Exploring the Concussion Experience Within Sport: An Autoethnographic Study

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## Dedication

To everyone that supported me through my concussion experiences, from diagnosis to recovery.

I truly could not do this without you.

To my Mom and Dad, whose worry was nothing but unrelenting love.

To my Supervisor Maureen Connolly, whose direction and patience steered me in the right

## direction.

Thank you from the bottom of my heart.

To all of those who have sustained a concussion: Never stop your journey of healing.

There is hope, there is light, there is community, even in the darkest of times.

#### Abstract

Concussions are a highly individualized experience, with different profiles of expression encapsulating a diverse range of symptom sequalae. However, the lived through experience of those who have sustained a concussion oftentimes takes a backseat to the more standardized quantitative medical approach to healing. The purpose of this thesis is to engage and address gaps in literature and document the necessity and benefit of qualitative research to understand the nuances of the concussion experience by utilizing an autoethnographic approach and a Critical Disability Studies (CDS) method of writing termed "Disability Life Writing." Additionally, this thesis attempts to remove a barrier to concussion information by presenting concussion knowledge in accessible terminology and language, aiming to make concussion awareness available to those without knowledge of medical terminology or discourse. Regarding concussions in sport, this thesis aims to illuminate hidden values and ideologies within a sporting culture that ultimately work to socialize an athlete to play through pain and hide/not disclose injuries such as a concussion to peers, coaches, or other members of the sporting culture. The author analyzed all the aims listed above through a CDS lens using core CDS concepts such as stigma, stereotyping, normalcy, and invisible disabilities as analytic touchstones.

Keywords: concussion, sport, autoethnography, disability,

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#### **Section One: Introduction**

This thesis will be broken up into two main sections. Section One will serve as an introduction to this thesis. Section One will be composed of three chapters titled Research Methods, Literature Review, and Design. These chapters will lay the foundation of how my research was conducted, the methods of inquiry being used, the literature that has formed the basis of my reflection and discussions, and the design which my thesis followed.

#### **Chapter One: Research Methods**

My first exposure to concussions in sport did not come from a personal experience, rather, it was Sidney Crosby and his concussive injuries that exposed me to this sporting injury. I also remember my first thought about that diagnosis: "It's a hit on the head, he has a helmet... what's the big deal?" Through some twisted cosmic justice, I found myself face to face with the turbulent reality of that very sentence a couple of years later.

With that being said, let it be known that I was no stranger to the nauseating and dizzying confusion of a knock to the head prior to hearing about Crosby. I have played competitive soccer since I was 6 years old. I've had black eyes from elbows, cleats, and knees to the face. In my position of centre-back I've preformed countless "headers," the act of playing an air-borne ball with one's head. I've stood in front of the shots from the top strikers in my league. In one game, I passed my goalie the ball so she could clear it, only to have it accidentally hit the left side of my head. I blacked out, only for a second that felt like minutes, my ears were ringing, the world was spinning. The only thought in my head: *Where's the ball? Find the ball. Find your player. Pull yourself together*. I shot my coach a thumbs up when I finally heard his frantic shouting from the sidelines, the rest of the game felt as though the pitch tilted to the left. "I'm good!" *I'm good… I'm good…* 

Even after the Crosby incident, my concussion knowledge was limited. I continued to play sports, heading balls with reckless abandon. I never self-monitored and I finished nearly every game with a headache. I don't believe this negligence was intentional on behalf of my coaches and league; I kept it a secret, I wanted to shake it off and play in my next game. That's what I did, until I was forced to report it. I wasn't forced by a policy or a procedure, I was never mandated to self-report. I was forced to acknowledge the damage my brain had sustained because my body was beginning to shut down. In late April 2013, I was in high school finishing up my Grade 12 year. I was sitting in biology, zoning out for large portions of my class time. The fluorescent lightbulbs felt like the sun. My eyes had stopped moving. I had no emotions. I'm positive I looked like a zombie when my soccer coach came to get me from class for our game that afternoon, which I had forgotten about. Dragging my feet and wobbling in front of him, I leaned against the doorframe of the classroom, and I forced out 6 words: "I think I have a concussion."

I don't remember anything afterwards until I'm in a wheelchair being rolled into the St Thomas Elgin General Hospital. All I have from that day are fragmented memories that flash through my mind: staring at the triage nurse's desk, a large orange curtain with yellow hexagons they brought me behind to take my blood pressure, piles and piles of heated blankets being brought to me by the nurse because I couldn't stop shivering, crying on my mother's lap in the waiting room, another mother with her crying baby asking the nurses to turn off the lights in the waiting room because I was wincing in pain when I opened my eyes. I was terrified, and that was only my first day.

## **Research Focus**

Throughout this thesis I am focusing on concussion education, with my main focus as sport concussion in team settings. My priority when speaking about concussions is making this knowledge accessible to all readers. The bulk of my thesis revolves around more nuanced topics of concussion recovery such as stigma and stereotyping which I analyzed through a concept called "athlete culture," a cultural aversion to failure, and a shared "narrative of overcoming." I also apply the concepts of stigma and stereotypes to the notion of "invisible disabilities," and we will explore barriers to recovery that are presented within the understanding of an "invisible disability." Intimately connected with stigma and stereotypes, I aim to bring awareness to postconcussion syndrome, as well as mental health challenges that accompany many concussions.

I am focusing my research on personal accounts of concussions. Mainly, my own personal account of my concussions and concussion rehabilitation will guide the flow of this thesis through autoethnography and the use of Critical Disability Studies (CDS) premises and theories. I discuss autoethnography as well as the outline of this paper later in Chapter Three of this proposal titled *Design*. I believe that exploring personal narratives of concussions provides an intimate connection between reader and storyteller that is missed in more conventional and quantitative methods of concussion research. My thesis aims to expose my readers to the complexity of concussion rehabilitation, and act as a cautionary tale to younger readers who, as myself, believe themselves to be invincible. I too was tricked by the "it won't happen to me" discourse that many teenagers and young adults fall prey to.

