University of Alberta

The Role of Physical Activity in the Recovery Process of Athletes with Post Concussion Syndrome

by

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ABSTRACT

This is an exploratory study based in symbolic interactionism focusing on the role of physical activity in the recovery of athletes with post concussion syndrome (PCS). Six athletes with PCS were interviewed. The interviews were taped, transcribed and then analyzed. A journal that was written during the first three years of the author's recovery from PCS was also used as data. A model titled "The Recovery Process of Athletes with Concussion" emerged from the data and outlines the recovery process consisting of three phases of recovery and psychosocial aspects of recovery (emotional reaction to injury, coping and support). Recovery is achieved when the symptoms dissipate and the athlete returns to pre-injury life or a re-conceptualization of self based on post concussion identity occurs. All of the athletes in this study were physically active while symptomatic despite recommendations to rest until asymptomatic. Implications for practice and future research are discussed.

PREFACE

When I was concussed on March 18, 2000, I never thought that concussion and post concussion syndrome would consume my life for the next five years. Since the injury, I have gone from someone who slept for 18 hours a day to someone who is a fully functioning and successful person. The recovery process has been long, slow, painful and frustrating. I have had to create a new identity and learn to accept the resulting deficits and consequences of the concussion. I believe that the physical activity I did during my recovery is one of the main reasons I have regained the vast majority of my pre-injury functioning.

The catalyst for pursuing my masters and this research was the profound lack of information and answers available to individuals with post concussion syndrome. In effect, this research became part of my own healing, providing me with answers, even if the answers were that "experts do not know". My hope is that this research will lead to more research focused on the role of physical activity in the recovery process of athletes with post concussion syndrome that will eventually lead to answers. Finally, I hope that more support and rehabilitation services will be available for those with MTBI and post concussion syndrome in the future and that physical activity becomes a key component of the recovery of athletes with post concussion syndrome.

ACKNOWLEDGEMENTS

There have been many people who have helped me throughout my recovery and in the completion of this research project. Without experiencing post concussion and the subsequent struggle for recovery, I never would have been driven to research this topic. Thus, there are many people that deserve thanks for cheering me on and motivating me to pursue this research.

Dr. Karen Johnston, Laura Leslie, and Dr. Gordon Bloom who took the time to hear my ideas, discuss the possibility of research in this field, and suggest potential graduate programs. These people were integral in supporting me during various stages of my recovery.

This could have never been possible without the continuous and genuine support of my mother, who seems to support me on all of the adventures or aspirations I seem to be compelled to chase. To my father who, while no longer living, instilled a sense of curiosity and an attitude of questioning that is still very prevalent in my personality.

I would like to acknowledge Dr. Vivien Hollis and Dr. Garry Wheeler who have always been supportive and excited about my research. Their ideas and suggestions throughout this process have always been appreciated.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE: INTRODUCTION

Mild traumatic brain injury (MTBI) and concussion affect a large number of people each year. It is estimated that there are between 1.3 million (Malec, 1999) and ten million (Fabiano & Daugherty, 1998) new cases of traumatic brain injury in the United States each year. It is an invisible injury that often has effects on many aspects of life, one of which is the ability to partake in physical activity. While most people recover from MTBI/ concussion, 10-15% of injured people have symptoms that linger for more than 3 months (Alves, Macciocchi & Barth, 1993; Ewing, McCarthy, Gronwall & Wrightson, 1980; Gronwall & Wrightson, 1974; Parker, 2001; Rutherford, Merrett & McDonald, 1979). Current guidelines for returning to physical activity suggest that the individual should be asymptomatic before resuming physical activity (American Academy of Neurology, 1997; Aubry, 2001; Cantu, 1986; Kelly et al., 1991; Roberts, 1992), however what happens when the symptoms linger for months, years or never completely dissipate? Physical activity and sports are an integral aspect of many people's lives. There is currently no research that focuses on the role of physical activity in the recovery process of people with post concussion syndrome.

The term concussion is used more often within a sports context. There has recently been more publicity surrounding concussions and MTBI because of professional athletes sustaining concussions while playing contact sports such as ice hockey, football, rugby, and soccer. The increased awareness of concussion in professional sports has helped bring MTBI to the forefront, however while the spectacular hits yield attention, the effects of the concussion on player's lives are rarely discussed. Professional or elite athletes often have access to medical staff who are trained and ready to quickly treat, plan and oversee rehabilitation, however, what happens to the vast majority of the population that do not have access to these specialized and quick services? How are amateur and recreational athletes affected by concussion, particularly by the lingering symptoms of concussion commonly termed post concussion syndrome?

The existing research on concussion mainly deals with epidemiology. There is debate surrounding the definitions of concussion, MTBI, and post concussion syndrome (McCrory & Johnston, 2002). It is unclear as to the cause of the symptoms. The current suggestions for recovery are to rest and wait until the individual is asymptomatic, followed by graded return to pre-injury activities (American Academy of Neurology, 1997; Aubry, 2001; Cantu, 1986; Kelly et al., 1991; Roberts, 1992). While most people recover from concussions and MTBI, a small minority of about 10-15% have lingering symptoms for months or even years (Parker, 2001). Symptoms from post concussion syndrome can contribute to a loss of function, forced changes in lifestyle, and in some cases a loss of independence (Parker, 2001). The symptoms associated with post concussion syndrome can be grouped into five categories: (a) physiological, (b) executive functions, (c) attentional processes, (d) cognitive and (e) psychological (Fabiano & Daugherty, 1998; Mittenberg & Strauman, 2000; Parker, 2001; Stoler & Hill, 1998; Wilson, Carlin & Tyburski, 2002). Often, people who have post concussion syndrome show no outward signs but have noticeable deficits to themselves and to those close to them. Symptoms may vary from person to person depending on what area of the brain was injured (Parker, 2001).

McCrory and Johnston (2002) have clinically observed that symptoms are often aggravated with altitude, atmospheric pressure, high ambient temperature and physiologic stress. This is of particular interest for athletes, as according to the return-to-play guidelines outlined by a number of researchers (Aubry, 2002; Cantu, 1986; Kelly et al, 1991; Roberts, 1992), athletes should be asymptomatic before the resumption of physical activity and should remain symptom free through a number of steps before returning to full competition or game play. Physical activity often increases physiologic stress on the body and depending on the location of the activity increased ambient temperatures can be an issue. These guidelines, however, are largely based on expert opinion rather than on scientific evidence.

Physical activity plays an important role in the lives of many people, whether they are recreational exercisers or high-end athletes and everything in between. The loss of ability to be physically active due to post concussion syndrome is often a big change and affect can not only physical fitness, but mental well being as well (Parker, 2001). This raises some important questions considering that post concussion syndrome symptoms can last from months to years, or never completely dissipate. There is almost no research that focuses on the resumption of physical activity while people are still symptomatic. This study explored the role of physical activity in the recovery process of athletes with post concussion syndrome.

Purpose of the Study

The purpose of this study was to explore the role of physical activity in the recovery process of athletes with post concussion syndrome. The study explored the experience of individuals with post concussion syndrome in relation to the circumstances of their concussion, access to information about recovering from concussion, experiences with health care professionals, participation in physical activity after their concussion, and more.

The Research Question

The broad questions that direct this study are:

1. What is the role of physical activity in the recovery process of athletes with post concussion syndrome?
2. What do athletes with post concussion syndrome experience in relation to health care services, lingering symptoms of concussion, physical activity and sport, and the effects of post concussion syndrome on their life and physical activity?

Operational Definitions

For the purposes of this study, the following terms are defined as:

Mild Traumatic Brain Injury

The definition put forth by the Mild Traumatic Brain Injury Committee of the Head Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine (1993) is used for this study. It is as follows:

> A patient with a mild traumatic brain injury is a person who has had a traumatically induced physiological disruption of brain function, as manifested by at least one of the following:

> 1. Any period of loss of consciousness;
> 2. Any loss of memory for events immediately before or after the accident;
> 3. Any alteration in mental state at the time of the accident (e.g., feeling dazed, disoriented, or confused); and
> 4. Focal neurological deficit(s) that may or may not be transient;
>
> But where the severity of the injury does not exceed the following:
>
> 1. Loss of consciousness of approximately 30 minutes or less;
> 2. After 30 minutes, an initial Glasgow Coma Scale (GCS) of 13-15; and
> 3. Posttraumatic amnesia (PTA) not greater than 24 hours. (p. 86)

Concussion

Concussion is a mild form of MTBI. The definition proposed by the Concussion in Sport Group Committee at the First International Symposium on Concussion in Sport in 2001 is as follows:

> A complex pathophysiological process affecting the brain, induced by traumatic biomechanical forces. Several common features that incorporate clinical, pathological, and biomechanical injury constructs that may be utilized in defining the nature of concussive head trauma.
>
> 1. Concussion may be caused either by a direct blow to the head, face, neck or elsewhere on the body with an "impulsive" force transmitted to the head.
> 2. Concussion typically results in the rapid on-set of short-lived impairment of neurological function that resolves spontaneously.
> 3. Concussion may result in neurolopathological changes, but acute clinical symptoms largely reflect a functional disturbance rather than a structural injury.
> 4. Concussion results in a graded set of clinical symptoms that may or may not involve loss of consciousness. Resolution of the clinical and cognitive symptoms typically follows a sequential course.
> 5. Concussion is typically associated with grossly normal structural neuroimaging studies. (Aubry, 2002, p. 58)

Post Concussion Syndrome

There are a number of varying definitions for post concussion syndrome. The definition used for the purposes of this study is slightly modified from the one listed in the Diagnostic and Statistical Manual IV.

> A history of head trauma that has caused significant cerebral concussion. Loss of consciousness (LOC), posttraumatic amnesia (PTA), or seizures are evidence of concussion.
>
> Three (or more) of the symptoms listed below should be present and persistent for at least 3 months:
>
> 1. becoming easily fatigued
> 2. disordered sleep
> 3. headache
> 4. vertigo or dizziness
> 5. Irritability or aggression on little or no provocation
> 6. anxiety, depression, or affective lability
> 7. Changes in personality (e.g., social or sexual inappropriateness)
> 8. Apathy or lack of spontaneity.
>
> Significant impairment in social or occupational functioning and significant decline from a previous level of functioning (Malec, 1999, p. 19).

For the purposes of this study, the term post concussion syndrome is used to refer to the participants' condition despite, in some cases, no formal diagnosis. The definition of post concussion syndrome outlined above was part of the criteria participants had to meet in order to be eligible for this study. All participants have a formal diagnosis of concussion. In addition, some were formally diagnosed with post concussion syndrome.

Recovery Process

The term recovery is important for this study. Recovery has often been viewed as complete when the person returns to pre-injury functioning without essential dysfunctions or discomforts (Parker, 2001). The recovery process is defined as:

> A deeply personal process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the effects of disability or illness (Bishop, 2001, p. 48).

Participant

For the purposes of this study, the term "participant" is used to refer to the individuals who were interviewed. "Participants" is used to refer to the six interviewees as a group. When the term "participants" is used, it excludes me.

Athlete

The term "athlete" is used to refer to the group of people who participated in this study. This includes the six participants and me. For this research, it is important to maintain a wide margin as to include both high-performance athletes, such as varsity sports players, as well as recreational athletes who engage in physical activity and sport for enjoyment, health or other reasons. It is important to note that professional or paid athletes were excluded. While the participants may not refer to themselves as athletes, all the participants have been or are currently involved in sport, and thus, fit the definition of athlete below. With this in mind, the Webster's Third New International Dictionary of the English Language Unabridged (1986) defines athletes as:

1. One who is trained to compete either professionally or as an amateur in exercise, sport, or games requiring physical strength, agility, or stamina.
2. One who has a natural aptitude for or is reasonably skilled in physical exercises, sports or games.
3. One who takes part in or is capable of taking part in exercise or activities requiring mental agility, endurance or strength (p. 138).

Using the above definition ensures that those athletes who were recovering from injury and were engaging in activities other than their sport, such as walking, jogging, aerobics etc...were included in the study's intended population.

Physical Activity

The definition of physical activity, for the purposes of this study, has been modified from the definition used in the 1999 Alberta Survey on Physical Activity: Concise Report (Spence & Poon, 2000). It is defined as:

Participation in planned physical activity that takes place in one' spare time and at a level that causes the person to breath faster and heavier. This can include sports related activity that requires light, moderate, or vigorous effort, including but not limited to participation in organized sport, sport training regimes and exercises associated with rehabilitation programs. Activities may include walking, jogging, swimming, gym works outs, and other similar activities. The wide range of types of physical activity allowed for people in all stages of recovery to be eligible for participation in the study.

Spontaneous Healing

Spontaneous healing is not well defined in the literature but there have been many anecdotal accounts published in newspapers of concussed athletes describing the sudden resolution of symptoms. It is often described as "suddenly coming out of a fog", "someone turned on a switch" or that their brain suddenly worked again. The term spontaneous healing is used throughout this study to describe a sudden, unexplained resolution of symptoms.

Limitations

There are a number of possible limitations, which largely stem from the lack of consistency with the definitions, lack of agreed upon processes for rehabilitation, and a slim base of scientific evidence in the field of concussion/ MTBI research and rehabilitation. A number of specific ones are presented here.

It is difficult to find and gain access to people who have post concussion syndrome because of the lack of follow up of this population by medical services, the lack of rehabilitation programs that offer programs for this very mild form of MTBI, and because many people who are concussed do not seek medical help. The response rate to recruitment was extremely low. Given this, the sample size is fairly small. The reason for this is unknown, considering the number of people who, in casual conversations, report having had a concussion/ post concussion syndrome or who know of someone who has had a concussion/ post concussion syndrome.

The participants were all from different sporting backgrounds participating at recreational to elite amateur levels. Differing socio-economic backgrounds, professions, stages of life, participation in different forms of sport and physical activity, and previous experience with the health care system ultimately shape one's experiences and attitudes. While this provides insight into a wide range of experiences across different sports and backgrounds, the participants' experiences may not necessarily be representative of the general experiences of other athletes in each sport, or of the whole population of concussed athletes. Comparing and contrasting the experiences of the athletes does, however, provide a small window into the wider phenomena of concussion and post concussion syndrome, and the experience of recovering from the injury.

Delimitations

Athletes

This study was limited to individuals between the ages of 18-39, who sustained a concussion within the two past years, were seen by a physician and diagnosed with a concussion, and had at least three of the listed symptoms for at least three months. Prior to the concussion, individuals were active at least two times per week and would like to resume or have resumed physical activity post concussion. Fluency in English was also a requirement.

Assumptions

The interest and drive for pursuing this topic came from my personal experience of sustaining a second-degree concussion and the long recovery process that followed. Having been an extremely physically active person and suddenly not being able to be physically active or work at my chosen profession as a wilderness guide, I began to look for information about concussion and return to physical activity. Not finding many answers, led me to pursue a masters degree and to this study.

It is important for a researcher to outline and acknowledge his or her assumptions and biases. The literature, personal accounts of people with MTBI, informal discussions with survivors, and personal experience have led me to think that MTBI and post concussion syndrome has a large effect on people's lives. It is often a hidden injury/disability, with no outward physical signs and symptoms, thus I believe that MTBI and post concussion syndrome are sometimes misunderstood, and misdiagnosed. During my recovery from post concussion syndrome, my personal experience with health care providers was generally positive despite long waits to be seen. There are, however, many athletes who have negative experiences when seeking medical treatment for concussion and post concussion syndrome. I believe that regular physical activity is an important part of the lives of many people. The inability to be physically active due to injury, for example, is a significant life change, whether temporary or permanent. This is especially true if physical activity is the basis for employment. That being considered, the resumption of physical activity following MTBI may be a significant part of the recovery process on many levels. Finally, I believe that how people define themselves is constantly changing based on each new experience throughout life. Going through an event such as MTBI/ post concussion syndrome and the recovery process from the injury changes the person, however the kind of changes are highly individualized.

Because my recovery experience is part of the data for this research project, my experiences are described in detail in chapter four. Providing detailed and thorough accounts of my experience regarding my own recovery helps to provide further insight into my assumptions and biases. In doing so, I feel that I have been transparent and forth coming with my beliefs, assumptions and biases related to this research.

CHAPTER TWO: LITERATURE REVIEW

There is a big gap in the concussion and mild traumatic brain injury (MTBI) research. While there are many studies focusing on the diagnosis, prognosis, injury to the brain structures, and the cause of symptoms, there is very little research on the treatment of post concussion syndrome. There is even less research that focuses on the role of physical activity in the recovery/ rehabilitation process of people with post concussion syndrome (M.W. Collins, personal communication, March 9, 2003).

Over the last few years there has been an increase in the publicity of professional athletes missing game play or being forced to retire due to concussions. Most people who sustain concussions recover quickly however there are a small percentage of people who experience prolonged symptoms for weeks, months or years (Fabiano & Daugherty, 1998). Most of the return-to-play guidelines for concussion suggest that an athlete must be asymptomatic before resuming physical activity (Guskiewicz, 2001). This raises two important questions: (a) what is the role of physical activity in the recovery process of athletes with post concussion syndrome, and (b) what do athletes with post concussion syndrome experience in relation to health care services, lingering symptoms of concussion, physical activity and sport, and the effects of post concussion syndrome on their life and physical activity?

Physical activity plays an integral role in the lives of many people. Post concussion syndrome can affect an individual's ability to perform many of life's daily activities, one of which is participation in physical activity. The literature reviewed in this chapter begins with an examination of the definitions of MTBI, concussion and post concussion syndrome, followed by symptoms, and rates of concussion and post concussion syndrome. Current recovery and rehabilitation recommendations for athletes are then presented. Literature on forced retirement from sport and adjustment to disability, and the effects of physical activity in the rehabilitation of people with moderate and severe traumatic brain injury is also examined. Considering that there is very little research on physical activity and post concussion syndrome, this research is based in symbolic interactionism to further explore the experiences of athletes with post concussion syndrome and the role that physical activity plays in their recovery. An in-depth discussion of symbolic interactionism is presented in chapter three.

Definitions

A good place to begin to understand the scope of the problems and issues related to studying MTBI, concussion, and post concussion syndrome is to examine the definitions of these terms. While there is a general lack of agreement regarding the definitions of concussion and post concussion syndrome (McCrory & Johnston, 2002), the definition of MTBI is widely accepted and used. Many of these definitions are outlined in chapter one.

The definition of mild traumatic brain injury proposed by the American Congress of Rehabilitation Medicine is one that is widely used and generally agreed upon, with slight variations among different researchers and experts (Malec, 1999). Definitions of MTBI are generally based on the duration of loss of consciousness, the period of post-traumatic amnesia, and a score of 13-15 on the Glasgow Coma Scale (Cooper, Ferrara, Mrazik & Casto, 2001; Parker, 2001; Wills & Leathem, 2001). The Glasgow Coma Scale is used to determine the severity of a traumatic brain injury. A score ranging from 3-8 indicates a severe injury, from 9-12 indicates a moderate injury and 13-15 indicates a mild injury. The highest score is 15 (Stoler & Hill, 1998). Most concussion patients have a score of 15. Differences between definitions usually focus on the duration of loss of consciousness, the presence or absence of loss of consciousness, and the length of post-traumatic amnesia.

Concussion is a term that is used more often used in relation to sports injuries and is generally defined as "a brief, temporary interruption of neurological function following head trauma; it can occur with or without loss of consciousness" (Wilson, Carlin, & Tyburski, 2002, p. 230). It is unclear whether permanent damage occurs in the brain following a concussion and most people fully recover within a few days to a few weeks. In the spectrum of traumatic brain injury, a concussion is a mild form of mild traumatic brain injury (D. Cassidy, personal communication, March 12, 2003).

Post concussion syndrome is often used to refer to "the array of cognitive, psychosocial and behavioral manifestations associated with the pathophysiological changes involved in with traumatic brain injury" (Fabiano & Daugherty, 1998, p 9). The term post concussion syndrome is also used as a phrase to refer to the many, and varied symptoms that may be present after a concussion. There is a fair amount of controversy and disagreement surrounding post concussion syndrome (Parker, 2001). The main conflict surrounds whether the cause of the symptoms originate from organic or psychological causes (Cooper et al, 2001). Regardless of the cause of the symptoms, the impact of post concussion syndrome can be significant on an individuals functioning, as well as his or her capacity to be physically active. Some of the symptoms are exacerbated with physical activity, which hinder athlete's ability to participate in sport and physical activity. It is important to note that post concussion syndrome can also occur in people who sustain moderate and severe TBI (D. Cassidy, personal communication, March 12, 2003), as well as in individuals with MTBI.

Symptoms of Concussion and Post Concussion Syndrome

Concussion

There are only a few validated symptoms of concussion in the acute stage, however many more anecdotal symptoms have been observed in clinical settings (McCrory & Johnston, 2002). The validated symptoms include amnesia, loss of consciousness, headache, dizziness, blurred vision, attentional deficit, and nausea. Anecdotal symptoms include vacant stare, irritability, emotional lability, impaired coordination and balance, sleep disturbance, noise and light intolerance, lethargy, behavioral disturbance, loss of memory, difficulty concentrating, and altered sense of smell or taste (Maddocks, Dicker & Saling, 1995; McCrory, Ariens & Berkovic, 2000; McCrory & Johnston, 2002). These symptoms usually dissipate within three months however research has shown that symptoms can persist for three, six, twelve months and more (Alves et al., 1993; Ewing et al, 1980; Gronwall & Wrightson, 1974; Parker, 2001; Rutherford et al, 1979).

Post Concussion Syndrome

The symptoms associated with post concussion syndrome can be grouped into five categories: (a) physiological, (b) executive functions, (c) attentional processes, (d) cognitive and (e) psychological (Parker, 2001). Symptoms in the physiological category include disruption in sleep, headaches, imbalance, and fatigue. Difficulties in executive functioning include problems with the capacity for planning and organizing, problem solving skills, mental flexibility, abstract reasoning, initiation, motivation, and regulatory behavior. Attentional process difficulties often permeate all aspects of behavior, often resulting in functional limitations. Cognitive functioning difficulties include attention, concentration, memory, mental speed, and higher level of problem solving. Finally, psychological manifestations that may result include irritability, anxiety, depression, and social and economic morbidity (Fabiano & Daugherty, 1998; Mittenberg & Strauman, 2000; Parker, 200; Stoler & Hill, 1998; Wilson et al., 2002). Some of the symptoms, such as the ones in the psychological category, may develop later as a result of other symptoms, such as difficulty with cognitive functioning.

The combination of many of the symptoms listed above can contribute to a loss of function, forced changes in life style, and loss of the ability to be independent in some or many areas of life. Many of the symptoms are difficult to diagnose because of the subjectivity of the complaint and the inability to objectively prove through current medical tests that the complaint is real. Many health care professionals are not aware or uncertain of the validity of post concussion syndrome and misdiagnose or dismiss the complaints, thus making the individual question themselves and their abilities (Parker, 2001).

There is some disagreement regarding the cause of concussion symptoms. Although there is evidence in the literature that concussion is caused by a trauma to the head or trauma to the body that transfers enough force to the head (McCrory & Johnston, 2002; Parker 2001; Varney & Roberts, 1999), it is uncertain whether the symptoms are due to damage to the brain structures or psychological reactions to the injury.

Rates of MTBI and Concussion

It is difficult to estimate the number of people who sustain a mild traumatic brain injury each year as it is estimated that up to 75% of people do not go to the hospital (Mittenburg & Strauman, 2000). However, the estimated range of new incidents per year in the United Stated of America is from 1.3 million (Malec, 1999) to seven to ten million (Fabiano & Daugherty, 1998). This includes all severities of traumatic brain injuries. Of the people who are hospitalized for traumatic brain injury, 50-75% are considered mild (McAllister, 1994).

The number of sports related concussions are difficult to estimate for a variety of reasons ranging from a lack of awareness of the signs of concussion, to unwillingness to report because of the desire to keep playing, and that many people do not go to the hospital. A study by Thruman, Branche, & Sniezek, (1998) estimates, however, that 20% of all head injuries are sports related. This translates into 306, 000 of all head injuries in the United States at an annual rate of 124 per 100, 000 people. This study reported that 34% did not see a doctor, 55% received outpatient care and 12% were hospitalized. Sports that are considered as high risk for concussion are boxing, football, ice hockey, basketball, rugby, martial arts, horse back riding, gymnastics, soccer and wrestling. Males from 15-34 years old are at the highest risk for concussion (Parker, 2001).

Recovery Suggestions

Most concussion experts agree that athletes should not return to play until asymptomatic both at rest and under physical exertion (Guskiewicz, 2001). It is also widely accepted that in general, concussion symptoms will resolve in time (D. Cassidy, personal communication, March 12, 2003). There have been a number of guidelines set out by experts in concussion research to determine when an athlete is ready to resume playing his or her sport. These include recommendations on how long a player must sit out of play based on the severity of the concussion and the return-to-play protocol. Since there is relatively little known about what actually happens on a molecular level when a concussion occurs, many of the management guidelines and suggestions are based on expert opinions rather than validated scientific evidence (Leclerc, Lassonde, Delaney, Lacriox & Johnston, 2001).

Guidelines suggested by a number of researchers (American Academy of Neurology, 1997; Aubry, 2002; Cantu, 1986; Kelly et al, 1991; Roberts, 1992) are meant be used to determine when an athlete can return to play based on the severity of the concussion. The use of a particular grading system is generally based on personal preference (Guskiewicz, 2001). The guidelines most widely used in sports medicine are those proposed by Cantu and the American Academy of Neurology (Leclerc, et al., 2001). There are generally three grades of concussion: grade one, grade two and grade three. The grade of concussion is based on loss of consciousness and post-traumatic amnesia. The differences in grading systems are in the length of post-traumatic amnesia and loss of consciousness. The recommendations for return to play also vary depending on the authors of the grading systems. Variations are usually in the length of time the athlete sits out and the number of concussions per season (Leclerc, et al., 2001). While these guidelines are generally useful in guiding trainers, coaches and athletes decisions on when an athlete returns to play, they do not address the resumption of physical activity when symptoms persist or in the case of post concussion syndrome.

The suggested treatment for a person who suffered a concussion is to rest until the symptoms dissipate (Aubry, 2002) followed by gradual return to pre-injury activity. If the symptoms worsen then it is a sign that the individual should rest some more. In terms of physical activity, the current return to play guidelines, suggested by the Concussion in Sport Group, are as follows:

The return to play following a concussion follows a stepwise process:

1. No activity, complete rest. Once asymptomatic, proceed to level 2.
2. Light aerobic exercise such as walking or stationary cycling.
3. Sport-specific training (e.g., skating in hockey, running in soccer)
4. Non-contact training drills.
5. Full-contact training after medical clearance.
6. Game play.

> With this stepwise progression, the athlete should continue to proceed to the next level if asymptomatic at the current level. If any post concussion symptoms occur, the patient should drop back to the previous asymptomatic level and try to progress again after 24 hours. (Aubry, 2002, p 62)

This strategy of resting until the symptoms resolve is effective for most people who sustain MTBI, as the vast majority of people will return to pre-injury functioning within a few months, however, there is little treatment available for individuals who experience persistent symptoms for a long period of time. There have been a few studies that have researched treatment approaches for people with post concussion syndrome. A study by Mittenburg and Burton (1994) surveyed members of the National Academy of Neuropsychology and the International Neuropsychological Society to determine what treatment approaches were being suggested for people with post concussion syndrome. The results of the survey showed that recommendations for the management of post concussion syndrome should include (a) education and reassurance about the expected symptoms and support in coping with the reactions to the symptoms, and (b) graded increase in activity, antidepressant medication and cognitive restructuring. The study also suggested that cerebral dysfunction, anxiety and depression were the most likely contributing factors to the persistence of symptoms.

Another study by Mittenburg, Canyock, Condit and Patton (2001), reviewed controlled treatment outcome studies from the past 2 decades from Canada, the Unites States, Great Britain and Scandinavia. Included in the paper is a list of the effective treatments suggested by neuropsychologists for post concussion syndrome. 82.1% of neuropsychologists recommended education about the expected symptoms, followed by support/ reassurance (74.4%), graded increase in activity (56.4%), antidepressant medication (44.9%), cognitive restructuring (44.2), progressive muscle relaxation (29.5%), anti-anxiety medication (25.6%), rest (21.8%), guided imagery (14.1%), and others.

The current suggestions for grading scales and return to play guidelines attempt to tackle the issues and concerns surrounding the resumption of physical activity following a concussion. There are no suggestions for the resumption of physical activity for the small minority of people who remain symptomatic for long periods of time. The treatment approaches suggested in the neuropsychology research do not mention physical activity, however physical activity resumption could fit into the graded return to pre-injury functioning category. There is a need for research that explores the resumption of physical activity in the case of the athlete with post concussion syndrome. Physical activity may play an important role in the recovery of an athlete with post concussion syndrome on a variety of levels from physical fitness to psychological coping and more. Research should also be done to ensure that resuming and continuing physical activity while symptomatic causes no further harm to the athlete.

Emerging Issues in the Study of Post Concussion Syndrome and Athletes

There are a number of issues that emerge from the literature which may be relevant in the recovery of athletes who remain symptomatic for long periods of time. Emotional response to the injury, forced retirement from sport, and temporary disability are three areas that are explored. Within these areas, there are a number of factors that affect the athlete's ability to successfully adjust to the changes created by injury. Issues such as chronicity, severity of injury, and functional ability are all aspects that may be important in the recovery process for people with post concussion syndrome. Prolonged rest may bring upon deconditioning and decreased functional capacity (Wetzel & Rorke, 2001) and the uncertainty of recovery time present unique challenges for the recovery of athletes with post concussion syndrome.

Emotional Response to Sports Related Injuries

Emotional response to injury is inevitable. Many factors play a role in determining the extent and the specific emotional responses to injury. Research has found that injured athletes have higher levels of depression and anxiety, lower self esteem, negative affect, and greater mood disturbance than their non-injured counterparts (McGowan, Pierce, Williams, & Eastman, 1994; Pearson & Jones, 1992). Identifying and understanding the emotional responses that concussed athletes experience are important parts of the recovery process. There is a lack of research focusing on the emotional response to concussion, and even less on the emotional response over time for those with post concussion syndrome.

A study by Johnston and Carroll (1998) studied the situational context and the emotional responses of athletes following a sport injury. They used grounded theory to examine the phenomenon. Sixteen athletes who were seriously injured were interviewed. The athletes participated in rugby, soccer, basketball, football, badminton, and swimming. The level of competition ranged from recreational, university, national and professional. Frustration and depression emerged as strong emotional responses throughout the recovery. The source of the frustration and depression varied over time. In the acute phase of the injury, the source was the disruption in normal function. In the middle phase of the injury, a negative appraisal of the rehabilitation process was the source. Impatience to return to sport was the main source toward the end of the rehabilitation process.

Quackenbush and Crossman (1994) studied the emotional phenomena experienced through four stages of athletic injury. The four stages are initially, the following day, during rehabilitation, and the return to practice. Sixteen men and nine women who experienced an athletic injury and had recovered were surveyed. The findings indicate that the negative responses experienced by the athletes changed over time. Anger, frustration, and discouragement decrease from the onset of the injury to the return to practice. In addition, the positive emotions of hope and optimism increased through the stages.

While general studies focusing on emotional reaction to injury provide some background and insight into recovering from post concussion syndrome, there is one study that focuses specifically on emotional response to concussions. Mainwaring, Bisschop, Green, Antoniazzi, Comper, Kristman, Provvidenza, and Richards (2004) studied the emotional reaction of varsity athletes to sport-related concussion. They compared data from sixteen concussed athletes, 325 non concussed teammates of the injured athletes, and 28 healthy, physically active undergraduate students. A profile of each participant was created using the Profile of Mood States assessment. The study found that pre-injury profiles were similar across groups however the concussed athletes showed a significant increase in levels of depression, confusion and mood disturbance. This subsided within three weeks of the concussion. The athletes in this study were eager to return to play. It is unclear whether the concussed athletes in this study fully recovered or if any experienced post concussion syndrome.

These studies provide some insight into the emotional reaction experienced by injured athletes. These studies do not address chronic injuries or emotions associated with long term disability or retirement from sport. Moreover, while interesting, the study by Mainwaring et al (2004) does not address the emotional reaction of athletes with long term, persistent symptoms of concussion.

Coping with Sport Injury and the Losses Associated with Forced Retirement from Sport

Physical activity and sport play a large role in the lives of many people. Research on the effect of physical activity on health has shown that people benefit from regular exercise both physically and mentally (Kosma, Cardinal & Rintala 2002; Ratey, 2001). Increased exercise has been shown to reduce the risk of heart attacks, hip fractures, diabetes, and lowering weight and blood pressure. It can increase muscle strength, endurance, flexibility, and cardiovascular endurance (Bouchard, Shepard, & Stevens, 1994; Frontera, Dawson & Slovik, 1999; Goldberg & Elliot, 1994). Exercise has also been shown to decrease anxiety and depression, and improve self-esteem, self-confidence and helps create identity (Kosma et al., 2002). Athletes also benefit from the social aspect of being part of a team (Ford & Gordon, 1999). Considering the benefits of physical activity, it important to understand the effect that sudden inability to be physically active can have on athletes. The literature on forced retirement from sport due to injury or de-selection and coping with sport injury sheds some insight into the losses an athlete with post concussion syndrome may experience.

A qualitative study by Ford and Gordon (1999) focused on the responses to rehabilitation, the experienced loss and the assistance required to facilitate the recovery process of athletes who were recovering from a major sport-related injury requiring surgery. There were four participants, including two professional athletes, one athlete at a regional level, and one at a recreational level. The study found that injured athletes experience a decrease in physical health, productivity and sense of achievement. Athletes also experienced financial concerns, loss of identity, lowered self-perception and a change in social roles. The study showed that social support is important in the recovery process. If some, or all, of the above losses can be minimized, the stress associated with being injured can also be minimized.

Fortunato and Marchant (1999) used grounded theory to better understand the experience of elite Australian Football League (AFL) athletes who were forced to retire due to injury or deselection. Loss and grief, perceived loss of control, financial issues, and social support were the four themes that emerged from the data. The study also noted that athletes who had support from outside of their sport, such as family and non-sport related friends, had an easier transition. This study found that the forced retirement experiences of the AFL athletes are consistent with the theory of loss and grief associated with death and dying developed by Kubler- Ross (1969). The model has five stages of progression that a dying person goes through in order to accept death. The five stages are: (a) denial, (b) anger, (c) bargaining, (d) depression, and (e) acceptance. The athletes related experiencing a sense of loss and grief for lost dreams, a lack of control over feelings of grief, and denial. Anger was also expressed.

Webb and Nasco (1998) studied the relationships between athletic identity, psychological adjustment to retirement, and the reason for retirement. There were two main assumptions on which this research was based; the strength of one's athletic identity and the circumstances of the retirement. The findings indicate that the relationship between athletic identity and retirement difficulty was stronger for injury related retirement, and athletic identity was related to a sense of vagueness regarding the future. There are two reasons for this. Since injuries are unexpected, there is usually no psychological preparation for retirement, as would occur when the retirement was chosen. Second, an athlete often goes thorough a period of rehabilitation attempting to return to play. The realization that the injury is career ending is often not immediate and the athlete must switch from the mindset of returning to play to one of retirement.

The athletes in this study who felt that they had little control over the events in their life reported diminished life satisfaction, increased vagueness and uncertainty about the future, and had a more difficult time with retirement. Sense of control over life's events was related to the context of retirement. The two major conclusions of this research are that athletic identity is an important variable in explaining athletic retirement and the reason for retirement matters.

Along with the physical symptoms of post concussion syndrome, there are a number of psychosocial and psychological symptoms that may arise (Parker, 2001). The loss of sport, unknown length of time sitting out of sport and physical activity, and possibly forced retirement may contribute to athletes' ability to adjust to the injury. These issues are important to address with this population in relation to the recovery process.

Coping with Temporary Disability and Post Concussion Syndrome

The loss of physical activity from the life of someone who is physically active can be tough and there are often many other aspects of life that are affected. Due to the symptoms, there can be functional loss in performing activities of daily life (Stoler & Hill, 1998). These losses are often subtle but enough to disrupt daily functioning. Thus, it is useful to examine literature on adjustment to disability and the recovery process, especially considered that there are currently no methods to estimate the length of time that symptoms might last, or whether there will be permanent damage due to the concussion or MTBI. The disability and loss of function that an individual may experience may last a few months or many years.

Hutchinson, Loy, Kleiber, and Dattilo (2003) studied how individuals used leisure as a coping resource for traumatic injury and the onset of a chronic illness. Qualitative data from two studies were used, one with individuals who sustained a spinal cord injury and the second involving people with chronic illness. The findings suggest that leisure was a buffer from the immediate stressors, was a mental distraction, provided escape from the confines of home or the hospital, was a source of motivation to sustain coping efforts, provided structure and a sense of purpose, provided a sense of belonging and acceptance, offered hope and optimism, maintained physical and mental health, and lastly preserved a sense of competence, independence and continuity of self.

A special article review by Bishop (2001) examined the recovery process and chronic illness and disability. While Bishop explores many points in regards to the topic, there are a number that are of relevance to individuals with post concussion syndrome. First, the term chronicity is defined as "the expectation that the condition is not curable, and that the presence of the condition is expected to be either long-term or permanent" (Bishop, 2001, p. 47). This is particularly relevant to post concussion syndrome and MTBI as it is often unknown whether the symptoms and deficits experienced will be permanent or how long these might last. Also noted is that an important part of adjusting and adapting to the disability is dealing with the emotional response to the chronicity or permanence of the disability. This may be particularity difficult in the case of individuals with post concussion syndrome.

Recovery is another important term to examine. It can be described:

> ...as a deeply personal process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the effects of disability or illness" (Bishop, 2001, p. 48).

Five assumptions of the recovery process are outlined, the first being that professional intervention is not necessary for recovery to occur. The second assumption is that support, belief and encouragement are all important factors in the recovery process of the injured person. Third, recovery can occur even though symptoms reoccur. Fourth, recovery is not dependent on the resolution of symptoms. There can still be recovery despite symptoms that are still present or reoccurring. The final assumption is that "the recovery from the consequences of a chronic illness or disability is sometimes more difficult than recovery from the illness or disability itself" (Bishop, 2001, p. 49).

A study by Tate and Broe (1999) focused on the important variables in psychosocial adjustment after a traumatic brain injury. A number of biographical, injury, impairment and psychological variables that were thought to influence psychosocial adjustment were explored in relation to severe traumatic brain injured people. It was found that the predictors of psychosocial adjustment were severity of injury and impairments, chronicity, and self-esteem.

Kendall and Buys (1998) explored the idea that adjustment to acquired disability does not follow a linear path, although there is a progression towards adjustment. They suggest that adjustment is a reoccurring process that is cyclical. Each new environment or challenge faced by the individual requires a development of a new schema to fit the new challenge, opportunity or environment experienced in life. The development of schemas is often guided by the (a) search for meaning in disability, (b) need for control over the disability and the environment, and (c) the need to protect and explore the post-disability identity.

Nochi (2000) used grounded theory to reconstruct self-narratives in coping with traumatic brain injury. In-depth interviews and observations were used. This study was part of a larger study that examined the subjective experiences that people with TBI encounter in relation to their TBI. Five self-narratives were discovered: (a) the recovering self, (b) the self living here and now, (c) the self better than others, (d) the grown self, and (e) the protesting self. Participants often compared their situation to ones that were worse. This can be characterized as the "better than others" category. Often, the TBI led to some positive growth. This is called the "grown self". With the "recovering self", participants viewed themselves as on the way to their pre-injury selves. The "self living in the here and now" category captured the one day at a time mindset where the participants attempt to restore feelings of self worth without the comparison to others or their pre-injury self. The "protesting self" refers to how people with TBI should interact with the world, based on certain images of the world, and on the stipulations and circumstances of TBI.

