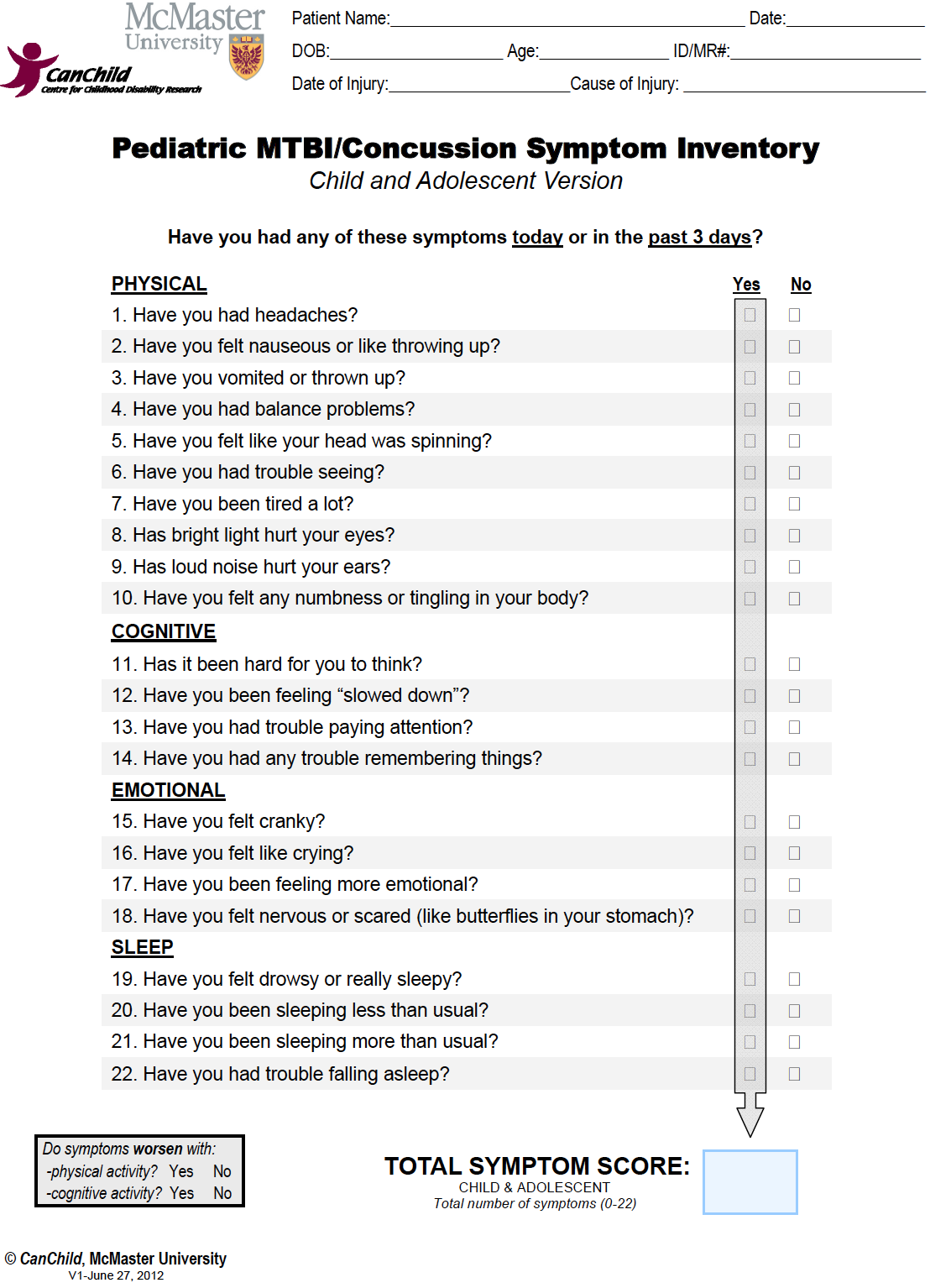
**Interview Guide/Child: Development of Depression after Concussion: Which children are at risk?**

Introduction: Thank you for agreeing to be interviewed. I am interested in your experiences with concussion recovery and in particular with the depressive symptoms that are a part of that. I am hoping that the information I gather will help to identify those children who may be at risk for depression and provide support for offering specific help to those families

|  |  |  |
| --- | --- | --- |
| Main Question | Additional Questions | Clarifying questions |
| Tell me the story about your  concussion. | Type of PC symptoms  Length of time of PC symptoms  # of concussions | Can you expand on this?  Can you give me examples?  Can you tell me anything else? |
| Tell me about the mood changes you have experienced since your concussion. | Probe for symptoms, timing  Probe any perceptions of precipitating events  Probe feelings, thoughts and beliefs | Can you expand on this?  Can you give me examples?  Can you tell me anything else? |
| Tell me about the impact of this on you? | Probe prior functioning  Probe productivity, self-care and leisure (school, friends etc) | Can you expand on this?  Can you give me examples?  Can you tell me anything else? |
| What has it been like for your family? | Probe for family dynamics, interactions (changes in these)  Probe for productivity, leisure issues (time off work, change in activity patterns) | Can you expand on this?  Can you give me examples?  Can you tell me anything else? |
| What are the things that have been helpful or challenging throughout this whole experience? | Probe for course of care  Probe for individual strengths | Can you expand on this?  Can you give me examples?  Can you tell me anything else? |
| Conclusion |  |  |
| Is there anything else you would like to add that you haven’t shared with me yet? |  |  |

Appendix

**Appendix E- Post-Concussion Symptom Inventory (PCSI)**



1. The word concussion will be used to denote the spectrum of a range of concussive injuries and mild traumatic brain injuries [↑](#footnote-ref-1)