Unfortunately, it is likely that you will experience a concussion sometime throughout your life, maybe as an athlete, or as a non-athlete. Concussions are a type of Traumatic Brain Injury (TBI), classified as a *mild* Traumatic Brain Injury (mTBI). There are approximately

200,000 concussions annually in Canada, with sport concussion being "among the most complex injuries in sports medicine to diagnose, assess, and manage" (Brain Injury Canada, 2022). This statement may have you wondering, "why? Why is a sport concussion so complex to diagnose?" The purpose of this thesis is to explore the complexities of sport related concussions. I will reframe concussions within the scope of a "disability" in an attempt to understand how hegemonic sport values within sporting culture such as: body sacrificing, warrior mentality, or fighting/playing through pain, for example, all socialize an athlete and complicate the concussive injury process. I believe that the *culture* of sport that athletes are acting within is what makes assessing and managing a concussion so difficult, and we will explore how sporting culture acts upon athlete decisions and autonomy throughout this thesis, most specifically in my chapter titled "You Can All Thank Kylie" which focuses exclusively on athlete culture. This thesis serves an additional purpose of making concussion education accessible to readers of all backgrounds and will therefore explore educational topics such as: what a concussion is, how you may sustain a concussive injury, general prognosis information, as well as possible complications such as Post-Concussion Syndrome (PCS), mental health, isolation, and Chronic Traumatic Encephalopathy (CTE).

### Orientation

To properly explore my own experience with concussions, and simultaneously allow for other third-party experiences with concussions, I am utilizing a social constructionist approach to inquiry. I had debated between the use of a social constructionist approach or a constructivist approach, and, ultimately, I believe that a social constructionist approach suits my thesis more appropriately. Social constructionism "emphasizes the hold our culture has on us: it shapes the way in which we see things... and gives us a quite definite view of the world" (Quinn Patton, 2015, p. 122). The reason I chose social constructionism is because I believe that the notion of culture is extremely important when discussing concussions and concussion rehabilitation. For example, I don't believe the experience of an athlete recovering from a sports concussion would be the same as a mother recovering from a concussion because of an accident. Shortly after the concussion I sustained in 2013, my neighbour, a forty-ish mother of four, sustained a concussion after her car was t-boned in an intersection. We joked about getting leather biker jackets with "Concussion Club" in sequins on the back of it. However, when we weren't joking, we were able to share more personal moments of our concussion process. She was the first person who knew about my non-disclosure of my previous head injuries, and as her mouth dropped open, "Kylie Jade! Why would you ever hide such a thing?" I listed off a bunch of reasons that I didn't even realize were wrapped up within an athlete's mindset, ableism, and an athletic culture: embarrassment and shame. I didn't want to be perceived as the weak link of my team. I was the Captain, I had to keep playing and set an example. Most of all, I wanted to keep playing, I didn't want to be off the field for anything. Not a water break, not to stretch, not a substitution, and certainly not for an injury that I "thought" I could play through.

Social constructionism also assumes that a universal truth cannot be obtained, as realities are shaped and constructed by different groups and different people (Quinn Patton, 2015, p. 121). This also means that an 'ultimate truth' can only be understood as shared meaning within a group of people, and people outside of that group may not experience the same truth. Again, this is where the concept of culture is important to account for. In addition, a constructionist qualitative inquiry accepts the idea of multiple truths and realities (Quinn Patton, 2015, p. 122). I would never consider my concussion experience to be the same as my neighbour's, or even another teammate's. We will all have different experiences with diagnosis, different doctors or

physiotherapists or chiropractors, we will all have a different recovery trajectory, some of us will develop Post-Concussion Syndrome (PCS), and some will heal completely within a month.

In my thesis I explore further the gaps in literature when it comes to qualitative methodologies of concussion research and information, as well as the need for expressive thoughts and research as catharsis.

#### **Critical Disability Studies Orientation**

It is very important that I utilize a Critical Disability Studies (CDS) orientation when I am conducting my research and writing my thesis. CDS does not only focus on the body or bodily differences, rather, CDS critiques external forces that disable a person from being able to participate fully in society (Cameron & Moore, 2014). Indeed, the pioneer of introducing Disability Studies into higher education, Mike Oliver, stated that the purpose of Disability Studies is to "bridge the gap between the academy and the actuality of disabled people's lives" and must always enlist the voices of those with lived experience of disability (Cameron & Moore, 2014, p. 37). Additionally, Disability Studies "should have direct impact on the dismantling of disabling barriers" as well as addressing how institutional causes of disablement have contributed to the current way that disabled people are regarded in society (Cameron & Moore, 2014, p. 37). I am attempting to address these institutional/cultural/societal causes throughout this thesis by illuminating the hidden norms and values that many sporting cultures hold and linking those values to how athlete's may or may not disclose injuries - in the case of my thesis: concussive injuries. To do this effectively, I am utilizing a style of writing that Couser (2017) terms as *Disability Life Writing*. Disability Life Writing further ensures that I am bridging the aforementioned gap between the academy and the actuality of disabled people's lives, as this style of writing positions the disabled person as the main storyteller, ensuring that their story is

told from their perspective not the perspective of outside sources or mainstream culture. Not only does this method of writing ensure that I am adhering to crucial aspects within a CDS framework, but also fills a key gap in the literature: the lack of subjective and personal accounts of the concussion recovery process.

In addition, I attempt to adhere to the four premises laid out by Meekosha and Shuttleworth (2009) in their essay titled *What's So "Critical" About Critical Disability Studies?* Meekosha and Shuttleworth (2009) list the four premises as:

the irreducibility of social life to objective facts; the requirement to link theory with praxis to fight for an autonomous and participatory society; the field must be aware of its historicity and critically reflect on its conceptual frameworks; and the need to engage in dialogue with other cultures on concepts and issues of significance (p. 175 - 176).