Nochi (2000) suggests that the above self-narratives fit into two categories. The "recovering self", the "self living here and now", and the "better than others" self-narratives fall into the first category, "in spite of TBI-related changes". This category is focused on how the relationship with TBI is conceptualized. The "grown self" and the "protesting self "are placed in the "because of TBI-related changes" category. This category focuses on the aspects of self represented in the narratives. These narratives and categories are important as they represent coping strategies associated with TBI that have been devised by individuals who sustained TBI. While these narratives do not focus on athletes or the resumption of physical activity, they do provide insight into the conceptualization of self after TBI. Athlete identity, recreating of self following forced retirement, adjustment to disability, and coping strategies of athletes all fit into this overall framework on some level.

Social Support, Sport, Injury and Post Concussion Syndrome

Social support may be another important component in the recovery of athletes with post concussion syndrome. Some studies have explored social support and injured athletes, as well as social support and disability. Post concussion syndrome is a unique case as it is often unknown when and if the symptoms will dissipate and whether the athlete will return to pre-injury levels of functioning. It is, perhaps, both an injury and a disability, albeit most likely temporary. With this in mind, it is important to examine a few of the studies that focus on social support. Mittenburg et al. (2001) published a paper on the treatment of post concussion syndrome following mild head injury. The results indicated that when patients were provided with an education package about concussion, what to expect during recovery, and some suggestions for resumption of daily activities, they recovered faster and had fewer symptoms than those received no education package. This is one form of support that seems to have an effect on the recovery of people with post concussion syndrome. Perhaps other forms of support might also help in eliciting a positive and faster recovery.

A study by Robbins and Rosenfeld (2001) looked at the athletes' perceptions of social support pre-injury and during rehabilitation provided by head coaches, assistant coaches and athletic trainers. Thirty-five male and female division one collegiate athletes participated in the study. Six types of support were examined: listening support, task appreciation support, task challenge support, emotional support, emotional challenge support, and reality support. The findings indicate that the athletes perceived that athletic trainers gave the most support and that the support given by the athletic trainers positively impacted the recovery of the injured athletes.

Udry (2002) interviewed 50 athletes recovering from ACL- reconstructions. Four types of social support emerged from the interviews: (1) esteem/ emotional, (2) informational, (3) tangible, and (4) motivational. The type of social support that was relevant to each athlete depended on the stressors that were occurring in their lives and recovery process. Problems occur when there is a mismatch between the needed support and the type of support given. Other important factors were the timing and the amount of support given. Thus, in providing optimum support it is important to match to type needed by the athlete, with the amount, which is given at the right time.

Another study by Natterlund and Ahlstrom (1999) looked at the experience of social support in rehabilitation using phenomenology. Thirty-seven people with muscular dystrophy were interviewed. Nine themes emerged: (1) psychosocial support, (2) meeting other people with muscular dystrophy, (3) knowledge and learning, (4) adjustment in daily life, (5) coping with illiness-related problems, (6) adjustment at work, (7) management of physical disability, (8) medical examination and treatment, and (9) involvement of relatives. It was also found that the support received was beneficial and access to recurrent rehabilitation should be given to people with muscular dystrophy.

Common to all the above studies was the benefit of social support in the recovery or rehabilitation from injury or illness. The emerging themes may differ but it is evident that social support is beneficial when it covers all aspects of the individual's life, including the physical, psychological, and emotional realms. Education, knowledge and learning also seem to be important in the recovery process. All of these aspects relate to the recovery of those with post concussion syndrome. Social support could be an important factor in the recovery of athletes with post concussion syndrome especially given the uncertainty regarding the recovery time and long-term deficits.

While the literature on coping with temporary disability, forced retirement from sport, and social support provide insight, the literature does not touch on the role of physical activity and exercise in the recovery of people with post concussion syndrome. This may be an important part in a successful recovery, as well as an important factor in the coping strategy of an athlete who finds him or herself dealing with a career ending or life altering MTBI. There are certainly a number of unanswered questions and the past research in this area is sparse.

Post Concussion Syndrome, Exercise and Physical Activity

There are no studies that focus on incorporating physical activity into the recovery/ rehabilitation process of people who have post concussion syndrome resulting from MTBI (M. W. Collins, personal communication, March 9, 2003). The current return to play guidelines are based on the person being completely asymptomatic before resuming physical activity, however in the case of symptoms that persist for months or years, the resumption of some physical activity may be beneficial.

There have been a small number of studies that have looked at physical activity and rehabilitation programs for severe TBI. It is beneficial to look at these studies, however many of the challenges and problems that a person with severe TBI faces in rehabilitation are different than those with post concussion syndrome and MTBI. It is presently unknown what role of physical activity plays in the recovery process of those with post concussion syndrome.

Severe Traumatic Brain Injury, Exercise and Physical Activity

There are a few studies that have focused on how exercise can be used as part of the rehabilitation of people with severe TBI. Sullivan, Richer and St. Laurent (1990) looked at the effect of including regular physical activity as part of a rehabilitation program for individuals who sustained severe TBI. The type of physical activity ranged from activity with aid from others to jogging/running depending on the functional ability of the TBI patients. This study found that patients had reduced fatigue, increased self-confidence and self-satisfaction, as well as increased work capacity, and patients were better able to carry out activities of daily living.

A few researchers have studied the effect of aerobic training on people with severe TBI. Wolman, Cornall, Fulcher and Greenwood (1994) looked at the effect of aerobic training in brain-injured patients. The study found that aerobic training reduced fatigue and had a beneficial effect on lessening depression. Another study by Bateman, Culpan, Pickering, Powell, Scott and Greenwood (2001) looked at the effect of aerobic training on severe brain injured people. The study had two groups, one that participated in an aerobic exercise program and the other that participated in a relaxation training program. The findings suggest that fitness training did not enhance functional independence, however did improved physical fitness. The group that participated in relaxation training was found to have decreased anxiety, improved activities of daily living skills, and improved functional independence.

Grealy, Johnson and Rushton (1999) looked at the role of virtual reality in addition to exercise in the cognitive rehabilitation of people with TBI. The participants exercised on a cycle ergometer that was linked to a virtual reality system. During exercise, the participants had to interact with the virtual environment. The study found an increase in auditory and visual learning, however not in the ability to memorize or organize. The use of virtual reality allows for external stimulus to be controlled thus reducing the stimulus overload on the brain.

Mild Traumatic Brain Injury, Exercise and Physical Activity

There is little research that addresses the role of physical activity and exercise in the recovery process of people who sustain MTBI and for those with persistent symptoms. Guidelines in the sport literature that discuss return to play protocol for athletes who sustain concussion are helpful in providing a framework for when concussed athletes can resume physical activity. These guidelines do not, however, address when or how physical activity can be integrated into the recovery / rehabilitation process of athletes with persistent symptoms.

Swaine & Friedman (2001) suggest activity restrictions for children who were discharged from the hospital based on the grade/ severity of concussion. These restrictions include physical activity, return to school, movies, video games and other daily activities. The recommended activity restriction time for a grade one concussion is one week, two weeks for grade two, and four weeks for a grade three concussion. The recommendations also suggest that the child should be asymptomatic for at least one week before the resumption of full activities. These recommendations are largely based on expert opinion rather than scientific evidence.

Wetzel & Rorke (2001) reviewed the case for including physical activity as a component of a rehabilitation program for people with MTBI. While this review is largely based on research done on people with moderate and severe TBI it alludes to some of the unique issues and problems associated with MTBI and physical activity. Physiological benefits of physical activity include increased aerobic capacity and resistance to fatigue, improved physical fitness, improved motor performance, a reduction of symptoms, and improved sleep. Psychological benefits include improved mental state, less depression, improved cognitive functioning, improved perception of health, increase in motivation, more self-confidence, and better quality of life. It is suggested that exercise commence once the initial cluster of symptoms are resolved or lessened and that the frequency, duration, and intensity increases only if there are no complications or reoccurrence of symptoms.

There are a few risks associated with being physically active before the resolution of symptoms including the reoccurrence and aggravation of symptoms, and re-injury. It has been clinically observed that symptoms are often aggravated with altitude, atmospheric pressure, high ambient temperature, and physiologic stress (McCrory & Johnston, 2002).

Considering all the unknown factors and uncertainty with respect to people with post concussion syndrome resuming physical activity, it is difficult to identify all the possible variables and there are very few studies that have attempted to identify these factors. It is important then, the gain a better understanding of the factors associated with the role of physical activity in the process of recovery from post concussion syndrome so that better care and support can be provided. The logical first step in the research of physical activity and post concussion syndrome is identification of the factors and to explore the experiences of athletes who have recovered or are recovering from post concussion syndrome.

Summary

This literature review examined the definitions and symptoms of MTBI, concussion, and post concussion syndrome. The rates of MTBI were presented, as well as current recovery suggestions. The literature on coping with forced retirement from sport, coping with temporary disability, as well as post concussion syndrome, exercise and physical activity was explored.

Research in the area of concussion, post concussion syndrome and MTBI is often sparse and conflicting. There is very little research that focuses on the treatment for and the recovery of people who have persistent symptoms from concussion and MTBI. There is even less literature on the role of physical activity in the recovery process of athletes with post concussion syndrome. A better understanding of the role of physical activity in the recovery process will provide valuable information for athletes with post concussion syndrome, coaches, rehabilitation professionals and others who work with this population.

CHAPTER THREE: METHODOLOGY

This chapter outlines and describes the theoretical framework, the participants, recruitment procedures, data collection procedures, data analysis, and the evolution of the study. A discussion on trustworthiness and credibility is also included. This research uses qualitative methodology to explore the role of physical activity in the recovery process of athletes with post concussion syndrome. This research was based in symbolic interactionism primarily because of the lack of existing research focusing on the resumption of physical activity while athletes have post concussion syndrome. The role of physical activity in the recovery process of an athlete with post concussion syndrome is currently not well understood.

Evolution of the Study

As with many studies, this study has evolved over time. This evolution provides insight into the field of researching concussion and post concussion syndrome. This research project began with the idea of building a theory on the role physical activity in the recovery process of amateur and recreational athletes with post concussion syndrome. Because of difficulties in finding suitable volunteers for the study, it has evolved over time. The details of this evolution are outlined in this section.

Through a thorough literature search, informal discussions with people, and personal experience, it became evident that there was very little information available for people who have lingering symptoms of concussion, or post concussion syndrome. While this is important, there was even less information about returning to physical activity while symptomatic. There seemed to be a big gap in the information and literature when it came to what to do with people who have post concussion syndrome with regards to physical activity. More over, it became clear that there were no research studies or information that looked at what people with post concussion syndrome were actually doing, if they were participating in physical activity, if they were following the advice of their health care professionals, and what information they were given about post concussion syndrome.

These questions shaped the study. In order to gain a fuller understanding of this experience, a study that focused on the role of physical activity in the recovery process of athletes with post concussion syndrome was planned. The study was based on grounded theory, which is "a qualitative research methodology that uses a systematic set of procedures to develop an inductively derived grounded theory of a phenomenon" (Strauss & Corbin, 1990, p. 24). Essentially, grounded theory, allows the researcher to collect data from a number of different areas related to the phenomenon being studied, in this case the recovery of athletes with post concussion syndrome and physical activity, and form a theory about that phenomenon derived from the data itself (Strauss & Corbin, 1990).

Using the grounded theory framework, three main groups of people related to athletes with post concussion syndrome were chosen; physicians who treat or consult people with post concussion syndrome, rehabilitation practionners who treat or consult with people with post concussion syndrome, and the athletes who had been diagnosed with post concussion syndrome. The idea was to interview 5-7 people in each of these groups to gain a better understanding of issues such as: (a) how long does someone with post concussion syndrome wait to resume physical activity?, (b) what kind of physical activity can they do?, (c) what are the recommendations given to people with post concussion syndrome regarding recovery?, (d) what role does physical activity play in the recovery of athletes with post concussion syndrome?, (e) what are athletes doing in terms of physical activity?, and (f) what are the experiences of athletes with post concussion syndrome? The physician group was chosen to represent the acute phase of the injury. The rehabilitation practionners were chosen to gain a better understanding of what is occurring when the athlete reaches the chronic phase of the recovery, and because rehabilitation practionners often have more contact with injured athletes. The athletes with post concussion syndrome were chosen in order to gain a better understanding of the personal experiences of living with post concussion syndrome and their recovery process. The interviews were estimated to be about one hour long.

While it was clear that finding people with post concussion syndrome would be difficult, it proved to be much more difficult than anyone had originally thought.

Recruitment for participants was done through a number of avenues including contacting individual physicians who treat people with post concussion syndrome, sending out the study information through the Physiotherapy and Occupational Therapy Associations in Alberta, visiting 15 physiotherapy and wellness centres in person, contacting sports medicine clinics in Alberta, contacting the Sports Medicine Council of Alberta, as well as numerous sporting associations in Alberta. Posters were also put up at the University of Alberta, and the study was posted on a number of sporting websites. Despite this, there was no response.

After a number of months of waiting for volunteers to respond and some discussion, the study was modified. The interviews with the physicians and health care professionals were dropped. This was done because there seemed to be some resistance to volunteer from these groups. Although it is unclear as to the reasons for the lack of response, it has been hypothesized that lack of time, unwillingness to share the knowledge, and confidentially issues may have been factors.

The interviews with the athletes became the main source of data and the number of participants was changed from 5-7 to10-12. While most of the criteria remained the same, the recruitment posters were modified to read "individuals who are physically active" from "amateur and recreational athletes". The most substantive change that was made was requiring only a diagnosis of concussion, not post concussion syndrome. This was an important change because if the injured person went to the hospital and was diagnosed with concussion they were now eligible for the study, versus having to be seen by a specialist to be diagnosed with post concussion syndrome.

All the while, the underlying ideas and questions driving the research remained the same. Digging deeper into the experiences of the athletes with post concussion syndrome about many of the issues previously discussed provides an important snapshot into the experiences of recovering from concussion and the information for recovery that concussed athletes receive. It also provides a better understanding of areas in which more research is needed. Thus, the evolution of the study, in particular the failures and road blocks, provide insight into the current phenomenon of athletes returning to physical activity while symptomatic and the effects on their lives.

Theoretical Framework

A Qualitative Study Based on Symbolic Interactionism

Given all of the changes since the inception of this study, grounded theory seemed to no longer be the most appropriate theoretical framework in which to fully explore the experiences of athletes with post concussion syndrome. The notion of symbols, context, environments and interactions associated with the experiences of recovering from post concussion syndrome is forefront in the shared stories of the participants. Thus, symbolic interactionism emerged as a well-suited framework in which to gain a fuller understanding of this phenomenon.

Symbolic interactionism is tied closely to pragmatism. Hewitt (2003) states that "pragmatism is a predominately American school of philosophy that views human beings, like all living things, as problem solving creatures who create knowledge as they seek to live in the world" (p. 32). There are a number of important consequences that stem from this line of thinking. The first, there are many obstacles and opportunities that are present for the people who live with in that environment. The second, human beings and animals must learn how to adapt to the environment. Active, goal oriented and knowledge seeking qualities are important for this learning process. Third, the truth is constructed, not absolute. The truth is not a fixed entity or end point; rather it is ever changing depending on the current time, events and environment (Hewitt, 2003).

Philosophers such as George Herbert Mead and Herbert Blumer were two of the philosophers who contributed to the development of symbolic interactionism, building on pragmatism. Much of their work was done in the first half of the twentieth century. Over the years, there have been a number of versions and thoughts stemming from their early writings, however there are a few general principles that remain consistent, which are outlined by Hewitt (2003).

First, as human beings, our behavior shows a good deal of regularity, otherwise known as socially structured behavior. The social processes are important in gaining a full and complete understanding of the patterns and regularities of human behavior. Second, meaning is something that is dictated by how human beings react and interpret the situation. “Meaning” is an important concept to consider here. People’s actions are planned and purposeful, striving towards a goal. How we conduct ourselves is meaningful because we have a purpose to our actions. Meanings are not fixed and inflexible. Situations, past experiences, current cultural and physical environments shape meaning for people. What is meaningful in America may not be meaningful in Zambia. Third, human beings see themselves as both an object and an acting subject in life experiences. The concept of self is important in that it is both internal and external interactions, which help one to define their own concept of self. Fourth, conduct is formed as situations unfold and begin with plans and purposes. People will then take into account themselves and interact with others. What is important to consider is that it is problematic situations that force people to interpret meanings, not the everyday mundane events. Fifth, it is people interacting with people that create a society. Culture is the environment in which we live, where meaning is constantly changing and evolving.

It is interesting to relate these principles to athletes with post concussion syndrome. The second principle that meaning is something that is directed by how human beings react and interpret the situation is especially relevant to those with post concussion syndrome. The pre-injury meanings of life and existence for an individual with post concussion syndrome may no longer apply since the injury caused a drastic change in life. This means that an individual’s ability to function and their relationship to their environment may change quite suddenly. Thus, they are forced to create new meanings. The participants in this study created new meanings through purposeful and planned actions, such as being physically active despite the symptoms and their health care practionners’ advice. Meanings were not fixed and changed over time. This was especially evident as the athlete progressed through the recovery process.

Hewitt (2003) suggested that situations, past experiences, current cultural and physical environments shape meaning for people. Through athletes’ participation in sport and sporting culture before the concussion, meanings were created. To a certain extent, these old meanings remained, as seen by attitudes towards concussion in various sports such as rugby, football and soccer. But the current cultural and physical environments also shaped meaning for the athletes. Interactions with health care practionners shaped the athletes meaning of being concussed. More information about the consequences of returning to play shaped new meaning about the value of participation in high risk contact sport.

Another interesting principle to consider is that it is problematic situations that force people to interpret meanings, not the everyday mundane events. Post concussion syndrome can be viewed as a problematic situation. Actions such as coping were often planned and purposeful with the athlete striving towards the goal of recovery. Meaning was derived from planned and purposeful actions. Finally, the idea that culture is the environment in which we live where meaning is constantly changing and evolving was very relevant to the athletes in this study. It appeared that the meaning of being concussed, having post concussion syndrome and the meaning of the life changes that athletes experienced were influenced by a number of factors in their surrounding culture. These factors included whether the athlete was in university or working, his or her family life, the support system, the health care practionner each athlete visited, and his or her ability to function within their physical environment.

On a broader scale, it seems that there has recently been a shift in the thinking related to concussion and post concussion syndrome in the sporting world. This may be partly due to increased awareness of concussion and the consequences of playing while still experiencing symptoms of concussion. But the long-terms effects and the lived experiences of people who are affected have yet to be explored. Symbolic interactionism offers a framework in which not only to explore the changes that take place when suffering from post concussion syndrome, whether temporary or permanent, but also helps to better understand the wider culture and environment associated with this phenomenon.

Sampling Methods

Since this study was exploratory in nature, a snowball sampling method was used. In order to gain a better understanding of the recovery of athletes with post concussion syndrome, it was important to have a wide range of people in the sample. This was to ensure that the data collection was not too narrow and represented the wider environment and culture.

The initial data collection was based on the researcher's personal experience, and on the existing literature. While there are currently few studies that focus directly on the experience of athletes with post concussion syndrome and physical activity, there are a number of other areas of research that can be drawn upon for background knowledge. The literature review examined these in-depth however it is worth mentioning some of the most pertinent topics in the literature. First, it has been suggested by a number of experts in the field of concussion and MTBI that the injured person should have no symptoms associated with concussion and MTBI before resuming physical activity (Guskiewicz, 2001). Second, the symptoms from MTBI and post concussion syndrome can last weeks, months, years, or never completely dissipate (Fabiano & Daugherty, 1998). Third, it is often unknown whether the individual will be symptom free and if the deficits experienced will be permanent. The literature on recovery from moderate to severe injury or illness suggests that the person develops new meaning and purpose in life based on the limitations or permanent effects of the illness or injury. (Bishop, 2001). This is often a process that takes place over time and is not limited to brain injury. It is unknown whether this is relevant for individuals with post concussion syndrome; however it is an interesting concept to consider for this population. Fourth, forced retirement from sport due to injury can create a sense of loss and affect a number of aspects of an individual's life (Ford & Gordon, 1999; Fortunato & Marchant, 1999). Finally, physical activity has been found to be beneficial in the rehabilitation of people with severe brain injury (Bateman et al, 2001; Sullivan et al, 1990; Wolman et al., 1994), but the effect of physical activity on those with MTBI and post concussion syndrome are unknown.

Participants

In order to gain a more comprehensive understanding of the role of physical activity in the recovery process of people with post concussion syndrome, athletes who fit the following criteria were interviewed: (a) between the ages of 18-39, (b) sustained a concussion within the 2 last years, (c) have been seen by a physician and been diagnosed with a concussion, (d) have at least three symptoms from the DSM IV definition of post concussion syndrome for at least 3 months, (e) Prior to the concussion, the person was physically active in organized sport at least two times per week and would like to resume or has resumed physical activity, and (h) fluent in English. Physical activity is defined in chapter one. Interviewing athletes who have post concussion syndrome provided insight into the experience of recovery and the role of physical activity in their lives and the recovery process.

In addition to the participant interviews, I was also included in this study as a research subject. During the first three years of my recovery process, I kept a journal. The journal focused on issues specific to recovery from post concussion syndrome and physical activity. The journal was not written with research in mind.

The difficulty in finding participants, as well as limiting the number of athletes to seven has some implications for the study outcome. The experiences may not represent the experiences of the general concussed population because of the low number of participants and their varied backgrounds. Having said this, the participants in this study represented many different geographical locations in Canada and a few in the United Stated of America. Thus, while the data was from only six individuals and my journal, the data spans many geographical regions.

Because of the low number of athletes, a complete understanding of the experience of recovery cannot be gained. This was because the participants had not progressed equally through the recovery process and thus could not comment on experiences they had not yet experienced. In addition, the participants had varying level of symptoms and recovery times. This created a lack of consistency.

Recruitment Procedures

Since the aim of this study was primarily exploratory in nature, a targeted approach to participant recruitment was appropriate in order to gain a broad yet in-depth picture of the experience of recovering from post concussion syndrome. The participants were required to meet the stated criteria to be eligible for the study.

Eligibility was verified by the researcher by phone before an interview date was set up. Participants identified themselves as having been diagnosed with concussion. No follow up with physicians was done to verify this information.

Recruiting was a difficult process that elicited few responses. A number of different methods of recruitment were used. Posters (appendix A) were placed in various places where athletes with post concussion syndrome were thought to frequent. This included a number of buildings at the University of Alberta. Letters (appendix B) were sent to or personally dropped off at clinics that treat people with MTBI and post concussion syndrome, to selected physiotherapy offices, and to sports teams explaining the study and inviting people to volunteer. An e-mail message explaining the study and calling for volunteers was put on a number of list serves (appendix C) was sent out to rehabilitation professionals, such as occupational therapists, physiotherapists, and athletic therapists. Physicians or rehabilitation practionners were also asked to inform clients who fit the criteria about the study and the opportunity to participate. The e-mail list serve message was also sent out to specific sporting organizations, teams and coaches in the Edmonton and Calgary area. The total number of organizations, teams, and coaches contacted was 72. Many of the people contacted forwarded the information on to people they knew. Alberta Football was also contacted to gain permission to contact football teams and to provide support for the study. Alberta Football supported the study and three teams were contacted. Advertisements were places on various websites including the Sport Medicine Council of Alberta, and the Northern Alberta Female Hockey Association. The Alberta Physical Therapy Association and the Alberta Association of Registered Occupational Therapists forwarded the study information to all of their members. Interested volunteers contacted the researcher by phone or e-mail and the eligibility criteria were verified at the time of contact. One participant volunteered for the study after attending my presentation at the Annual Brain Injury Association of Minnesota Conference.

Procedures

Data Collection

Consent for the study was obtained before the Mini Mental State Examination and interview took place. The researcher presented an information letter (appendix D) and asked the participant to read it. A verbal explanation of the content of the information letter was also provided. Both the researcher and participant initialed the letter. The researcher and the participant also signed a consent form (appendix E) at that time. There were two copies of the information letter and the consent form for each subject, one for the research project files and one for the participant to keep.

The Mini Mental State Examination (appendix F) was administered to identify whether the athlete needed follow up care (Folstein, Folstein & McHugh, 1975). If the score on the mini mental state examination was 24 or more, the interview commenced. If any of the participants had scored less than 24, they would have been withdrawn from the study and referred to their physician. None of the participants received a score lower than 24. If a participant had scored lower than 24, care would have been taken in explaining the reason for withdrawal from the study, ensuring that appropriate sensitivity and support was given at the time.

Data was collected using semi-structured interviews. All participants participated in one interview which was approximately one hour in length. The interviews were conducted in an atmosphere that was comfortable for the participant, which was either in the participant's home, in a conference room in the University of Alberta, or in other similar settings.

Before the interview began, the participant was fully informed of the study's purpose, the voluntary aspect of the study, and reminded that all of the answers are confidential. The interviews were taped, transcribed and kept in a Microsoft Word file. The data was kept in a locked cabinet. The information will be destroyed after a period of at least five years after the study is completed.

The researcher began with a list of questions (see appendices G) that acted as a guide throughout the interview. Using semi-structured interviews allowed for the flexibility to explore interesting topics brought up by the participant that provided further insight into their recovery experience. The list of open-ended questions was based on the researcher's personal experience from recovering from post concussion syndrome, the literature, insights of physicians and rehabilitation practionners, and interactions with other people who have had post concussion syndrome. The list of questions changed over time depending on the participant's background and based on issues raised during other participant interviews.

Shortly after the interviews, each participant was sent a copy of their transcript for verification. All of the participants responded and made slight changes to their transcripts, mostly in spelling of names and order of events. Once the data was analyzed and the findings and discussion chapters were written, each participant was sent a summary of the research (appendix H). They were asked to comment on the findings. Of the six participants, four were successfully contacted. The remaining two had e-mail addresses that were no longer valid.

Data Analysis

The data analysis was grounded in the theoretical perspective of symbolic interactionism. Symbolic interactionism ultimately attempts to determine how people define their world and how that definition shapes their action. Given the changes the athletes in this study experience as a result of their concussion and subsequent post concussion syndrome, symbolic interactionism provides an excellent methodology in which to explore the role of physical activity in the recovery process of athletes with post concussion syndrome. The athletes in this study were attempting to define their world within the context of suffering from post concussion syndrome. They were also attempting to define themselves in relation to physical activity, or their inability to be physically active. Athletes were attempting to understand the chronicity of their condition and their concept of self within this context. Interestingly, it appeared that the athletes were attempting to find meaning in the intricate interrelationships between themselves, those around them, and their role in their environment. It was my job to ensure that I remained open, willing and able to adequately interpret those symbols and meanings.

One of the central notions of symbolic interactionism is that of putting oneself in the place of others (Crotty, 1998). This is supported by Psathas (1973) who explained that "the situation must be seen as the actor sees it, the meanings of objects and acts must be determined in terms of the actor's meanings, and the organization of a course of action must be understood as the actor organizes it. The role of the actor in the situation would have to be taken by the observer in order to see the social world from his perspective" (p. 6).

This notion was one that I strove to achieve throughout the analysis. In one sense, having experienced post concussion syndrome, I have a unique understanding of the situation. If not careful, this personal experience may have clouded my ability to interpret the meaning the other participants placed on the experience of recovery and the role of physical activity in their recovery process. Being aware of this helped me to stay focused on the data alone, and not on the recovery issues I was experiencing during the duration of the research project. My memory loss also helped me to focus only on the data at hand. When I felt I was becoming overwhelmed by the data, I would put it aside for a few weeks. By the time I re-examined the data, I had forgotten enough to ensure that I was looking at and examining the data with fresh eyes. The last aspect that worked in my favor in terms of ensuring the data was unbiased during collection was that my journal was written before I was ever thought about entering graduate school or this research project. By the time I analyzed the journal, I had no emotional memories associated with the events described, nor was I aware of the contents.

Attempting to see the situation from the point of view of the actor was a guiding factor in my analysis. In order to ensure that this occurred, I was constantly revisiting my research questions. In addition, my experience of being brain injured helped to determine meaning that was relevant to me. In doing this, I then searched for key words or phrases in the participant transcripts to find similar meaning or variations in the meaning of the concepts and categories that emerged from the data. This process was also reversed, searching for meaning in the participant transcripts and then verifying this in the data from my journal.

The systematic procedures for analyzing the data were borrowed from grounded theory, which was influenced by symbolic interactionism. Grounded theory is a research methodology that is used to develop theory based on and through the data itself. This is done through a series of specific and carefully planned steps (Crotty, 1998).

The interviews were recorded, transcribed and then analyzed manually. The journal was photocopied and then analyzed. Analysis began by coding the data. There were three types of coding involved in the data analysis: (a) open coding, (b) axial coding, and (c) selective coding. Coding generally took place at the end of the data collection process because all the interviews were done in a short time frame. In open coding, phenomena were named and categorized. These phenomena were labeled and then called concepts, and were logical to the researcher. The development of the concept's properties was based on the characteristics of the phenomenon. Physical symptoms, medical related, emotional/ mental, physical activity, healing, recovery, and self were the concepts that emerged during open coding. Within each concept, categories emerged and specific codes were assigned to the different aspects of each concept and category. An example of some of the codes that emerged for "Physical Symptoms: Acute Symptoms" are as follows:

1. ASYM: Acute Symptom
2. ASYME: Acute Symptom energy
3. ASYMF: Acute Symptoms Fatigue
4. ASYMH: Acute Symptom Headache

Following the assignment of codes, the quotes were grouped according to the codes in a separate document. This was done in order to better identify emerging themes within each category and subcategory. A detailed description of the concept was then written to summarize the concept and outline the characteristics of the phenomena.

Axial coding further develops categories, making new connections between the categories and the subcategories. Conditions and context of the categories were important to explore and develop through axial coding. The relationships between the categories and sub categories were formed during axial coding. Figure one is an example of the relationship between categories and subcategories for "Physical

Symptoms". This was done for all of the main categories for both the participant interviews and the journal.

In selective coding, a few core categories were selected to which the other categories are connected. "Connections are solidified using a combination of inductive and deductive thinking, in which the researcher moves between asking questions, generating hypothesis and making comparisons" (Strauss & Corbin, 1990, p. 130). Constant comparison of the data took place as the analyzing progressed over time. This was to ensure continuity and completeness of thoughts and emerging concepts throughout the entire data set over time, as well as verification of data against data. During selective coding, the data was further analyzed by comparing the diagrams, such as the one presented in figure 1, generated during the axial coding stage from participant interviews to the ones that emerged from the journal. From this comparison, the model titled "The recovery process of athletes with post concussion syndrome" presented in figure 5 (also see Appendix H) emerged.

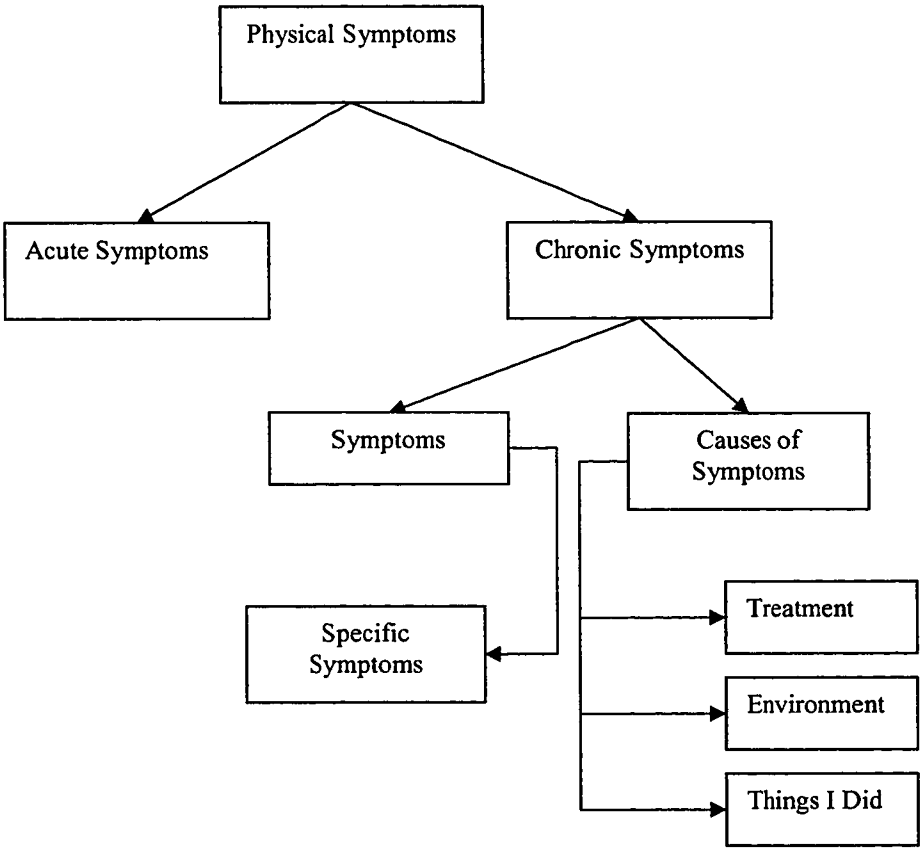


Figure 1: *Relationship between categories and subcategories in axial coding.*

In grounded theory, coding and analysis all takes place simultaneously throughout the research process, ending when the categories are saturated (Glasser & Strauss, 1967). Saturation occurs when no new concepts are being found and nothing more is being added to the concepts. For this study, data collection ended after six participants had been interviewed and the recruitment options had been exhausted. Theoretical saturation did not occur. Data analysis results in the creation of categories and concepts, which were then linked to each other, and eventually organized.

Coding and analysis of my journal also occurred. The journal was written over three years and focused on my attempt to return to my pre-injury level of participation in physical activity and sport. It chronicles the symptoms experienced, specific types and duration of physical activity, emotions associated with experiences, and detailed descriptions of my interactions with health care practionners. The journal was photocopied, coded, analyzed and then compared to the participants' data. The findings of this study reflect the experiences of the participants, as well as my own experiences outlined in my journal.

Trustworthiness and Credibility

In research, it is important to maintain objectivity. It seems unrealistic to think that complete objectivity can be obtained because the researcher brings his or her biases and life experiences into the research. This is inevitable. Having said this, it is important for the researcher to maintain some distance between the data and his or her own experiences and beliefs. This is especially important when the researcher is a subject in the study.

Although I am a participant in my own study, I feel that my brain injury and the memory deficits I experience have allowed me to maintain, on some level, a more objective approach. I cannot remember much of my past, although I do remember the major events. I also do not have emotions associated with memories. So while I may remember the event, I have no emotions about that event, nor do I feel that I have lived that event. Re-reading my journal felt like reading someone else's journal. Since I felt no emotions regarding the events described in the journal, I was able to focus on the written word.

In research, it is important to take steps to ensure that both the project and the researcher are trustworthy and credible. While qualitative research presents some challenges in this area, there are a number of procedures and steps that were taken to ensure credibility and trustworthiness. Triangulation, member checking, transparency regarding my biases and beliefs, and that my journal was written before this study was ever conceived all help to ensure validity and reliability. I also worked closely with my supervisor to ensure that appropriate steps were taken and to problem solve and discuss issues that arouse throughout the process.

"Data triangulation involves using diverse sources of data, so that one seeks out instances of a phenomenon in several different settings, at different points of time or space" (Seale, 1999, p. 54). Data triangulation was done with two data sources. My journal and the participant interviews were analyzed separately. The findings from the separate analyses were then compared. It was from these two sources that the final findings were derived. In addition, while not intentional, the geographical locations where the participants received treatment were all different. The athletes' recovery experiences took place in Vancouver, Montreal, Maine, Australia, southern Ontario, and south, central and northern Alberta. That the athletes reported similar experiences of recovery from post concussion syndrome provides more credibility to the findings.

Member validation is another method of making sure that the analyzed data is representative of the participants' actual experiences and thoughts. As Seale (1999) explains, the participants are asked to judge the accuracy of the researcher's account. There are two versions: strong and weak. In the weak version, the participants comment on the accuracy of some of the documents, such as interview transcripts. Each participant was sent a copy of the transcripts for verification shortly after their interview. All of the participants responded, providing feedback on the transcripts. In the strong version, the participants evaluate the final report. A summary of research findings was sent out to four of the six participants near the end of the research project. The remaining two were not sent the summary as their contact information was no longer current. The summary of research findings document included a model, a description of each component of the model, and other key findings. The participants were asked to comment of the findings. Only one of the participants responded, however no comments were provided except for confirmation that the summary was received.

It is important to note that the journal was not written for the purposes of research. I started the journal while consulting with a sport psychologist early in my recovery process. He asked me to keep a detailed journal on very specific topics such as duration and type of physical activity, symptoms experiences, emotional reactions, and visits with health care practionners. I decided to keep writing in the journal after I stopped seeing the sports psychologist. The journal was written without the assumption that it would be used for anything other than personal use therefore; I was honest and personal in my writing of the journal.

One other important aspect in trustworthiness and credibility is identifying and discussing researcher biases. This has been done in chapter one and throughout the thesis. Readers can better understand my background, experience and biases as they are well documented. Chapter four is solely dedicated to my recovery experience and includes the findings from my journal, explanations and background information about what happened to me. In writing chapter four, I feel that I have been transparent regarding the life experience that led me to this study and to who I am now.

Finally, I worked closely with my supervisor and my committee to ensure that the necessary procedures and documentation were followed to ensure that the methods used in this study were appropriate. The combined knowledge and experience of the members of my committee strengthened the study and helped me to solve problems as they arose. Combining all of the above steps helped to ensure that the study is credible and trustworthy.

CHAPTER FOUR: JOURNAL FINDINGS

On March 18, 2000, I sustained a concussion playing ice hockey. In late April 2000, I was diagnosed with post concussion syndrome and my symptoms lingered for almost three years. I still experience a few symptoms, however I consider myself to be fully recovered from post concussion syndrome. This chapter presents a first hand perspective on recovering from post concussion syndrome and is based on a journal I kept for close to three years following the concussion. The journal was not written specifically for research. I was seeing a sports psychologist for about a year following the post concussion syndrome diagnosis. The sports psychologist requested that I keep a journal in order to track my progress. I continued keeping the journal after I stopped seeing the sports psychologist.

The journal focuses on my return to physical activity, the challenges, struggles, improvement, and changes I experienced as time passed. I have, at times, added in some personal reflections on the experience based on the few memories I have of the past. One of the lasting effects of my brain injury is memory loss. While I have regained most of my memory, I do not have emotional memory or visual memory. I remember THAT things happened to me, or that I was a part of past experiences but I have almost no emotions associated with those past experiences. In addition, I cannot remember what things look like. That being said, I do remember a few sporadic moments very clearly. Perhaps the best way describe what this feels like is that it is like reading a biography. The reader knows what happened but does do not know what it felt like to actually have lived those experiences. Given the memory loss, I am relying solely on the journal that I wrote during that time. There are also a few large time gaps where I did not write anything, in particular the first six months following my injury.

This chapter begins with a descriptive summary of my experience of recovering from post concussion syndrome. It is meant to give some context to the findings. This is followed by a description of the phases of recovery. Three distinct recovery phases emerged from the data, the major distinguishing factor being the symptoms or absence of symptoms. Emerging categories throughout the recovery are then presented. These categories include physical activity, frustration, coping, environment, social, and recovery process. Categories that are specific to phase one and two, symptoms and medical, are presented next, followed by categories specific to phase three. Re-growth and self concept are the major categories in phase three.