The first premise is the irreducibility of social life to objective facts. This means that a society, a culture, or in the case of my research, an experience, is much more dynamic and fluid than a single truth or understanding. The fluidity of culture, meaning making, and understanding cannot be quantitatively measured by numbers, but rather it needs to be qualitatively expressed through stories, with an understanding of meaning, both from a cultural and social standpoint. Without careful attention and dedication to understanding every experience as unique to the person living it, we risk overgeneralizing experience and missing out on nuances that help understand a phenomenon on a deeper level. This is especially important when conducting concussion rehabilitation as research is showing that many different aspects should be considered when determining the complexity of a concussion, and the possible complications that may come during recovery. A couple things that should be considered during every concussion

rehabilitation are a history of concussions, and/or history of mental health diagnoses. I discuss the importance of these areas in particular throughout my thesis.

The second premise may be more difficult to incorporate into my research, and that is linking theory with praxis. Of course, there are gaps when it comes to delivering concussion research in a comprehensive and accessible fashion, especially to the younger generation. A study conducted by Chrisman et al. (2012) polled 50 varsity athletes and found that almost all athletes had an extensive understanding of concussion symptoms and knew how serious concussions were, and yet there were still barriers to reporting their symptoms. Researchers have been exploring ways to treat a concussion and we are making large strides when it comes to acknowledging complications, such as Post Concussion Syndrome (PCS). Researchers are discovering more and more about the biomechanics of a concussion and what happens to our brains on a cellular and even molecular level after it sustains an injury. However, this knowledge and theory renders itself useless if we cannot find a way to implement this knowledge into *preventative care*, or in other words, *link theory with praxis*.

The third premise is that the field is aware of its historicity. To ensure that I am aware of the concussion field's historicity, that is, its formative premises and assumptions and its awareness of historical and societal influences on its own development, I will include a brief history of concussions in my thesis. Concussion symptomologies have been recorded as far back as 1700 BCE in the Edwin Smith Papyrus, which recorded 48 cases of injuries, wounds, dislocations, fractures, and tumors (Bloom and Caron, 2019). I find it remarkable that in 400 BCE, Hippocrates stated that "no head injury is too trivial to ignore" (Bloom and Caron, 2019), and yet here in the year 2022 AD, we still have difficulties recognizing the severities of head injuries, no matter how "trivial" they may be.

Finally, the fourth premise outlined by Meekosha and Shuttleworth (2009) is dialogue between cultures about concepts and issues of significance. Meekosha and Shuttleworth (2009) explore this concept by considering the disproportionate focus on Western ideologies when it comes to exploring disability. In my thesis I am using the same concept of consulting other cultures within a different framework. As athlete culture is a large focus in my thesis, I think it is important to understand experiences outside of an athlete culture to bridge gaps in the concussion experience. Additionally, much can be learned from people experiencing brain traumas in other forms such as tumours or cancer. While it is not an injury sustained after physical blunt trauma, I believe that there is information to be learned and experiences that need to be accounted for to embody a full scope of the repercussions of brain trauma on a person.

Ultimately, I feel an unrelenting obligation to raise awareness on concussion injuries. I believe that utilizing people's lived through experiences through qualitative inquiry creates a relationship between reader and storyteller. I aim to explore these experiences in an ethical and respectful manner by implementing Meekosha and Shuttleworth's (2009) CDS premises wherever possible.

#### **Chapter Two: Literature Review**

I grew up reading everything I could get my hands on. In Grade 1, I sat in a large wooden rocking chair and read *Frog and Toad Are Friends* to my classmates, all seated on the carpet around me while my teacher sat at the back of the class. I always had a book in my hand, usually the cover was worn and withered from being tossed from bag to bag, car to car. By Grade 3 I was reading 300-page novels about a boy and his dragon. Books followed me to bed, to the bath, to the backyard. Books were stuffed under my pillow, piled on my nightstand, and scattered in the backseats of my parent's cars. Books even accompanied me on road trips to State-Side soccer tournaments. To top it off, if I couldn't read a book, I was writing my own stories, my own poems, my own songs... I'm sure you can appreciate the emptiness, the pain, the frustration, the misery, that I felt when I was unable to read after my concussions.

At first, I wasn't allowed to read. It was a major no-no from my physiotherapist as it would place too much strain on my eyes and my head. *I've been reading since I was 3 years old*, I thought to myself. *Surely, it cannot be that bad*. Yet, as I sat down to try and read *Eragon*, a book about that beloved boy and his dragon that I have read almost yearly since grade 3, my head was throbbing, my vision was swimming, I was dizzy, I was nauseous, I couldn't remember the sentences that I had read. Hopeless, I would put the book down and crawl back into my bed, allowing myself to sink back into the deep dark pit of my depression.

The most "reading" I was able to do were the motor eye movement exercises taped to the walls of my living room. My eyes lazily counting from one to twenty, struggling to find the next number in succession amongst the jumble of numbers printed on a white sheet of printer paper. I spent weeks upon weeks laying in bed, or sleeping on the living room couch, eyes closed, head pounding, eternally exhausted, helpless, and hopeless. Slowly, as the months passed, I could read

a couple of words, but moving from sentence to sentence proved to be impossible. I re-read the same paragraph what felt like a thousand times, still without any retention or recollection of what I had read.

Years have passed, and unfortunately, progress seems to be moving at a snail's pace. Over time, I have delved deep into different topics surrounding concussions and head trauma. I've read publications in journals, books, personal narratives, and news articles. When the reading became too much, I would turn to documentaries or online videos, trying to understand what was happening to my brain, and trying to unravel the trauma, physical, emotional, spiritual, and mental, that accompanied such an injury that redefined who I was.

As I write all of this, my chest swells with great pride to walk my reader through a literature review. During my depression, I was positive I would never read again, I would never write again. I was positive I had lost a piece of myself that gave me safety, security, expression, and confidence. Today, I can tell you, that I still struggle to read. It must be slow and purposeful. But I am reading, and even better, I am writing.

#### What is a Concussion?

The most logical place to begin my literature review and thesis, is to explain what a concussion is. To begin, the term "concussion" comes from two Latin words: *concutere*, meaning "to shake violently," and *concussus*, meaning "the action of striking together" (Bloom & Caron, 2019). The original Latin term for concussions was *commotio cerebri*, which meant "commotion of the brain" and was found in the *Hippocratic Corpus*, a collection of medical documents from Ancient Greece dating back to the year 400 BCE (Bloom & Caron, 2019).

In modern day, The Centres for Disease Control and Prevention (CDC) define a concussion as a type of Traumatic Brain Injury (TBI), typically categorized as a mild traumatic

brain injury (mTBI); a concussion is sustained as the result of blunt force trauma caused by a bump, blow, or jolt to the head or body (CDC, 2019). Meaney & Smith (2011) distinguish between two forms of forces that can cause concussions: contact force and inertial force. Contact force occurs when the injury is a result of direct contact to the head (Meaney & Smith, 2011). Comparatively, inertial force, typically occurs when impact to the body creates a rapid whipping motion of the neck and head, also known as whiplash (Meaney & Smith, 2011). The sudden movement in both contact and inertial impact causes the brain to move around in the skull, often knocking off the boney walls designed to protect it.

On a biomechanical and molecular level, a couple of different changes happen within the brain when it's bounced around against the skull walls. Firstly, the brain is not one uniform density, it will have areas that are thicker and some that are more viscous; generally, the overall consistency of the brain is comparable to Jell-O (Meaney & Smith, 2011). When the body sustains impact, the brain is jostled around in the skull at different velocities depending on the density, which creates microtears in the approximately 90 billion neurons that comprise our brain (TED-Ed, 2017). These neurons are responsible for transmitting and relaying all information that our bodies process, through message systems called "axons;" tiny strand-like connectors that link one neuron to another (TED-Ed, 2017). As the brain moves in the skull, these neurons and axons stretch and tear, which can cause the axon to break (TED-Ed, 2017). When the axon breaks, a neural information pathway is disrupted, and the myelin sheath that protects the axon emits a toxin that spreads and kills surrounding neurons (TED-Ed, 2017). This damage to the axons is called a "diffuse axonal injury" (Busch & Alpern, 1998). It is the combination of these factors that creates the injury we all know as a *concussion*.

#### **History of Concussions**

Concussions are not a newly discovered injury. Despite the sudden surge of research dedicated to this complex injury within the last couple of decades, the history of concussions dates back for millennia. The earliest evidence of concussion symptomology dates to 1700BCE, where symptoms such as coma, stupor, and confusion were documented in the Edwin Smith Papyrus (Bloom & Caron, 2019, p. 8). The Edwin Smith Papyrus is the oldest known medical document created by the Ancient Egyptians, and it documented 48 cases of injury or trauma (van Middendorp, Sanchez & Burridge, 2010). In 400BCE, the Latin term for concussions, *commotio cerebri*, appears to describe "commotion of the brain" in a collection of medical document Hippocrates observes this "commotion" in Greek wrestlers and fighters and states "in cerebral concussion, whatever the cause, the patient becomes speechless… falls down immediately, loses their speech and cannot see and hear" (Bloom & Caron, 2019, p. 9). In fact, Hippocrates goes on to state that "no head injury is too trivial to ignore" (Bloom & Caron, 2019. p. 9). Oh, Hippocrates, if only us in the modern age could be as reflective as you were.

In the following centuries more and more physicians document their own diagnoses of concussions, all following the same symptomology as the Ancient Egyptians and Ancient Greeks. In the 10<sup>th</sup> century AD, an Arabic physician by the name of Rhazes identified that a concussion is a problem with brain function with an *absence* of a structural injury – in other words, this was the first time that a concussion was identified as a *functional* injury instead of a *structural* injury (Bloom & Caron, 2019). In the 14<sup>th</sup> century AD, two European surgeons, da Capri and Paré treated members of the Royal High Courts with concussion-like symptoms after a jousting tournament and noted distinctions between temporary symptoms of a concussion

compared to structural brain injuries (Bloom & Caron, 2019). Paré and da Capri observed that sport-related concussions presented more problems with speech and memory in addition to the common concussion symptoms such as dizziness, imbalance, and loss of consciousness (Bloom & Caron, 2019).

A major milestone in concussion research emerged by the early 17<sup>th</sup> century with the creation of the microscope. The microscope allowed scientists and researchers to analyze the brains of the deceased and identify the differences between a concussion and moderate to severe brain injuries. Most of these accounts described a softening and/or inflammation of the brain tissues in concussed brains which was linked to athlete's behavioural changes after a concussion, along with an absence of lesions or bleedings characteristic of moderate to severe brain injuries (Bloom & Caron, 2019). Researchers determined that the absence of gross structural changes aligned with the resolution of concussion symptoms such as sensitivity to light, tinnitus, and headache, which was typically reported within two weeks. Interestingly enough, the research conducted with microscopic imaging corroborates earlier discoveries by Rhazes, da Capri and Paré.

The most prescribed "cure" to a concussion is rest and withdrawal from sports, or other activities that may prove to be too strenuous for the brain in its injured state, such as reading or writing as an example. This recommendation dates to 1863, and a physician by the name of John Hilton (Bloom & Caron, 2019). Yes, that's right. The "cure" that is most prescribed by many doctors and/or physiotherapists in our modern age dates back to 1863. I'm positive there are cases where this is the appropriate starting point, such as my own where I was physically incapable of many activities and therefore rest and withdrawal was a logical place to start to allow my brain to *begin* to heal itself without excess strain or stimulation. However, modern

practices and research indicate that in many instances, those healing a concussion benefit from light activity (sometimes referred to as "active rest/rehab"), within reason that does not exacerbate or induce an influx of symptoms. I discuss this topic in more depth in my next chapter, "We Need to Re-Regulate Your Heart," and therefore it is imperative that each concussion rehabilitation program is geared towards the patient in question, but I digress... for the moment...