My Recovery Experience

My injury happened on the evening of Saturday March 18, 2000. I was playing in the Quebec provincial ice hockey tournament in Montreal. It was the end of the third game of the day. My team had lost the first two games and was loosing the third. I remember that the game had become quite rough and some of my teammates opted to sit out. There were about five minutes left in the game. Another player and I were chasing the puck in the centre ice area towards the boards. I hit the boards head first going full speed. I do not think that I lost consciousness. The memories from here on are sporadic at best but I remember telling my coach that my head hurt and that I should not drive home. I remember sitting on the bench with my helmet on backwards. I am unsure how I got to the dressing room, but I do remember sitting on the floor of the dressing room with a towel over my head and complaining that it was too noisy. In reality, there was complete silence. I am unsure of how I got changed out of my hockey equipment.

Having gown up in Montreal, I was bilingual. Once I was changed, I waited in the hallway for my coach to take me to the hospital. I remember a tournament organizer speaking to me in French but not being able to understand what he was saying. It sounded like a language I had never heard. I have faint memories of trying to stay awake while waiting in the hospital and leaving after about six hours without being seen.

From what my family and friends have told me, I was repeating things over and over, complaining of a headache, nausea, blurry vision, and was generally out of it. Despite this, I remember telling my mother, who was away in Vermont, that I was fine. On Monday, I went skiing with some friends at Jay Peak in Vermont and had one of the best ski days I had had in a long time. On Tuesday, I was scheduled to work at a local bike shop. I could not remember how to use the computers, the credit card machine or speak French well enough to serve the French customers. In addition, I remember feeling really tired and nauseous. I left at lunch, called my mother and we went back to the hospital emergency department. We waited for at least eight hours. The doctor said that I had a concussion, that the neurological exam was normal, the CT scan was normal, and that I should be better in 2 weeks. As it turned out, I was not better in 2 weeks. In fact, I had no energy, slept for about 18 hours a day, was nauseous, had no appetite, blurry vision, loss of balance to the right, a really painful headache, and was really sensitive to light and noise, especially mechanical noise.

For two years I had been planning a 60-day canoe expedition in the Yukon, NWT and Alaska with five other people. On June 20, 2000 we were scheduled to fly to our start point high in the mountains on Bonnet Plume Lake. I had 3 months to get well. Six weeks after my concussion, I was still not any better. I went to see a neurosurgeon that specializes in sports related head injuries. She scheduled an MRI, which was normal. She told me I had post concussion syndrome and that time would tell if I got better. Some people get better but some do not. About the same time, I started seeing an osteopath who did cranial sacral therapy treatments to help with some of the symptoms, particularly the headaches. I saw her every 8-10 days for about six weeks. When I was not at doctor's appointments, I was sleeping or lying on the couch listening to the T.V. I could not watch T.V because the visual stimulus made my headache worse.

In early June, a week before I was supposed to leave for my canoe expedition, the doctor and the osteopath gave me clearance to go. They figured that if I could deal with the symptoms, the expedition and associated physical activity would not hurt me. On June 8, 2000, I left Montreal and drove to Whitehorse, Yukon. From there, my group and I flew into Bonnet Plume Lake and began our expedition. I remember very little from my expedition except that there was a pretty major spontaneous healing that took place while on the Rat River in the Northwest Territories.

It was day 47 of the expedition. We were making our way up river to the continental divide. The first 30 km can be paddled as the current is not too strong. At a place called Destruction City, the current is too strong to paddle upstream so we had to get out and drag our canoes up river. I remember being in a great deal of pain that evening. I took 60 mg of codeine and went to bed. The next morning, I woke up and THOUGHT “I am thinking”. Up until that point, my mind was blank and I was merely getting through the day. As the expedition went on, I gained strength, more tolerance for reading and saw a slight improvement in the symptoms. I remember being in great physical shape and feeling good mentally from the physical activity but remarking on how much worse the symptoms became when I was actually engaging in physical activity. This was especially true when I did anything that raised my heart rate.

The expedition ended and we returned to Whitehorse, Yukon. I took my time driving back to Montreal. I was still in a lot of pain and found that the symptoms would get worse if I did any kind of physical activity or did too much during the day. In late September, I went to a conference in Tokyo, Japan. The shear amount of visual stimulus made the symptoms return and all I wanted to do was sleep. I arrived back in Montreal in mid October and resumed sleeping for about 18 hours a day. I continued with the osteopathic treatments and saw some more doctors and specialists.

Looking back on the first six months after my injury, it is evident that all I was trying to do was deal with the pain, the fatigue and the other symptoms. Until the end of October, I felt bad enough that sleeping 18 hours a day and spending the other 6 lying on the couch did not bother me one bit. In that second it took to get the concussion, I went from a really active person playing competitive sports, skiing, directing a telemark ski school, wilderness guiding and being gainfully employed to not being able to take care of myself.

In my quest to get better, I started seeing a sports psychologist. I really wanted to go back to work as a wilderness guide but needed help to get back to where I could meet the physical requirements of the job. This is where the journal begins. As a result, little data that was recorded from March 18 to November 6, 2000, however there are journal entries that refer to that period of time.

The sports psychologist helped to devise a plan to slowly increase my physical activity level, ensure that my diet was healthy and helped me to regain the necessary confidence to be successful at my chosen profession. I began by walking for about 30 minutes and then slowly increased the time and intensity over a period of two months. In addition, I tried jogging slowly, despite the advice of my osteopath. I was also wall climbing. I was becoming increasingly unhappy living in the city and thought that a change of environment may help. I have always felt more comfortable in rural or nature settings. Both the osteopath and naturopath I was seeing endorsed the change of environment.

In early December 2000, I decided that despite the symptoms, I would look for a job as a wilderness guide working with youth at risk in a wilderness therapy program. I took a job in Maine and started on January 4, 2001. The job was positive in that it provided challenge, a supportive community, physical activity, and a chance to work in the outdoors. Working for a therapeutic wilderness program for youth at risk was ultimately a good choice as we were in the business of therapy, which involved supporting and helping people recover for various challenges. The friends I made while working in Maine became a wonderful support system of friends, doctors and therapists.

I worked there for about 10 months. In that time, I went from being unable to hike without the symptoms worsening within 30 minutes of the hike, to being able to complete entire four day hikes without symptoms worsening. I had reached my goals and I had saved enough money to go traveling. In addition, I wanted to take the next step in regaining my previous level of physical activity.

I decided to go to New Zealand and Australia for eight months. The idea was to use a bicycle as the main mode of transportation. The logic being that if I could hike without symptoms worsening, cycling would challenge me to be consistently physically active at a moderate intensity level. I felt that the next step in my recovery process was to increase the intensity level of the physical activity I was doing. I also felt that I might see some more improvement if I listened to my body and slept when I was tired, ate when I was hungry and took some time to sort out how I felt about being brain injured.

I left for New Zealand on October 25, 2001. I spent two months in New Zealand, and only the first seven days cycling. Cycling made the symptoms progressively worse so I decided to buy a car. I was really sore during my time in

New Zealand and spent the time listening to my body. Consequently, I slept quite a bit. I did, however, work through many of the emotional thoughts and feelings that had been plaguing me since the concussion a year and a half earlier.

I flew to Australia in late December and was hired to work at an outdoor company that provided outdoor education programs for private high schools. Since I started work in February, I went cycling for the month of January. I was still very sore. My main goal was to cycle until I could cycle without the symptoms getting worse. By the middle of January, I had reached that goal. I spent February and March working and spent April and May cycling. In general, I was able to cycle and travel without too many limitations due to symptoms, however I needed to take care of myself. If I pushed too far, the symptoms returned and I felt bad again. In the end, I cycled over 2200 km.

Over the two years, I saw marked improvement in the symptoms and my ability to tolerate different stressors, whether they were physical, environmental, social or emotional. I had worked my way from no physical activity, to wilderness guiding, and to moderate physical activity by pushing the limits and learning when to stop.

In June 2002, I returned to Montreal and moved to Edmonton. In September of 2002, I started my master's degree. The logic behind doing a master's degree was that if I could challenge myself mentally and academically as I had physically, maybe I would regain a fully functioning brain. I found graduate school difficult and tiring, but slowly, I was able to do more without being as tired. On January 22, 2003, I experienced a spontaneous healing. Spontaneous healing is not well documented in the literature however a number of professional athletes have described in newspaper articles feeling that the fog was lifted, a light switch was turned on, or that their brain suddenly functioned again. That morning, I woke up and found that I felt different. I realized that I had no headache, could exercise without the return of many of the symptoms and was only sleeping six hours a day but I still felt that my brain was foggy and the other symptoms where still there. On January 29, 2003, I woke up and all the symptoms except memory loss were gone. My brain went from working at about 30% capacity to about 95%. In the absence of symptoms, I was acutely aware of the environment around me and consequently embarked on a period of relearning, self-discovery and growth. I felt that my brain "woke up" to a foreign world and I had to spend time figuring out how to navigate my world. I was hoping that once my brain woke up, I would continue on where I left off in March of 2000 before I had my concussion. That was not the case. In reality, the real work was just beginning, partly because I became more aware of my surrounds and my lack of strategies and skills to deal with the situations that arose. The journal entries end in October 2003.

Phases of Recovery

It became evident that my recovery process consisted of three phases. Symptoms emerged as the main limiting factor to recovery, as well as, being the distinguishing factor between each phase of recovery. While phase one and two showed a heavy focus on dealing with the symptoms in order to "get through the day", it was the absence of symptoms in phase three that was the major difference in sparking the rapid growth and relearning that took place.

Phase One

The first phase was characterized by an inability to function well, a great deal of pain, and an inability to work. I spent most of my time feeling too bad to actually do anything but sleep. I had difficulty performing activities of daily living because I was too tired and in too much pain. Small improvements occurred to the point where I felt I could endure the pain and other symptoms to perform activities of daily living necessary for taking care of myself and re-enter the work force. This phase began when the concussion occurred on March 18, 2000 and ended when I returned to work as a wilderness guide on January 4, 2001

Phase Two

The second phase was characterized by motivation and determination to continue on with life despite the symptoms and limitations I experienced. Most of what I did was done with the recovery in mind, however many of my goals revolved around physical activity with the major one being an improvement in physical fitness and mental functioning in order to “get back to where I was before the concussion”. During this phase, I saw moderate improvement and was determined to continue living as best I could despite my limitations and symptoms. This phase ended with a major spontaneous healing where I woke up one morning to find that my brain was clear, functioning and the vast majority of the symptoms were gone, except emotional and visual memory loss. Phase two lasted two years.

Phase Three

The third phase was characterized by an effort to relearn how to function effectively in the world and my environment while rediscovering and reinventing myself. More importantly, it was the absence of symptoms that allowed much of this to take place. In the absence of symptoms, I was able to focus more on the environment around me than merely on the management of the symptoms. This was a period of having to relearn and redesign coping strategies to effectively navigate my physical, social and academic environments. Most of the relearning took place during the first ten months following the spontaneous healing with the effort I have to invest becoming less and less as time went on.

Emerging Categories throughout Recovery

There were a number of categories and concepts that emerged from the journal. Some of the categories and concepts are relevant throughout the entire recovery process, while others were only relevant for parts of the recovery process. Physical activity, frustration, coping, environment, social, and recovery strategy emerged through out the entire recovery process. While the specifics for each category changed with time as I recovered, there were aspects of each category throughout. The emerging categories and concepts are outlined in figure 2.

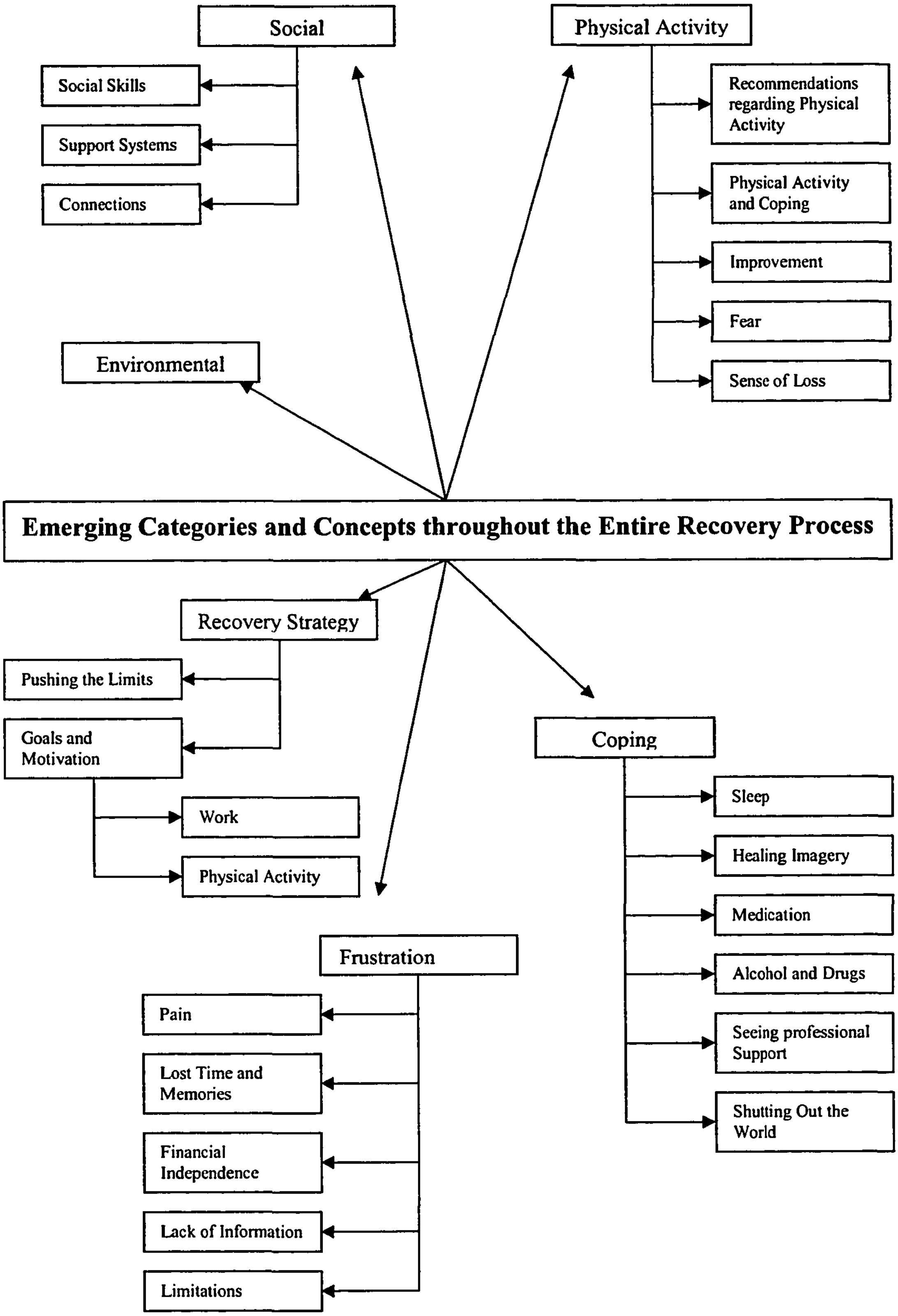


Figure 2: *Emerging categories and concepts throughout the entire recovery process.*

Physical Activity

Prior to my concussion, I was very involved in sports. Physical activity was something I did daily. My ability to participate in physical activity drastically changed after my concussion. Despite my inability to participate in physical activity, or perhaps because of it, physically activity emerged as a major category. Recommendations regarding physical activity, fear, sense of loss, coping, improvement, and rehabilitation emerged as concepts related to physical activity.

Recommendations Regarding Physical Activity

When the concussion occurred, I was a competitive hockey player and was planning a two month canoe trip for the coming summer. All I wanted to know was when I could play hockey again and if I would be able to go on the expedition. As the weeks and months passed and I was not improving these questions became more pressing.

When I discussed the possibility of resuming physical activity, in particular hockey and the canoe expedition, with the doctors and specialists I received similar answers. They suggested I follow the step by step return to play guidelines. Once I could perform all the steps without the symptoms returning, I could play hockey. All of the doctors and specialist suggested that I should rest until the symptoms were resolved.

While this was effective in the first few months post injury, as time passed I was becoming more and more restless with not being able to participate in physical activity. I was told that contact sports should not be played until the symptoms were gone. I was given clearance to go on the canoe expedition since the risk of head injury in canoeing is low.

About six months after the concussion, I saw a sports psychologist who helped me to come up with a plan that would allow me to return to work as a wilderness guide. It involved increasing the amount and intensity of physical activity slowly over time. It began with walking for short periods of time. The sports psychologist was the only health care professional that recommended any kind of concrete plan or advice for the resumption of physical activity while symptomatic.

As the years passed, I became more and more physically active but not nearly to the extent I was before my injury. I received little concrete advice as to what I could safely do, except to let the symptoms be my guide. Given that physical activity was a major aspect of my life before the concussion, I made up my own plan for the resumption of physical activity because I felt that physical activity was important for a healthy and happy life.

Physical Activity as a Way of Coping

Physical activity and sport was the main method of coping with the challenges of life before my concussion. It was how I dealt with stress and maintained a mental balance between school, work, recreation and social. It was the foundation for ensuring that I was content.

In the absence of physical activity I struggled to maintain the balance. While I realized that I could not participate in the types of physical activities I did pre-injury, I tried to be physically active in other activities. One of the main activities in which I participated throughout the recovery process was climbing. It began when I enrolled in a French climbing course that focused on body movement in climbing. The instructor presented the class with a number of exercises designed to improve our balance, body awareness, sense of equilibrium while on the wall, and instill the idea that climbing is more about feel than about specific techniques. It was through this course that I learned and developed many skills that I later used for problem solving, creating strategies for re-learning, and coping with the challenges. Climbing became the one form of physical activity that I consistently used for coping throughout the recovery from post concussion. A large part of this is because I could climb without raising my heart rate and still have a challenging work out.

Following the spontaneous healing in January 2003, climbing once again became the major coping strategy I used to get through that time. It was the only thing I found that would turn off my brain. I had gone from having a brain that was generally blank to one that was constantly working and thinking and I could not turn it off. Climbing offered me a break from myself. It was a place where I could immerse myself in something that was cognitive but I was also very focused. The following quote speaks to this:

> Climbing has become a total release of energy for me. I'm starting to really feel the comfort in smooth body movements and finding the equilibrium and fluidity of movement. It helps me learn how to solve problems; especially how to start… it is the process of figuring out how to start to figure out the process. I've been feeling good climbing and is probably the one place/thing that I have found that will turn off my brain.

Climbing was a good way of coping with my overactive brain but I could only climb for so long. I began climbing about three days a week in October 2002 but when I realized that I could turn my brain off, I increased the frequency to five days a week. I found that my body became ineffective and tired so I had to limit climbing to three days a week.

> I'm finding it difficult to cut out all the background noise or the unimportant stimulus/ information. Also how to turn my brain off to get some peace. Climbing seems to be working but I can only climb for so long. My brain is just kind of overactive and I feel like I need something that can turn it off.

As beneficial as climbing was, I did not climb consistently throughout the recovery process. This was partly due to geographic location, lack of partners, loss of motivation and interest to climb, and financial reasons. It is evident, however, that physical activity, namely climbing, was an essential part of my recovery. In addition, climbing also provided rehabilitation for many of the deficits that resulted from the concussion. It was one of most effective forms of rehabilitation I experienced. I kept returning to climbing over and over again. The following quote expresses the benefits of climbing:

> In my head, I keep returning to climbing as a great venue for rehabilitation. It covers enormous grounds from self-confidence, to challenging physical and mental limits, to working on balance and fine motor controls, re-establishing body spatial awareness and planning and visualization. It gives the opportunity for the individual to be solely present… no distractions.

This last quote is a good introduction to the benefits I felt I gained using climbing as part of my rehabilitation. As I was guided by the instructor through the series of exercises presented in each class, I worked on a number of different skills while having fun. This led to a marked improvement in symptoms such as loss of balance, planning, concentration and more.

I did participate in other forms of physical activity throughout my recovery, although not consistently. Walking and slow jogging were two activities that I did early in my recovery to increase my tolerance for exercise. Hiking, canoeing, and snowshoeing were activities that I did for work as a wilderness guide. I also telemark skied and cycled at various times over the three years. What is important is that participation in all of these activities provided me with many benefits, most notably a sense of normalcy and connection to my past life. Participation in physical activity helped me to cope with being brain injured.

Improvement

Participation in physical activity allowed me to monitor my recovery. I could feel changes in my body, in the symptoms, and in the duration and intensity of physical activity I was able to do. It was a good indication of how I felt my recovery was progressing.

> I can feel my body getting stronger and stronger. My threshold for biking has increased and I can do longer days, although the terrain is less hilly (elevation) on the east side. I am quite proud of myself for being able to do this, although I find it quite boring. In general, I feel myself getting stronger and stronger. When I am physically active I feel better.

While working at the wilderness therapy school, it was hiking that became the activity of choice because I was hiking as part of my job. Later on, it was cycling. The above quote refers to my long distance cycling trip though New Zealand and Australia. Cycling was an activity where I could control the intensity, speed, distance, and ultimately the return of symptoms, while achieving a good workout. In addition, it is a solitary activity where body contact is not an issue.

Fear

While there were many positive aspects related to physical activity, fear of re-injury was and still is very prevalent.

> Part of me wants to play [hockey] again but another BIG part of me is still really scared. I can't control or have any say over the other players. With outdoor activities, I can predict what the whitewater will do to my canoe, the rock does not move and although there are risks to these activities, good judgment and skills reduce those risks.

For a long time, I was worried about putting myself in situations where I could sustain another concussion. I eventually did try playing hockey again but was still too afraid of sustaining another concussion. Ultimately, it was fear of re-injury that prompted me to retire from competitive hockey. The decision to retire from hockey prompted feelings of loss. I defined myself as a hockey player for many of my formative teenage years and into my twenties. Hockey was a big part of my life and who I was.

Sense of Loss

The doctors advised me that I should never play contact sports again because I experienced symptoms for so long. I was a competitive ice hockey player for many years and played between four and six times a week. Hockey was more than a game for me; it was a release of energy, my way of staying fit, a place where I could socialize, and a big passion in my life. It was also something at which I was very successful. Playing made me feel good about myself. Not being able to play at a competitive level left a big void that has been difficult to fill. I would even say that I have been unable to replace it. These sentiments are expressed below:

> Saw hockey the other day and REALLY miss it. More, I miss being part of something, exercising regularly and competing as a team. I miss feeling like I can fly. I miss the feeling of playing and shooting and skating hard. I feel a big void in me where hockey was. Perhaps it is physical, mental… I'm not sure. Been thinking of something to replace it… paddling in the summer but I'm at a loss for a winter one (which happens to be the longest season in

> Canada). Not really passionate about skiing. Needs to be something I won't get bored with. Need to find motivation for something again.

When the doctors recommended that I should not play hockey again, I never realized the void that not playing would leave. In a sense, it was like loosing my identity. I also lost my friends, my daily exercise, and something that made me feel good about myself. No other activity I have tried has come close to the satisfaction, feeling, and physical workout I experienced playing hockey.

Frustration

Frustration emerged as a major category in the recovery of post concussion syndrome. There were many sources of frustration over the course of my recovery. The frustration was particularly prevalent during phase two, when I was cognizant and well enough to know what I wanted to do but still struggling with symptoms. During phase one, I was too sore and tired to really care. There were a number of - concepts that emerged from the journal including pain, loss of time and memory, financial independence, lack of information and services, and limitations. These concepts provide a more in-depth understanding of the underlying source of the frustration I experienced.

Pain

One of the major frustrations was pain and most often it was the headache pain. This frustration came up numerous times throughout the journal. It was evident from the following comment that the frustration was intense.

> What is frustrating is that nothing I have tried gives me relief from this. I have been just dealing with this for over a year but now, I really don't have hope that it will get better or/and because I really don't know what is out there for treatment/ services, feel quite lost. I guess the hardest part is that it is stopping me (or slowing me down) from doing what I want to do. Even if the hope that I will at some point loose the headache is fading, I will achieve what I want… it will just be in more pain.

Much of this frustration stemmed from the lack of effective treatment or medication to help manage the headache pain. Headache pain was by far the most debilitating of all the symptoms I experienced. Had the pain been better managed, I think I would have been better able to function in my activities of daily living and return to work sooner. The management of headache pain emerged as being one of the most important aspects of my recovery. A lack of viable pain management options were presented to me by the health care practionners. In the end, the headache disappeared and I was, only then, able to truly recover from post concussion syndrome.

Lost Time and Memories

The memory loss I experienced was a source of frustration. I found it difficult to relate or remember past experiences. There were quite a few changes happening in my life during that time. A number of people died and many other friends moved away. I felt a loss for the past and that I had lost all those precious memories of my family, childhood, old friends, and cool experiences. The following quote refers to the canoe expedition I took during the summer of 2000. It was written a few months after the expedition ended: "I feel like because I can't really remember a lot that I got cheated out of what was supposed to be a really cool experience [the canoe expedition]". In addition, I felt that I was wasting my time being sick: "I guess the most frustrating part of all this is that I feel I have "lost" all this time since March".

Frustration over lost time and memories has been an issue throughout the recovery process. The most difficult aspect of this has been uncertainty as to when the memory will return and how long the concussion symptoms will impair my ability to fully participate in the life that I want. It would also have been helpful to have some specific exercises or guidance on memory improvement techniques. In the end, however, I have learned to accept that I have lost time and memories.

Financial Independence

One of the things that I found difficult during phase one of my recovery was that my mother supported me financially. While I was grateful for the financial support and most likely would have had to apply for government assistance if not for the support of my mother, my inability to be financially independent was frustrating. When I had my concussion, I had recently graduated from University and felt ready to head out into the world and make some money. I was excited at the prospect of supporting myself. Because I was injured playing sports, I was not eligible for worker's compensation. The deadline for making a claim on the insurance from the Quebec Hockey Federation was no later than a month from the date of the injury. It took two months to see the appropriate specialist and be diagnosed; therefore I was also ineligible for insurance coverage from the hockey federation. I was also not considered sick or injured enough to receive any disability benefits. This created a situation where I was unable to work and not eligible for any financial assistance. I had some savings, which I used to support myself for a while but as time went on I depleted my savings. This quote speaks to this: "I've spent all my savings and now I find myself having to be supported by my mother again. The pressure I feel to be financially independent is immense".

Living in Canada, most of my health care costs were covered by Medicare. Even so, I paid out of pocket for many of the rehabilitation practionners. Financial independence and the ability to afford the cost of seeking the appropriate health care was a major source of frustration and stress for me while recovering from post concussion syndrome.

Lack of Information on Post Concussion Syndrome and MTBI Services and Treatments

Another major frustration was a lack of information about post concussion syndrome, the lack of available services for people who have post concussion syndrome, and what seemed to be a general lack of knowledge on the part of the health care professionals I saw. The following quote reflects the frustration I felt after visiting many "experts" who all offered no concrete information or prognosis on my condition.

> Through the whole process of doctors and health people, I have felt so frustrated and annoyed. I'm paying these people to tell me that they have no idea why I still have symptoms and that they can suggest nothing.

The next quote alludes to the frustration I felt when none of the health care practionners I saw knew anything about rehabilitation programs, support groups or other services for people with post concussion syndrome.

> This whole thing is all very frustrating and uncertain. I wish they could tell me how long this will last and when I will feel better and more direction about treatment and healing options.

It was important for me to see progress in my recovery. There were many questions and thoughts that were circulating in my head throughout the recovery process. It would have been very valuable to be part of a support group or to have been part of a rehabilitation program specifically designed for the needs of people recovering from post concussion syndrome. While I ended up creating my own form of rehabilitation and my own group of supportive people, this process was largely experimental. It was a slow and frustrating process. Having rehabilitation services for people with post concussion syndrome would be immensely beneficial for helping injured people regain the appropriate skills needed to function better in daily life, as well as provide a support system.

Limitations

Limitations were also a source of frustration. I found that the symptoms limited me to what I could reasonably accomplish. This meant that I was not able to do the things I did before the concussion because I would get too tired or sore. The following quote alludes to this:

> The past 3 weeks have probably been the most frustrating and emotionally tough (but maybe not since I can't remember much). I feel well enough to want to work and do things again but sore and tired once I do or over do them.

During phase one and two, it was the relentless symptoms that often prevented me from doing what I wanted to do. I was relatively unprepared to deal with this and at times it was difficult to keep a positive attitude. The following quote speaks to this:

> What is frustrating is that nothing I have tried gives me relief from this. I have been just dealing with this for over a year but now, I really don't have hope that it will get better or/and because I really don't know what is out there for

> treatment/ services, feel quite lost. I guess the hardest part is that it is stopping me (or slowing me down) from doing what I want to do. Even if the hope that I will at some point loose the headache is fading, I will achieve what I want… it will just be in more pain.

The limitations I experienced due to the post concussion syndrome lessened with time. Acceptance of the limitations was also a key factor in reducing the amount of frustration I experienced because of the limitations.

Coping

Coping emerged as a major category. I used both positive and negative ways of coping with the symptoms of post concussion, as well as the frustrations and other feelings related to the struggles I experienced. Before my concussion I used physical activity as my primary coping strategy. After my concussion the physical activity I did before my concussion was not available as a coping strategy either because the health care practionners advised against being physically active or that physical activity aggravated the symptoms to a point where I did not want to be physically active. For a good portion of the three years of recovery, the latter was the case. Even now, some symptoms return when I am physically active.

There were a number of coping mechanisms I used in place of physical activity. Some were at the advice of various health care practionners, and other were ones I came up with on my own. Not all of them were positive ways of coping. Sleep, healing imagery, medication, alcohol and illegal drugs, seeing outside support, and shutting out the world emerged as concepts of coping.

Sleep

The first coping mechanism I used was sleep. In the early stages of phase one, I would sleep because I was tired and because it was the only time I could find relief from the brutal headaches I experienced.

> Today I felt pretty shitty. I had a very sore head and felt pretty wiped out. Slept most of today.

Sleep not only provided relief from the symptoms, but necessary recovery for my body and brain when I over exerted or over stimulated myself. At times, sleeping was the only coping mechanism I used because I felt too sore, sick and tired to do anything else.

Healing Imagery

One of the first coping skills I was introduced to was healing imagery. The sports psychologist gave me information on this and encouraged me to try it. Since healing imagery is largely based on visualization, and I had lost my visual memory it was, at times, difficult to do. I ended up using other senses such as sound and movement. I found that once I practiced and improved my healing imagery skills, I was able to see some benefits. There were times when I was able to disassociate from my body and also disassociate from the pain and soreness I felt. This would provide short breaks from the reality in which I was living. As time passed, I felt that I needed to do healing imagery less and less. I usually did healing imagery for about 15 minutes. This is one example of how I used healing imagery.

> During the hike, whenever my head got sore, I imagined that it was the pain exiting from my head and that there has to be a finite amount of pain so it was getting emptier and emptier of pain.

Healing imagery was one of the skills that helped me to cope. It was a skill that I learned after my concussion to help with recovery.

Prescription and Over the Counter Medications

In an effort to manage the headache pain, I tried all sorts of over the counter medication. None of the over the counter medications worked to even take the edge off of the headache. Having been unsuccessful with over the counter medications, I tried prescription medication. One of the first was an antidepressant medication that when taken at low dosage has been shown to help manage headaches in some people. It is taken every day. While it did manage the pain somewhat, I felt the side effects of the medication were worse than living with the pain of the headaches. In addition, I tried five different migraine medications. These were used when a bad headache was imminent. They are supposed to take away the pain and most of the ones I tried were supposed to have a drowsy effect. None of these migraine medications had any effect on me. In terms of coping, I tried these medications in the hope that something would work. In reality, nothing worked. Early on, however, I did take some codeine that I had left over from some dental work. I was self medicating.

Alcohol and Illegal Drugs

Alcohol was one form of coping that I used for a number of months. While I do not remember drinking as much as the journal described, I do remember the first night in a year and a half that I tried drinking. I wanted to see what effect alcohol would have on me and if it was different than before the concussion. That night I drank five beers in about two hours and was very drunk. It started a trend that was a bit scary. Being drunk changed the pain and gave me a break from my normal reality. It also made me feel bad both in feeling hung over the next day and waking up feeling like I had another concussion. None the less, I began to feel that I wanted to drink all the time so that I would not have to feel the pain of the headache and the other symptoms. I distinctly remember drinking alone in my room on a number of occasions. This went on for about six months or so. I struggled with the temptations. I knew that drinking was a poor option for coping, but it was such an easy option. The following quote expresses my thoughts on drinking:

> The past 2 nights I got drunk. I know that drinking is really bad for me but it takes me away from my reality for a bit. This morning, not only did I have a hangover but I had most of the symptoms back too. Today I feel shitty. All of my logical mind tells me not to drink, but it is kind of nice to get the feeling of some other uncomfortableness. These past few days, had I been able to get my hands on some pot I would have done that too. I'm so fucking sick of being in pain. At this point, anything is looking good.

At that point in the recovery, I had been dealing with the symptoms and headache for over a year. They were still pretty intense and because I was not finding any answers from the health care practionners or seeing much improvement, I began to look for opportunities to self-medicate. There were a number of times when I would have also done whatever illegal drugs I could have obtained, however I did not want to get caught and loose my American work visa or get in trouble with the American authorities.

Working at a wilderness therapy program for youth at risk, there were always people who could get any illegal drug desired. I knew that when the pain became really bad I would become so desperate to find something to kill or change the pain that I would have taken just about anything. In order to prevent myself from doing this, I asked a few friends to monitor me when I was very sore. I remember a number of times pleading with them to get me some kind of drug. All of them said no. They did not know about the drinking. In fact, no one knew.

Seeking Outside Professional Support

Seeking outside professional support was a key aspect in coping with the emotional and mental challenges I experienced as a result of post concussion syndrome. While a few of my colleagues at the wilderness therapy program sometimes played the role of counsellor, it was mostly a sports psychologist in Montreal who I turned to when I felt like I needed some support. I saw him early on and he helped me to gain the necessary confidence and physical fitness to return to wilderness guiding. Later on, we often talked about coping strategies for dealing with the frustrations, the loss of my sense of self and my past, and the forced retirement from hockey. In addition, he was the person I contacted to help me when I realized that drinking was becoming a problem. He was an integral part of my recovery and in ensuring that I use positive and constructive coping strategies. The following quote is an example of my interaction with the sports psychologist:

> Today I spoke with [sports psychologist]. He was supportive and we talked about some issues/ fears I have been having. As far as the drinking, he suggested when I feel like that do something else instead. I will find something... maybe running. We talked about the importance of staying active and finding something to keep me active. I think I want solo canoeing to fill that gap. Maybe climbing as well. Part of keeping active is working towards a positive attitude. The not remembering my interactions with people and that affecting my friendships was also something we talked about.

Shutting the World Out

Shutting the world out was a coping strategy I used after the spontaneous healing of January 29, 2003. I found the world to be an overwhelming place. I could only process a limited amount of information so every now and then I would spend a few days in my room regrouping and processing what recently happened. The following quote illustrated how I often felt:

> The world is so foreign and strange. It is as if I woke up to a completely new world that I have never seen before. All this stuff that I don't know what to do with. So much info going into my brain. I find over the past 2 days, especially today, that it is much easier to shut everything and everyone out because I find that I can't be selectively filtering out unnecessary stimulus. I find that today I was going back to not seeing the world because it is too much to handle. I feel myself pulling inwards and shutting out the world and everyone. Part of me wants to reach out but most of me wants to go back and hide and shut out the world because it is too much to handle at the moment. I don't feel ready to jump right in completely alone.

I used this coping strategy for the first two or three months until I felt more comfortable in my environment. As time passed, I felt like I needed to do this less and less, however even now when I find myself in new situations I sometimes retreat into myself in order to process the new situation.

Environmental

Environment was another source of frustration. I was a Quebec resident and needed to stay in Quebec to have treatments and doctors visits covered by Medicare. All of the health care professionals I was seeing were based in Montreal and so it made sense to live there. After a year, however, I was becoming increasingly unhappy living in the city. Many of my friends had moved away and since I was no longer playing hockey or any other team sports, I had little social contact.

The outdoors has always been the place where I feel at home and comfortable. I find that if I spend too much time in the city, I loose my sense of self and become very unhappy. One of the main considerations when I was looking for employment was the environment in which I would be working. Ultimately, I ended up working in the White Mountains in New Hampshire and living in rural Maine because of the physical environment and the opportunities to work and live outdoors. The following quote expressed this: “I feel trapped and my insides get crushed. I need adventure, outside challenges and I like being outside. It is where I am happiest”.

I often wonder whether my choices to go on long paddling expeditions, work in the outdoor field, and cycling overseas had an effect on the healing that took place. In total, I had five spontaneous healings where all of a sudden I would have a major improvement in the symptoms. Three of the five came when I was working or living in the outdoors. More than anything, I always felt more calm, confident and content when I was living in a rural or wilderness area. I found that it was less noisy and cluttered there.

Another aspect of environment that emerged from the journal is increased awareness of the environment around me. This was a major change that occurred after January 29, 2003. The comment I wrote in my journal on the morning of January 29, 2003, a few hours after I woke up puts this into perspective.

> I can’t stop smiling! It all feels so good I don’t know what to do with myself. I feel so good. I now have this incredible mental clarity and energy… the passion has returned and the drive. Things mean stuff and I feel an acute sense of awareness and atunement to what is around me.

It was like some one suddenly turned on the lights and I could see again. After a few days my new reality began to sink in:

> The world is a fascinating place with so much going on and so much to learn. I don’t know where to start but it feels so good to be alert and awake…feels good to feel passionate about life again and amazing to feel animated when I speak.

I began to realize that the way I saw the world had changed since my brain woke up:

> …the heightened sense of awareness, the mental clarity. It is a re-awakening and a new way to see the world.

A week after my brain woke up it became apparent that I would have to make some adjustments.

> I suppose, on a good note, I have not lost or taken a step back from the really cool awakening on Wednesday but in a sense it has opened the door WIDE open to a whole new set of challenges and learning and trying to get used to the newness of everything.

Environment emerged as an important category in my recovery. It was apparent that the physical environment was important in influencing my mood and attitude. When I spent too much time in the city, I became frustrated and unhappy. When I spent more time out in nature, I was happier, calmer and less stressed. It was the absence of mechanical noises that made the difference. This was also true before my concussion. The second important aspect of environment was my awareness of the environment around me. This occurred in phase three of the recovery process. The increased awareness of my surrounding environment was overwhelming and yet another challenge to overcome. I had to learn how to process the events and objects within my surrounding environment. It was a stage of relearning that took place because of this awareness.

Social

Social skills, social support and connections all emerged as important concepts in the recovery process. Good social skills are important skills that are necessary for creating social support systems and connections with others. Without effective social skills, I found it difficult to make connections with others, to interact in the world, and set up appropriate social support.

Social Skills

The full extent to which I lacked social skills after my concussion did not really become clear until after the spontaneous healing on January 29, 2003. I did, however, notice early on that my social skills were not as effective as before my concussion. I felt like an outsider, not really fitting in anywhere. The process of relearning appropriate social skills began with the realization that there was a problem. This realization occurred in phase two.

> I think the biggest thing is that I feel different than before. I feel like I'm on the outside looking in. I'm kind of part of life but not really. I don't fit in anywhere.

Part of this realization was that I did not know what to do in social situations. This is evident in the following quote, which was written when I was forming a friendship with a co-worker at the wilderness therapy school in Maine.

> The thing that I find hard is that when I open up to her [friend], I don't really know what to do next. I don't really remember how to continue on with the friendship, maybe more that I don't really know how to be social or what is appropriate. I just can't remember. On the surface, my relationships are fine, although I think I talk about myself too much, but it is what to do once those relationships become more personal.