In 1927, Osnato and Giliberti analyzed 100 patients who had concussions and suggested if symptoms do not completely resolve, a degeneration of the brain may occur, which was also noted the following year in 1928 by Martland who used the colloquial term of "punch drunk" to describe the long-term sequelae of repeated concussions in boxers (Bloom & Caron, 2019). Specifically, Martland noted that these boxers were exhibiting Parkinson-like symptoms such as postural instabilities like shuffling, as well as speech problems, unusual, explosive, or inappropriate behaviour, which would eventually lead to the boxer retiring or being mentally institutionalized (Bloom & Caron, 2019). Yes, these are all the first known documentations of what we currently understand as chronic traumatic encephalopathy (CTE), a degenerative brain condition that is caused by repetitive head injuries such as concussions. The term traumatic encephalopathy was coined by Parker in 1934, and officially turned into chronic traumatic *encephalopathy* to better describe the lingering symptoms and a tendency for these symptoms to gradually worsen over time (Bloom & Caron, 2019). In 1981, Kelly was among one of the first in our modern day to acknowledge that prolonged symptoms could be a result of a failure to properly treat and/or acknowledge the injury (Bloom & Caron, 2019).

This is certainly not an all-encompassing history of concussions, but I found it interesting that we have known about concussions for a very, very long time. Since 1700BCE, there has

been an acknowledgement that a hit on the head contributes to mental distress and cognitive dysfunction. However, the ambiguity of this injury continues to puzzle researchers. Why can some people sustain four or five hits to the head before exhibiting any concussion symptoms, while others can only sustain one? Why do some people experience prolonged recovery while others do not? What contributes to different symptom expression? Why do some people struggle with speech while others struggle with migraines? Why do some people develop Post-Concussion Syndrome (PCS) while others completely recover? Why do some people experience mental health complications such as depression, anxiety, or suicidal ideation while others do not? With an influx of technological advancements in the modern era, we are coming closer to the answers of some of these more complicated questions, while other answers still seem to elude scientists and researchers. My hope is that throughout this thesis I can answer questions that some of my readers may have.

### What are Common Symptoms of a Concussion?

When trying to understand concussion symptomology it is important to remain mindful that no two brains are the same, and therefore, no two brains will experience the same symptom expression. There is an expansive list of concussion symptoms, and within that list of symptoms there are a core few that are experienced by many people. Some people will experience immediate symptoms, while other people may have no immediate symptoms but exhibit complications days later. The nuances within concussion symptomology illustrate how important it is to self-monitor after sustaining impact to the head or body, and to always err on the side of caution when it comes to concussions.

According to Parachute Canada (2020), there are different categories of concussion symptoms: physical, cognitive, and emotional. Your brain is responsible for everything your

body experiences, from pain to pleasure, sleeping to waking life, and the various levels of your emotional state. It should be no surprise then, that when your brain is injured, this injury manifests itself in many different areas of your body due to the body's holistic interconnection.

Physical symptoms of concussion include headache, pressure in the head, dizziness, loss of consciousness, nausea and/or vomiting, blurred vision, sensitivity to light and/or sound, ringing ears, balance problems, fatigue and/or exhaustion both mentally and physically, drowsiness, changes in sleeping patterns, and the ambiguous *I don't feel right* (Parachute Canada, 2020). The most commonly reported symptoms are: headache (94.7%), dizziness (74.8%), difficulty concentrating (61%), sensitivity to light (46.6%), and sensitivity to noise (39.3%) (Bloom & Caron, 2019).

These symptoms may not surface all at once. My first physical symptoms were headache, confusion, and pressure in the head. Within 24 hours, more symptoms progressed until it felt as though all my muscles in my body ceased to function. I was overwhelmed with intense exhaustion: my eyes were stuck in one spot and could hardly open, moving my limbs became burdensome, and speaking a simple "yes" or "no" felt as though I had just finished a weekend tournament with back-to-back games in 40-degree weather and heat stroke. I would like to take this moment to stress to you, reader, that the diagnosis of a concussion does not rely solely on whether you have lost consciousness or not. You can remain entirely conscious and be diagnosed with a concussion, just as I was.

Cognitive and emotional symptoms are harder to identify but they include: not thinking clearly, problems concentrating, memory problems, feeling slowed down, confusion, and feeling like you're in a "fog" (Parachute Canada, 2020). I became very "spaced out," and unable to concentrate which progressed until thoughts no longer occurred to me. Have you ever zoned out

in class, work or at home and came "back to reality" without much recollection of what you were thinking about? This was essentially how I spent my days, staring at the wall in my living room or the ceiling of my bedroom.

Concussions may also create a certain degree of emotional turbulence as your brain and nervous system work to regulate themselves. This can manifest in mood swings, new or increasing feelings of nervousness or anxiety, sadness, and becoming easily frustrated or angered (Parachute, 2020). There are also increasing studies proving that concussions may cause a "flat affect," where someone may exhibit little to no emotions in response to appropriate emotional stimuli (BrainLine, 2010). Immediately after a concussion, you are likely to experience physical and cognitive disfunction, while emotional and sleep-related disturbances, such as difficulties falling asleep or abnormal sleep patterns, often occur later into recovery (Sandel et. al, 2017).

### **Prognosis and Potential Implications of Concussions**

Overall, recovery prognosis for concussions is quite positive. The majority of mTBI cases resolve themselves with little to no complications within a timeframe of approximately three months (Mooney & Speed, 2001). Most people that have sustained a concussion are able to return to work, school, or play within the three-month recovery time, sometimes through a gradual return schedule that should be tailored to each person. Most athletes who have sustained a concussion report symptom resolution around the two-week mark of their recovery (Bloom & Caron, 2019). However, approximately 10-20% of concussion patients have incomplete, complex, or prolonged recovery (Todd et al., 2018). Those of us grouped into that 10-20% may experience a complication called Post-Concussion Syndrome (PCS).

#### **Post-Concussion Syndrome (PCS)**

Post-Concussion Syndrome, or PCS, is diagnosed by a clinical professional when concussion symptoms persist past the anticipated recovery time. Most PCS diagnoses are made when concussive symptoms persist past two months (Concussion Legacy Foundation, n.d.). The severity of PCS symptoms, as well as the duration, vary from person to person and the symptoms can continue for months to years after sustaining a concussion (Ryan & Warden, 2003). The most common symptoms reported by people living with PCS include headaches, fatigue, vertigo/dizziness, irritability, emotional lability or irritability, cognitive difficulties such as concentration or memory problems, sleep disturbances, and increased or new feelings of depression or anxiety (Broshek, De Marco & Freeman, 2015). Additionally, females are more likely than males to experience prolonged recovery compared to their male counterparts (Bloom & Caron, 2019). Initial research surrounding sex differences in the concussion experience pinpoint a couple of key areas where differences are noted: hormonal differences, style of play, equipment/game rules, and biological differences such as neck strength (Bloom & Caron, 2019, p. 127). Female athletes are more likely to have longer recovery time as I mentioned above. Additionally, females "demonstrate increased symptom scores and neurocognitive deficits following concussion" (Bloom & Caron, 2019, p. 140). Preliminary research has also pointed to sex differences in mental health expression following a sport-related concussion (Bloom & Caron, 2019). However, more research is needed to understand the complexities and underpinnings of these findings, such as why these sex differences seem to manifest themselves.

Perhaps the most significant complication of PCS are the mental health implications. In an article by Todd et al. (2018) the researchers explore various ways your mental health can be affected after a concussion. Todd et al. (2018) state that "a Major Depressive Episode will be

experienced by at least 35% of concussion sufferers" (p. 2). Todd et al (2018), state that "those with a history of 3 or more concussions are 24.4% more likely to develop clinical depression," and "20% of concussed athletes experienced an increase in depressive symptoms, compared to 5% in non-concussed controls" (p. 2). Additionally, the prevalence of post-concussion anxiety is as high as 24% (Todd et al., p. 2, 2018). Unfortunately, there are increasing studies documenting the link between concussions and an increased risk of suicide and/or suicidal ideation in comparison to the general population (Fralick, Thiruchelvam, Tien & Redelmeier, 2016; Teasdale & Engberg, 2001; Wasserman et al., 2009). Research has found that the long-term risk of suicide amongst those with a concussion is three times higher than the general population (Bloom & Caron, 2019).

## **Chronic Traumatic Encephalopathy (CTE)**

An emerging area of interest for TBI research is the prevalence of a condition called Chronic Traumatic Encephalopathy (CTE). In 1934, Parker coined the term *traumatic encephalopathy* to characterize a progressive state of neurological degeneration following a series of blows to the head, specifically with the focus on boxers (Bloom & Caron, 2019). The word "chronic" was later added to describe how symptoms lingered and showed a tendency to gradually worsen over time (Bloom & Caron, 2019). CTE manifests itself progressively in stages, and the most common symptoms of CTE include: behavioural and mood changes, memory loss, loss of impulse control, cognitive impairment, and dementia (McKee, Stein, Kiernan & Alvarez, 2015). Often, the disease peaks years to decades after an athlete has retired and culminates in symptoms similar to Parkinson's and Alzheimer's Disease such as: staggered, slow or shuffled gait, slow or slurred speech, ataxia (loss of muscle control), and dysphagia (inability to swallow) (McKee et al., 2009). CTE is also linked to increased thoughts of suicide and increased risk of death by suicide as displayed by the class action lawsuits against the National Football League, and consequently, the National Hockey League. Former two-time Stanley Cup Winner, Dan Carcillo, stated in an interview about his concussions, "I'm going to choose when I'm going to go… I'll make that decision of how much pain I'm going to put my loved ones through that are around me" (Global News, 2019). Carcillo speaks openly about the extreme bouts of depression and suicidal ideation he experienced as a result of his repetitive head traumas he sustained as a *League Enforcer* (the fighter of the team) for the Chicago Blackhawks.

After years of professional treatments and expensive rehabilitation that gave him little respite, Carcillo treated his brain injuries with an emerging area of treatment for advanced or complex brain injuries: psilocybin mushrooms (The Star, 2020). I do not recommend everyone who is dealing with a concussion to immediately jump to a psychedelic to treat their ailments, especially without physician approval. However, as more and more research unfolds surrounding the healing properties of psilocybin mushrooms, Carcillo, as well as many other natural medicine advocates such as former UFC fighter Ian McCall, remain hopeful that psilocybin will become a widespread option for treatment in the near future. In essence, psilocybin kickstarts neuroplasticity within the brain, creating new neural pathways and enabling the broken neural pathways sustained during a head trauma to heal themselves all on their own (Ly et al., 2018). I look forward to discussing "alternative" treatments such as this in a later chapter.

## **Invisible Disabilities, Stigma, and Stereotypes**

While this heading may seem expansive to cover as one topic, invisible disabilities are subject to complex layers of stigma and stereotypes. Before we explore the concept of invisible (or non-visible) disabilities, we must differentiate between a *disability* and an *impairment*. In the Disability Studies field, we utilize the word *impairment* to describe a physical or mental

difference, such as a lost limb, paralysis, or Down Syndrome (Cameron, 2014). Comparatively, *disability* refers to the barriers that someone with an impairment encounters that prohibits them from participating in society, such as physical barriers like lack of ramps, or more nuanced barriers such as stigma and/or stereotypes (Cameron, 2014). For example, it is not my ocular fatigue (impairment) that keeps me from completing a project, rather it is the way that the project needs to be completed (barrier), such as our new pandemic-world of online learning that creates the disablement. With this distinction in mind, I would like to clarify "invisible" or "non-visible" disabilities.