The sentiments and realizations expressed in the above quotes became more defined in phase three. Much time was spent on relearning these skills through experimentation and observation. While I was somewhat aware of the lack of social skills in phase one and two, it was shortly after my brain woke up was that I realized I was missing the vast majority of social cues.

> I feel like I miss the vast majority of social cues and non-verbal messages from people. I find that I don't know where the "social code" or social subtleties are…or how to really interact with folks on a purely social level. When it comes to work/ school that is ok because I have something to focus on. It has totally been a funny process of re-awakening and re-discovery. I was thinking that it would be fun to do some social experiments to test the limits of social appropriateness on random people on the street and then blame it on the brain injury! But really, I feel that that is the next major step… re-finding social skills and boundaries and working on forming relationships and how to build them.

It was an ongoing process of relearning by placing myself in unfamiliar situations. As a result, I became more comfortable in social settings. My last journal entry on October 18, 2003 alludes to this.

> Overall, what I find the hardest is having to figure out each new situation in which I find myself. It takes some time and I think that at times people read it wrong.

With more practice, patience on the part of my friends, and time spent refining my social skills I slowly became more comfortable in social settings. Despite this, the difficulties in reading social skills made it difficult to create deeper friendships, and therefore, create a social support system.

Social Support

Social support became more prominent when I began to be aware of my deficits. Once I gained awareness, I began to seek social support from family, friends, professionals and my boyfriend when I had one. I often found that despite being surrounded by people, I did not feel that I had any support. I often felt alone, especially once I left Montreal, when I left my job in Maine, and when I decided to leave Australia leaving behind a very supportive partner and great relationship. The following quote reflects the loneliness I felt.

> I feel quite alone in the endeavor and also that my support system is so far away or pretty sparse. I'm not really sure where to start to form more bonds.

In contrast to the above quote, there were times when I did feel supported and had wonderful people supporting me. This was particularly true when I was working at the wilderness therapy program.

> There [wilderness therapy program] I felt good and supported. It is the first time ever that I feel that I have had such accepting friends and strangely so, I found them in the USA.

Once I moved to Edmonton, I decided I needed to set up a support system of people I could turn to if I had questions or wanted to talk. This was prompted by the realization that I had to re-learn numerous skills after the spontaneous healing of January 29, 2003. I decided to ask one of my professors, a peer in my graduate program, and a good friend. This covered most areas of my life. Setting up the support system was a way of coping with the challenges of relearning. The act of setting up this support system was the most important step, as I did not call on these people very often. It did, however, provide me with a feeling of security.

> I thought about asking a few folks to be part of my "support /learning" team to help me figure out some of the more basic stuff that I now have to re-learn. I asked [grad student] but think that I will also ask [professor] since he's already helping me out with the academic part.

Social support was something I cherished when I had it and wished for when I did not have a social support system. It was an important part of my recovery process, allowing me to share emotions, forget my brain injury, and drop the "I am normal" façade and show my weaknesses. Most of my support system is spread out across North America, and overseas. Because of the memory loss, it is hard to maintain connections with them because they are not physically in the same city.

Connections

One of the major barriers to meaningful social connections I experience was a sustained connection with others and with past events. This stems from the emotional memory loss. Essentially each event is an event unto its own. Events are not connected to each other. After a week I begin to forget. After two weeks, I have lost most of the emotional connection the event and after three weeks any emotional connection is gone. If I have daily contact with people then maintaining a connection is not an issue. If two weeks pass between interactions then it is like meeting the person for the first time except that I cognitively know things about the other person or past events. Over time I have learned to live with it. The following quote sheds some light on what this is like:

> I can't seem to find any connectedness to events in my life. It feels like I read a book or watched a movie about my life, I can tell other people what events happened but I don't feel like I lived them.

At times, I have become quite emotional and frustrated with the lack of connectedness and memories associated with the past.

> I find it sad that I cannot remember them [friends at wilderness therapy program] and the support I felt. I find it REALLY hard that I have no

> memories of my dad and my family. When I look at photos, they don't bring back any memories, or feelings... anything! They could be someone else's. How do I deal with essentially having no past? Of not feeling that I identify with anything? Or of constantly having to keep myself occupied and interested by moving around? How do I stop from loosing interest in life? How do I remember?

Most of my good friends do not live in the same city as me, so I found that I missed the support of my close friends.

> I kind of wish that I had my goods friends to support me and help me navigate through the world and wish I wasn't so alone here in Edmonton. I feel like I have no connection with anyone... like I never truly get to know them. That has been bothering me.

My visual and emotional memory was not one of the symptoms that returned. I found it difficult to make lasting connections when I did not see people everyday therefore I never really felt that I had a group of supportive friends in Edmonton, although I did have the support academically and professionally.

Forming connections with others was a big part of forming a social support system. Appropriate social skills are the basis forming connections. I needed to re-learn social skills in order to form connections with others who later became part of my social support system. During the more difficult times, my social support system was integral to ensuring that I stayed focused, and more importantly that I stayed out of trouble.

Recovery Strategy

There were a number of strategies I used in my recovery from post concussion syndrome. These strategies span across all phases of recovery. One of the things I consistently did was push the limits of what I could do. This included physical, mental, emotional and academic. I found it difficult and frustrating but I feel that I would not have seen the improvements I saw if I had not done this. In addition, I created realistic goals throughout my recovery. This was important in keeping me motivated.

Pushing the Limits

Pushing the limits was very important in my recovery process. It was particularly important in relation to physical activity during the first three years post injury because my chosen career as a wilderness guide was based on my ability to sustain a certain level of physical activity. Figuring out where the limits were was important and something I did periodically. I needed to know how far I could physically push my body because if I pushed too much I would be unable to function for a few days. The following quote expresses this:

> Took some time off work to hang out and ski. Part of this trip was to test the limits, physically to see where the limits are. I wanted to be able to push and by pushing, extend the physical limitations of my body. It was only at the end of the day where I started to feel the symptoms. I hit the wall and decided not to push through it. I felt pretty off balance, more of a headache and blurry vision at times. Good to know though, how far I can go and what happens now.

Later on, I would continue to push the limits in other areas of my life. In pushing the limits, I learned how far I could push without going too far. In addition, I was constantly challenging myself to learn.

Goals and Motivation

I have been setting goals for recovery from the time I sustained my concussion. The first goal was to recover enough to be able to participate in the 60-day canoe expedition during the summer of 2000. After achieving that goal, I set many more. There were goals that were work related, but the majority of them were physical activity related. In setting realistic goals and achieving them, I was generally able to stay motivated. One of the most basic goals was the following: “I’d love to be able to do stuff without feeling like throwing up or not being able to see straight”.

Some goals were quite large, such as using a bicycle as the only form of transportation around New Zealand and Australia, while others were more day to day in nature. Regardless, I felt that goal setting was important for keeping me motivated and interested in life. Early on, the goals were related to returning to work.

Work.

> During phase one, my big goal was to return to work.
>
> I think I need to re-evaluate the situation I am in and set some goals. I really do need to find an outdoor job, for various reasons, but mostly because I think that putting myself in that kind of environment will actually contribute to healing.

Reflecting on if I reached the goal of working, I wrote: “My goal, the major one anyway, was to be working by January and I realized that goal.” In addition to achieving the goal of returning to work, I made other goals that were work related. This helped me to determine my success in recovery but also helped me to maintain a positive outlook on life through difficult times. Integral to goal setting was choosing goals that were attainable.

Physical activity.

Most of the goals I set were related to physical activity. There was a cross over in some work related goals as I was a wilderness guide. Many of my goals focused on regaining my pre-injury level of physical activity as illustrated in the following quote.

> My biggest goal now is to get back in shape. I’m not really sure where to start to do that. I think for starters, I will begin by running 4 times per week for 10 minutes. Each week I will up the time by 5 minutes. In 2 months I should be up to 45 min. Yes, my next big challenge will be to get my cardio back up to par. For me this will be a big challenge because I really hate running. For now, this is really the only viable way of getting my cardio back where I want it to be.

The next quote provides a reflective look at my goal to cycle tour without symptoms getting worse. I achieved that goal, although it was not a static outcome. There were times when I did not take care of myself or pushed myself too hard and the symptoms returned with physical activity.

> When I think back to my over all goal for this trip to New Zealand and Australia, I have done it.... To see progress on my recovery and to be able to bike with no symptoms. I'm on my way again.

Setting and achieving goals helped me to stay motivated throughout my recovery. Goals related to physical activity were very important to me because a large part of my identity was based on my ability to be physically active. In a sense, working to regain my pre-injury level of physical activity was a way to re-discover myself. In the end, I was not able to return to all of my previous physical activities, however through goal setting I have been able to set new goals and maintain a general level of motivation to continue on despite my limitations.

Categories and Concepts Specific to Phase One and Two

Symptoms and medical emerged as categories in phase one and two of the recovery process. The symptoms emerged as the main limiting factors in my ability to function. The severity and intensity of the symptoms also affected my ability to function as well as continuing to do the things I wanted to do in life, such as take care of myself, work, travel, engage in social situations, and more. In response to the symptoms, I consulted many different kinds of health care practionners. In this section, the symptoms I experienced and the health care practionners whom I visited are presented. Figure 3 provides an overview of the emerging categories and concepts relevant only to phase one and two.

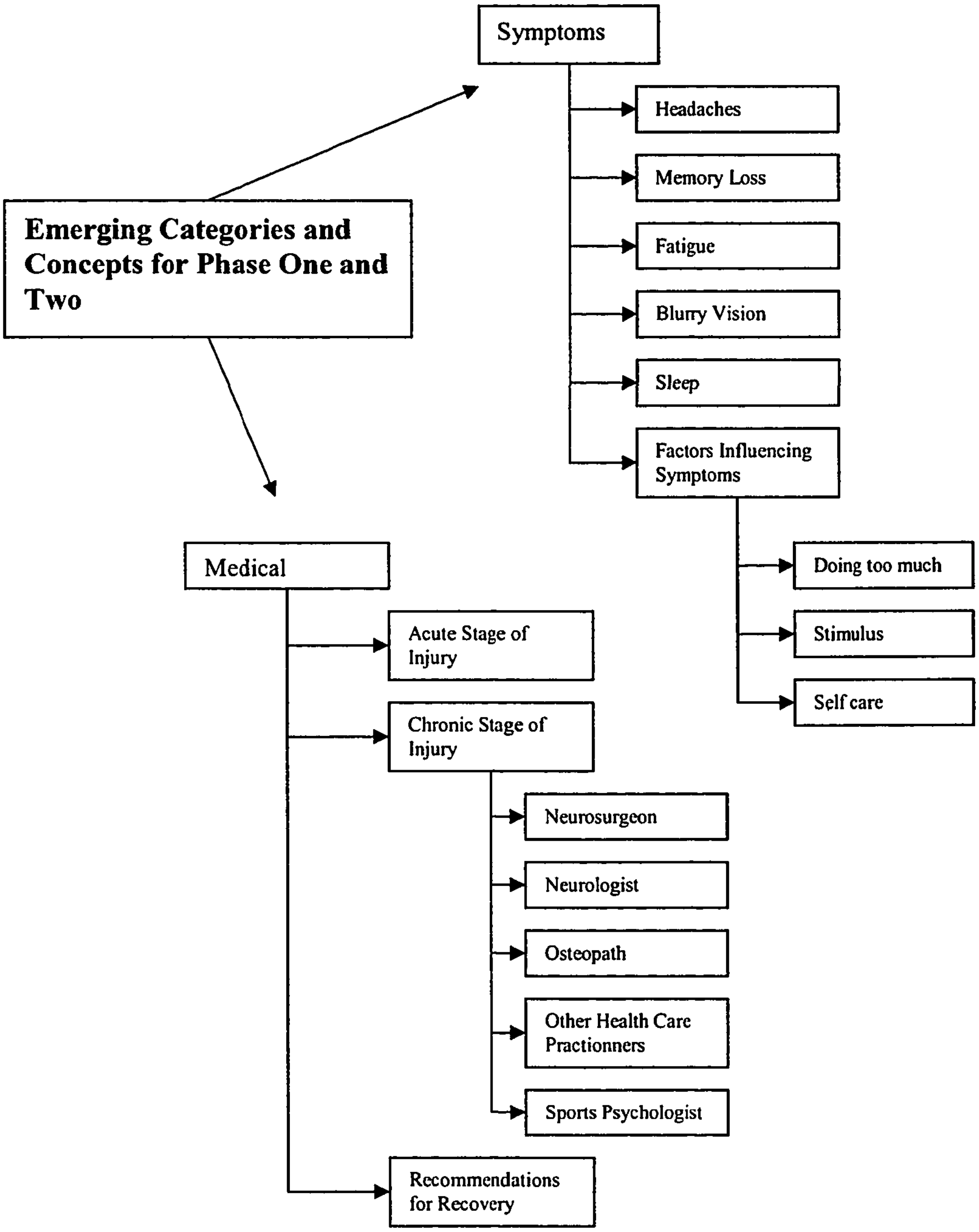


Figure3: *Emerging categories and concepts for phase one and two only.*

Symptoms

Symptoms emerged as the central category in phases one and two of the recovery process. I found the symptoms were the most severe and debilitating in the six months following the concussion. The following acute symptoms occurred during the first three months: (a) headache, (b) sensitivity to light and noise, (c) nausea, (d) memory loss, (e) loss of language, (f) loss of balance, (g) loss of appetite, (h) lack of energy, (i) increased sleep, (j) fatigue, and (k) blurry vision.

General comments such as “Can’t remember much about that time but I know that I had no energy, no appetite, a brutal headache, blurry vision, and could not think, read or write anything. I felt pretty shitty though and spent most of the days sleeping” characterize the acute symptoms. Memory loss was evident from the very beginning: “Again, I have no or almost no visual memories of this [the float plane ride] except the photos I took with my camera”. The loss of my second language was also commented upon early on. “Not understanding the French guy asking me questions. It sounded like a language I had never heard... I am bilingual”.

Specifics regarding the chronic symptoms were more detailed because I had begun writing in the journal and recording my thoughts, physical activity, and symptoms as I experienced them. The chronic symptoms are as follows: (a) fatigue, (b) increased sleep, (c) memory loss, (d) headache, (e) nausea, (f) blurry vision, (g) sensitivity to light and noise, (h) loss of balance, (i) loss of appetite, and (j) slowed thinking. Some of the symptoms that were mentioned more frequently in the journal are discussed below.

Headaches

I experienced a headache continuously for close to three years, which I called the baseline headache. Not surprisingly, headache emerged as a major concept of the symptoms. There were many references to the specifics of the headaches, as I found them radically different from any other type of headache I had previously experienced. These headaches were very distinct. The pain was also very specific and unique to the headaches related to the concussion, versus other headaches I have had.

> I’ve been struggling with the pain and the past week it has been as bad as it was last year. I’m not really sure why. It moves around and varies in intensity. The base headache is always there. It feels like someone is taking a blunt object and trying to force it through my head from the inside out. Sometimes it feels like someone is using knitting needles to do that as well. I get pain

> behind my eyes, but not all the time and it is not constantly on one. Sometimes it's between my eyes on the bridge of my nose. Lastly, occasionally it feels like someone is taking a belt to my head (where the hat line is) and tightening it.

This last quote provides a good summary of the specific details of the headaches. These specifics were consistent from the time of the concussion on March 18, 2000 to spontaneous healing on January 22, 2003. The headache was always there, however the intensity and location of the pain varied depending on the day. Above all, the headaches were the worst of the symptoms and I got used to living with them. As time went on, the really painful headaches became less frequent, while the baseline headache remained largely the same. In fact, I forgot what it was like to live without a headache. When I woke up without a headache on January 22, 2003 it was one of the happiest days I have ever experienced.

Memory Loss

Memory loss also emerged as a prominent symptom. This was consistent throughout my recovery and I still have memory loss today. Unlike the other symptoms, which got better over time, the memory loss I experience remains the same as when I first got my concussion.

> It is still a pretty odd feeling not being able to remember of all the traveling I have done, I just do not remember much, not even what I did, let alone what I saw or how I felt. I look at myself in the photos and it doesn't seem like me… it could be someone else. It is all so strange. I wonder if those memories will ever come back. Strange to go through life without memories.

It is important to note that my memory loss is very specific to visual and emotional memory loss. Other aspects of my memory are fine. This has been the case since my injury.

Fatigue

Fatigue also emerged as an important concept of symptoms. I remember being constantly tired. Often times my brain would feel tired and sore. There is a distinction between the headache pain and the soreness I felt. The soreness felt more like how muscles feel the day after a work out. After I did too much or was exposed to too much stimulus, my brain would feel really tired and sore. The following quote expressed this: “I started work. It is a positive experience but quite overwhelming. I find that my brain gets tired though”. At times, I experienced general fatigue as the following quote suggests: “I just remember being so wiped out”.

Fatigue was a major limitation to participation in activities of daily living and in a good quality of life. My response to the fatigue was to sleep. As time passed I felt less and less tired, but it was not until the symptoms resolved that the fatigue became much less.

Blurry Vision

Blurry vision was mentioned a number of times in the journal. What is interesting is that blurry vision seemed to have been made worse by other factors. In addition, I remember having blurry vision continuously for about the first eight months after my injury. After that, it was only when I was tired or did too much.

> It was mostly sore [headache] when I have lots of stimulus. Last night I was also feeling dizzy and had blurry vision too.

Looking back on the time where I had blurry vision, I should not have been doing certain activities, like driving. I did not want to give up my freedom and felt that, at the time, I could drive safely. Blurry vision is a symptom that has consequences and people with post concussion syndrome may not always be honest when it comes to reporting blurry vision.

Sleep

A change in sleep patterns was one the biggest changes I noticed as a result of my concussion. Before my injury, I needed about six hours of sleep. I have always been someone who stays up until about 2 or 3 AM. My sleeping patterns were disrupted as a result of the concussion. I slept about 18 hours a day until around November 18, 2000. That day was when I returned to my pre-injury sleep schedule, except that I needed about 10-14 hours, instead of the six hours I used to function on before the concussion. The following comments allude to the change in sleep patterns to pre-injury patterns.

> It seems that I'm back to my old schedule of being the most productive and pensive between 10 pm and 2 am.

It was also evident that sleep was still an issue after November 18, 2000 despite the return to pre-injury sleep patterns, as illustrated in the following quotes:

> For the past week I've been having trouble falling asleep. Even though I'm tired, it usually takes me almost an hour even though the drugs are supposed to make me sleepy.

Change of sleep patterns is something that was very prevalent during my recovery process. It was important that I listened to my body and slept when I was tired. If I did not, I always felt that the other symptoms worsened. My sleep patterns changed both in the duration of sleep but also in the difficulty I experienced in falling asleep.

Factors Influencing the Symptoms

Stimulus, doing too much, and taking care of myself emerged as factors that affected the severity and intensity of the symptoms. Doing too much was consistently mentioned when I wrote about bad headaches. Doing too much includes not getting enough sleep, staying up too late, and too much physical activity. Going to places where there was too much stimulus, such as movies, bars and shopping malls were also factors in the worsening of symptoms.

Doing too much.

Doing too much was something that I struggled with throughout my recovery. I wanted to accomplish the goals I had set out for myself, but in the process I often went too far. I would not get enough sleep, or eat enough and I would find myself in situations where I knew would make the symptoms worse. An example of this is expressed in the following quote.

> I over did it and felt pretty awful (nauseous, bad headache, really tired, and very sore). I think that by not taking it easy on Tuesday, and staying up late and then being really active all week, never giving me time to recover.

Stimulus.

Too much stimulus often made the symptoms worse. Florescent lights, lots of ambient noise in a closed environment or loud mechanical noise, and lots of visual movement are some of the types of stimulus that made me feel worse. The following quote expresses this:

> This headache leaves a strange taste in my mouth. Although I don't have much of a sense of taste, it is more like rust or maybe acidy. I'm not quite sure. It is made worse by florescent lights and lots of harsh visual movements and loud noises.

This second quote mentions mental stimulus: "Went to a movie tonight and found that the mental/ visual stimulus really hurt my head as well".

Self care.

When I did not take care of myself, the symptoms often worsened. The following quote written during my time in New Zealand expresses this.

> I spent a good 3 days sleeping. Since I bought the car, I have felt pretty awful. I really think being physically active is part of me feeling good. I really have not been eating well either, which is also contributing.

Self care is something with which I struggled. If I did not take care of myself then the symptoms were often worse, however, when the symptoms were bad, I did not take care of myself because I felt too tired, sore or sick to make the effort. The main things I needed to do to keep the symptoms from becoming too bad were ensuring that I slept enough, ate at regular times throughout the day, ate enough, and avoid situations that made the symptoms worse.

Medical

Another major category that emerged was medical. In the search for answers and for something or anything that would make the symptoms go away, I visited many medical and health care practionners. This section describes who I saw, the recommendations, the treatments, and the outcomes of the visit and/or treatment. I saw health care practionners in Montreal, Maine, Australia, and Alberta. The health care practionners recommendations were fairly consistent regardless of the province or country in which they practiced. This section describes my experience with health care practionners during the acute and chronic stages of injury.

The Acute Stage of Injury

The first type of health care practionner I saw was the emergency department doctor at a hospital in Montreal. I saw this doctor three days after the concussion. She did a standard neurological exam and after some persuading from my mother, sent me for a CT scan. The CT was normal. The recommendations were to rest. If the symptoms worsened, then I was to go back to the hospital. I was diagnosed with a concussion and sent home. The wait time to see the doctor was about eight hours.

About a month after the concussion, I was still not any better so I saw my general practionner. She did a standard neurological exam and confirmed the original diagnosis of concussion. She referred me to a neurologist. When I made the appointment for the neurologist, the wait was about three to four months.

About the same time I saw my general practionner, my mother called some friends and colleagues to find out more information on concussion and why I was not getting better. A colleague of hers' suggested we contact a neurosurgeon who specialized in sports related head injuries. Because my mother worked in the health care industry for 35 years, we got an appointment in two weeks, instead of waiting the usual four months or longer. This was late April 2000. The neurosurgeon scheduled an MRI, which was normal, and made a diagnosis of post concussion syndrome. She suggested I take another two weeks off work and rest. She also told me that I was not to be physically active until the symptoms went away. She gave me a copy of the return to play guidelines. At that point, she did not rule out the possibility of playing hockey again. I continued to be followed by this neurosurgeon for another year and a half.

Around the same time that I saw the neurosurgeon, I started to see an osteopath who had worked treating people with post concussion syndrome. The osteopath did cranial sacral therapy and osteopathic adjustments. She also suggested rest. I saw slight improvements in energy level, appetite, and headache pain. I found the treatments made things worse for a few days and then I started to see improvements. This treatment was especially hard on me, as it would take about two weeks or longer to feel well enough to do anything other than sleep. The long-term benefits out weighed how awful I felt after the treatments. I continued to see this osteopath off and on from about the end of April 2000 to June 2002.

The Chronic Stage of the Injury

During the chronic stage, I saw many different health care practionners. Some I only saw once while others I saw numerous times. I was looking for answers for why I was still experiencing symptoms, looking for something that would help to lessen the negative effects of the symptoms or to take them away completely, and generally learn more about post concussion syndrome. What I really wanted was to live symptom free again and to "get back to where I was before my concussion".

Neurosurgeon.

The neurosurgeon continued to follow me from when I first saw her in late April 2000. I saw her two more time after the initial visit. The first time was in early November of 2000. I distinctly remember sitting in her office that day. I also wrote a journal entry summarizing what happened during that visit. I asked if I would get better. I remember telling her that I did not have the energy and I could not work the way I was. I distinctly remember her response. She told me that she tells professional athletes and people like me the same thing. There is no "cure" and that in time I may get better but I may be like this for the rest of my life. She said that I should get on with my life and let pain and the symptoms be my guide. She said that no one could predict how long it will take to recover, if at all.

The second time I saw here was in late June 2001. I went to see her because I was still experiencing symptoms. That visit really hit me hard as she confirmed what I had already been thinking. The following quote explains more.

> I saw [neurosurgeon] on Thursday. She told me that, as I already know, there is no treatment for this and at this stage of the injury, I just have to live with it and get on with life. This is something that I knew but to hear it from her just makes it all a bit more permanent and made it hit home a bit harder. It FUCKING sucks. I'm really tired of all the stuff. She referred me to see

> [neurologist] but that appointment is not until September 17. All I really want is something to take away the pain on the really sore days. [Neurosurgeon] said that it was a reasonable request. I'm kind of bummed, not sure what to do with myself. I can never play hockey again... or contact sports and hitting my head again would be bad. I'm just bummed at the permanency of how it all seems. I don't want to live with it, mostly the pain.

Neurologists.

Another group of health care practionners I saw was neurologists. I saw two different ones, the first on November 8, 2000 and the second on September 17, 2001. Both neurologists said that there is no treatment for post concussion syndrome. They both said that rest and time are the major factors in recovering from concussion. Both neurologists prescribed medication to help with the headaches, one of which was an antidepressant. I took the drug for a while but found that the side effects were worse than living with the symptoms. I also was prescribed a variety of migraine drugs, but found that none of them had any effect on relieving the pain.

Osteopaths.

I saw three osteopaths in total. The first one was in Montreal. I saw her for cranial sacral therapy and osteopathic adjustments off and on from about six weeks post injury to late June 2002. The treatments were about 30 to 45 minutes long and usually made me feel quite sick after. It would take about a week and a half to feel somewhat normal again, and about three weeks to fully recover from the treatment. I always saw improvement however and felt that the treatments were beneficial over the long run.

This osteopath advised me on many aspects of my recovery. She suggested that I begin physical activity again starting with walking, skating or cross-country skiing. She discouraged me from contact sports until the symptoms were gone. She told me to participate in physical activity and other daily activities when I was felt ready. She also discouraged running.

Over the two years I saw her, I saw a decrease in symptoms, especially in headache, blurry vision, and nausea and increased energy and appetite. She also commented on the improvement she saw in me over time, specifically in the amount of deep work she could do and the reactions my body would have post treatment.

The second osteopath I saw was also the doctor at the wilderness therapy program where I worked in Maine. I saw him a few times because he was easily accessible through work and I did not have to pay to see him. I saw him mainly for information, in particular about MTBI recovery programs and support groups in the area. He said that I was likely to see the most improvement during the first year following the concussion. After that "what had not come back would be slow to come back or not at all".

The third osteopath was in Edmonton. I saw her for about six months starting in October 2002. The goal was to decrease the headaches. I reacted to the treatments but not as severe as the treatments I had from the first osteopath. I stopped going to the osteopath in Edmonton because I did not have health care coverage and it was too costly. I do not remember her telling me anything about recovery from concussion.

Sports Psychologist.

I began seeing a sports psychologist in Montreal in early November of 2000. My goal was to be able to work as a wilderness guide again. I needed to increase my physical activity level to where I could do the physical work involved in wilderness guiding. Part of the plan was to slowly increase the level of physical activity without the symptoms getting worse. I began by walking for 30 minutes and slowly increasing the time. I was also wall climbing. I tried skating and telemark skiing as well. In addition, we discussed a plan for a good diet. To compliment this, we spent a good deal of time working through mental and emotional issues related to healing from injury. We discussed retirement from sport and various methods of coping with the injury, the losses I felt, and visualization techniques the help promote healing. I saw the sports psychologist for about a year.

Other health care practionners.

I saw a naturopath in Montreal for the first year following my concussion. She suggested that I keep going to the osteopath I was seeing. She gave me some homeopathic medication to help the healing. I often felt really sick for about 24 to 48 hours after taking the homeopathic medication. In addition, she suggested that a change of environment from the city to the country might help promoting healing.

I saw a chiropractor in Australia. I saw her while I was travelling. She told me that I would feel better if my body was structurally sound. Realigning my body would help with the headaches and energy level. I saw her for a while but stopped because I felt that it was too disruptive to work and travelling at the time. I often had reactions to the treatment where I was unable to do anything the day after.

I saw a massage therapist in Maine. We worked on decreasing the headaches through massage techniques. I had some reaction to the treatments but in general it was okay. I found that there was little benefit because the positive effects did not last long after the treatment. She had no advice regarding recovery from post concussion syndrome.

Recommendations for Recovery

The major recommendation from the various health care practionners for recovery in both the acute and chronic stages was to rest until the symptoms went away. In addition, the neurosurgeon, the emergency department doctor, my general practionner, and the neurologists said that there was nothing they could do to "treat" post concussion syndrome. Nor could they make any predictions as to when or if I would fully recover. Both of the neurologists prescribed medication to help with the headaches. As the time passed, however, the neurosurgeon suggested graded return to previous activity using symptoms as my guide and a return or worsening of symptoms being the signal to stop.

The chiropractor, osteopaths, massage therapist and naturopaths each recommended some kind of treatment, whether it was a manipulative treatment as in the osteopathic, chiropractic or massage, or homeopathic medications in the case of the naturopath. In addition, some saw these treatments as complimentary to each other such as the osteopathic and the naturopathic treatments. I was also encouraged to begin light physical activity and to go back to pre-injury activities using symptoms as my guide.

Categories Specific to Phase Three

"Living without pain and actually SEEING and EXPERIENCING life once again. So cool!" The spontaneous healing on January 29, 2003 started phase three of my recovery process. This was when the symptoms disappeared and my brain was fully functioning again. For three years I felt like I was in a fog, that my thinking and processing were not sharp, and I often felt like I was oblivious to many of the happenings around me. In the absence of symptoms, I was acutely aware of my environment. The shear amount of stimulus that entered my brain was overwhelming. During the first month or so, I did not know how to filter out the stimulus. All the bits of information that entered my brain seemed to be of equal importance. My brain "waking up" was something for which I had been waiting and hoping but when it happened, I found that the world I "left" was nothing like the one I "woke up" to. I was fascinated by what I saw and all of the little subtleties in the world around me. I watched the traffic for the first four days after my brain woke up. I had to figure out how it worked before I felt comfortable navigating the city streets. It was all so chaotic. I went to the mall and watched the goings on to try to figure out how people interacted. I realized that almost none of the strategies I had used for the past three years worked with my fully functioning brain and the world around me. It was overwhelming to realize that I had to relearn how to effectively navigate my environment. In addition, I realized that I did not understand social cues that are common in social interaction. Because I felt that I missed most of the social cues, I shied away from social situations for a while.

These small realizations led me to a big realization that I would have to "trudge back to the bunny slope and start to re-learn how to snow plow...so to speak". This started the ultimate relearning process. I spent a lot of time at the indoor climbing gym watching social interactions. I observed people interacting in different places and in different contexts. I subtly tried little experiments on my friends and colleagues and watch their reactions to my body language and things I said.

I also spoke to a number of different people and told them what was happening. I asked each one to support me in specific areas of my life including academics, social and work. I wanted to make sure I had some people who I could consult if I had questions. In general, I did not consult these people, but knowing that I was supported and I had a place to go if I needed help was a very important step in my recovery process.

As time passed I became more and more familiar in my environment. I was able to spend more time relearning, redefining myself. I saw a new person emerge in the absence of pain and I really liked that person. I often commented in my journal that I saw three distinct people: one before my concussion, one during phase one and two, and the person who was emerging after the spontaneous healing. I felt that once I relearned enough skills to effectively navigate my environment, I would be fully recovered from concussion and post concussion syndrome, despite a few lingering symptoms.

There are two major categories that emerged from the journal that are relevant only to phase three. Relearning and re-growth, and self concept are important in this final stage of recovery. In the absence of symptoms, re-learning and forming a new self-concept separate from the injury could now take place.

Relearning and Re-growth

Relearning and re-growth emerged as a major category in phase three. I felt that I relearned many skills in a short period of time. This was at times difficult and I often wished I did not have to relearn. Social skills were one of the main things that I felt that I needed to relearn. I spent many days figuring out strategies for relearning skills. In addition, sorting out some of the emotional issues I had been dealing with was a major step in my personal growth and my success in recovery. The following quote provides some insight into what it was like when my brain began to function again.

> Waking up, my brain that is, is a bit like waking up from a very long sleep and while sleeping, the world has changed. It is completely fascinating to observe the goings on of the world. I feel like I have a ton of stuff to learn and figure out.

Part of the relearning process was identifying areas in which I felt I lacked skills and consequently figuring out a process for relearning those skills.

> I'm starting to get used to all this and starting to be able to focus on stuff like school. Stuff is all starting to work out or at least I'm starting to be able to find some way to harness the energy and put some of it into useful things. I'm starting to learn how to tame my mind a bit and in the past few days I have been able to start the process of learning about my new body and brain and the limits. All a huge learning process.

I felt the process of relearning was important but was also frustrated by it:

> I was kind of hoping that my brain waking up would be the end of that process and I would be to back just knowing how things work and I would just not have to go through the intense re-learning struggle all the time… that I would not have to go through the process of having to figure out what things mean first and then coming up with a plan and then struggling through the plan.

In the end, I felt successful at the relearning process and the strategies I had gained:

> I've spent the last 6 months or so figuring out the world and trying to sort out systems for coping. It's getting easier and easier each day.

Another aspect of the re-growth and relearning was dealing with my thoughts and feeling about being brain injured. One of the really positive things I did was spend some time sorting out the emotional and mental issues that had been plaguing me throughout the recovery process.

> There has been a pretty cool change, morph over the past month… I've been doing some house cleaning per say on the emotional front. I've done a ton of work, put to bed a lot of issues and also become way more comfortable with school (starting to figure out stuff) and my environment. The house cleaning has happened in the past 4 days or so.

In figuring out how I felt and taking a hard look at the emotions I felt, I was able to come to terms with the issues. It was a process that, once completed, enabled me to move on and feel good about my situation. I had accepted the consequences of my injury, as well as the deficits I still experience.

Self Concept

Self concept emerged as an important category in phase three. I often feel that my life has been lived by three different people. The person I was before my injury was vastly different than the one that lived through phase one and two of the recovery process. After the spontaneous healing of January 29, 2003 I felt a new person emerging and growing. As I recovered from the concussion, I sometimes felt that my family and my old friends expected me to be the person I was before my injury. Due to the memory loss, I cannot remember who I was before my concussion. The experience of post concussion syndrome and the recovery process changed me. The following quotes provide a perspective on the changing self concept I experienced:

> There is this really cool person emerging and I'm feeling more content and comfortable in my body and I really like the person that is emerging. I often don't know what will come out but I'm having fun and enjoying the feeling of content. I know that things will be okay.

I felt that subtle physical changes also occurred.

> Interesting thing, over the past 2 weeks, but really over the past week, I have been noticing that I look different. I wondered if it was because just seeing myself through "new" eyes but [friend] said that I look better after I told him that my brain woke up. [another friend] said tonight that I look different. When I asked her how she said that perhaps it was that I look more alert… but wasn't sure. Not only have I been checking myself out how I look different, but I feel fundamentally different as well. The person I was for the past 3 years is no longer and there is a new me. I'd like to give it time to grow and develop. I'd like to spend some time thinking and contemplating where to go and what to do next, essentially re-inventing myself.

Creating a self concept was one of the highlights of the recovery process. I was able to create a new person, a new sense of self and a new direction in life. The absence of a past and the absence of symptoms enabled me to do this. The majority of this occurred during phase three.

Conclusion

This chapter outlines the findings from a journal about recovering from post concussion syndrome that I kept for three years following my concussion. A description of my recovery process provides context for the findings. Three phases of recovery are then presented. Physical activity, frustration, coping, environment, social, and recovery strategy are categories that emerged throughout the entire recovery process. The medical and symptoms categories were relevant only to recovery phases one and two. Relearning and re-growth, and self concept emerged as categories that were only relevant to phase three.

There were a number of important aspects that emerged from the journal. First, my recovery revolved around symptoms or the lack of symptoms. During phase one and two, I was only attempting to get through the day. When the symptoms dissipated, phase three was spent re-acquainting myself with my world and relearning. I was able do this because I was no longer dealing with the symptoms. Second, physical activity was a very important part of my life, both before and after my injury. It was a coping mechanism, a source of frustration and pain, a way to measure improvement, a tool used in goal setting, a source of motivation, and something I sorely missed. Returning to my pre-injury physical activity was by far the biggest underlying motivation for my recovery. Third, coping played an important role in my recovery. There were positive and negative coping strategies. Fourth, social support, social skills, and connections with the past and others were aspects with which I struggled. Had I had better social skill, social support and connections, I feel I would not have engaged in negative coping strategies, such as drinking. Finally, my recovery strategy was centred on pushing the limits and setting goals. In achieving goals and feeling like I was moving forward, I was able to stay motivated.

CHAPTER FIVE: INTERVIEW FINDINGS

The findings from interviews with six athletes with post concussion syndrome are presented in this chapter, which is divided into two sections. The first section focuses on the participants, their experience with post concussion syndrome, and their return to physical activity. In this section, a detailed account of each participant's experience is followed by categories that emerged only from that participant and are relevant in gaining a more in-depth overall understanding of the recovery experience. The second section explores the main categories that were relevant to more than one participant. Symptoms, medical, and physical activity are the major categories that emerged.

Participants

A detailed look at the experiences of the six participants who were interviewed will help to gain a better understanding of the role of physical activity in the recovery process of athletes with post concussion syndrome. Each participant's experience is described focusing on how the concussion occurred, the symptoms experienced, the health care practionners visited, recommendations for recovery, and more. Categories that emerged from an individual interview but did not emerge from the other interviews are discussed at the end of the section describing each participant. These categories are included because they provide some further understanding and are relevant to the overall recovery process.

John

John is 33 years old, currently lives in a major urban centre in southern Alberta and works in the hockey industry. He has always been active in sports throughout his life, starting with high school football and rep hockey when he was in school. After high school, he played tier two hockey until he was 20 or 21 and then played various intramural sports. Before he sustained his last concussion, he played recreational hockey once a week, pick up basketball, football or soccer once a week and was physically active at least 3 times a week. He also lifted weights, biked and worked out at the gym.

John considered himself to be physically fit and feels that physical activity plays a large role in his life. He feels that there are many benefits to being physically active, although he no longer participates in physical activity because of the symptoms he experiences. Physical activity makes him feel healthier, think better, and gives him more energy. He believes that “you’re mentally stronger when you are physically fit”.

He has been diagnosed with four concussions. He lost consciousness in all four of his diagnosed concussions. The longest loss of consciousness John experienced was one minute. His first diagnosed concussion occurred at the age of 16 or 18 while playing football. The second and third concussions were sustained while playing hockey and the fourth concussion was a result of a car crash. It was after the fourth concussion, which occurred in February of 2003, that he began having lingering symptoms. John acknowledges that he sustained many more undiagnosed concussions over the years he played contact sports, although he did not realize it at the time.

Except for the most recent concussion, John has recovered from his concussions with no noticeable long term effects and in a reasonable amount of time. After his fourth concussion, John experienced memory loss, dizziness, nausea, blurred vision, disorientation, lack of concentration, irritability and headaches in the acute stage. John took about three days off of work and said that he felt “a bit” normal after about 10 days.

The symptoms he currently experiences include disorientation, lack of concentration, headaches, blurry vision, irritability, and slurred speech. He also has significant memory loss. During the interview, he describes the headaches he experienced over the last few years: “I’ve been getting a lot of headaches. Um, the last 2 years, I think… every now and then I’ll get that piercing one right through…it just feels like someone’s driving a spike through your head”. The severity of the symptoms he experiences vary depending on the day, hours slept, the quality of his sleep, the demands of his job, and if he attempts to be physically active. He no longer does any physical activity because the symptoms worsen when he is physically active. John feels that he is more tired and run down because of his inability to be physically active.

John has seen a number of medical practionners over the course of his four concussion diagnoses including a family doctor and a doctor in a clinic. After the car crash, John was taken to the hospital by ambulance and saw the emergency department doctor. It was there that he was diagnosed with his fourth concussion. When John went to the emergency department following his car crash, he received a CT scan. This scan revealed a contusion and bleeding on his brain, but it was determined that he did not need surgery.