Invisible disabilities are disabilities that cannot be seen outwardly (Samuels, 2017). For my thesis, the invisible disability that we are exploring is concussions, and concussion complications such as PCS, or the ensuing mental health diagnoses that may accompany some concussions. Oftentimes, people living with invisible disabilities do not appear outwardly to be disabled or impaired, and many of us can "pass" as a non-disabled person, meaning we can "mask" or "hide" our symptoms or impairment and be seen (and therefore *treated*) like a nondisabled person. This creates a disunion between a person's appearance and their inward identity. Almost all symptoms that I live with on a day-to-day basis, such as headache, neck pain, fatigue, difficulties concentrating, memory loss, and ocular fatigue/sensitivity to light are not readily apparent to people who do not know me. Due to this discrepancy, I am subject to many different interpretations of "what is wrong" with me; and this leads us into a conversation about stigma and stereotyping.

## **Stereotypes and Stigma**

When I am irritable for "no reason" because I'm on day 4 of a persistent headache, I am "having my woman time." When I am in bed until noon on a Tuesday because of my fatigue, I

am considered lazy. When I forget to do something, or complete a task, I am irresponsible. When I struggle to look at someone because my eyes are overwhelmed from stimuli, I am rude. These are all examples of stereotyping. A stereotype is "a set of beliefs about the members of a social group and usually consists of personality traits, behaviours, and motives" (Blaine, 2013, p. 28).

Stereotypes are learned through social conditioning, meaning the set of beliefs about members of a group are constructed by social norms and values. Stereotypes can be positive or negative in their attribution. However, oftentimes these stereotypes have negative consequences for members of a social group, such as the stereotype of disabled people being incapable. For example, "capability" is defined by social standards and norms, and anyone that falls outside of the qualifications for "capability" are automatically assumed to be incapable. What traits or behaviours come to mind when you hear the words Brain Injured? Dumb? Dependent? Incapable? Whether subconsciously or consciously, I highly doubt your first attribution to the words "brain injured" is a capable and smart post-graduate master's student writing a thesis paper. Thus begs the question many invisibly disabled people face: do we disclose our disabilities and risk falling prey to damaging stereotypes, or do we push through our struggles and continue to "pass" as non-disabled person to avoid those stereotypes? This question of disclosure is faced in many different situations and may become a matter of risk versus reward.

Stigma operates similarly to stereotypes, but the main difference is that stigma is always negatively charged. The word *stigma* originated with the Greeks and referred to a physical mark (typically a burn, tattoo, or cut) that indicated the bearer of said mark was "a slave, a criminal, or traitor" (Goffman, 2017, pg. 133). The purpose of the mark was to identify the bearer as someone to be avoided, and someone who was "less than" due to the characteristic the bearer possessed, such as being a criminal. These stigmatized people were outcast from society and

avoided at all costs, especially in public spaces. A defining feature of stigma is the disconnect from society, which has permeated into our present society where we alienate those we stigmatize. In a later chapter we will examine stigma within a sport context, and how the stigma of mental weakness often leads to non-disclosure of concussive injuries due to the fear of being outcast by teammates – or society in whole. Goffman (2017) argues that today, the stigma is associated more with "the disgrace itself [rather] than to the bodily evidence of it" (pg. 134), and states that *shifts* have occurred in what qualifies as a "disgrace" – alluding to the dynamic and ever-changing fluidity of what traits can be stigmatized and what traits are acceptable; in other words: stigma is constantly shifting and changing with societal and cultural perceptions. Goffman (2017), similarly, to Coleman-Brown (2017), acknowledges that stigma is socially constructed, and constantly changing.

Coleman-Brown (2017) provides a walkthrough on the social construction of stigma in her essay titled *Stigma: An Enigma Demystified*. Essentially, stigma boils down to human difference, and it is the *undesirability* of this difference that creates stigma (Coleman-Brown, 2017). Stigma is constantly shifting and changing as it reflects values within a culture and a historical period, which also means that *all* human differences have the risk of becoming stigmatized (Coleman-Brown, 2017). When a trait becomes stigmatized, it relegates people with those traits to a lower position on the social hierarchy (Coleman-Brown, 2017). Perhaps the most interesting thing about stigma is that it requires an agreement, either conscious or subconscious, between both parties (the stigmatized and non-stigmatized) that the trait in question is undesirable, because without this agreement, the stigmatized do not feel the superior/inferior relationship dynamic that is necessary for stigma to be effective (Coleman-Brown, 2017).

#### The Role of Culture

The role of culture is important to recognize when we are exploring concussions. There are different aspects of culture that may impact an athlete's decision to disclose an injury. We have broad cultural norms shaped by Western ideologies such as narratives of overcoming, an aversion to failure, and individualism. Ideologies such as these will influence subcultures, such as athlete culture and sport demands. In this section on culture, I try to illuminate the links between culture and subcultures. We must remain mindful of stereotypes and stigma while trying to understand the full impact of culture on an individual, as both stereotypes and stigma are socially and culturally constructed.

Western culture places a high value on individualism, and a high value on productivity. Western standards of productivity are typically unattainable by even the most non-disabled person. Western citizens often have a work-life balance that tilts precariously more towards work, leading to decreased hours to enjoy or pursue other interests in life such as hobbies. Western obsession with consumerism fuels this cyclical nature of worker and consumer, you must work more to buy more to have more to "be more." I know that this standard of productivity is nearly impossible to attain as someone with a "passing" impairment and has extremely negative consequences for our more severely impaired brothers and sisters.

I believe that Western culture's value of individualism is a major contributor to many other constructions within our culture. Compared to more collectivist cultures, Western culture places a high value on independence, praising and rewarding people who can do things on their own. In other words, Western countries are more likely to have citizens who believe they are independent versus interdependent. This independence negatively impacts people who are unable to meet standardized expectations of independence, such as those with disabilities who would

benefit from interdependent communities and relationships. This value of individualism creates challenges when speaking out about mental health or other ailments, especially when those ailments may come from the independent nature of a culture. Research conducted by Hughes & Coakley (1991) show one of the four internalized beliefs of an athlete is a: striving for distinction. I believe this value closely mirrors a larger cultural value of independence; and because athlete culture is a subculture, it will ultimately be influenced by larger social values.