It was not until he was forwarded the information about this study that he really took stock of his situation and the effects of his concussion. It was because of this that he began to question the symptoms he has been experiencing, consulting his wife and co-workers about his change in behaviour since his car crash, and finally sought the advice of a sports medicine doctor to determine if his symptoms were indeed due to his concussion. John is fortunate. He has fast and easy access to knowledgeable sports medicine doctors and physiotherapists who treat professional, national and elite level athletes because he works in the hockey industry

The doctor confirmed that he had post concussion syndrome and began to explore the extent of the symptoms and effect on John through a number of questionnaires and tests. The sports medicine doctor had John fill out a questionnaire rating the severity of the symptoms John experienced. Memory tests and a basic physical neurological exam were also administered.

John began to visit a physiotherapist to help him resume physical activity. He began by riding a stationary bike under the supervision of the physiotherapist. He started off at five minutes. He was advised to stop if the symptoms returned. While he was riding the stationary bike, he wore a heart rate monitor to ensure that his heart rate was below or at the predetermined target rate. John rode the bike almost daily for about two months but stopped going because he was frustrated after not seeing any improvement. The longest time he was able to ride the bike without symptoms was six minutes. He often felt dizzy and his headache returned. He was told by the physiotherapists and the sports medicine doctor not to "push through it" and continue on despite the symptoms. He took their advice and stopped when the symptoms returned.

Of all the health care practionners John has visited, he feels that the sports medicine doctor has given him the most information about concussion and post concussion syndrome. It is because of the sports medicine doctor that he has taken concussions more seriously. It seems like John has gained respect for this particular doctor because he has been honest about the prospects of recovering from post concussion syndrome, namely that there is not much known about concussion and that although he may recover, there is a possibility that he may not. In addition, he spoke about the possible consequences of sustaining another concussion while still symptomatic.

Despite the very positive experiences with the sports medicine doctor and the physiotherapists through his place of employment, John was not impressed with the quality of the healthcare provided when he sustained his first three concussions. In general, he felt that the health care practionners at the emergency department and the clinics he visited did not give adequate information and that the visit was rushed.

He feels that the concussion has affected his life in a number of areas, such as his employment, his recreation and his family life. He finds that he often forgets things, which has direct consequences on his job performance. He often feels unwell, has headaches and is irritated. He has stopped all form of physical activity as recreation, which he finds difficult as he has always been a physically active person. His co-workers and wife have all noticed a difference in him since his fourth concussion.

John feels that his lingering symptoms are the major barrier to being physically active. After he sustained his fourth concussion and before he began seeing the sports medicine doctor, John continued to play recreational hockey once a week and other sports activities but he found that he became dizzy, disoriented and had blurry vision when he exerted himself. Before his fourth concussion, he was able to participate in physical activity at a high intensity level. After his fourth concussion he is only able to participate at a low intensity level. He expressed frustration over his inability to be physically active at his pre-injury level.

John felt that there were both benefits and drawbacks to being physically active while recovering from post concussion syndrome. He feels good about himself and healthier when he is physically active, however he cannot do what he did before because it is "too disorienting" and he becomes too dizzy. He reiterated that physical activity and mental contentment go hand in hand. He feels that because he is not currently physically active, he is worn down, tired and more irritable.

The experience of recovering from post concussion syndrome has raised John's awareness of concussion and the long term effects that can result from concussions. He has gained a better understanding of the numerous hockey players who have been forced into retirement due to the effects of concussion. Perhaps the most salient comment that John made was regarding some advice that he received from the sports medicine doctor: "you have to address the issue because it won't go away. This is not going to go away like a sprained ankle". In the end, John expressed hope that one day his symptoms would just "go away" and he would then be able to return to pre-injury levels of physical activity.

Frustration

Frustration emerged as a main category for John. Throughout the interview, he often mentioned that he felt frustrated by his inability to do any symptom free physical activity. He expresses this frustration in the following quote:

> That's the biggest thing, It's just so frustrating… and those…. The guys [physiotherapists] downstairs are really, really good about it but you just get so frustrated. Like why can't I bike for more than… and you try to think "well, you now what, I'll push through it". That's one thing they make sure…do not try to push through it. This is not as if you are tired and you're trying to push through the burn and whatnot… you have to stop. Well, I'm getting dizzy… I got a headache.

He refers to not "pushing through" the symptoms as many athletes do when they are injured. John listened to the sports medicine doctor and the physiotherapists and stopped his physical activity when the symptoms returned. Others did not. He elaborated on his frustrations and his lack of participation in physical activity in the following quote:

> I don't do anything now and it's because I get too dizzy and it's... It's, you know, just too disorienting and I can't do it the way I used to do it. So I guess mentally the drawback is that you can't do what you used to be able to do. It's frustrating.

Attitude towards Concussion in Hockey

John spoke of the attitude toward concussion in hockey and about how people do not recognize that they have had a concussion.

> And in our sport [hockey], you don't cry about getting your bell rung, I mean, you gotta keep playing. Um, if you have a broken arm, broken leg, something physically that they can see, that's a bit different story. But you never go and say you're feeling dizzy and stuff like that, you just play through it. Scary to know how many times you knocked in the head that weren't diagnosed.

This attitude may not be isolated to hockey.

Jen

Jen is 23 years old and lives in rural, Minnesota. She is a college student at a State College and played varsity basketball on a division two college team. She has played basketball for the past 15 years. She has always been physically active and sees benefits in pushing herself physically. In the past, she used physical activity to get her frustrations out and finds that if she does not exercise everyday, she becomes crabby. She views herself as a basketball player and enjoys being a part of a team and what it represents. When she sustained her concussion, she was in her fourth year of eligibility to play college level sports.

Her concussion occurred on December 4, 2002 during a basketball practice when she collided with another player and hit her head. The main impact point was right behind her ear. She did not loose consciousness and kept playing. That weekend, she left on a road trip with the basketball team. The team had two games that weekend. She played in both of them although she was in "la la land". It was not until four days later that she told the team's athletic trainer about her concussion and related symptoms. She did not want to say anything but a friend encouraged her to bring her concussion to the attention of the athletic trainer. The athletic trainer scheduled an appointment to see the general practionner the following Tuesday.

During the acute phase, Jen experienced blurred vision, tunnel vision, dizziness, severe headaches, lack of concentration, fatigue and an increased need for sleep. During the chronic phase and at the time of the interview, she experienced severe headaches daily, fatigue, sensitivity to light and sound, lack of concentration, is easily over stimulation visually and auditory, and she developed depression.

In the year and a half between the time that Jen sustained her concussion and the time of the interview, she visited many different health care practionners in an attempt find some treatment for a number of symptoms that she experiences. The general practionner, who she saw shortly after sustaining her concussion told her that she could not exercise until she was symptoms free for one week. Then she could slowly return to physical activity starting on a stationary bike and working her way "back onto the court" for practices and eventually for games. She never reached a week without symptoms so she eventually lied about being symptom free because she "wanted to get back on the court so bad". It took her two months to return to play a few minutes in a varsity basketball game, although she was still experiencing symptoms and she lied to her coaches and athletic trainer telling them that she was symptom free. This was because she was in her last year of eligibility to play at the college level. He comment on this was "I just put up with the excruciating headaches but I just wanted to play 'cause it was my last year".

Despite her eagerness to play, she experienced very bad headaches, tunnel vision, and dizziness when she played basketball and engaged in other forms of physical activity. She finds that the symptoms worsen when she raises her heart rate during physical activity however she is currently physically active despite the return of symptoms, the fatigue, and severe headaches she experiences. She finds that sleep is the only thing that helps to reduce the severity of the headaches and the other symptoms.

She is currently physically active playing pick up basketball three times a week, lifting weights four times a week, running on a tread mill four times a week and teaching water aerobics two times a week. Despite the amount of physical activity Jen does, she has yet to be symptom free and has not been able to return to play basketball at the competitive level, or even in formal team play.

Jen feels that being physically active despite the symptoms is important because it makes her feel better and it is a benefit in her life. She did express that the major drawback is that it makes her head hurt and, at times, makes her very tired. The concussion has had a major effect on her life. She had to take extra time to finish her college classes and it will take her one extra year to complete her college degree because of the fatigue and the lack of concentration she experiences. She finds it very difficult to be in public places because of the stimulation and ambient noise, therefore feels that her social life is sometimes limited. She finds that she can deal with social settings where there is relatively little ambient noise or in one on one situations. In addition, she finds that she is often frustrated with her situation. Jen's family and friends have noticed a difference in her since her concussion, especially in the amount of time she spends sleeping and her lack of energy.

Because of the length of time that Jen's symptoms have lingered, she has visited many different health care providers. She visited two general practionners, two different neurologists, a neuropthmologist, a chiropractor, an optometrist, and a visual therapist. She was referred to the optometrist and the neuropthmologist because as she describes:

> Cuz, a lot of my headaches came on to like, so much in my visual, like, like at practice when there's like so many people running around and there's balls flying everywhere... it's so much for my brain to like, um, process that it would just like confuse me and like give me a headache. So they thought "well, maybe there's something wrong with your eyes". If your eyes aren't working together or something...

Both of these health care practionners and the visual therapist said that there was nothing wrong with her eyes.

She visited two different neurologists. The first one prescribed some antidepressant medication. Jen did not find the medication helpful and after expressing this to the neurologist, the dose was increased quite a bit. Jen found that the antidepressant drugs caused unpleasant side effects and she could no longer function well in class and other areas of her life. She took herself off these drugs with appropriate supervision and then tried three or four other antidepressant drugs. She does not think that they really helped. The second neurologist she saw is a specialist at the Mayo Clinic. This second neurologist prescribed antidepressant medication, although it was one that Jen had already tried. Both neurologists told her that she would eventually get better by taking the antidepressant medication and in time. They told her that sometimes symptoms of concussion last longer than expected. She did express feeling that the neurologists did not take enough time with her or answer her questions.

Jen was given a CT and an MRI scan, which were both normal. Because she was a member of the varsity basketball team, she took the ImPACT test at the beginning of the season. In order for her to return to basketball, she had to retake the ImPACT test and her post injury scores needed to the same as or better than her pre-injury test scores. The first time she took the test post injury, she saw a significant decrease performance in all areas of the test. After taking the test a number of times, she did see some improvement in the test results but she said that while her symptoms and the effects of concussion remained the same, the improvement on the test scores was because she was learning how to take the test.

Jen was given one sheet of written information on what to look for and expect in the acute stage of the concussion, but was given no written and little verbal information about post concussion syndrome or return to sport and physical activity. Jen was being monitored for a while by the basketball team's medical staff but her return to physical activity has been mostly done without supervision. While she has been told that she should wait until she is symptom free before resuming physical activity, she has disregarded these recommendations because she feels that the benefits of being physically active despite the symptoms outweigh the negatives. She is frustrated that she cannot participate at her pre-injury level of physical activity. She generally tends to push through the unpleasant symptoms that she experience in part because of how regular physical activity makes her feel after she is done her work out.

Coping

Jen used physical activity to cope with being depressed. She expressed that being physical activity helps her feel better.

> it makes me feel better cause it helps me… I like developed depression and um, it helps me feel better… like… "ok, I'm out there and doing the stuff I kinda used to do before" but at the same time it'd hurt my head. And I would usually take at least a 2 hour knap after I worked out, you know.

She ultimately expressed that physical activity helps her cope mentally and emotionally and helps her to maintain a sense of normalcy, but it aggravates her symptoms.

Sandy

Sandy is a 22 year old university student. She is currently pursuing an undergraduate degree and lives in a major urban center in central Alberta. Her family lives in British Columbia where she lived until she moved to Alberta. She is passionate about soccer and has played at the elite level. Soccer has played a very large role in her life. She loved winning, the game, and she was good at it. Before transferring to the University in Alberta, Sandy played soccer for the college she attended in British Columbia.

She sustained her first concussion when she was playing floor hockey in a Grade 11 physical education class. One of the opponents missed the ball and hit her head instead. She said that she has "technically" had 13 concussions, technically meaning that the little ones do not count. Of the 13 concussions, she has lost consciousness three times. The longest loss of consciousness she experienced was 30 seconds.

Her last concussion was April 22, 2003 when she was kicked accidentally in the head while playing in a soccer game. Sandy was playing in a provincial tournament. She was recovering from a concussion she sustained a week earlier during practice. She had been cleared by a doctor to return to play. At the time, she had decided not to head the ball when she played soccer; however she decided to resume heading the ball during the provincials and said that she felt slightly dizzy, disoriented, and off balance during the game. Then she tackled a player from the other team and continued playing despite feeling “like crap”. There were five minutes left in the half and she decided to wait until half time to make a substitution. It was during this time that she sustained her last concussion. The ball was bouncing to the side and a player from the other team went to clear the ball. Sandy’s head got in the way. She does not remember much about what happened next, but does remember feeling very sick and throwing up. She was told that she was down on the field for about 15 to 20 minutes. She went to the hospital in an ambulance. The provincials were on Vancouver Island and Sandy was eager to catch the ferry back to the main land. The hospital let her go sending her away with a “blue sheet” of paper and with instructions on what to do if her condition worsened during the acute phase.

The acute symptoms that Sandy experienced after her last concussion included nausea, loss of memory, irritability, loss of concentration, headaches, vomiting and loss of balance. Some of the symptoms persisted and at the time of the interview Sandy experienced memory loss, irritability, distractibility, and lack of concentration. Other symptoms, in particular dizziness and light headedness, return when she is physically active and raises her blood pressure. Sandy was given a MRI because the CT scan showed some abnormalities. The MRI did not show anything convulsive.

Before her last concussion, she played elite level soccer and was very physically active playing pick up football and shinny hockey with her brothers. Sandy used physical activity as a form of stress relief and she felt good because she was staying in shape. She played sports to get exercise and is not keen on “just” working out to stay in shape.

Sandy has seen a number of health care professionals since her last concussion. One of the health care practionners she saw regularly was a physiotherapist who specializes in concussions. He administered the Folstien Mini Mental test, with which she had difficulty. She took this test a few times and expressed that with experience, she learned how to take the test and practiced before visiting the physiotherapist. The physiotherapist told her that she is more susceptible to concussions because she has been concussed many times. Sandy was told about second impact syndrome. The physiotherapist suggested that she never play contact sports again, but recognized that she would play soccer again so he told her to be careful and wear helmets when playing sports that allow them.

In addition to the physiotherapist, Sandy saw a family doctor who referred her to a neurologist. The neurologist told her that she had inner ear damage as a result of the concussion and treated her for this. It was the neurologist who sent her for the CT and MRI. She has had three CT scans and one MRI since her first concussion in Grade 11.

She has received numerous information sheets outlining what to look for and expect in the first 48 hours after the concussion and what to do if the symptoms worsen, but nothing written about post concussion syndrome or return to play. None of the health care practionners recommended physical activity as part of the recovery process, only that she needed to be symptom free before resuming physical activity.

For the first two or three months post injury she was told that she could not do anything that would raise her blood pressure. After two or three months, the physiotherapist allowed her to do yoga or Pilates and begin walking. After a while, she was able to try running but was told that if she felt dizzy, she was to stop exercising. Because she was persistent, she was eventually allowed to practice with her soccer team running up and down the side lines passing the ball. Despite clearance from the physiotherapist to begin walking and running, she felt very unmotivated and did not participate in any form of physical activity. She noticed changes in her body as her muscle mass decreased from the lack of physical activity.

In general, she has been told that she should never play soccer or other contact sports again. If she decides to play soccer again, she is advised to never head the ball and in other sports, to wear a helmet. In contrast to the advice of the specialists, she was told by the emergency department doctor that she can play soccer again as long as she is symptom free for seven days. Despite the variations in opinions about recovery and return to physical activity, she felt that her experience with health care practionners was generally positive, especially with the physiotherapist she was seeing regularly.

Looking back on a previous concussion, she told me that she wanted to return to play so badly that she lied about her symptoms. The athletic director of the college said that she needed a note from a doctor clearing her to play. So Sandy went to the school doctor who was not aware of her history of concussions and her lingering symptoms. She was given a note clearing her to play, but she was not allowed to head the ball. When asked why she lied to her coach and athletic director, she said that she did not understand the possible consequences of playing while still symptomatic. She said that she was never told that a concussion could have the long term effects that she is experiencing.

The concussion has affected her life in that she can no longer play soccer. Soccer is the love of her life and not being able to play has left a big void. She had tried other non contact sports, but they do not replace soccer. The physiotherapist she was seeing told her that she should at least wait a year before she begins to play soccer again. One of the main questions she posed is "what am I going to do for the rest of my life? Not play soccer, not play hockey?". This is a valid question. Despite the advice of the health care practionners, Sandy was playing drop in soccer at the time of the interview. She reported experiencing symptoms but played anyway. She said that they are not as bad the longer she plays. She currently plays drop in soccer three times a week and tries to run even though she dislikes running. She is able to participate in physical activity at a moderate intensity level. She still becomes light headed.

She feels that lack of motivation, limitation in the types of physical activity and symptoms were the main barriers to physical activity post injury. She expressed that she misses playing soccer because it was her "entire life" before the concussion. She acknowledged that her career as an elite level soccer player is over although she contradicts herself by saying that she is planning to play elite level soccer again.

She struggles with some of the lingering symptoms and although they seem to have not affected her ability to achieve in university, they do affect her life outside of school. This is especially poignant with regards to her memory. Sandy is aware of the potential consequences of sustaining another concussion, as she has already experienced what it is like to struggle with post concussion syndrome however the temptation to play and her lover for soccer again is still very strong.

Attitude towards Concussion

Sandy's attitude towards concussion was interesting. She acknowledged the severity of her symptoms and that she had sustained 13 concussions in about 5 years, yet was considering playing elite level soccer despite the doctor's advice to retire. She suggested that "you know like the little ones don't really count. Ummm, someone's going to hear this and say "oh my god... they do". After visiting the specialist, who told her that she should never play again and informed her about second impact syndrome, she said the following: "I was first told of second impact syndrome.... Scared the shit out of me". She learned that because she has had numerous concussions, she is more susceptible to being concussed in the future. Despite the knowledge that she gained from the health care practionners she returned to playing drop in soccer.

Sandy's attitude towards concussion was contradictory. On the one hand, she is knowledgeable about the risks of playing with symptoms and the risk of sustaining another concussion given her history, yet she chose to play contact sports while experiencing symptoms. At one point, she recognized that her career as an elite soccer player is over because of her concussions: "I went to school to play soccer and now I can't play so I'm like ah, I guess my career's over". At the time of the interview, however, she had located a premier team to play for during the up coming summer season. She summed up this contradictory attitude towards concussion as "Not in my best interest but... I can't really stop myself".

Dawn

Dawn is 39 years old and lives in a major urban centre in southern Alberta. She is a high ranking national level skeleton racer and competes for Canada. She sustained her concussion on January 30, 2003 at a world cup race in Germany. This was her first concussion which occurred when she entered a corner late and her sled flipped over. She fell from about 12 feet and slid on her back for another 3 corners of the race track before she stopped. She sustained the concussion when she was spinning on her back after she fell off her sled.

Dawn has been an elite athlete in a number of sports. She said that she is either a "sloth or and elite level athlete". At the time of the interview, she was a member of the Canadian National Skeleton Racing Team. Part of her training included sprint training and weight training. In addition, she does yoga and Pilates. She usually trained two to three hours a day before the concussion. Before her involvement in skeleton racing, she was ranked second in the world in power lifting, was a professional body builder, and was ranked third internationally in bob sleigh.

Her acute symptoms included severe headaches to the point where she thought her head would explode. She felt nauseous and she could not stand up for any length of time because she would become extremely dizzy. Dawn had difficulties speaking, especially verbalizing what she was thinking. In addition, she developed insomnia about a week after the crash. She experienced difficulty writing coherently. The acute symptoms lasted between a week and two weeks. Chronic symptoms included panic attacks, headaches, lack of patience, frustration and anger. The chronic symptoms were present for about a month to a month and a half, with the exception of the panic attacks, which lasted longer.

The panic attacks would occur while she was on the track racing. Dawn realized that she was experiencing panic attacks about two months into the new season of sliding because she was loosing a significant amount of time in the bottom half of her run. She would begin her run and be doing well. She was typically fast coming into the high G force corner two thirds down the track. As Dawn explains:

> And what would happen is my entire body would cease up, my head and my shoulders would come up, and um, it was like I was bracing for another crash. What else happened was, the doctors figured that my eyes were going in the panic mode and the rapid back and forth movement or something, because even though I had my eyes wide open, I couldn't see. We realized that in Germany when I was going into the high G corner, where you need to watch the wall beneath you for the oscillation, cause it just feels like one big pressure otherwise. And I would see the first one and I wouldn't see anything after that, it would just be black, even though my eyes were wide open, so I would crash out of that corner every time. I didn't get another concussion

> there, I was just battering myself up because it wasn't that bad of a track, it wasn't that hard of a track.

It was her body thinking that the crash was going to happen again.

She began to seek solutions to her panic attacks because she wanted to continue racing at the world class level. She began to use EMDR, eye movement desensitization reprogramming, to retrain her brain so that she would not have panic attacks on the track. EMDR begins by visualizing whatever it is that brings on the panic attack. In Dawn's case this was the crash in Germany. Dawn explained how she used EMDR:

> ... It's whatever is bilateral stimulation to the brain. And it just... it helps to... it helps the brain to file away the experiences and, you go over and over the visualization, until the stresses start to relieve. And you go through it over and over again until there's nothing there.

EMDR is generally used by therapists, such as psychologists, but can be administered by other health care providers. It is possible to practice EMDR at home and Dawn still does EMDR using a small machine that has two pulsers attached to provide electrical stimulation. The person holds one pulsar in each hand.

Dawn saw a number of different health care practionner over the course of her injury. She sustained her concussion in Germany and there were no medical staff travelling with the Canadian team in Europe so she was pretty much on her own when the crash occurred. An American team doctor did consult with her and gave her some anti-nausea medication and a pain killer. The American team doctor, who is an emergency department doctor, told her that if she walked into his emergency department and he was treating her, he would admit her right away because she could barely walk and was quite out of it. As it turns out, she did not go to the hospital in Germany.

After Germany, she travelled with the team to Japan for another world cup race. She did not race in Japan but did see the team Canada chiropractor. He explained the return to play guidelines to her, but she feels that the guidelines are not specific enough to determine whether an athlete is ready to return to skeleton racing. As she put it:

> we need a little more hands on supervised stuff like that because we go from jogging around, you know the block and doing a sprint session to hurtling our bodies a 124 km an hour so... it's a big jump, you know... for us.

When she returned to Canada, she visited her general practionner who sent her for a CT scan. It came back normal and she started training again. She went to see her chiropractor and massage therapist to treat the neck pain she experienced. The massage therapist did active muscle release to relax the muscles and to relieve the pain at the base of her neck.

The concussion affected her life immensely. She did not race in the other world cup races, greatly affecting her international ranking. She ended up finishing the season at 17th in the world and lost her government funding. Although she represents Canada in skeleton racing, and has consistently placed in the top ten in the world throughout her career, she still has to pay for all of her own travel and other expenses associated with her sport. There are only a limited number of carded racers per sport and in skeleton racing there are fewer cards than athletes on the Canadian National Skeleton Racing team. Being carded means that the athlete receives $18 000 tax free from the Canadian Government to help out with the athlete's expenses. She lost her carded status because of the effects of the concussion.

In addition, she runs her own business making racing suits for luge, skeleton and bob sleigh racers and was unable to work for a while, resulting in more financial losses. As it is, the commitment to training and racing take up quite a bit of time in Dawn's life. She is on the world cup race circuit for approximately four months each year and then there is all the time she spends training. Thus, at the very least, she takes four months off of work each year to compete. Couple this with the time that she took off work because of the concussion and related symptoms, she experienced significant loss of income, which is important as she has a family to support.

She found that her ability to be physically active while symptomatic was drastically reduced. Now that her symptoms have resolved and her panic attacks are under control, Dawn has been able to resume her pre injury level of functioning in all areas of her life. She expressed that fear was a barrier to being physically active while she still experienced symptoms. She did not even want to participate in yoga because the symptoms would return when she did participate. While she did not have pressure from her coaches to return to her sport before she was ready, she did feel some pressure from her team mates. They felt she was overreaching.

At the time of the interview, all of her symptoms had cleared up and she had resumed racing and training again. She was still working to control the panic attacks, but seemed to be successful. While she had resumed normal life again, she expressed that when she was still symptomatic, her symptoms worsened when she increased her heart rate, specifically dizziness, headache, and nausea. She expressed that she felt lucky to come out of this experience and live a normal life again with no long term effects. She is currently advocating for better education and training for coaches, doctors, trainers, and event organizers in her sport about concussion and the proper care in the acute phase, as well as during the chronic phase.

Coaches, Athletes, Trainers and Organizations' Knowledge of Concussion

Dawn feels that there is a lack of knowledge in her national sport organization about concussion and of the serious consequences of sustaining a concussion. She feels that many mistakes were made in the weeks following her concussion. The following quote provides some insight into her experience:

> Well what I've done is made some ah recommendations that #1 that there's a certain level of training that's mandatory for all coaches or managers, um, that are traveling with the team. Cause we're not always with a medical person. I mean if, almost everything that could have been done wrong in my case was... so I'm just really lucky that I came out of it ok. And can go back to racing... and can go back to a normal life... but ah, you know... there is absolutely no way that it should be up the injured athlete to figure out what they should do. There should be a plan in place and a protocol in place that is more detailed than the return to play... and that insists there be supervision...

Dawn expressed the importance of having support for injured athletes so that they do not have to make decisions about their care in the case of a head injury. She felt this was important because after she sustained her concussions, her mental state was not clear enough to make decisions about her medical care.

Angela

Angela is 33 years old and lives in a medium sized northern Alberta town. She has sustained two concussions, the first when she was 15 years old and the second on August 2, 2002. She has always been active in sport and physical activity.

Angela quickly recovered from the concussion she sustained when she was 15 however the concussion that occurred on August 2, 2002 took longer. It was a very hot summer day and she had played a rugby game. After the rugby game, she and her team mates went out for some beer. Angela had four drinks and, not feeling well, went home. She drank little water that day and did not realize that she was dehydrated. As she walked up the walkway to her house, she blacked out and fell, hitting her head on the concrete close to the door step. She was unconscious. Her dog came over to her and began barking. The neighbors, upon hearing the dog barking came out to see what was happening and called an ambulance. She was unconscious for about 45 minutes. The dog barked until she came to and talked to him. When she fell, she hit the concrete so hard that she had two black eyes and could not see. She was at the hospital for about six hours. The doctors told her that her retinas were detached and she needed to wait until they reattached themselves. She waited about four hours until her sight came back. Then she waited another two hours just to ensure that everything was going back to normal.

Before her concussion, she was physically active between 6 and 7 days a week. She alternated between lifting weights, cardio work outs, rugby, hockey, running stairs and yoga. She finds that physical activity is a stress reliever. She is a police officer and finds that her job is often stressful. If she does not get enough physical activity, she finds that she does not sleep well, she does not eat well and she is less focused. She feels that physical activity is a huge part of her life.

After her concussion on August 2, 2002, she experienced numerous acute symptoms such as vision problems and loss of vision, nausea, sore neck, dizziness, and lack of focus. The doctor at the emergency department gave her an anti-inflammatory medication which caused her to sleep quite a bit in the first week following the concussion. She took two weeks off of work because she could not focus well enough to do her job.

She began exercising two weeks after her concussion. When Angela exercised, her symptoms worsened and she felt dizzy, saw stars and felt nauseous. It took her about a month to feel good again, although she was still not entirely symptom free with intense physical activity. It took her about three months to be able to exercise at a high intensity level without symptoms. Even two years post injury, she still experiences "seeing stars" if she raises her heart rate too high when she is physically active, although this rarely occurs. Angela feels that the most significant long term effect of the concussion is that she slightly more hesitant when she is playing sports. She does not want to sustain another concussion. Angela experienced the return of symptoms with an increase of ambient temperature.

She noticed that smaller, less significant hits in her rugby games sometimes brought back slight symptoms of concussion. Shortly before the interview, she had been in a snow mobile accident and she gently knocked her head when she crashed. When she went to the doctor, she was diagnosed with Miners disease which she describes as

> "it's a thickness... when your spinal fluid and whatever else that goes in your ear drum, um, it gets thick and causes a balance problem and nausea and sickness and it's usually results from after you've hit your head".

Her doctor felt that the slight knock on the head she received when she was in her snow mobile accident would not have caused this so he attributed it to her concussion in 2002. This resolved itself over time.

Angela saw a few health care practionners over the course of her recovery. The emergency department doctor was the first health care practionner she saw. All she was told at the hospital was that if her symptoms worsened she was to return to the hospital. She was not given any written information about concussion. Angela wondered if this was because she often works closely with the hospital, because of her job as a police officer, therefore the doctors assumed that she already knew what to do.

A few weeks later, Angela visited her general practionner. She was sent for a CT scan and referred to an ophthalmologist because of her visual problems. The results of the CT scan were normal. The ophthalmologist said that everything looked like it was healing well and continued to monitor Angela's progress. Her general practionner suggested that she not do any physical activity for a month and no contact sports. He continued to follow Angela for the next month or so. Her general practionner was concerned about the severity of Angela's concussion because she had two black eyes as a result of hitting the concrete walkway. He gave her a sheet with acute symptoms and some information about what to expect in the first few days following a concussion, however all the information about return to physical activity and to her job were verbal. After one month had passed, she was told that she could resume physical activity when she felt ready. Her general practionner trusted her judgment and told her to let her symptoms be her guide but contact sports were out of the question while she was symptomatic. Despite the recommendation not to resume physical activity until a month had passed, she began to be physically active after two weeks.

Angela felt that there were benefits to being physically active while still symptomatic. She did what she felt she could and stopped when the symptoms became too bad. She does not think that her symptoms lasted longer because she was physically active while still symptomatic. She felt that the benefits were both mental and physical. She expressed this well.

> like you're already feeling bad already, you're feeling crappy and you don't get the exercise... more of a mental thing... so I think there are more benefits to physical activity than to just wait it out.

Angela felt that the longer she waited to resume physical activity, the longer it would take to get back to her pre-injury level of physical activity. She would have to start from the beginning. She experienced frustration and disappointment over not being able to play her sport and be part of her team. Physical activity helped her to deal with these frustrations and disappointment.

Angela decided to sit out the rest of the rugby season. It was a tough decision because she loves playing sports, but sports do not pay her salary. In the end, she felt that her job was more important than playing sports. She made this decision in part because of the information that her general practionner gave her. She felt her decision not to finish the season was supported by her coach and her team mates and she acknowledged that most of the pressure to play came from her. She also thought that she was letting her team down by not playing the rest of the season.

Her concussion had a big effect on Angela's life while she still experienced symptoms. She was put on a desk job until she was cleared by her general practionner to return to her regular duties. She did a desk job for about a month and was unable to participate in sports as she did before. Angela was fortunate because she recovered from the concussion and currently experiences no long term symptoms. In general, her experience with the health care system was positive. She does feel, however, that she should have been given more information at the emergency department. When asked what she learned from the experience, she said that she does not think that there is enough awareness about concussion by players, coaches and others in the sporting community to which she belongs. She said that the "play through injury" attitude is still very prevalent and that in the case of concussions, this may not be the most beneficial attitude.

Awareness of Concussion

Angela felt that there was a lack of knowledge about concussion and post concussion syndrome in the recreational sports she plays. She feels that there should be greater awareness of concussion by the athletes and coaches alike. This is evident in the following quotes:

> Interviewer: do you find that in Rugby, here in [name of town], is there a general awareness about concussion... on the teams that you play?
>
> Angela: no, you know what? I don't think so, I don't know if it is a tendency for people to say I'm tough, I can handle it. So just from my experiences, I don't think people really have, um, you know, the knowledge.
>
> Interviewer: The coaches and the training staff... awareness about concussion...

> Angela: um, honestly, in my experience, in... at least the level that we play, um I would say not. I would say that there isn't a big awareness... maybe it is because of the sport that we play.

Angela expressed that attitude and awareness about concussion from coaches, trainers and athletes alike seemed to be lacking in the rugby community to which she belongs. She attributed it to the attitude of the sport of rugby. It seems that attitude towards, and awareness of, concussions in sport need to change in order for athletes to feel comfortable telling their coaches and trainers about their concussion symptoms.

Michelle

Michelle is a 19 year old university student who lives in a large southern Alberta urban centre and attends the local University. She has been active in sports throughout her life. She played basketball, volleyball, rugby, baseball, works out and lifts weights. She has had three concussions, two in 2001 and one in January of 2002. Two concussions were sustained playing rugby and one occurred while playing basketball.

Before her last concussion in 2002, she was playing high school basketball and rugby. Her latest concussion occurred when a basketball hit her forehead. The basketball season is usually during the winter. Rugby season begins in March. At the time of the latest concussion, she was playing basketball. She participated in one basketball game and two practices a week. Physical activity is an important part of her life. She finds that physical activity helps her to be mentally and physically healthy. She feels that she does not get sick as often and experiences less depression when she is active. The only drawbacks to being physically active is when she participates in too many sports, becomes bored of the sport, or the sport takes up too much time. She has made many friends playing sports.

After her last concussion, she experienced memory loss, an increase need for sleep, dizziness, blurry vision, and headaches. Her symptoms cleared up quite quickly. At the time of the interview, she experienced increase in sleep, irritability, dizziness and headaches. It is difficult to link these symptoms to her concussion as she has recently been diagnosed with depression.

Remembering back to the time shortly after she sustained her concussion, she experienced an increase in symptoms, especially dizziness, if she pushed herself too hard physically. She felt that she was more cautious playing sports because she did not want to sustain another concussion. She had to change her method of studying from only reading her notes, to writing things down. If she does not write things down, she does not remember.

She visited her family doctor and two other general practionners, one in each of her three concussions. None of the doctors gave her any written information about concussion. One of the general practionners told her not to participate in rugby until he gave her clearance to return. She did not have any CT or MRI scans. One of the doctors performed a basic neurological exam. Another doctor told her that she could return to physical activity when she felt ready. Her experience with the health care providers she visited was generally positive.

Her experience with concussions has made her more hesitant playing sports. She is more aware of herself and her opponents. While she was still symptomatic, she expressed that symptoms were the main barriers to returning to physically activity. Once her symptoms cleared, she was able to resume physical activity. After her second concussion, she experienced pressure to play from her rugby coach. He made her feel guilty for not playing and she decided to play before she was completely healed because of the pressure from her coach. Her basketball coach supported her decision not to play after her third concussion.

Michelle feels that physical activity helped her to deal with irritability and helps her to relax. Being physically active helps her sleep better and helps with her headaches. She was a little more timid playing sports during the first six months after her last concussion, but now feels that she has completely recovered and has no long term effects. Her experience with concussions has made her more aware that she should take care of herself as she only has one body and one brain.

Support

Michelle found that the support of her basketball coach eased the frustration and isolation of not being able to play basketball. This allowed her to still be a part of the team when she was recovering from concussion. The following quote expresses this:

> But, like we went to a game and I wanted to...to dress so badly cause I wanted to play and the coach, was... told me that I couldn't... that I had to sit on the bench with her. So then she tried to get me involved in like taking care of people that needed tape or, like putting people on and stuff like that. So that was cool, like I didn't have a problem with that. It made sitting on the bench 'cause I was head injured better.

This was important to her. She did not feel guilty about sitting out as she had when she sustained her concussion playing rugby.

Emerging Categories and Concepts from Participant Interviews

Symptoms, medical, physical activity and effect of post concussion syndrome on every day life emerged as the main categories from the interviews. The emerging categories and concepts are outlined in figure 4.

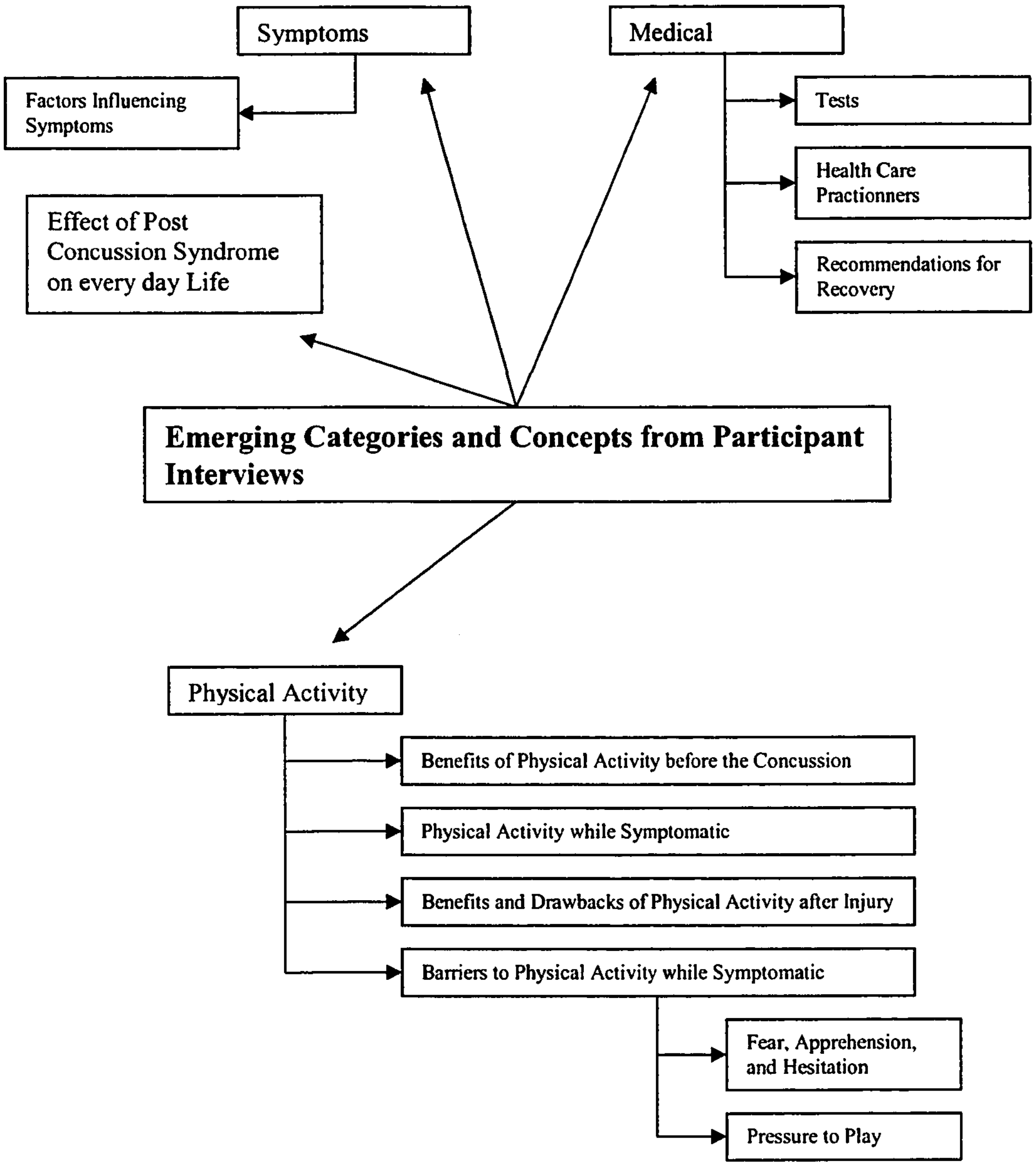


Figure 4: *Emerging categories and concepts from participant interviews.*

Symptoms

All of the participants experienced symptoms in the acute phase. Four of the six participants experienced lingering symptoms and at the time of the interviews three of the participants continued to experience symptoms. Table 1 summarizes the acute symptoms that each participant experienced.

Table 1

Acute Symptoms Experienced by Each Participant

	John	Jen	Sandy	Dawn	Angela	Michelle
Memory loss	X		X	X		X
Dizziness	X	X	X	X	X	X
Blurry vision	X	X			X	X
Disorientation	X					
Lack of concentration	X	X	X		X	
Irritability	X	X				
Headaches	X	X	X	X		X
Sensitivity to light and noise		X				
Fatigue		X				
Sleep issues		X		X		X
Loss of balance			X			
Nausea			X		X	
Vomiting			X			

The three participants who still experienced symptoms at the time of the interview felt that the symptoms played a large role in preventing them from participating in sports, physical activity, and hindered their participation in family life, employment and academically. Table 2 summarizes the symptoms experienced by the participants in the chronic phase.

Table 2

Chronic Symptoms Experienced by Each Participant

	John	Jen	Sandy	Dawn	Angela	Michelle
Disorientation	X					
Lack of concentration	X	X	X			
Headaches	X	X		X		
Blurry vision	X					
Irritability	X		X			
Slurred speech	X					
Sleep issues		X				
Fatigue		X				
Sensitivity to light and noise		X				
Memory loss			X			
Distractibility			X			

Lack of patience				X		
Panic attacks				X		

Factors Influencing Symptoms

A number of the participants felt that certain environments and actions increased the severity of their symptoms in the chronic phase. John commented on how increasing his heart rate exacerbates his symptoms.

> What I was doing down stairs [with the physiotherapists he was seeing] was all around my heart rate and stuff. And they'd [physiotherapists] get it [heart rate] up to a level that I'd have to take it at. You know you'd be sitting there on the bike kind of going "this is stupid". I mean, I could so this for about a year. All of a sudden I get dizzy and I thought "wait a minute here" and then I'd be like "oh it's because I didn't get a good night's sleep or this or that". And then you know downstairs they'd be saying "no, you're doing this everyday. You're getting dizzy everyday. No we're not bringing it up." I go "no, if I can just push it a little bit higher, then I'll be ok".

John was under the supervision of physiotherapists who treat elite level athletes and who have worked with people with post concussion syndrome in the past. It is interesting to note that John attributed his dizziness to other non concussion related factors, while the physiotherapists recognized that it was concussion related. Jen also commented on this.

> The more my heart rate goes up, the more my head hurts. Like when I lift, I get really dizzy and um, just my heartbeat goes pounding... boom, boom... you know. And the treadmill is pretty... makes me dizzy and a headache.

Jen acknowledged that her symptoms were aggravated by over stimulation of her brain and talked about how public places often make her symptoms worse:

> I'm really sensitive light and sound. So, It's hard for me to go to public places like where there's several people or not even a lot of people like...even if I'm in a group of 5 or more, it's hard for me to concentrate if there's more than one conversation. It's hard for me to kind of... you know... just like to focus

> on one because I hear them all coming at me. So it's hard to go in, like restaurants that's really loud and um, shopping malls and stuff are really hard my eyes… and so, I wear sun glasses all day pretty much everywhere I go.

Some of the participants stated that an increase in ambient temperature make their symptoms worse. Angela discusses how the heat affected her.

> Heat… it just seemed to bring everything on more. I don't know what it is but I would find that the heat would make it [symptoms] worse.

John expressed that a lack of sleep often makes his headaches, dizziness, disorientation and the feeling that he "is in a fog" worse.

It is evident that a number of different factors influence the severity of the symptoms that the participants experienced. Increase in heart rate, an increase in ambient temperature, lack of sleep, ambient noise, and visual stimulus all emerged as factors. Most of the participants sought medical attention for many of the symptoms, as well as information about the resumption of physical activity.

Medical

The participants in this study had numerous encounters with various health care practionners. A number of them participated in various tests, the most common ones being CT and MRI scans. All the participants were given some kind of recommendation for recovering from post concussion syndrome. The recommendations all had common aspects, while at the same time were all quite varied. Almost no information was given on the resumption of physical activity while symptomatic other than rest until the person is symptom free.

Tests

All of the participants spoke of the tests that they were given at various times throughout their recovery from concussion and post concussion syndrome. Table 3 summarizes the tests that each participant was given. CT and MRI scans were by far the most common tests that the participants took. The CT scan was usually given first and shortly after the concussion occurred. An MRI was suggested if there were any abnormalities in the CT scan or more time had passed without an improvement in symptoms. Most of the participants had normal CT results and all had normal MRI results.

Table 3

Tests Taken by Each Participant

	John	Jen	Sandy	Dawn	Angela	Michelle
CT	X	X	X	X	X	
MRI	X	X	X			
IMPACT		X				
Blood test	X					
Folstien Mini mental			X			
Memory related	X					

Jen took the ImPACT test, which is generally used with athletes. It is a web based test that athletes take at the beginning of the season to establish a baseline functioning for performance such as memory and reaction time. Should an athlete sustain a head injury during the season, the athlete repeats the ImPACT test. In order for the athlete to return to playing their sport, they have to obtain the same or higher score than their pre-season test results. Jen's results on the ImPACT test she took after her concussion were significantly worse than her pre-injury results. She ended up taking the test five or six times.

The physiotherapist Sandy visited gave her the Folstein Mini Mental test. She was given this test a few different times in order to track her recovery progress. She had difficulty with aspects of this test the first time, especially spelling WORLD backwards, word recall and counting backwards in increments of sevens. She took this test a number of times and did slightly better each time.

One of the interesting aspects related to concussion testing is that the participants' report learning how to obtain a better score. This was an attempt to return to play sooner because of their desire and determination to play their sport despite the concussion symptoms they continued to experience. Sandy expressed how she approached the test:

> Counting backwards I couldn't do. Random things weren't working out so well and that was like a month or 2 afterwards. And each time went back, he'd give me another mini thing and then he realized that I remembered how to…

> like, I thought about how to spell WORLD backwards before I walked in there and practice counting backwards from 7.

Jen took the ImPACT test because all of the athletes on her basketball team were required to take the test before the season began. When she was attempting to return to play, she was required to re take the ImPACT test. She explains:

> And um, so I took that [test] again after I hit my head and I had a huge decrease in like, I can't remember the number but... my numbers went way down and they said once I took that test, and it was back to my baseline, or whatever you call it... then I could get back on the court. So I took it like 5 or 6 different times... and you know... eventually you like, get... I mean, it's random... but get to learn how to take the test, you know. So, I'm catching on.

If athletes learn how to take tests and obtain better scores in spite of lingering symptoms, they may be cleared to return to contact sports before they are ready.

Health Care Practionners each Participant Visited

The participants reported visiting a number of different health care practionners and at various times throughout their recovery. Some health care practionners required referrals, others were at clinics and some were through connections that the participants had through work. It seemed that the participants visited more specialists the longer their symptoms lasted. Table 4 shows the health care practionners that the participants visited.

Table 4

Health Care Practionners Visited by Each Participant

	John	Jen	Sandy	Dawn	Angela	Michelle
Emergency Department Doctor	X		X	X	X	
General Practionner		X	X	X	X	X
Neurologist		X (2)	X		X	
Ophthalmologist		X			X	
Neuro-Ophthalmologist		X				
Massage therapist				X		
Chiropractor				X		
Athletic Trainer		X				

Physiotherapist	X		X			
Sports medicine doctor	X					
Psychologist		X				

While there was some consistency in health care practionners recommendations for recovery during the acute phase, the advice varied widely for the chronic phase of the injury. Recommendations varied from the general practionners and the specialists and whether the health care practionner had a history of treating the participant.

Recommendations for Recovery and Return to Physical Activity

The participants in this study reported a variety of recovery recommendations given to them by the different health care practionners. Rest and not participating in physical activity were the two main recommendations. This is exemplified by the following quote:

> Interviewer: when you saw those people in the hospital, the doctor, the family doctor, the clinic person and maybe the guy here, what did they recommend to get better?
>
> John: Rest

This recommendation was common with the other participants' experience, especially in the acute phase of the concussion. Angela's general practionner suggested that she take some time off of her job as a police officer because of the physical nature of the work. She worked at a desk job for about a month.

When asked how the information about concussion and post concussion syndrome was conveyed to the participants, most said that the information was given verbally. While some where given a "blue sheet" explaining what a concussion is and what signs to look for in the acute phase, as well as signs that the person should seek more medical care, the majority of the participants were not given any more detailed information. The following quote from Sandy reflects her frustration with the lack of information:

> Here's your blue sheet... read this... don't do this make sure you get woken up every hour or 2 hours... ummmm. There's no point in going to the doctor or hospital, they tell you the same thing.

Jen's athletic trainer was the one who gave her information on concussion as she expressed in the following quote:

> You know, I think the only paper I got was from my athletic trainer. Just a little, you know, 4 by 6 card or whatever saying, you know... whatever... watch for this, this and that. But I don't think I got any from the doctors. Just things to look for like... when you first have your concussion, make sure someone's with you or checking up on you.

Angela also spoke about this:

> It was verbal and a sheet. He gave me a sheet of symptoms and stuff like that but the physical activity and everything else that he did not want me to do or to stay away from or if I experienced after, um, that was verbal.

It was evident that the information given by healthcare practionners, whether it was verbal or written, in the acute phase was fairly consistent. When it came to recommendations and information about post concussion, there were many different opinions. This was especially poignant with regards to the return to physical activity and post concussion syndrome. All of the participants in this study received information about post concussion syndrome verbally. There was no written information given to the participants about what to expect, treatment, support or returning to pre-injury life. Jen commented on this lack of information:

> They didn't really give me anything on post concussion syndrome. They just told me that, like with the antidepressants they were giving me... eventually that would maybe help my headaches and I'd get better with the medicine. They would say "you know... sometimes people with concussions, it lasts, you know longer. And so they'd just throw me a new medicine and then I'd be off and it wouldn't work. I went to... the first neurologist, I went to 3 different times and then I felt like I wasn't getting answers from her so I went to a different neurologist and he said... he just told me the same exact thing, which was "yeah, sometimes concussions last longer and the symptoms... and he

> just threw me a different antidepressant and told me to go back to the first one [medication]. After I'd already told him I wasn't happy with my first one... that's why I was seeing him.

In Jen's case, the neurologists kept on prescribing anti-depressant medication. Sandy's physiotherapist told her about second impact syndrome.

> He said if I still have symptoms and you touch someone with post concussion syndrome... it's extremely rare. I could get hit, like a little flick or a poke... it could be like that ... and then... or you can fall on your head or whatever in the wrong spot and just have a hemorrhage, stroke and die.

Advice regarding return to physical activity was more varied. Some were told to wait a week, others to wait a months. For a previous concussion, Sandy visited the emergency department and was checked out by one of the doctors. She had given him her concussion history. He gave her the following advice, despite her history with concussions:

> that was the guy that said to me that as long as I'm symptom free for 7 days that I can play, knowing full well that I've had a lot of concussions and stuff. And "you'll be fine sweet heart. See you later".

Contrast this with the advice of the sports medicine doctor she visited who specializes in concussions:

> And, ah, they told me... my sports med doctor is like "I'd recommend never playing again but you will.... So wait a year pretty much.

Angela was told that as long as she felt up to it, she could be physically active.

> he said that if, you know, if depending on what I experience that he trusted my judgment, if I felt that... if I felt that I could, you know, do it again, then to try it again. If I felt I needed to wait a couple days before I did it again then he said just use your common sense and judgment and go from there.

She was also told the following:

> He [doctor] didn't want me... well his main concern was he didn't want me going to play contact sports. And he didn't want me doing any thing that would cause too much strain on everything and he didn't want me doing

> physical activity for about a month, he didn't want that. I kind of went after 2 weeks but it... it was a month before I could even get back into it so.

Michelle was told the following:

> So, like don't go back to practice. [Doctor] said don't go back to practice until you see me again.

In contrast to this, some health care practionners did recommend physical activity, although none recommended a return to contact sports or other activities that have a high head injury risk. John was being followed by a sports medicine doctor and physiotherapists who see elite and professional athletes. He was able to do some physical activity and it was closely monitored.

> [Doctor] who's the only guy that knew I was active and he recommended my to the physio guys down stairs to bring me back slowly. And that's when I'd get on the bike and I could do it with my dress clothes 'cause you don't even sweat and they strap the heart monitor on you and they keep you at the pace you're supposed to stay at for whatever... couple minutes or whatever it was and then you stop. Or until you get headaches or whatnot.

Jen was told that once she has seven days without symptoms she could begin participating in physical activity again by starting slow and working her way back to full game play.

> He [family physician] told me, you know, I couldn't exercise. The old... whole routine of when you can have a week straight of no symptoms then you can go back to exercising. Start off on a bike, you know, and then work your way up. Like drills on the court and then eventually, way back into practice but I never really... at the end of the season, I got back to that point of being on the court but I... it took too... like I never, I never reached a full week of no symptoms, I just eventually lied [both laugh].. cause I wanted to get on the court so bad... you know.

Perhaps the most salient point in Jen's comment was that she did not see any progress so she lied about her symptoms so that she could play basketball again. This will be explored later in the chapter.

Sandy explains her experience with being physically active while still symptomatic. She was followed by her sports medicine doctor with whom she had some interesting discussions.

> For the first while… for the first 2 or 3 months I wasn't allowed to do anything. Nothing, he's like "don't take the stairs, take the elevator", don't raise your blood pressure at all" because he just didn't know how bad it was or anything and just the number I've had and the symptoms, he's like… "ok, you can start like Yoga or Pilates. He's like "you can start walking"… And did that for a while. He's like "ok, try running. If you feel dizzy, stop". And did that for a while and felt crappy. I couldn't do anything where it involved being hit by anything.

Sandy's sports medicine doctor told her to wait a year before playing soccer again. He had the following advice for her when she did play soccer or participate in other forms of physical activity:

> And don't head the ball, umm, pretty much the standard from people is don't play anymore and I can play as long as I don't head the ball [laughs]. So why not play? And just wear a helmet when I do anything like skating and stuff like that.

Sandy pressed him about returning to play soccer before a year had passed.

> I said "if I feel up to it?" He said "no way, don't do it". He knows… he knows I play [laughs] he's just like "make sure you're really careful but"…. I don't know. I have to play [laugh] but the symptoms are still there…. They're definitely still there.

Dawn was only given the return to play guidelines to guide her in her return to physical activity. While she acknowledges the usefulness of these guidelines, she feels that there needsto be higher standards and guidelines to determine whether a skeleton racer is well enough to return to racing. She explains:

> We need a little more hands on supervised stuff like that because we go from jogging around, you know the block and doing a sprint session to hurting our bodies a 124 km an hour so… it's a big jump, you know… for us.

The participants experience with the health care practionners, tests and advice they received were quite varied. While there was some consistency in recommending no contact sports while symptomatic and in what to do and look for in the first week after the concussion, there were numerous and varied recommendations regarding recovering from post concussion and participation in physical activity while still symptomatic. In addition, the participants reported that little information regarding post concussion syndrome, treatment or expectations for recovery was given, verbally or written, by the health care practionners. One of the most interesting aspects of this is that while the participant sample is only six, they are all from different geographic areas. Health care practionners were seen in Canadian cities including Vancouver, Nanaimo, Calgary, Lethbridge, Fort McMurray, southern Ontario, and in the United States in Minneapolis, and St. Cloud. In addition, while Dawn was racing in Europe, she saw a German and an American doctor, as well as her team Canada chiropractor. Included in the group of health care practionner are the general practionners, family doctors, emergency doctors, and specialists.

Physical Activity

Physical activity emerged as a main category. Interestingly, most of the participants were physically active despite still experiencing symptoms. Some knowingly disregarded the advice of their health care practionners; others were physically active under the supervision of a health care practionner. Some of the participants were not given much advice or guidance regarding what they should and should not do with regards to physical activity so they participated in activities based on their comfort levels. All of the participants felt that physical activity was beneficial before their concussion and the majority of them felt that there were benefits to being physically active while still symptomatic. There were, however, some drawbacks. Some felt frustrated at not being able to be physically active in the same capacity as before the injury and most felt some kind of fear or apprehension about returning to physical activity where there was a risk of re-injury, as in contact sports. Some participants experienced pressure to play from coaches, team mates, organizations and themselves.

Benefits of Physical Activity before the Concussion

All of the participants felt that physical activity was beneficial before they sustained their concussions. Angela's comment expresses a number of benefits to being physically active.

> well for me it's a stress reliever… um my job is stressful so um, I use it as a stress reliever and I find if I don't… if I kind of fell off the band wagon there for a bit… even like a couple of work outs or running, I find that I don't get good sleeps or um… I even my eating suffers because I'm not really focused. I don't find my focusing is as good.

Sandy also found that physical activity was a stress reliever. When asked if she found other benefits to being physically active, she commented "I wasn't getting fat [laugh], stress relief huge". Dawn commented that sports offer her a competitive outlet, but also expressed that it was a form stress relief and said that she felt healthier.

> well part of it is I just love to do competitive sports, so it doesn't matter, you know when I leave skeleton, I'll probably go back to competitive sailing so I just… I find it's a competitive outlet for me. It's also a stress relief. It's ah, a confidence thing, because I just prefer to be in shape as opposed to out of shape. I guess that would be about it. A health thing too.

John felt that physical activity was about over all health. He commented:

> It… helped… more energy. Just all around healthiness. I believe that you're mentally stronger when you are physically fit. I feel more run down now because I don't… I'm not active now and just tired… don't feeling like thinking as much… not sure how much contributes to the concussion stuff and how much contributes to being not active.

Jen said that playing basketball was what she loves to do and she enjoys playing. When asked how she feels after playing basketball, she commented:

> Your body feels tired and you know you worked hard and you can go to bed feeling good about yourself.

Given that all the participants felt there were benefits to being physically active, it is not surprising that most of them were physically active after their concussion even while symptomatic. The type of physical activity depended largely on the extent of their symptoms and how badly their symptoms returned when they raised their heart rate. The amount of information they received from their health care practionners influenced the type of physical activity.

Physical Activity while Symptomatic

Most of the participants were physically active despite the symptoms. The participants who were physically active despite their symptoms had various reasons for continuing to play their sport or be physically active. John played hockey and pick up soccer or football once a week. He usually played forward in hockey but after his concussion, he started to play defence because he became too dizzy playing forward. He explained this:

> I used to play forward... and after that I couldn't. I had to sit back and... like I wouldn't go as hard. Just couldn't... just too dizzy.

John said that his intensity level when playing hockey after the concussion was low. It was because of the recruitment poster for this study that John sought the advice of the sports medicine doctor. While he realized that he was experiencing symptoms, he was not aware of the consequences of playing contact sports while still symptomatic. The following quote expressed this:

> He [sports medicine doctor] plays noon hour hockey as well and he's like "don't come back out". I'm like "yeah, yeah, ok. So I can go play again". And to be honest, because of [sports medicine doctor] down stairs, I've taken it a lot more serious than I think I would have. He actually knows me and whatnot... and works for professional athletes and just the stuff he tells me... like, you know "we don't know what's going on... like, you might be ok but you might not be ok and you don't want to get that one hit that puts you over the edge and whatnot". It just... he's really, I'm not sure educated me so much as...

John decided to stop playing sports but he was riding the stationary bike under the supervision of the sports medicine doctor and the physiotherapists. He eventually stopped all forms of physical activity because his symptoms were too bad.

> … I mean I don't do anything now and it's because I get too dizzy and it's… It's, you know, just too disorienting. I can't do it the way I used to do it.

His current physical activity and the effect his symptoms have on his ability to be physically active can be summed up in the following quote:

> The most physical stuff I do now is chase my daughter around the house, but I gotta stop sometimes when I get so dizzy. Um, and I don't play anymore sports.

John played sports while he had symptoms because he did not fully understand or have the awareness of the consequences of playing while symptomatic. John is very limited in the types of physical activity he can currently do because he become dizzy and disoriented when he is physically active. In contrast, Sandy was aware of the possible consequences and began playing soccer despite the return of symptoms.

> Not in my best interest but… I can't really stop myself. Like what am I going to do for the rest of my life? Not play soccer, not play hockey?

She expressed her desire to play on an outdoor soccer team during the summer.

> I'm not supposed to be playing [soccer], but when I first started playing again, I did notice head spinning and things like that. Um, yeah, I think I'm fine. How I feel when I exercise anyways. I feel better, I feel like I'm ready to play on a team again and stuff like that.

In contrast to Sandy, Jen is not active in basketball but has resumed other forms of non contact physical activity despite her symptoms. Like John, her symptoms limit her participation in physical activity. The following quote expresses this:

> I was trying to play basketball like 3 times a week, and that just hurt my head so bad 'cause it… my… as soon as my heart rate would go up so high like that, I'd get dizzy and tunnel vision again and just, my head would pound. So I just decided I had to stop that. And ah, so now I just… I lift weights 4 times a week and ah, I do cardiovascular about 4 times as week too. I do like, water aerobics, umm, twice a week for an hour and then um, I like run on the tread mill for like, for like 20 minutes.

Despite being told to stop when her symptoms return or worse, Jen pushes through them.

> I mean… to be honest… cuz I… I feel like crap because I can't do the things I could do before, like play basketball for 2 hours and now when I lift weights for 45 minutes, I… you know, my head just feels like crap. And so, I figure that I can do 45 minutes of lifting. I make myself get through it. But if it does get too… I'll go until it's unbearable, but usually I'll work through it.

Jen really wanted to be able to play basketball again. While the physical activity she was doing was good for a work out, it did not necessarily satisfy her.

> Because it's not as intense and I'm not going balls to the wall for, you know, 3 hours straight. The most I'll do is an hour ah work out where before I'd go for 3… 3 or 4… you know. With a team and someone's yelling at you and telling you… "You can go faster than that"… well now, I'm by myself and I can regulate myself. If I'm tired, I can push the button and I can go slower on the treadmill, you know… so, I don't know. It's not the same, but I mean it's better than nothing.

Angela was physically active while symptomatic because she did not want to loose the fitness she had worked so hard to gain.

> I had no drawbacks from starting 2 weeks after I had that concussion. I don't think my concussion lasted longer than if I hadn't been exercising. And maybe even worse if I waited a whole month or 3 months before I went back to physical exercise. My whole… everything would, you'd have to build up everything again….

Since most of the participants were physically active despite their symptoms, they were asked if there were any benefits and drawbacks to being physically active while symptomatic. Physical activity seemed to be a very important part of the participants' daily lives. Living without physical activity seemed to be difficult for most of them.

Benefits and Drawbacks of Physical Activity after the Concussion

The majority of the participants interviewed said that the felt there were benefits to being physically active after their concussion, despite the symptoms. They felt that the worsening of the symptoms was the main drawback to being physically active while still symptomatic. Some participants expressed disappointment over not being able to do what they did before. Angela expressed some of the benefits of being physically active while still symptomatic:

> I think definitely there are some benefits in the fact that maybe you get things going again and ah, for me, I don't think I did anything… I wouldn't change anything that I did. You're already feeling bad already, you're feeling crappy and you don't get the exercise… more of a mental thing… so I think there are more benefits to physical activity than to just wait it out.

Jen's felt that while physical activity was beneficial, there were drawbacks to being physically active.

> It makes me feel better cause it helps me… I like developed depression and um, it helps me feel better… like… "ok, I'm out there and doing the stuff I kinda used to do before" but at the same time it'd hurt my head. And I would usually take at least a 2 hour knap after I worked out, you know.

John expressed similar thoughts to Jen.

> I think its more of a personality thing personally, cause I… for me I want to be physically fit. I mean I don't do anything now and it's because I get too dizzy and it's… It's, you know, just too disorienting. I can't do it the way I used to do it. So I guess mentally the drawback is that you can't do what you used to be able to do.

For Sandy, being physically active was not enough; she wanted to return to her sport. So, even though she had been cleared to exercise she was not motivated despite the benefits she might gain.

> Even when I was allowed to, ok, you can run, and I'm like exercise, I was totally unmotivated. I didn't care. And I was, for probably about 3 or 4 months, I didn't give a shit or anything. I've been unmotivated to do

> anything. "I'm not even going to bother any more. I'll just wait it out" and then I just started back at the end of March.

Since she returned to soccer, her enthusiasm returned:

> Ah, with soccer, I feel brilliant. I like, the first couple of times, I'm like, I suck and then once I got my touch back, I'm like "I love this".

Barriers to Physical Activity while Symptomatic

Symptoms were the main barrier returning to pre-injury physical activity after a concussion. This is exemplified by John's comment:

> Like I went a couple times [to hockey] and was just too dizzy to play right now. Um, so since then, I haven't done really anything. I went down to physiotherapy... I went down for a bit on the bike when they strap that thing [heart rate monitor] on you and everything... but just... I just stopped doing it. I got too frustrated because I couldn't... the biggest thing for me is that I'm such an active person and it... to ride the bike for 5 minutes is nothing... but I get dizzy. I just got fed up with the work because I couldn't... like I wasn't sweating.... I wasn't working out. But I'd get dizzy and stuff like that so I just... enough's enough.

Jen expressed that symptoms effected what she did but pushes through the dizziness and other symptoms.

> I feel like crap because I can't do the things I could do before, like play basketball for 2 hours and now when I lift weights for 45 minutes, I... you know, my head just feels like crap. And so, I figure that I can do 45 minutes of lifting. I make myself get through it.

In addition to the benefits and drawbacks of returning to pre-injury physical activity levels mentioned above, fear, apprehension and hesitation played a role for some of the participants.

Fear, apprehension and hesitation.

Some of the participants expressed fear or apprehension with the prospect of returning to play and with the uncertainty of recovery. Michelle expressed this:

> … if I'm going up against some huge lady that I know is going to crank me hard, then I'm a little more timid then more anxious to get rid of the ball.

Dawn discussed some fear that she felt:

> Maybe it was more my fear than anything, but I ah, I didn't want to… even going to something as healing as Yoga, I didn't want to do that, because with your head down, as much as it is, I didn't want to have the blood rushing to my head and have the same problem that I was having before…and just kind of start back at square 1 over and over again. I don't know if that was a legitimate fear or not.

John expressed fear of the unknown.

> It just… the unknown about what's going on, the fear of…like nobody really knows what's going on with your head. And then once you hear this type of stuff and then when I go see the Doc and he says "woo, wait a minute", I don't have a cut, I'm not bleeding, It's not broken, what's the matter?

Some of the fear, apprehension, and hesitation may result in returning to play too soon, in part because of pressure from others.

Pressure to play.

Pressure to play emerged as a factor in some of the participants returning to play. The pressure came from a number of different sources including team mates, coaches and themselves. Michelle felt pressure to return to play from her coach.

> He's just like "What, you can't play?" and I'm just like no, I feel so bad and he made me feel so guilty and stuff so then I was like "ok, I can't take a guilt trip for a week" so I went back after a week. I'm a people pleaser so I don't want to… just get him off my back and leave me alone. So, fine, I'll go back and play… but…

Dawn felt pressure from her team mates:

> From my team mates, right then, they all thought I was over reacting… except for one girl on the team, who was… helped to look after me when she was there. Everyone else just thought I was over reacting.

Angela felt that she put pressure on herself:

> I think more it's internal. I think it's yourself that puts to pressure on you. I guess, from my point of view is that you're always thinking about… "well they must think I'm faking it"….

Physical activity was important to each of the participants both before and after his or her concussion. It is evident that returning to pre-injury levels of physical is an important mile stone. While physical activity is important, so too are the effect of the post concussion syndrome on the other aspects of the lives of the participants.

Effects of Post Concussion Syndrome on Every Day Life

All of the participants felt that post concussion syndrome disrupted their lives. Reduced capacity or inability to carry out responsibilities related to employment was only one aspects of this. Some participants found they could not fulfill their academic requirements and had to ask for extensions or take more time to complete courses. Others felt that it affected the quality of their family life. There was no question that the effects of concussion went beyond the inability to be physically active. Angela explained how post concussion affected her ability to perform her job and the consequences of this.

> My job requires you know, adrenalin, um it requires me to get into physical activity… not activity but actual fighting and um, I… my job requires that and they can't put somebody out there that may be able to do it… So, my job did suffer because, um I had to be taken off the streets and given a desk job for the 4 weeks that… until my doctor gave me the ok to go back to work.

Dawn spoke of how the concussion affected her life.

> Basically, everything came to a screeching halt. Um, because I couldn't, I… I had to lay down, had the light dim, and have a quiet… I couldn't do much work. Everything basically came to a halt except for going to the doctor for my um , headaches and my neck problem I was getting that worked on a couple times a week. Other than that, I didn't do anything for a couple of months.

Jen found that she had trouble keeping up with her college classes.

> It affected my college, like my classes a lot because that…that semester, I was given all incomplete because I couldn't finish any of my classes. And it took me all summer to complete em. And um… so I just, I slowly started falling behind in schools… like I was a really good student…like, A-, B+ average and then I turned to incompletes and just whatever worked… you know. I just don't do my homework because my head hurt and I didn't have the concentration that… you know when I read, it hurt, or I read and I didn't understand it I'd get frustrated and I just… eventually I just got so frustrated that I didn't.. I didn't even want to looks at my books you know. Um. So in that sense, it's put me about a year behind in school.

John feels that his day to day functioning has been effected.

> I'm probably more short tempered now where before I was way more laid back than I think I am now… you know the biggest way it's changed me is, you know, the headaches and stuff… I've learned to… it affects you on the day to day stuff that you can and can't do. And then being physically fit has a huge affect on my life.

Conclusion

This chapter presented the findings from six athletes with post concussion syndrome. The participants shared the experience of living with post concussion syndrome, the effects of post concussion syndrome on their ability to participate in physical activity and their everyday lives, and their experience with the health care system. These experiences provide further understanding of the experience of recovering from post concussion syndrome and participation in physical activity.

This chapter tells the story of each participant's experience beginning with how they sustained their concussion, the health care practionners each participant visited, the health care practionners recommendations for recovery and return to physical activity, and their participation in physical activity while symptomatic. This is followed by the categories that emerged from the participant interviews. One of the main emerging categories is symptoms. Many of the participants experienced similar symptoms in both the acute and chronic stages. Factors influencing symptoms are discussed. Medical also emerged as a main category. Within this category, the tests that each participant took are discussed, as well as the health care practionners each one visited. Recommendations of the health care practionners for recovery and the return to physical activity are presented. Physical activity is also a main emerging theme. Included in this category are the benefits of physical activity both before and after concussion, the drawbacks of being physically active while symptomatic, pressure to play, and fear, apprehension and hesitation to return to physical activity. Effect of post concussion syndrome on the everyday lives of the participants is the final category in this chapter.

The emerging categories and concepts from the participant interviews provide valuable insight into recovering from post concussion syndrome and physical activity. Coupled with the emerging categories and description of my experience presented in chapter four, a broader understanding of the extent to which concussion and post concussion syndrome has affected the lives of seven people can be gained. Chapter six discusses the findings presented in this chapter, the findings from chapter four and the existing literature.

CHAPTER SIX: DISCUSSION

"A minor traumatic brain injury is only minor when it happens to someone else" Parker (2001). The quote holds true for the majority of the athletes in this study and perhaps for the millions of others who experience MTBI and post concussion syndrome. The effects of post concussion syndrome transcended many areas of the athletes' lives. This research explored the role of physical activity in the recovery process of athletes with post concussion syndrome and helps to better understand the experience of recovery from post concussion syndrome.

This chapter brings together the research from chapter two and the findings from chapter four and five and attempts to provide a deeper understanding of the role that physical activity plays both in the lives of athletes and in the recovery from post concussion syndrome. A model emerged from the data and is presented on the following page in figure 5. It provides the framework for this chapter.

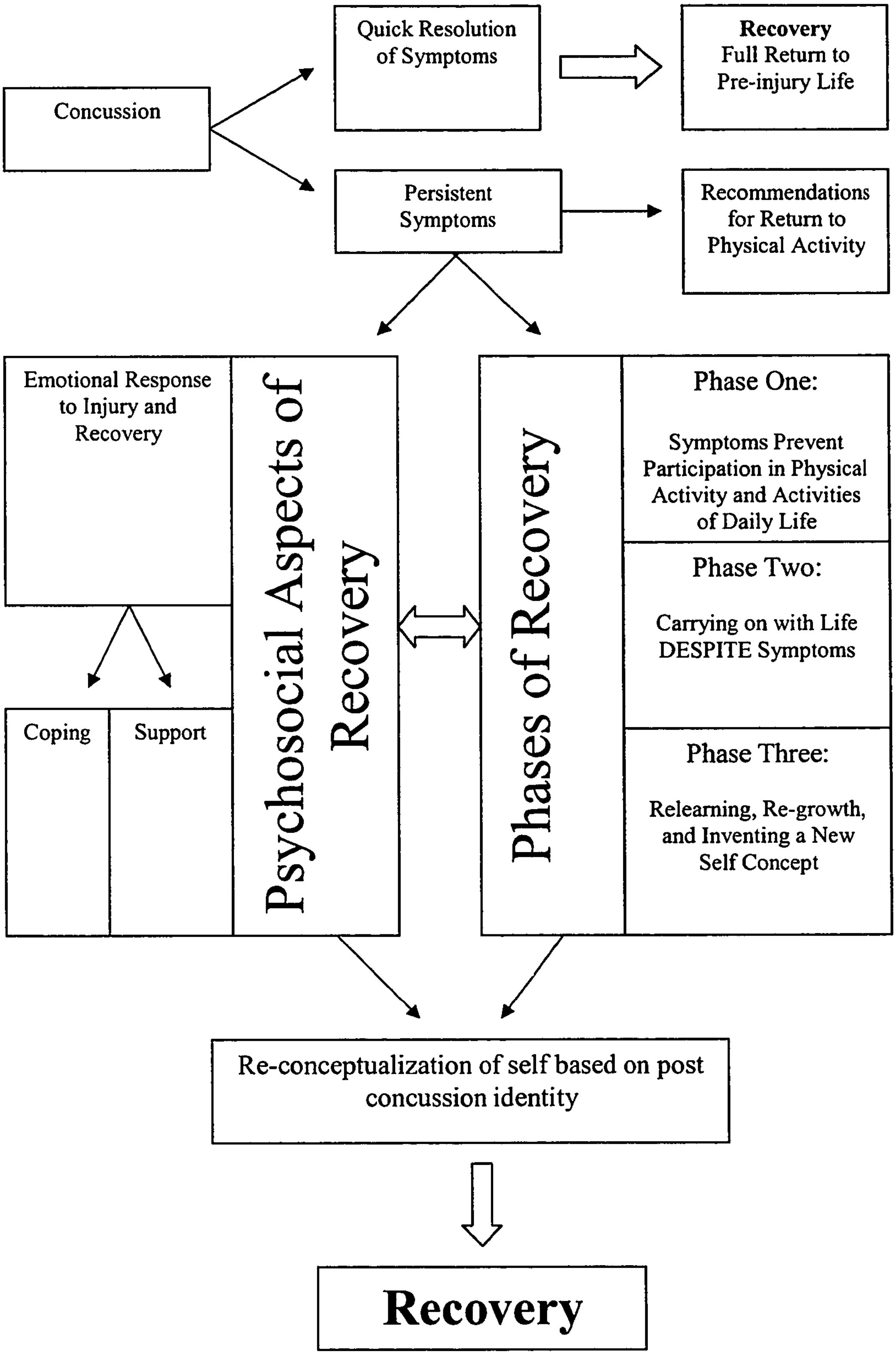


Figure 5.*The recovery process of athletes with concussion.*

Chronicity

It is important to consider, at this stage in the discussion, the concept of chronicity and its implications for the recovery process of athletes with post concussion syndrome. Chronicity is defined as “the expectation that the condition is not curable, and that the presence of the condition is expected to be either long-term or permanent” (Bishop, 2001, p. 47). There are currently no widely recognized methods of predicting the severity and persistence of concussion, post concussion syndrome and MTBI symptoms one experiences (Parker, 2001). Thus, those that are diagnosed with post concussion syndrome are, more often than not, left wondering whether their symptoms will resolve, how long they will suffer from the deficits they experience, and if they will be permanently disabled as a result. Bishop (2001) noted that an important part of adjusting and adapting to the disability is dealing with the emotional response to the chronicity or permanence of the disability and that when the consequences of the injury or illness are known, the injured individual can then work through the emotional response to the illness and disability. In the case of post concussion syndrome, chronicity and permanency are often unknown. The athletes in this study expressed difficulty in dealing with unknown prognosis and outcome of post concussion. John expressed this view in the following quote:

> I think it’s more of the no answers one because if I sprain my ankle, I know that… what’s happening to it and I gotta wait and rest it and rest it… well I’ve rested… why aren’t I better?

This unknown may be a major barrier to recovery, as the individual with post concussion syndrome not only has to deal with the deficits he or she experiences in the present, but has to come to terms with an unknown future.

This has implications on future participation in sport, the ability to be physically active, relationships, professional careers, and in some cases, the ability to be financially independent (Parker, 2001). This may also prevent athletes with post concussion syndrome from searching for meaning in their disability, and exploring and creating a new post-injury identity since they are often left hanging on to the possibility that when or if their symptoms resolve, they can return to their pre-injury life and sport. This was the case for a number of the athletes in this study. Both Jen and Sandy were attempting to return to their sport even though they were still symptomatic. As Sandy expressed, "Not in my best interest but… I can't really stop myself. Like what am I going to do for the rest of my life? Not play soccer, not play hockey?". This may be especially true in the case of competitive, elite and professional athletes who have devoted a significant amount of time and energy into their sport.

The participants in this study struggled with chronicity and the unknown prognosis. All of the symptomatic participants were attempting to return to their pre-injury activities at the time of the interview. A major focus for all of the participants, symptomatic or asymptomatic, was the ability to play their desired sport and participate in physical activity in their pre-injury capacity. When asked if John would play hockey again if his symptoms cleared, he responded: "They [symptoms] better clear. I gotta go back and play".

The difficulty is that concussed athletes are told that they can return to play when they are asymptomatic and are given no other guidelines for return to physical activity and little information about their prognosis. Therefore it is understandable that the symptomatic athletes in this study held onto the hope and the possibility that when or if their symptoms dissipate, they would return to their pre-injury level of participation in sport. This hope prevents athletes from shifting their mindset to one of retirement from sport and from creating a new self identity beyond that of athlete and in the absence of the "athlete" identity. Sandy, Jen, John and I all experience this reluctance to truly accept and create an identity without a component of "athlete" in part because of the hope that the symptoms will clear and we can go back to our pre-injury participation in sport and physical activity. While I cannot speak for the participants, realistically, I know that I will never be able to go back to my pre-injury participation in elite contact sport. Too much time has passed and I am not sure that playing contact sport and risking another head injury is worth the consequences of another concussion.

The Recovery Process

There are two possible scenarios that occur when an individual sustains a concussion. These scenarios are presented in figure three. The first is that the symptoms of concussion resolve within a reasonable amount of time and the individual is able to return to pre-injury life and participation in physical activity and sport without any long term effects. This occurs in the majority of concussion incidences (Alves et al, 1993; Ewing et al, 1980; Gronwall & Wrightson, 1974; Parker, 2001; Rutherford et al, 1979). In the second scenario, the individual experiences persistent symptoms. These persistent symptoms limit or prevent the individual from functioning at his or her pre-injury level of daily activities, including participation in sport and physical activity. It is estimated that between 10 to 20% of people who sustain a concussion will experience persistent symptoms (Alves et al, 1993; Ewing et al, 1980; Gronwall & Wrightson, 1974; Parker, 2001; Rutherford et al, 1979). It is this second scenario that is the focus of this discussion.

It is important to preface this discussion with the following: there was an unspoken assumption among the athletes in this study that they would return to pre-injury life and level of participation in sport and physical activity. While athletes may have questioned the validity of this assumption the longer the symptoms persisted, none of the athletes fully let go of this assumption. This has consequences.

Symptoms

Symptoms are an extremely important part of understanding the role of physical activity in the recovery process of athletes with post concussion syndrome. The athletes reported that symptoms are the main barrier preventing them from resuming activities of daily living, and more importantly, participation in physical activity and sport. The severity of the symptoms experienced and the factors that exacerbate symptoms were the two most important variables in determining whether the athletes in this study progressed through the recovery process.

Three levels of symptom severity emerged. The first level is characterized by very severe symptoms that prevent the athlete from participating in the majority of activities of daily living. Dawn explained this as:

> Everything basically came to a halt except for going to the doctor and getting my um, headaches and my neck problem, I was getting that worked on a couple times a week. Other than that, I didn't do anything for a couple of months.

The second level of symptom severity is characterized by painful and disruptive symptoms that are not severe enough to inhibit all participation in activities of daily living. Jen expressed this in relation to her participation in physical activity in the following quote:

> I feel like crap because I can't do the things I could do before, like play basketball for 2 hours and now when I lift weights for 45 minutes, I… you know, my head just feels like crap. And so, I figure that I can do 45 minutes of lifting. I make myself get through it.

Many of the athletes in this study pushed through the symptoms at this stage. The third level of symptom severity is characterized by an absence of the disruptive symptoms. Symptoms may still persist but they do not disrupt daily living. This is the case for Dawn. She experienced panic attacks as a result of her concussion. They were very disruptive to her ability to race. Once she went through EMDR and managed the panic attacks, they did not disrupt her life anymore. Essentially, athletes may still have symptoms, but they do not interfere in functioning.

Athletes who considered themselves to be recovered did not experience disruptive symptoms. Disruptive symptoms are symptoms that disrupt athlete's ability to function. A few examples of disruptive symptoms include headache pain, inability to concentrate, sensitivity to light and noise, and blurry vision. Of course, any particular symptom can be a disruptive symptom if is it bad enough to disrupt the athletes ability to carry out activities of daily living.

Some athletes considered themselves to be recovered despite still experiencing symptoms. The symptoms the recovered athletes did experience were ones that did not significantly impact functioning. I consider myself to be recovered despite experiencing visual and emotional memory loss because these symptoms do not significantly affect my ability to work, succeed academically or participate in activities of daily living.

Considering this, reviewing the symptoms that were reported by the athletes during the acute and chronic stages of injury will help to provide some background on what athletes with post concussion syndrome experience. During the acute phase, the athletes collectively self reported the following symptoms: (a) memory loss, (b) dizziness, (c) blurred vision, (d) disorientation, (e) lack of concentration, (f) irritability, (g) headaches, (h) sensitivity to light and noise, (i) fatigue, (j) sleep issues, (k) loss of balance, (l) nausea, (m) vomiting, (n) loss of consciousness, (o) loss of appetite, and (p) loss of ability to speak or understand a second language.

All but two of the symptoms reported by the athletes are either validated by previous research or have been anecdotally identified in clinical settings. The two exceptions are loss of language and loss of appetite. Symptoms validated by research include amnesia, loss of consciousness, headache, dizziness, blurred vision, attentional deficit, and nausea. Anecdotal symptoms include vacant stare, irritability, emotional lability, impaired coordination and balance, sleep disturbance, noise and light intolerance, lethargy, behavioral disturbance, loss of memory, difficulty concentrating, and altered sense of smell or taste (Maddocks et al, 1995; McCrory et al., 2000; McCrory & Johnston, 2002).

The acute symptoms usually dissipate within three months however research has shown that symptoms can persist for three, six, twelve months and more (Alves et al., 1993; Ewing et al., 1980; Gronwall & Wrightson, 1974; Parker, 2001; Rutherford et al., 1979). Individuals who experience persistent symptoms and who meet the requirements outlined in the DSM IV are diagnosed with post concussion syndrome. The chronic symptoms self reported by the athletes are as follows: (a) disorientation, (b) lack of concentration, (c) headaches, (d) blurry vision, (e) irritability, (f) slurred speech, (g) sleep issues, (h) fatigue, (i) fatigue, (j) sensitivity to light and noise, (h) memory loss, (j) distractibility, (k), lack of patience, (l) panic attacks, (m) nausea, (n) slowed thinking, (o) loss of appetite, and (p) loss of balance. Previous research has identified these symptoms as symptoms of post concussion syndrome (Fabiano & Daugherty, 1998; Mittenberg & Strauman, 2000; Parker, 2001; Stoler & Hill, 1998; Wilson et al, 2002).

The athletes reported that their symptoms returned or were exacerbated when they raised their heart rate and with increases in ambient temperature. A worsening of symptoms with increased altitude, increased atmospheric pressure, high ambient temperature and physiologic stress has been clinically observed (McCrory & Johnston, 2002). The athletes also reported that their symptoms worsened when they were visually or audibly over stimulated or were in situations with lots of ambient background noise. This is important to consider for athletes because an increase in physiologic stress through physical exertion is inherent in most physical activity and sport. Depending on the sport, some athletes may play in hot environments.

Given that the athletes reported that symptoms were the main barrier to recovery, it is important to understand the symptoms that each individual athlete experiences and the aggravating factors. Considering that the absence of disruptive symptoms emerged as the main factor in determining whether the athletes in this study considered themselves to be recovered, effective symptoms management may decrease recovery time of athletes with post concussion syndrome and may improve the quality of life of the athlete during the recovery process. Symptom management in the early stages of post concussion syndrome may also help to lessen or prevent secondary symptoms, such as depression. Williams and Evans (2003) call for pain management in the rehabilitation of those with TBI and MTBI. Also discussed is the issue that symptoms, such as cognitive deficits or depression, may result from injury to specific areas of the brain, the pain associated with the injury, or the emotional response to the losses the individual experience because of the TBI. A few studies have reported that those with post concussion syndrome who are given reassurance and education regarding their condition recover faster than those who do not receive any information (Mittenburg & Burton, 1994; Mittenburg et al, 2001). Thus recognizing and determining the cause of the symptoms is imperative in the treatment and management of the post concussion syndrome. By understanding the cause of the symptoms athletes can be reassured that what they are experiencing is valid and expected. Treating the symptoms appropriately and providing reassurance may lead to a faster recovery.

Recommendations for Recovery and Return to Physical Activity

The athletes reported that the main recommendation they received regarding recovery from concussion and post concussion syndrome was rest. This recommendation is consistent with expert opinions and the medical norm on treatment and management of post concussion syndrome (Aubry, 2002; Parker, 2001; Stroller & Hill, 1998). Once symptoms are resolved, or in some cases lessened, a graded return to pre-injury activities, work, and school is suggested. The recommendations for return to physical activity and sport were similar.

All of the athletes were told that they should rest until they are asymptomatic before returning to physical activity. This is consistent with the various recommendations and guidelines for returning to game situations (AAN, 1993; Aubry, 2002; Cantu, 1986; Kelly et al., 1991). The only recovery recommendation the athletes in this study reported during the acute phase was rest until the symptoms resolve.

When symptoms persisted, however, the recommendations began to vary widely. Perhaps more significant is that the longer the symptoms persisted, the more the athletes searched for answers regarding participation in physical activity beyond the "rest until asymptomatic recommendation". Essentially, athletes wanted to know if participation in physical activity while symptomatic was harmful to their health and recovery. Because health care practionners were not able to answer this, the athletes searched for a health care practionner who gave them the answer they wanted to hear (e.g. you can play your sport again), or they would lie to their doctors, coaches, trainers and other health care practionners in order to be given clearance to play.

The recommendation of rest until asymptomatic, currently the main criteria for return to play, has serious implications for the lives, identities, social circles and in some cases financial independence of athletes. Having lived through a long recovery from post concussion syndrome, I do not entirely disagree with the recovery recommendations and criteria for return to play, especially when returning to full contact sport. However, what happens when athletes are symptomatic for months or years? Is it realistic to expect athletes to rest for months or years?

The findings of this study indicate that while athletes with post concussion syndrome recognize the importance of rest in the recovery process, at some point, athletes appear to need to resume participation in physical activity. All of the athletes in this study were physically active while symptomatic. Even more telling, athletes were physically active despite the reoccurrence or worsening of symptoms and most without being followed by health care practionners. Given this finding, although based on seven people's experience, it may be appropriate to re-examine the recommendations for returning to physical activity for individuals with long term post concussion symptoms because it appears that the benefits of participating in physical activity while symptomatic outweigh the drawbacks.

Symptoms and chronicity are small but important aspects of the recovery process. Recommendations for recovery and the information the athlete receives may influence athletes' behaviour during the recovery process, but there are other factors involved. In order to gain a better understanding of the recovery process that emerged from this study, it is important to understand the phases of recovery that an athlete with post concussion syndrome experiences during the recovery process.

Phases of Recovery

Three phases of recovery emerged from the data. Progression through each phase of recovery is based on the ability to participate in activities of daily living and the severity of the symptoms experienced. Progress through the phases of recovery is linear, with individuals over time, moving towards a life without disruptive symptoms. Having said this, the psychosocial aspects of recovery (i.e. emotional response to injury and recovery process, coping, and support) and athletes' participation in physical activity are not linear. Psychosocial aspects of recovery reflect the issues the athletes experience as they move through the phases of recovery. Participation in physical activity seemed to be a cyclical process.

Phase One

Phase one is characterized by a significant decrease in functioning, severely disruptive symptoms, and an inability or limited ability to fulfill work or academic responsibilities. The individual may also have difficulty performing activities of daily living because of pain, fatigue, memory loss or other symptoms. Small improvements occur to the point where the individual can resume activities of daily living and work. The time spent in this phase may be very short.

Shortly after being concussed, individuals may decide to seek medical attention. The athletes in this study all visited health care practionners, most often their general practionner or the emergency department, and were diagnosed with a concussion. Most concussions were not graded. Some athletes were given a CT or MRI scan early in the recovery process. All of the athletes received the same recommendation for recovery from concussion during the acute stage. Some received written information and others received the information verbally but the advice was the same: (a) Rest until asymptomatic and (b) graded return to pre-injury activities. These recommendations are consistent with the research on management of concussion during the acute stage (Parker, 2001; Stroler & Hill, 1998). Some athletes also received information, either verbally or written, regarding the return to physical activity and sport following a concussion. This was most commonly the return to play guidelines outlined by the American Academy of Neurology (1993), Cantu (1986), Kelly et al (1991) and Aubry (2002). Depending on the length of time spent in phase one, some athletes also saw specialists, such as neurosurgeons or neurologists, and were diagnosed with post concussion syndrome.

In general, the athletes did not participate in physical activity during phase one. They followed the return to play guidelines and the recovery suggestions given to them by their health care practionners, partly because they did not feel well enough to participate. There were a few exceptions to this. Some participants continued to play their sport because they did not realize the possible consequences of playing contact sport while symptomatic. This was the case for Sandy. She did not realize that second impact syndrome, which is sometimes fatal, can occur. John kept playing recreational hockey while he was still experiencing symptoms because he had "had his bell rung" before and kept playing without any adverse consequences. Both Sandy and John stopped playing once their health care practionners gave them more information about the consequences of sustaining a concussion while still experiencing symptoms from a previous concussion.

Phase Two

Phase two is characterized by motivation and determination to continue on with life despite the symptoms and limitations experienced. This includes a return to work, school and other pre-injury activities of daily living. This phase is typically when athletes are diagnosed with post concussion syndrome. The focus during this phase is to maintain as normal a life as possible despite the symptoms and to return to their pre-injury level of functioning and pre-injury life. Individuals in phase two spend a great deal of energy managing symptoms and "getting through the day". This was the case for John and Jen at the time of the interviews. Both said that they were just managing to get through the day because of the severity of the symptoms they experienced. During this phase, moderate improvement can be expected. This phase ends when the major disruptive symptoms resolve. This phase can last a long time or a few months.

Phase two is typically the time when the athletes searched for answers to why they were still experiencing symptoms. This search usually led to many encounters with health care practionners including neurologists, neurosurgeons, general practionners, ophthalmologist, neuro-ophthalmologists, massage therapists, osteopaths, chiropractors, athletic trainers, physiotherapists, sports medicine doctors, and psychologists. Unlike the recommendations for recovery from concussion, the participants who visited a number of different health care practionners received different opinions regarding recovery from post concussion syndrome. These ranged from rest, medication, a graded return to pre-injury activities based on symptoms, and "just wait until the symptoms go away".

During phase two, athletes may experiment with returning to physical activity and sport despite the symptoms. The athletes in this study were engaging in physical activity during this time, although it was not usually full game play in their desired sport. The athletes were often participating in physical activity without the consent of their health care practionners because the benefits of being physically active outweighed the drawbacks. Some athletes pushed through the symptoms trying to increase tolerance for physical activity, while other found the symptoms too frustrating and stopped being physically active for long periods of time. Having said this, being physically active restored a sense of normalcy to the athlete's life.

Phase Three

Phase three is characterized by an effort to relearn how to function effectively in the world and the surrounding environment while rediscovering and reinventing oneself. The following quote sums up my own mindset entering phase three:

> I have so many unanswered questions, some fundamental to who I am and the direction I want to go in. I'm not sure how or where to start to re-identify myself. I feel that I'm a very different person than I was before.

Interestingly, it is the absence of disruptive symptoms that allow the re-learning and self discovery to take place, enabling the individual to focus on the environment in which he or she exists rather than on the management of symptoms. This phase focuses on relearning and redesigning coping strategies to effectively navigate physical, social, academic or work environments.

Interactions with health care practionners during this phase are limited, largely because the disruptive symptoms have dissipated. Having said this, athletes may seek counselling services or consult a sport psychology professional in an attempt to either deal with the life changes as a result of the concussion or to become psychologically prepared to return to their sport. This is an important step in recovery because the participants whose symptoms had resolved said that they were more hesitant, had a fear of re-injury and were apprehensive about playing their sport, especially contact sports such as rugby and hockey. These emotional reactions are consistent with studies focusing on athletes returning to play after a major injury (Johnston & Carroll, 1998; Petitpas & Danish, 1995; Quackenbush & Crossman, 1994).

Participation in physical activity during phase three is largely based on the comfort level of the individual athlete. It is my hypothesis, based on my own experience and on the research focusing on recovery and return to sport following severe injury, that the longer the progression through phase one and two, the less likely the athlete is to return to play the sport he or she did prior to the injury. Recovery from post concussion syndrome, especially when symptoms persist for many months and years, changes the athlete. Participants in this study felt that brain injuries were potentially more serious than other bodily injuries because of the effect on cognitive functioning.

Some athletes questioned the importance of playing competitive sports given the increased risk of future concussion. The athletes were aware of the research suggesting that the effects of concussion are cumulative and that those who have sustained a concussion are more likely to sustain subsequent concussions (Gronwall & Wrightson, 1975; Iverson, Gaetz, Lovell & Collins, 2002; Kelly & Rosenberg, 1997; Webbe & Barth, 2003). The subsequent concussions often lead to more persistent and severe symptoms and longer recovery time (Collins & Hawn, 2002). These concerns and questions have been prevalent in my recovery.

Phase three is, in essence, when the athlete is discovering their post injury identity. For some, the decision will be to retire from sport, to try other forms for physical activity and to create an identity beyond that of athlete in their chosen sport. Webb and Nasco (1998) found that injured athletes often go through a period of rehabilitation attempting to return to play. Inherent in the rehabilitation of injured athletes is that the optimum outcome is a return to game play, although this is not always the case. The realization that the injury is career ending, or that the brain is too important to risk another head injury, is often not immediate. The athlete must then switch mindsets from one of returning to play to one of retirement from sport. Perhaps integral to a change in mindset is a re-definition of self identity beyond that of athlete.

Psychosocial Aspects of Recovery

Emotional response to injury, coping, and support are important aspects of the recovery process. Frustration emerged as the main emotional response to injury and was prevalent throughout the entire process. Athletes used coping and support in each of the three phases to deal with the emotional response to the concussion and to the persistent symptoms. Unlike the phases of recovery where the athletes progressed linearly, the psychosocial aspects of recovery were cyclical. This is consistent with Kendall and Buys (1998) finding on adjustment to disability that each new environment or challenge faced by the individual requires a development of a new schema to fit the new challenges, opportunity or environment experienced in life.

Emotional Response to Injury and Recovery

Frustration was the most frequently mentioned emotional response to the concussion, post concussion syndrome, and recovery. John said over and over throughout his interview “It’s just so frustrating”. This was echoed by other participants. Numerous studies have reported frustration one of the main emotional responses to injury (Johnston & Carroll, 1998; Putukian & Echemendia, 2003; Quackenbush & Crossman, 1994; Smith, Scott, & Wiese, 1990). The participants mentioned a number of sources of the frustration including (a) the medical system, (b) the lack of knowledge of doctors, (c) inability to participate in physical activity, (d) the return of symptoms when participating in physical activity, (e) the lack of progress in recovery over time, and (f) the frustration of not being able to do what they could before their injury. The frustration I felt resulted from constantly being in pain, lost time and memories, lack of financial independence, lack of information about post concussion syndrome, lack of services, lack of treatment options, and the limitations I experienced as a result of my concussion.

All of the athletes in this study felt that there were benefits to being physically active before their concussion. Jen expressed one of the benefits in the following quote: “[physical activity is] a way to get your frustrations out… you know, your daily frustrations and stress out”. Her comment is representative of other participants in this study. For some, it was the feeling of being fit, the aesthetic look of their body, or a form of stress relief. For others, participation in sport and physical activity was a social event. Not surprisingly, athletes were frustrated about not being able to participate in physical activity. The longer the symptoms persisted, the more frustrated they became. Not being able to participate had huge impacts on their lives.

With this is mind, frustration became a never ending, self perpetuating cycle. Athletes were frustrated about not being able to participate in physical activity. They experience the stress of everyday life and the added stress of injury. For many of the athletes, physical activity was their main form of stress relief, which they could no longer do. When the athletes tried to participate in physical activity, the symptoms returned. Not only were the athletes frustrated that the symptoms returned, preventing them from being physically active, but that participation in physical activity made them feel physically sick and in pain.

In addition, participating in physical activity while symptomatic brought out fear, apprehension, and hesitation (Johnston & Carroll, 1998; Petitpas & Danish, 1995; Quackenbush & Crossman, 1994). The athletes who were symptomatic also felt a sense of loss because they could not participate in their desired sport, or participate in physical activity in their pre-injury capacity. A feeling of sense of loss due to injury and forced retirement from sport is well documented in the forced retirement from sport literature (Ford & Gordon, 1999; Fortunato & Marchant, 1999; Leddy, Lambert & Olges, 1994; Udry, Gould, Bridges & Beck, 1997).

A number of studies have found that when an athlete is injured their mood is effected (Crossman, Gluck, & Jamieson, 1995; McDonald & Hardy, 1990; Pearson, & Jones, 1992; Quackenbush & Crossman, 1994; Smith, Scott, O'Fallon & Young, 1990). McDonald and Hardy (1990) found that the athlete's perceived success during the rehabilitation progress led to increasingly positive emotions as time passed. Most of the athletes in McDonald and Hardy's (1990) study had a clear understanding of the rehabilitation expectations and the expected outcomes of their injury. This is important to consider in relation to those with post concussion syndrome. Because there are so many unknowns and questions surrounding the long term recovery process, outcomes, and more importantly the length of recovery time, athletes with post concussion syndrome may present more severe emotional reactions to the injury and the recovery process. John asked "where does it all end?" when speaking about his persistent on going symptoms of headache, blurry vision, inability to participation in physical activity, as well as the increased risk of future concussions. In addition, these athletes may also experience a cyclical emergence of emotions throughout the recovery process as the concussed athlete revisits the notion of chronicity, permanent brain damage, an unknown prognosis, as well as decreased functioning, and the uncertainty of whether they will be able to participate in sport and physical activity. This is consistent with Kendall and Buys (1998) study on adjustment to disability.

A recent study by Mainwaring, et al. (2004) studied the emotional reaction of varsity athletes to sport related concussions. They found that increase in transient depression and confusion occurred following a concussion and that athletes in the study returned to baseline moods two or three weeks post injury. Furthermore, they suggested that the mood disturbance is not attributed to pre-morbid functioning. This study did not, however, study athletes with post concussion syndrome therefore it is difficult to make any inferences in relation to those with post concussion syndrome and mood disturbance. Presumably, the athletes in Mainwaring et al's (2004) study recovered in a reasonable period of time and experienced no lingering symptoms. Giza and Houda (2000) suggested that depression in brain injured people may be a consequence of biochemical disturbance as a result of the brain insult. This may also be something to consider with mood disturbances in brain injured athletes.

There have been numerous professional athletes with post concussion syndrome who have reported waking up one day to find that all of their symptoms are gone; like someone turned on a switch and everything worked again. Early in my recovery, one of the health care practionners I was seeing told me that this might happen but could not predict when or if it would occur.

When I woke up on January 29, 2003, I felt different and soon realized that all of the disruptive symptoms were gone. It felt like my brain went from working at about 30% capacity to 95%. It was the happiest day of my life! I soon realized that I had woken up to a new and foreign world without any coping skills or strategies to navigate through everyday life. I often felt overwhelmed by the confusion of the world around me; especially by the enormous amount of relearning I had to do. In the end, much time and effort went into re-learning and re-acquainting myself to my physical, social, academic and work environments. Most of the other participants in this study had not experienced this, partly because they were not at this phase in the recovery. While not all athletes will experience this, it is important to consider this as a possible component of emotional response to injury and the recovery process of athletes with post concussion syndrome. I could not find any literature on this spontaneous recovery phenomenon.

Recognizing emotional responses to injury and the recovery process is integral for athletes to move through the phases of recovery. If athletes identify the emotional responses they experience during the three phases of recovery, an appropriate support system of people can be put in place and coping strategies can be developed. Early identification of emotions combined with positive coping strategies and a strong support system throughout the entire recovery process may lead to the emergence of fewer secondary symptoms, such as depression, and a faster recovery in general.

Coping

Coping emerged as an important part of the recovery process. The athletes were coping with both the post concussion symptoms and the emotional response to the injury and recovery process. Athletes used positive and negative coping strategies during their recovery process.

The specific strategies for coping changed in each phase of recovery with sleep, and over the counter and prescription medications being the most often used strategies during phase one. Athletes were mainly dealing with disruptive physical symptoms, most commonly headaches, blurry vision, nausea, and fatigue. During phase two, the participants used over the counter and prescription medications, as well as physical activity and shutting out the world. In addition to the forms of coping mentioned above, I also used alcohol, sport psychology counselling, and healing imagery. The majority of the data from phase three is based on my recovery experience. Coping in phase three included shutting out the world, physical activity, and creating strategies to overcome the deficits in memory and my perceived lack of the more subtle social skills. The specific areas of re-learning may depend on a number of factors, such as the injury site, pre-injury functioning and more. It is important to discuss negative coping strategies and the reasons for using them. Williams and Evans (2003) discuss numerous topics related to emotions and brain injury. They suggest that alcohol and substance misuse is common in those with brain injury, and is used to cope with pain, anxiety, and depression. They also suggest that alcohol misuse can develop in those who are pre-morbid non users. This was the case in my recovery. The headache pain I experienced was intense and the lack of timely services and support for dealing with the pain led me to experiment with alcohol. I do not normally drink. After about six months of alcohol use, I sought help and stopped but the experience made me realize that if the appropriate positive coping strategies and support were in place, I never would have turned to alcohol. Williams and Evans (2001) also point out that substance abuse often put users at risk for subsequent head injuries from falls, car crashes and more. The experience led me to understand the importance of helping athletes with post concussion syndrome find positive and healthy coping strategies that lead to improved functioning. Strategies should include a plan for pain management and for dealing with the emotional reaction to the injury and recovery.

All of the athletes in this study reported that physical activity was the main strategy for coping with stress before sustaining their concussion. The "rest until asymptomatic recommendation", while necessary in the acute phase, eliminates one of the main coping strategies used by the athletes to deal with the stresses of life and the injury. Not surprisingly, many of the athletes reported that physical activity was a form of coping during recovery as well, despite the aggravation of symptoms. Jen expressed this in the following quote: "it feels so good to exercise and so what I'm, you know, what I'm so accustomed to doing on a daily basis, you know… get it out and sweat and feel good".

Hutchinson, et al. (2001) studied leisure as a coping resource in coping with traumatic injury and illness. One of the main assumptions of the researchers is that leisure is a resource for emotion, problem focused coping, and as "the foundation for subsequent adjustment following a negative event" (Hutchinson et al., 2001, p. 145). The study found that participants used leisure to cope with the challenges of everyday living in the following manner: "(a) as a buffer from immediate stressors, and (b) as a source of motivation to sustain coping efforts" (Hutchinson et al, 2001, p 149). Within these two categories, there are themes that relate specifically to athletes with post concussion syndrome. Hutchinson et al (2001) found that leisure preserved a connection to the past by creating a sense of normalcy, by symbolically connecting to the past. Another finding was that leisure helped to maintain physical and mental health. The participants in Hutchinson et al.'s (2001) study reported that physical activity was important in maintaining or improving physical function. Sport and physical activity is a form of leisure.

Hutchinson et al.'s (2001) study support the findings from this study that physical activity is an important coping strategy. By enabling and encouraging athletes with post concussion syndrome to be physically active during the recovery process, athletic identity, sense of self and a physically active life style can be maintained. Because the number of significant life changes that occur as a result of the concussion are minimized, fewer secondary symptoms may present, therefore reducing the recovery time.

Support

Support is extremely important in the recovery process of athletes with post concussion syndrome. As with coping, the type of support changes as the athlete progresses through the phases of recovery, but the need for support is consistent throughout. As with coping, support may come from varying sources.

The athletes reported that support came from coaches, trainers, team mates, friends, spouses, significant others, health care practionners, teachers, professors, co-workers, and sport psychologists. The types of support included advocacy, providing knowledge and information about recovery and post concussion syndrome, problem solving, strategy and skill development, and just being a friend. These finding are supported in the literature (Natterlund & Ahlstrom, 1999; Robbins & Rosenfeld, 2001; Urdy, 2002).

Having described the generalized findings regarding support, it is interesting that the athletes in this study found their own people to support them rather than seeking support from existing organizations or groups. Given that support emerged as an integral component in the recovery process and that post concussion syndrome is not uncommon in contact sport, there should be places where athletes with post concussion syndrome can access professional and knowledgeable support.

Recently, there have been a few researchers who speculated about the potential role of sports psychologists in the recovery of athletes with post concussion

syndrome. Bloom, Horton, McCrory and Johnston (2004) suggest that the use of sport psychology techniques may be useful in the treatment and management of post concussion syndrome, particularly with regards to the psychosocial aspects of recovery, and the emotional reaction to injury and the recovery process.
Kontos, Collins and Russo (2004) discuss the role of the sport psychology consultant in the management of sports related concussion. The roles of sport psychology consultants include (a) education, recognition and prevention information, (b) systematic approaches to managing recovery such as computer testing, consistent symptom evaluation and referrals, (c) consulting with concussed athletes to help athletes cope with fear of re-injury, confidence, anxiety and other return to play issues, and (d) if the concussion is career ending, consultation regarding retirement from sport and adjustment to disability and illness.

Perhaps one of the more important and qualified people to have on the support team of athletes with post concussion syndrome is a sports psychologist. Since athletes are generally striving to return to pre-injury levels of physical activity and sport, sport psychologists provide a unique set of skills specifically suited to this population. Should the athlete be faced with forced retirement from sport, sport psychologists can help with the transition. Speaking from experience, one of the most valuable people supporting me during my recovery was a sport psychologist, especially during the late stage of phase one and throughout phase two. Through regular visits, he helped me to develop a plan designed to regain some physical fitness, provided support when I was having difficulty with alcohol and other negative coping strategies, and helped to work through some of the issues related to retirement from sport.

Recovery: A Re-Conceptualization of Self in the Absence of the Athlete Identity

The notion of recovery and the recovery process of athletes with post concussion syndrome are interesting when compared to the literature on recovery from illness and disability. While there is no research that focuses on the recovery process of people with post concussion syndrome, some studies in the area of disability have discussed aspects that apply and support the findings of this study.

Bishop (2001) described recovery as:

> a deeply personal process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the effects of disability or illness (p. 48).

This quote describing the recovery process is certainly one which can be related to those with post concussion syndrome who experience symptoms that last many years. While the athletes who were interviewed had not yet reached the stage where they had developed new meaning and purpose in one's life as one grows beyond the effects of the disability, I, for the most part, did. I accept my limitations, however, I continue to make goals and work towards re-learning and re-training my brain to overcome the limitations I experience.

Bishop (2001) outlines five assumptions of the recovery process. The first assumption is that professional intervention is not necessary for recovery to occur. Second, that support, belief and encouragement are all important factors in the recovery process of the injured person. Third, recovery can occur even though symptoms reoccur. Fourth, recovery is not dependent on the resolution of symptoms. The final assumption is that "the recovery from the consequences of a chronic illness or disability is sometimes more difficult than recovery from the illness or disability itself" (Bishop, 2001, p. 49).

Examining a few of these assumptions in relation to the findings of this study provide insight into the recovery process of the athletes with post concussion syndrome. The assumptions that recovery can occur even though symptoms reoccur and that recovery is not dependent on the resolution of symptoms are assumptions that are worthy of some discussion. I consider myself to be recovered but it was the resolution of disruptive symptoms that was the main factor in determining my recovery. Those who were asymptomatic at the time of the interview felt their recovery was largely based on the resolution of symptoms. Those who were still symptomatic felt that symptoms were the main barrier to the resumption of pre-injury participation in physical activity and activities of daily living. All of the symptomatic athletes were striving to be asymptomatic and felt that once that occurred, they would consider themselves to be recovered. Thus, contrary to Bishop (2001), it appears based on the athletes in this study that the resolution or management of the most painful and disruptive symptoms must occur for the athlete to be able to complete the recovery process. This study provides little information about those individuals who experience symptoms for many years, thus it is difficult to speculate on the validity of Bishop's (2001) research on recovery for long term post concussion syndrome sufferers.

The assumption that "the recovery from the consequences of a chronic illness or disability is sometimes more difficult than recovery from the illness or disability itself" (Bishop, 2001, p. 49) was very poignant in my recovery from post concussion syndrome. The concussion I sustained left me without emotional and visual memory. The consequence of this is that I have difficulty maintaining connections with people. This is alienating, often lonely and I often feel that I have no connection with the world around me. The participants also supported this assumption. They spoke about how their inability to be physically active led to depression, and that the depression was difficult to deal with. Some athletes experienced financial losses because of their inability to work. Addressing these consequences is a key component in recovery.

Kendall and Buys (1998) suggest that each new environment or challenge faced by the individual requires a development of a new schema to fit the new challenges, opportunity or environment experienced in life. The development of new schema is often guided by (a) search for new meaning in disability, (b) need for control over the disability and the environment, and (c) the need to protect and explore the post-disability identity. Throughout my recovery of post concussion syndrome, there were a number of times where I searched for meaning in my post-injury life. I gave myself time to explore the meaning of being "brain injured" and to devise a plan to retrain my brain and body. This was essentially my way of maintaining control over my disability/ injury and my environment. Creating a new self was a very important part of my recovery process.

It is fair to say that recovery is the ultimate goal for all injured athletes. For some, recovery means a return to pre-injury life and participation in physical activity and sport without long term effects. For others, recovery will involve a lengthy symptomatic period followed by the resolution of symptoms. Once the symptoms resolve, the athlete can return to normal functioning and participation in physical activity, however the recovery process leads to a re-conceptualization of self base on a post concussion identity and the absence of the "athlete" identity. Lastly, there are a small percentage of people whose symptoms never resolve. A re-conceptualization of self may also occur in this population however, they are left coping with the symptoms and more severe consequences of the injury. For these athletes living is synonymous with coping (Charmaz, 1991; Miller, 2000; Robinson, West, & Woodworth, 1995).

Regardless, athletes with persistent symptoms progress through the three phases of recovery and the various psychosocial aspects of recovery. The end result is recovery, although recovery can mean either a return to pre-injury functioning, activities of daily living, and physical activity, or a re-conceptualization of self in the absence of the athlete identity.

Physical Activity and Post Concussion Syndrome

Participation in physical activity and sport was an integral part of the lives of the athletes in this study. Their main goal for recovery from concussion and post concussion syndrome was, and is, the return to pre-injury participation in sport and physical activity. The return to play recommendations provide valuable guidelines for returning to contact sport, however what happens if the athlete never progresses past step one; rest until asymptomatic? All of the athletes in this study were participating in physical activity despite the recommendations of their health care practionners. The longer the symptoms persisted, the more likely it was that the athletes participated in physical activity while symptomatic. The reason for this is best summed up by the words of one of the participants, John: "I believe that you're mentally stronger when you are physically fit".

Wetzel and Rorke (2001) speculated about the benefits of including physical activity in the rehabilitation of people with MTBI based on the studies done with moderate and severe TBI patients. Many of their speculations were supported by the athletes in this study. Some were not.

Wetzel and Rorke's (2001) first speculation is that people with MTBI may become less physically active because of the injury. This was true for the participants who were interviewed, as well as for me. None of the athletes who were symptomatic were able to participate in physical activity at their pre-injury intensity level because exercise exacerbated their symptoms. Wetzel and Rorke (2001) also found evidence that with injuries in general, the person experiences a period of inactivity "creating a cycle of deconditioning and diminished functional capacity" (p. 190). John, Sandy, Jen, Angela and I all experience this.

At the time of the interview, John was not physically active because he was advised by his doctor not to push through symptoms. Sandy and Jen were participating in physical activity by pushing through their symptoms. Despite their efforts or desires to be physically active, their capacity to engage in physical activity diminished as a result of their concussion and subsequent post concussion syndrome. In John's case, he tried to maintain his participation in physical activity and sport, but found the symptoms to be too intense, so he stopped all physical activity. During my recovery process, participation in physical activity occurred in chunks. I would be very active for months at a time and then be inactive for many months. This led to an overall deconditioning despite times where I was very fit. All the symptomatic athletes experienced deconditioning and diminished functional capacity in relation to their ability to participate in physical activity and sport.

Research has shown that there are many benefits to participation in regular physical activity including improved overall fitness, physiological benefits, increase in strength, decreased risk of disease and more (Burnham, 1998; Frontera, et al., 1999; Goldberg & Elliot, 1994). Wetzel and Rorke (2001) also found evidence that physical activity enhanced the feeling of well being. While the purpose of this study was not to identify the physiological benefits of physical activity, the athletes expressed that one benefit of being physically active was that they felt better. Clarifying this, athletes said that they did not feel good while exercising or directly after being physically active but that the overall feeling of being fit, feeling healthly, and conditioned made them feel good.

Physical activity has been shown to improve psychological health. Being physically active has been shown to reduce depression, stress, and anxiety, and improve sleep (DiLorenzo, Bargman, Stucky-Ropp; Brassington, Frensch, & LaFontaine, 1999; Kirkcaldy & Shepard, 1990). Findings of this study support this. Jen commented; "I, like, developed depression and um, it [physical activity] helps me feel better". All of the athletes used physical activity as a form of stress release before their concussion. Therefore, it was not surprising that the athletes attempted to use physical activity as a way to relieve stress during the recovery process. Perhaps encouraging athletes to engage in safe, low risk forms of physical activity during recovery would enable them to use engrained coping strategies, e.g. physical activity, to lessen or prevent the onset of secondary symptoms, such as depression or anxiety. Not only are the athletes with post concussion syndrome benefiting from the reduction of stress, anxiety and depression, and improved sleep, but by allowing and encouraging them to engage in recovery appropriate forms of physical activity, the changes in life style may not be as dramatic as a result.

Wetzel and Rorke (2001) discuss the possibility of secondary symptoms developing as a result of inactivity, deconditioning, personal helplessness, and social isolation. Personal helplessness did not seem to be an issue for the athletes in this study. Perhaps this is because all of the athletes were driven by their desire to return to full game participation in their preferred sport. Many of the athletes had concerns about following the "rest until symptom free" advice of the doctors the longer the symptoms persisted because of deconditioning. Angela summed up this concern when asked why she only took two weeks off of physical activity to rest following her concussion: "you'd have to build everything up again". Social isolation was also a concern for the athletes. Those who played on a team often socialized with their team mates. Jen missed playing basketball partly because she missed being part of the team. Since she was unable to play because of the post concussion syndrome, she not only lost friends but access to the medical support system that was associated with the basketball team. Interestingly, it seems that one of the factors in the development of secondary symptoms was the athlete's inability to participate in sport and physical activity, because sport is such an integral part of the life of an athlete. Take away the ability to participate in sport because of injury and the athlete looses their social circle, fitness, part of his or her identity and more.

Finally, based on studies focusing on exercise and migraine headaches, Wetzel and Rorke (2001) suggest that aerobic exercise may decrease the severity and intensity of headaches in people with MTBI. While research with migraine sufferers may support this, the findings of this study do not. All of the athletes said that symptoms, including and particularly headaches, were exacerbated with aerobic exercise (e.g. when they raised their heart rate). This phenomenon has been reported clinically by physicians (McCrory & Johnston, 2002). Having said this, many of the athletes were physically active anyway and dealt with the worsening symptoms because they felt the psychosocial benefits gained outweighed the negatives.

There were some unexpected findings that emerged from this study. While recommendations for return to play, computer concussion testing programs, and more education on the part of coaches and trainers are beneficial in preventing athletes with post concussion syndrome from returning to play too soon, it is also useful to understand the perspective of those who have post concussion syndrome. Especially important to consider is what the athletes are actually DOING in their attempt to return to play. There are three key pieces of information that emerged from this study that anyone associated with athletes with post concussion syndrome should be aware of:

1. Athletes lied about being symptom free so that they could return to play.
2. Athletes learned how to take the tests (such as ImPACT, Headminders and the Folstien Mini Mental) that they had to pass in order to be cleared to play. Therefore, the improved score did not necessarily reflect an improvement in symptoms, rather improvement in test taking skills.
3. Athletes were physically active while symptomatic despite the advice of their health care practionners and the recommendations.

In addition, many athletes commented on attitude towards concussion in sports. Interestingly, the rules of both rugby and soccer discourage injured athletes from leaving the field. Sandy and Angela commented on this at length. Both sports have a limited number of substitutions per game. If a player is taken off the field because of an injury, it is counted as a substitution. Once the substitutions are used up, the team then plays short handed if a player is injured and leaves the field. Angela and Sandy discussed playing through injury because they did not want to use a substitution or leave their team short handed. In Sandy's case, she was concussed during the first half of a soccer game but chose to play until half time. In the time between the first concussion and half time, she sustained another concussion from which she has yet to recover. The play through injury attitude is not unique to rugby and soccer. Football and hockey have similar unspoken expectations. One of the participants, John, works in the hockey industry and had this comment regarding the play through attitude towards injury:

> And in our sport [hockey], you don't cry about getting your bell rung, I mean, you gotta keep playing. Um, if you have a broken arm, broken leg, something physically that they can see, that's a bit different story. But you never go and say you're feeling dizzy and stuff like that, you just play through it.

This attitude is discussed in a recent article by Yeoman (2004) in *Discover*. The article focuses specifically on contact sports, the attitude of playing through injury and the long term effects of repeated concussions. While attitudes towards concussion in sports are changing slowly, the old mentalities still exist. More attention should be focused on ensuring that concussed players feel comfortable sitting out. Rules of the game should be adapted to allow injured players to leave the playing field without penalizing their team.

Finally, the athletes in this study found that participation in physical activity while symptomatic made them feel better physically and mentally. It helped them to cope with life and with secondary symptoms, such as depression. It helped prevent them from falling into a sedentary life style and provided or maintained a social network. While all the athletes agreed that participating in physical activity with symptoms was not the same as before the injury, it was an integral part of their lives. The main drawback was that exercise aggravated their symptoms.

Implications for Practice

While this study is exploratory in nature, it does provide insight into the experience of athletes recovering from post concussion syndrome and the importance of physical activity to the health and well being of the concussed athlete. The athletes generally came from different geographical regions, thus, represented are recovery experiences from Minnesota, Ontario, Vancouver, and from southern, central, and northern Alberta. Including my experience, the geographical regions can be extended to Montreal, Maine, and Australia. Thus, the findings of this study may be indicative of a more general recovery experience, despite the small sample size.

A number of implications for practice emerged from this study. First, physical activity is an integral part of an athlete's life. Recommending that an athlete with post concussion syndrome rest until asymptomatic may not be the most appropriate or healthy recommendation in achieving an overall recovery outcome over the long term. The athletes in this study were physically active despite the symptoms. Based on this, the current return to play guidelines and recommendations for recovering from post concussion syndrome should be re-conceptualized to include physical activity in order to provide more guidance for those individuals with persistent symptoms. It makes sense to provide individuals recovering from post concussion syndrome with guidelines for physical activity while symptomatic, rather than recommending against all forms of physical activity. Participation in low head injury risk physical activity should be included and encouraged in the recovery process of athletes recovering from post concussion syndrome. Having said this, it is important that athletes consult their physicians prior to resuming physical activity. In addition, athletes should not participate in contact sports and activities while symptomatic.

Second, while concussions are often referred to as mild traumatic brain injuries, or as minor head injuries, they can have huge impacts on the lives of athletes. It is important that athletes with post concussion syndrome, and all people with lingering symptoms from MTBI, be provided with information about the injury, the risk of re-injury, as well as information regarding expected symptoms and recovery. Research by Mittenburg and Burton (1994) and Mittenburg et al (2001) found that education and reassurance were the main recommendations for management of post concussion syndrome. In addition, people with post concussion syndrome experienced fewer persistent symptoms when education and support were provided than those who received no education or support. More importantly, health care practionners should not dismiss the concerns of those with post concussion syndrome.

Third, specialized physician led care teams should be the standard of care for athletes with post concussion syndrome and MTBI. The team should consist of the needed specialists to ensure that the team is collectively knowledgeable in all aspects of mental, physical and psychological recovery. This is important, because while the athlete may be physically cleared to play, psychologically he or she may not be ready. Consequently, sport psychologists should play a significant role in this specialized care team.

Fourth, athletes should be followed and supported by health care practionners as they resume physical activity, especially while the athlete is symptomatic. A plan should be devised and take into account each individual athlete's situation and sport, as well as his or her short and long term goals for recovery. In doing so, coaches, trainers, sport psychologists, and physicians will be better able to assess when, or if, athletes are ready to return to play. If retirement is the end result, the athlete should have the necessary support personnel in place in order to make the transition out of sport easier.

Fifth, brain injury support groups generally tend to be focused towards moderate and severe brain injured individuals. The issues that people with post concussion syndrome face are often different than those with moderate or severe brain injuries, thus support groups specifically for mild traumatic brain injury and those with post concussion syndrome may help athletes cope with their recovery and temporary disability. Professional support, in the form of one on one or group counselling, should be available to help athletes with returning to pre-injury activities of daily living and physical activity. In addition to this, athletes with post concussion syndrome may find it useful to ask co-workers, teachers, family, friends, team mates, coaches, trainers and health care practionners to be a part of their support system. In doing this, the athlete not only plays an active role in his or her recovery, but creates a team of people to support them when difficulties are experienced.

Sixth, neuropsychological testing, and sideline and computer based testing can provide valuable information that can be used in the decision to allow an athlete to return to play, however these are only tools. Some of the participants reported learning how to take the tests to obtain a better score, thus the better score represented athletes ability to take the test, not an improvement in their condition. Athletes want to play and some will go to great lengths to do so.

Seventh, journaling can be a useful tool in the recovery from post concussion syndrome. There are a number of benefits to journaling, both to the practionner and to the athlete. Over time, the journal can provide a record of events and recovery progress, which can be useful for the practionner in determining the effectiveness of the treatment and in planning future treatment. It also reminds the athlete how far he or she has come since the injury. Journaling also provides an outlet for the athlete to express emotion in an appropriate manner.

Finally, recovering from post concussion syndrome is a process and the end result is not always a return to play. For those whose symptoms persist for months, years or never completely dissipate, recovery means creating a new self concept with the absence of the "athlete" identity. It is imperative that the athlete is supported throughout the entire recovery process. This means having access to the necessary services as the needs of the athlete changes as he or she progresses through each phase of recovery and the associated challenges. This access to services should be available for professional and recreational athletes and everyone in between.

Future Research

Concussion research, and in particular, recovery from concussion and post concussion syndrome is in its infancy. There is a great deal that is still unknown. This study provides insight into the experience of recovering from post concussion syndrome and the return to physical activity. It also draws attention to many more unanswered questions and possibilities for future research. The following are only a few of the many possibilities:

1. Incidence and injury rates of MTBI, concussion and post concussion syndrome in Canada.

2. The development of management and treatment options and protocol for post concussion syndrome, especially for those with persistent post concussion symptoms.
3. The development of better resources and strategies for recovery, rehabilitation, and support specifically for those with MTBI and post concussion syndrome.
4. The role of the sports psychologist in the recovery process of athletes with post concussion syndrome, specifically in aiding the athlete to come to terms with the unknown chronicity of the injury and the re-conceptualization of self beyond that of athlete.
5. Understanding athletes' emotional responses to post concussion syndrome and the recovery process.
6. Further understanding of the role of support and coping in the recovery process of those with post concussion syndrome.
7. The use of low head injury risk activities as rehabilitation from post concussion syndrome.

There are enormous possibilities for future research in the area of recovery/ rehabilitation from post concussion syndrome. This study is only the beginning.

Conclusion

Physical activity played an important role in my recovery process. This was also the case for all of the participants who were interviewed. All those who participated in this study were physically active while symptomatic. This sends a clear message that physical activity is an important part of the recovery process of athletes with post concussion syndrome. Participation in physical activity while symptomatic created a sense of normalcy, lessened the deconditioning the athletes experienced as a result of their injury, was an important form of stress release, maintained social connections, helped to cope with depression, and made the athletes feel good mentally. On the other hand, physical activity and exercise aggravated symptoms, especially headaches, fatigue, dizziness, and blurry vision. Thus, the dilemma is that participation in physical activity and exercise makes the athlete with post concussion syndrome feel good mentally but bad physically. That being said, there was an overwhelming consensus from the athletes in this study that they need to be physically active to be healthy. In the end, this need motivated them to be physically active despite the aggravation of symptoms.

REFERENCES

Alves, W., Macciocchi, S. N., & Barth, J. T. (1993). Postconcussive syndrome after uncomplicated mild head injury. *Journal of Head Trauma Rehabilitation, 8*(3). 48-59.

American Academy of Neurology. Report of the quality standards subcommittee. (1997). Practice parameter: the management of concussion in sport [summary statement]. *Neurology, 48,* 147-152.

Aubry, M. (2002). Summary and agreement statement of the first international conference on concussion in sport, Vienna 2001. *The Physician and Sportsmedicine, 30*(2), 57-63.

Babcock Grove, P. (Ed). (1986). *Webster's third new international dictionary of the English language unabridged.* Springfield, MA: Merriam-Webster Inc.

Bateman, A., Culpan, F. J., Pickering, A. D., Powell, J. H., Scott, O. M., & Greenwood, R. J. (2001). The effect of aerobic training on rehabilitation outcomes after recent severe brain injury: a randomized controlled evaluation. *Archives of Physical Medicine and Rehabilitation 82*, 174-182.

Bishop, M. (2001). The recovery process and chronic illness and disability: applications and implications. *Journal of Vocational Rehabilitation, 16*, 47-52.

Bloom, G. A., Horton, A. S., McCrory, P., & Johnston, K. M. (2004). Sport psychology and concussion: new impacts to explore. *British Journal of Sports Medicine, 38*, 519-521.

Bouchard, C., Shepard, R. J., & Stephens, T. (1994). *Physical activity, fitness and health.* Champaign, IL: Human Kinetics.

Burnham, J. M. (1998). Exercise medicine: Health benefits of regular physical activity. *Journal of Louisiana State Medical Society, 150*, 319-323.

Cantu, R. C. (1986). Guidelines for return to contact sports after a cerebral concussion. *Physician and Sportsmedicine, 14*, 75-83.

Charmez, K. (1991). *Good days, bad days: The self in chronic illness and time.* New Brunswick, NJ: Rutgers University Press.

Collins, M. W., & Hawn, K. L. (2002). The clinical management of sports concussion. *Current Sports Medicine Reports, 1,* 12-22.

Cooper, E. R., Ferrara, M. S., Mrazik, M., & Casto, S. (2001). Definitional problems in mild head injury epidemiology. *Athletic Therapy Today, 6*(1), 6-12.

Crossman, J., Gluck, L., & Jamieson, J. (1995). The emotional responses of injured athletes. *New Zealand Journal of Sports Medicine, 23,* 1-2.

Crotty, M. (1998). *The foundation of social research: Meaning and perspective in the research process.* London: SAGE Publications Ltd.

DiLorenzo, T. M., Bargman, E. P., Stucky-Ropp, R., Brassington, G. S, Frensch, P. A., & LaFontaine, T. (1999). Long-term effects of aerobic exercise on psychological outcomes. *Preventative Medicine, 28*, 75-85.

Ewing, R., McCarthy, D., Gronwall, D., & Wrightson, P. (1980). Persistent effects of minor head injury observable during hypoxic stress. *Journal of Clinical Neuropsychology, 2*, 147-155.

Fabiano, R. J., & Daugherty, J. (1998). Rehabilitation considerations following mild traumatic brain injury. *Journal of Rehabilitation*, *64*(4), 9-15.

Folstein, F. M., Folstein, S., & McHugh, P. R. (1975). Mini-mental state examination: A practical method for grading cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189-198.

Ford, I. W., & Gordon, S. (1999). Coping with sport injury: resource loss and the role of social support. *Journal of Personal and Interpersonal Loss, 4*(3), 243-257.

Fortunato, V.,& Marchant, D. (1999). Forced retirement from elite football in Australia. *Journal of Personal and Interpersonal Loss, 4*(3), 269-281.

Frontera, W. R., Dawson, D. M., & Slovik, D. M. (Eds). (1999). *Exercise in rehabilitation medicine.* Champaign, IL: Human Kinetics.

Giza, C. C., & Hovda, D. A. (2000). Ionic and metabolic consequences of concussion. In R. C. Cantu (Ed.), *Neurological athletic head and spine injuries* (pp. 18-100). Toronto: Saunders.

Glasser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Chicago: Aldine Publishing Company.

Goidberg, I., & Elliot, D. L. (1994). *Exercise for prevention and treatment of illness.* Philidelphia: F.A. Davis.

Grealy, M. A., Johnson, D. A., & Rushton, S. K. (1999). Improving cognitive function after brain injury: the use of exercise and virtual reality. *Archives of Physical Medicine and Rehabilitation 80*, 661-667.

Gronwall, D., & Wrightson, P. (1974). Delayed recovery of intellectual function after minor head injury. *Lance, 2*, 605-609.

Gronwall, D., & Wrightson, P. (1975). Cumulative effect of concussion. *Lancet, 22,* 995-997.

Guskiewicz, K. M. (2001). Concussion in sport: the grading-system dilemma. *Athletic Therapy Today, 6*(1), 18-27.

Hewitt, J. P. (2003). *Self and Society: a symbolic interactionist social psychology.* Boston: Pearson Education, Inc.

Hutchinson, S. L., Loy, D. P., Kleiber, D. A., & Dattilo, J. (2003). Leisure as a coping resource: Variations in coping with traumatic injury and illness. *Leisure Sciences, 25*, 143-161.

Iverson, G. L., Gaetz, M., Lovell, M. R., & Collins, M. W. (2002, October). *Cumulative effects of concussion in amateur athletes.* Paper presented at the National Academy of Neuropsychology Annual Conference, Miami, FL.

Johnston, L. H., & Carroll, D. (1998). The context of emotional responses to athleteic injury: A qualitative analysis. *Journal of Sport Rehabilitation, 7,* 206-220.

Kelly, J., Nichols, J., Filley, C., Lillhei, K., Rubinstein, D., & Kleinschmidt-Demasters, B. (1991). Concussion in sports: guidelines for the prevention of catastrophic outcome. *Journal of the American Medical Association, 226*, 2867-2869.

Kelly, J. P., & Rosenberg, J. H. (1997). Diagnosis and management of concussion in sport. *Neurology, 48,* 575-580.

Kendall, E., & Buys, N. (1998). An integrated model of psychosocial adjustment following acquired disability. *Journal of Rehabilitation, 64*(3), 16-21.

Kontos, A. P., Collins, M., & Russo, S. A. (2004). An introduction to sports concussion for the sport psychology consultant. *Journal of Applied Sport Psychology, 16,* 220-235.

Kirkcaldy, B. D., & Shepard, R. J. (1990). Therapeutic implication of exercise. *International Journal of Sport Psychology, 21,* 165-184.

Kosma, M., Cardinal, B. J., & Rintala, P. (2002). Motivating individuals with disabilities to be physically active. *QUEST, 54,* 116-132.

Kubler-Ross, E. (1969). *On death and dying.* New York: Macmillan.

Leddy, M. H., Lambert, M. J., & Ogles, B. M. (1994). Psychological consequences of athletic injury among high school competitors. *Research Quarterly for Exercise and Sport, 65,* 347-353.

Leclerc, S., Lassonde, M., Delaney, J. S., Lacriox, V.J., & Johnston, K. M. (2001). Recommendations for grading of concussion in athletes. *Sports Medicine, 31*(8), 629-636.

Maddocks, D. L., Dicker, G. D., & Saling, M. M. (1995). The assessment of orientation following concussion in athletes. *Clinical Journal of Sports Medicine, 5*(1), 32-35.

Mainwaring, L. M., Bisschop, S. M., Green, R. E. A., Antoniazzi, M., Comper, P., Kristman, V., Provvidenza, C., & Richards, D. W. (2004). Emotional reaction of varsity athletes to sports-related concussion. *Journal of Sport and Exercise Psychology, 26,* 119-135.

Malec, J. F. (1999). Mild traumatic brain injury: scope of the problem. In N. R. Varney & R. J. Roberts (Eds.), *The evaluation and treatment of mild traumatic brain injury* (pp. 15-37). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

McAllister, T. W. (1994). Mild traumatic brain injury and the postconcussive syndrome. In J.M. Silver, S.C. Yudofsky, & R.E Hales (Eds.) *Neuropsychiatry of Traumatic Brain Injury,* (pp 357-392). Washington, DC: American Psychiatric Press.

McCrory, P. R., Ariens, T., & Berkovic, S. F. (2000). The nature and duration of acute concussive symptoms in Australian football. *Clinical Journal of Sports Medicine, 10*(4), 235-238.

McCrory, P. R., & Johnston, K. M. (2002). Acute clinical symptoms of concussion: assessing prognostic significance. *The Physician and Sportsmedicine, 30*(8), 43-48.

McDonald, S. A., & Hardy, C. J. (1990). Affective response patterns of the injured athlete: An exploratory analysis. *Sport Psychologist, 4,* 261-274.

McGowan, R. W., Pierce, E. F., Williams, M., & Eastman, N. W. (1994). Athletic injury and self-determination. *Journal of Sports Medicine and Physical Fitness, 34,* 299-304.

Miller, J. F. (2000). *Coping with chronic illness: Overcoming powerlessness.* Philadelphia, PA: F. A. Davis.

Mittenburg, W., & Burton, D. B. (1994). A survey of treatments for post-concussion syndrome. *Brain Injury, 8*(5), 429-437.

Mittenburg, W., Canyock, E. M., Condit, D., & Patton, C. (2001). Treatment of post-concussion syndrome following mild head injury. *Journal of Clinical and Experimental Neuropsychology, 23*(6), 829-836.

Mittenburg, W., & Strauman, S. (2000). Diagnosis of mild head injury and postconcussion syndrome. *Journal of Head Trauma Rehabilitation, 15*(2), 783-791.

Natterlund, B., & Ahlstrom, G. (1999). Experience of social support in rehabilitation: a phenomenological study. *Journal of Advanced Nursing, 30*(6), 1332-1340.

Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science and Medicine, 51*, 1795-1804.

Parker, R. S. (2001). *Concussive brain trauma: neurobehavioral impairment and maladaptation.* Boca Raton, FL: CRC Press LLC.

Pearson, L., & Jones, G. (1992). Emotional effects of sports injuries: Implications for physiotherapists. *Physiotherapy, 78,* 762-770.

Petitpas, A., & Danish, S. (1995). Caring for injured athletes. In S. Murphy (Ed.), *Sport psychology interventions* (pp. 255-281). Champaign, IL: Human Kinetics.

Psathas, G. (Ed.). (1973). *Phenomenological sociology: Issues and applications.* New York: Wiley.

Putukian, M., & Echemendia, R., J. (2003). Psychological aspects of serious head injury in the competitive athlete. *Clinics in Sports Medicine, 22*(3), 617-630.

Quackenbush, N., & Crossman, J. (1994). Injured athletes: A study of emotional responses. *Journal of Sport Behavior, 17*(3), 178-187.

Ratey, J. J. (2001). A user's guide to the brain: perception, attention, and the four theaters of the brain. New York: Vintage.

Robbins, J. E., & Rosenfeld, L. B. (2001). Athletes' perceptions of social support provided by their head coach, assistant coach, and athletic trainer, pre-injury and during rehabilitation. *Journal of Sport Behavior, 24*(3), 277-297.

Roberts, W. (1992). Who plays? Who sits? Managing concussion on the sidelines. *Physician and Sportsmedicine, 20*(6), 66-72.

Robinson, F. M., West, D., & Woodworth, D. (1995). *Coping + plus: Dimensions of disability.* Westport, CT: Praeger.

Rutherford, W. H., Merrett, J. D., & McDonald, J. R. (1979). Symptoms at one year following concussion from minor head injuries. *Injury, 10*(3), 225-230.

Seale, C. (1999). *The quality of qualitative research.* London: SAGE Publications Ltd.

Smith, A. M., Scott, S. G., O'Fallon, W. M., & Young, M.L. (1990). Emotional responses of athletes to injury. *Mayo Clinic Proceedings, 65*, 38-50.

Smith, A. M., Scott, S. G., & Wiese, D. M. (1990). The psychological effects of sports injuries. *Sports Medicine, 9*(6), 352-369.

Spence, J. C., & Poon, P. P. L. (2000). *1999 Alberta survey on physical activity: concise report.* Alberta: Alberta Centre for Well-Being

Stoler, D. R., & Hill, B. A. (1998). *Coping with mild traumatic brain injury: a guide to living with the challenges associated with concussion/ brain injury.* New York: Avery.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: grounded theory procedures and techniques.* Newbury Park: SAGE Publications.

Sullivan, S. J., Richer, E., & Laurent, F. (1990). The role of and possibilities for physical conditioning programs in the rehabilitation of traumatically brain-injured persons. *Brain Injury 4*(4), 404-414.

Swiane, B. R., & Friedman, D. S. (2001). Activity restrictions as part of the discharge management for children with a traumatic head injury. *Journal of Head Trauma Rehabilitation 16*(3), 292-301.

Tate, R. L., & Broe, G. A. (1999). Psychological adjustment after traumatic brain injury: what are the important variables? *Psychological Medicine, 29*, 713-725.

The Mild Traumatic Brain Injury Committee of the Head Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine. (1993). Definition of mild traumatic brain injury. *Journal of Head Trauma Rehabilitation, 8*(3), 86-87.

Thurman, D. J., Branche, C. M., & Sniezek, J. E. (1998). The epidemiology of sport-related traumatic brain injuries in the United States: recent developments. *Journal of Head Trauma Rehabilitation, 13*(2), 1-8.

Udry, E. (2002). Staying connected: optimizing social support for injured athletes. *Athletic Therapy Today, 7*(3), 42-43.

Urdy, E., Gould, D., Bridges, L., & Beck, L. (1997). Down but not out: Athletes response to season-ending injuries. *Journal of Sport and Exercise Psychology, 19*, 229-248.

Wade, D. T., King, N. S., Wenden, F. J., Crawford, S., & Caldwell, F. E. (1998). Routine follow up after head injury: A second randomized controlled trial. *Journal of Neurology, Neuropsychology and Psychiatry, 65*, 177-183.

Webb, W. M., & Nasco, S. A. (1998). Athlete identity and reactions to retirement from sport. *Journal of Sport Behavior, 21*(3), 338-362.

Webbe, F. M., & Barth, J. T. (2003). Short-term and long-term outcome of athlete closed head injuries. *Clinics in Sport Medicine, 22*(3), 557-593.

Wetzel, A. J., & Rorke, S. C. (2001). Mild traumatic brain injury: a call for increased awareness, intervention, and physical activity. *Clinical Exercise Physiology 3*(4), 186-193.

Williams, W. H., & Evans, J. J. (2003). Brain injury and emotion: An overview to a special issue on biopsychosocial approaches in neurorehabilitation. *Neuropsychological Rehabilitation, 13*(1/2), 1-11.

Wills, S. M., & Leathem, J. M. (2001). Sports-related brain injury research: methodological difficulties associated with ambiguous terminology. *Brain Injury, 15*(7), 645-648.

Wilson, R. F., Carlin, A. M., & Tyburski, J.G. (2002). Sports concussion: implications of the exam after head injury. *Consultant, 42*(2), 230-234.

Wolman, R. L., Cornall, C., Fulcher, K., & Greenwood, R. (1994). Aerobic training in brain-injured patients. *Clinical Rehabilitation 8*, 253-257.

Varney, R. N., & Roberts, R. J. (1999). Forces and accelerations in car accidents and resultant brain injuries. In N. R. Varney & R. J. Roberts (Eds.), *The evaluation and treatment of mild traumatic brain injury* (pp. 39-47). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Yoeman, B. (2004). Lights out: Can contact sports lower your intelligence? *Discover 25*(12), 68-73.

APPENDIX B: LETTER OF RECRUITMENT FOR PHYSICIANS AND REHABILITATION PRACTIIONNERS

Add recipient's address and date

Dear ___________,

I am conducting a study on the role of physical activity in the recovery process of amateur and recreational athletes with post concussion syndrome. The study is a partial requirement for a Master's degree in Physical Education and Recreation from the University of Alberta. The Health Research Ethics Board at the University of Alberta has approved my research proposal. I am looking for volunteers to interview.

The interviews will be at the convenience of the study participant and will be approximately between one hour and one and a half hours long. One interview will be conducted with the possibility of a follow up interview for clarification or for gaining more information if needed, at a later date. The interviews will be tape-recorded and will focus on physical activity and athletes with post concussion syndrome to gain a better understanding about:

1. The recommendations regarding the resumption of physical activity.
2. Experiences of athletes with post concussion syndrome and physical activity,
3. The current use of physical activity in the rehabilitation of athletes with post concussion syndrome.

I am looking to interview amateur and recreational athletes with post concussion syndrome, physicians who treat and/or consult athletes with post concussion syndrome, and rehabilitation practionners who work with athletes with post concussion syndrome.

This study is voluntary and participants may, for any reason and at any time, choose to refrain from answering any questions or discontinue participation in the research project. All information will be kept strictly confidential and anonymity will

APPENDIX C: LIST SERVE LETTER OF RECRUITMENT TO REHABILITATION PRACTIONNERS AND PHYSICIANS

Research Volunteers Needed.

We are conducting a study on the role of physical activity in the recovery process of amateur and recreational athletes with post concussion syndrome. We are looking for both volunteer athletes and volunteer rehabilitation practionners to interview for this study. The interviews will focus on physical activity and athletes with post concussion syndrome to gain a better understanding about:

1. The recommendations regarding the resumption of physical activity
2. Experiences of athletes with post concussion syndrome and physical activity
3. The current use of physical activity in the rehabilitation of athletes with post concussion syndrome.

Criteria:

Athletes

- Men and women between 18-35 years old
- Sustained a concussion within the last year and has at least 3 symptoms for at least 3 months.
- Has been seen by a physician and been diagnosed with post concussion syndrome
- Was physically active at least 2 times per week before the concussion/ mild traumatic brain injury.
- Desire to be physically active or physically active since the concussion/ mild traumatic brain injury.
- Fluent in English

Rehabilitation Practionners and Physicians

- Actively treating or consulting athletes with concussion and post concussion syndrome
- Consults at least 1 person with post concussion syndrome or concussion per month
- 2 years experience in treating people with post concussion syndrome or concussion
- Fluent in English

This study has been approved by the Health Research Ethics Board at the University of Alberta and is a partial requirement for a Master's degree in Physical Education and Recreation. If you or any of your clients are interested in participating

Witness (if available):

____

Printed Name:

____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Researcher:

____

Printed Name:

____

* A copy of this consent form must be given to the subject.

APPENDIX F: FOLSTEIN MINI-MENTAL STATE EXAMINATION

("MMSE")

Name: **Date:**

You may give support and encouragement, and force a precise reply, but you should not give clues, verbal or non-verbal.

1. ORIENTATION

What is today's date?
What is the year?
What is the month?
What day is today?
What season is it?
What is the name of this hospital?
What floor are we on?
What is the name of a street nearby (or near your home)?
What town or city are we in?
What country are we in? **Score 0-10:**

2. IMMEDIATE RECALL

Ask subject to repeat these words. Allow 1 second per word, and up to 6 trials.
Score = how many recalled after the first try only.

Ball
Flag
Tree

Number of trials needed to learn all 3:
Score 0-3:

3. ATTENTION AND CALCULATION

Begin with 100 and count backwards by 7 93→86→79→72→65
Correct response = any reply that is 7 less than the previous number.
AND THEN spell the word "World" backwards DLROW
Score = the best of the two **Score 0-5:**

4. RECALL

Can you recall the words I said before?

Ball
flag
tree **Score 0-3:**

5. LANGUAGE

What is this?

Watch
Pen/pencil

Repeat after me "No ifs, ands or buts"

Must be fully correct first time.

Score 0-3:

6. PRAXIS

Take this paper in your right hand,	1 point	
....fold it in half....	1 point	
....and put it on your knee"	1 point	**Score 0-3:**

Avoid non-verbal cues.

7. LANGUAGE READING COMPREHENSION

Do as this says: "Close your eyes"

Should be printed, in capitals, on a separate piece of paper. **Score 0-1:**

8. PRAXIS

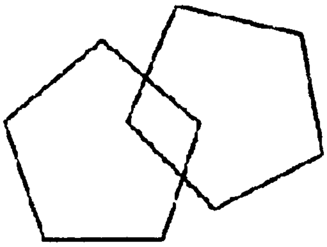
Write a sentence

Any sentence; must include a verb and make sense. Arguably, "Help!" is a satisfactory response.

Copy intersecting pentagons

Must draw 2x5-sided figures, with the central diamond preserved. **Score 0-2:**

TOTAL: /30



Source: http://www.jr2.ox.ac.uk/geratoll/mmse.doc which references the following as the source:

Folstein, F. M., Folstein, S., & McHugh, P. R. (1975). Mini-mental state examination: A practical method for grading cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189-198.

APPENDIX G: SEMI-STRUCTURED INTERVIEW GUIDE

1. Before the concussion
    a. When did you sustain the concussion/ MTBI?
    b. How did the concussion/MTBI occur?
    c. What was your involvement as an athlete before the concussion/MTBI?
    d. How often were you physically active?
    e. What were the benefits of physical activity in your life? Negatives?
    f. What role did physical activity and/or sport play in your life before the concussion/ MTBI?
2. Experience of concussion and recovery
    a. What symptoms did you experience?
    b. What symptoms do you still have?
    c. How has your life changed since the concussion/ MTBI?
    d. Have you changed? Explain.
3. Experience with medical and rehabilitation practionners
    a. What kind of health care professionals did you see?
    b. What were the recommendations for recovery from these health care professional?
    c. What were the recommendations regarding physical activity and/or participation in sport?
    d. Did any of them suggest physical activity as part of your recovery? Explain.

  e. What was your experience with health care providers in relation to physical activity?

4. Physical activity after the concussion
  a. Has your ability to be physically active and/or to participate in sports changed since the concussion/MTBI?
  b. Are you currently physically active? If so, what activities do you do? What intensity and how often? If not, why not?
  c. What are the barriers, if any, to being physically active while recovering from concussion/ MTBI?
  d. Do you miss being physically active and/or participating in sports as you did before the concussion? Explain.
  e. What are the benefits of physical activity while recovering from concussion/ MTBI? Are there any drawbacks?
  f. What role does physical activity and/or sport play in your life after the concussion/ MTBI? Explain.

APPENDIX H: RESEARCH SUMMARY SEND TO THE PARTICIPANTS AS A MEMBER CHECK

The Recovery Process of Athletes with Concussion and Post Concussion Syndrome: Summary of Findings

A research study by:

Margo Millette, HBOR, BSc

and Dr. Michael Mahon, PhD

The Faculty of Physical Education and Recreation

University of Alberta

February 2, 2005

This is an overview of the findings from the study titled: The Role of Physical Activity in the Recovery Process of Athletes with Post Concussion Syndrome. The following is a brief description of the model, which emerged from the data, presented in figure A and other key findings.

The Recovery Process of Athletes with Concussion and Post Concussion Syndrome

Summary of the Findings:

The findings of this study are based on interviews with six athletes who are recovering from or have recovered from post concussion syndrome and on a personal journal written during the researcher's recovery from post concussion syndrome. The journal was written over three years and was not written specifically for this research. At the time of the interview, the athletes were between the ages of 18 and 39, had sustained a concussion within the past two years, been diagnosed with a concussion, and were physically active at least two times per week before their concussion. Since the sample size is small, the findings cannot be generalized to the broader population of athletes with post concussion syndrome, however since the recovery experiences of the participants and the researcher took place in Alberta, Ontario, British Columbia, Quebec, Maine, Minnesota, and Australia, the findings may be indicative of a broader recovery experience.

Participation in physical activity while symptomatic created a sense of normalcy, lessened the deconditioning the athletes experienced as a result of their injury, was an important form of stress release, maintained social connections, helped to cope with depression, and made the athletes feel good mentally. On the other hand, physical activity and exercise aggravated symptoms, especially headaches, fatigue, dizziness, and blurry vision. Thus, the conundrum is that participation in physical activity and exercise makes the athlete with post concussion syndrome feel good mentally but bad physically. That being said, there was an overwhelming consensus from the athletes in this study that they need to be physically active to be healthy. In the end, this need motivated them to be physically active despite the aggravation of symptoms. A model outlining the recovery process of athletes with post concussion syndrome and concussion is presented in figure A. A description of each section of the model follows.

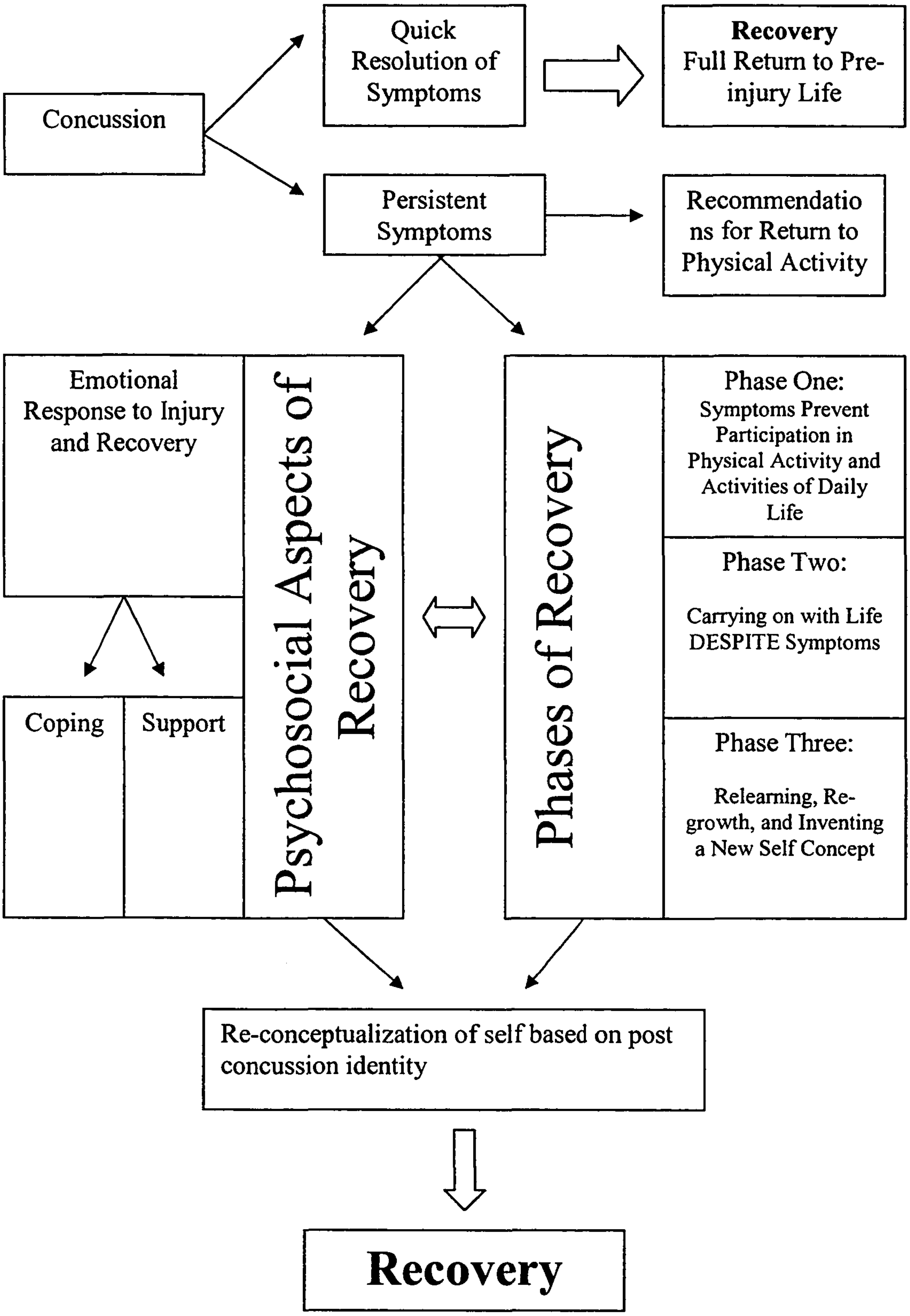


Figure A. The recovery process of athletes with concussion and post concussion syndrome.

There are two possible scenarios for the recovery of an athlete who sustains a concussion:

1. The athlete experiences symptoms that resolve in a reasonable amount of time and he or she returns to normal life and participation in physical activity.
2. The athlete experiences persistent symptoms, which limit functioning. The athlete progresses through three phases of recovery, which include the psychosocial aspects of recovery. At the end of the process, the athlete develops a new concept of self based on a post concussion identity.

Each of the main components of recovery for scenario 2 is described below:

Recommendations for Return to Physical Activity:

Acute Stage:

Rest until asymptomatic, followed by a graded return to pre-injury activities and physical activity. If symptoms re-occur, stop the activity and rest.

Chronic Stage:

There were no consistent recommendations reported for return to physical activity for those with post concussion syndrome. The recommendations varied widely among health care practionners including: (a) rest until asymptomatic, (b) graded increase in physical activity. If symptoms worsened, the athlete was to stop, (c) the athlete could return to physical activity when he or she felt ready, (d) retirement from contact sport, (e) be active but do not push through symptoms, and (f) to follow the "return to play guidelines".

Phases of Recovery:

Phase One:

Phase one is characterized by a significant decrease in functioning, disruptive symptoms, and an inability or limited ability to fulfill work or academic responsibilities. The athlete may also have difficulty performing activities of daily living because of pain, fatigue, memory loss or other symptoms. Progression through this phase can be very quick.

Phase Two:

Phase two is characterized by motivation and determination to continue on with life despite the symptoms and limitations experienced. This includes a return to work, school and other pre-injury activities of daily living. The focus during this phase is to maintain as normal a life as possible despite the symptoms; and to return to pre-injury level of functioning and pre-injury life. Individuals in phase two spend a great deal of energy managing symptoms and "getting through the day". This phase is typically when athletes are diagnosed with post concussion syndrome.

Phase Three:

Phase three is characterized by an effort to relearn how to function effectively in the world and the surrounding environment while rediscovering and reinventing oneself. It is the absence of disruptive symptoms that allow the re-learning and self discovery to take place, enabling the individual to focus on the environment in which he or she exists rather than on the management of the symptoms. This phase focuses on relearning and redesigning coping strategies to effectively navigate physical, social, academic or work environments.

Psychosocial Aspects of Recovery:

Emotional Response to Injury and Recovery:

Frustration was the main emotional response. The following were reported as sources of frustration: (a) the inability to participate in physical activity and sport, (b) the return of symptoms when participating in physical activity, (c) the medical system, (d) the lack of knowledge of doctors, (e) the lack of progress in recovery over time, (f) the frustration of not being able to do what they could before their injury, (g) constantly being in pain, (h) lost time and memories, (i) financial losses, (j) lack of information about post concussion syndrome, and (k) lack of services and treatment options.

Fear, apprehension, hesitation, irritability, depression, confusion, and feeling overwhelmed also were expressed emotions.

Coping:

Athletes coped with the symptoms, and the emotional reaction to the injury and the recovery process. Physical activity was one of the main forms of reported coping strategies.

- Coping in phase one included: (a) sleep, and (b) over the counter and prescription medication.
- Coping in phase two included: (a) sleep, (b) over the counter and prescription medication, (c) physical activity, (d) shutting out the world, (e) alcohol, (f) sports psychology counselling, and (g) healing imagery.
- Coping in phase three included: (a) shutting out the world, (b) physical activity, and (c) creating new strategies for dealing with the world.

Support:

The athletes reported that support came from coaches, trainers, team mates, friends, spouses, significant others, health care practionners, teachers, professors, co-workers, and sport psychologists. The types of support included advocacy, providing knowledge and information about recovery and post concussion syndrome, problem solving, strategy and skill development, and just being a friend. Most athletes found and facilitated their own support personnel.

Recovery:

Recovery from post concussion syndrome is either: (a) the resolution of symptoms enabling the athlete to return to pre-injury life, including physical activity, with no lingering effects, or (b) a re-conceptualized identity without the "athlete" identity (or a changed athlete identity). Athletes said that they were recovered when they were asymptomatic or when the disruptive symptoms had gone away.

Other Key Findings:

- The main barrier to the participation in physical activity and sport was the symptoms.
- Chronicity (not knowing how long the symptoms will last or if they will be permanent) was one of the main factors preventing recovery for those with persistent symptoms.
- Athletes sometimes withheld the truth about the symptoms they experienced from coaches, trainers, doctors; visited unfamiliar doctors; and learned how to take tests in order to be cleared to participate in sport.
- Symptom free participation at pre-injury levels of physical activity and sport was the thing the athletes wanted the most.

Participation in physical activity was an important part of the lives of athletes with post concussion syndrome, both before their concussion and during their recovery. Most athletes were told not to be physically active while they still experienced symptoms however most were despite the health care practionners recommendations. This study revealed an interesting conundrum; participation in physical activity and exercise is beneficial mentally, psychologically, and socially, however it often makes the athlete feel worse physically because the symptoms are aggravated. Despite this, the athletes in this study overwhelmingly felt that the benefits of physical activity while symptomatic outweighed the negatives. It is important to note that athletes should consult their physician before resuming physical activity and should obtain the necessary medical clearance before returning to contact sport.