Another Disability Studies topic that is deeply connected to concussions in the sporting world is the Personal Tragedy Model (PTM). The PTM is a "cultural expression... materialized through the recycling of disciplinary messages that 'able-bodiedness' is valued while impairment is a mark of misfortune" (Cameron, 2014, p. 117). The PTM confirms a "largely unchallenged view that treats health as the normal condition most people enjoy, and departure from health as an inconvenient state of being to be endured and battled with temporarily until normal functioning is restored" (Cameron, 2014, p. 117). In other words, in the PTM, disability is seen as negative and only accepted so long as the disabled person is actively working towards becoming "healthy" and "overcoming" their disability. The PTM makes it difficult for disabled people to navigate their identity without invasive opinions from non-disabled people on what the disabled person should be doing to "get better," even if the disabled person feels no urgency or need to "get better." This notion of getting better is deeply rooted in a Western value of physical health, rather than a *holistic* value of health to encompass all aspects of a person: emotional, physical, mental, spiritual, and social. When this Western ideology of physical health prevails over a holistic view of health, we limit our understanding of people's happiness, value, and ability to the state of their physical body more than any other aspect of that person.

The PTM also assumes that the disabled person is responsible for comforting the nondisabled person in their distress over another's impairment. This is often the times where you hear cultural scripts such as: "I'm fine!" "Everything is alright." "It's all good, I've got this." All words that are familiar to injured athletes. Oftentimes these phrases are echoed back to us by a coach or a teammate: "You're fine, right?" "You're doing great!" "You've got this!" These words bounce around in our head, and even if we know that we are injured, oftentimes we will nod our heads and try to believe we are fine.

Later in this thesis, we will explore a study by Hughes and Coakley (1991), which alludes to some connections between the duties of athletes and the PTM. For example, Hughes and Coakley (1991) found that athletes believe they must be striving for distinction and "refusing to accept limits in the pursuit of possibilities" (p. 309-310). During an injury, these two areas of the athlete experience, striving for distinction and the refusal to accept limits, may converge with aspects of the PTM. Athletes may be rushed back to play before they are ready, because of the athletic duty to "refuse to accept limits" and the PTM belief that you must *always* be striving to get better, because illness or disability is not acceptable. Cultural scripts such as those listed in the paragraph above (p. 32) may also deter an athlete from being forthcoming with their injuries.

## Athletes and Injury Non-Disclosure: Sociological and Cultural Creations

There are a couple of different reasons that athletes ignore their gut instinct and try to play through injuries. We will explore those reasons through different aspects of an athletic subculture. Subcultures are not immune to the beliefs of a culture, rather subcultures are often heavily influenced by the beliefs of the culture. For this thesis, the subculture that I am exploring is a sports team. Teams are an interesting subculture to examine because teams, or at least good teams, require all members to be working towards a common goal. I will be using a publication

by Howard L. Nixon II (1992) to attempt to explain why athletes will consciously or subconsciously attempt to play through injuries. Nixon (1992) states that a major aspect of an athletic subculture that influences athlete's decisions is a "culture of risk in sport" (p. 128). This culture of risk insinuates that playing through injuries is rational as "part of the game" and "for the good of the team," while also linking pain tolerance to a stronger (masculine) character (Nixon, 1992, p. 128). Nixon (1992) adds the word "masculine" into his statement, and I believe that this is accurate. As a woman playing in a woman's sport, there is still a subcultural presence of masculinity in sport. Oftentimes women (and girls) are shamed into "playing like a man" or "growing balls" to play though pain or adversary; least we been seen as "a pussy," "a bitch," or my favourite "you play like a girl!" for stopping play because we are hurt. These are all examples of cultural scripts, like the ones described in the previous paragraph on p. 33.

A culture of risk also implicitly or explicitly influences athletes to believe that accepting the risks of playing with pain or an injury is the only way to keep their spot on a team (Nixon, 1992). This is corroborated by a study conducted by Chrisman et al. (2013), who found that athletes were worried that if they were wrong about being concussed, they would suffer negative ramifications from their coach such as: removing them from a starting position, a reduction in their future playing time, or infer their reports of a potential concussion made them "weak" (p. 334). Please keep in mind that athletes often play their sport because they find a sense of empowerment, joy, and purpose in playing that sport, and often when faced with a "playable" injury, or sitting out, we will frequently choose playing through an injury. A female soccer player reported "you want to keep playing. You're always going to think it's something little and it will go away... like, can't you just play through it or something?" (Chrisman et al., 2013, p. 332). A football player agreed with the sentiment: "... that is what you practiced the whole summer for and there are only like 10 or 12 games and 40 minutes a night, and you do all that work, you don't want to come out" (p. 332).

Perhaps the most influential aspect of an athletic subculture when it comes to a rationalization of risk is the supportive interaction, or social support, they receive from other members of the subculture. Social support typically helps an individual by providing them with a sense of comfort, control, and even boost esteem when you're feeling doubtful, however when the social support is perpetuating harmful values, it quickly becomes a dangerous road to travel. Nixon (1992) found that other athletes are quick to support another when it comes to playing through injuries and will even go so far as to not disclose injuries to a coach or training staff member in solidarity to their teammates. This becomes increasingly dangerous, as the injured player will often only turn to people within the subculture when speaking about their injuries, as people outside of an athletic subculture may not understand why an athlete would participate in a dangerous activity in the first place (Nixon, 1992). Not only does this discourage the athlete from reaching out to people outside of their athletic subculture (such as a parent, friend, or medical professional) in the future, but it will consistently turn the athlete back into the athletic subculture to try and determine the appropriate course of action regarding their injury.

Athletes also tend to fall into a "role engulfment" where they become engulfed in their role as an athlete, and thus surround themselves with other athletes and diminish other roles such as academia or other hobbies to fully immerse themselves into an athletic subculture (Nixon, 1992). If I think back to my high-school days, where I sustained most of my concussions, all of my friends were athletes. In my group of 20 close-knit friends, 19 of them were athletes playing football, hockey, soccer, or some combination of the three. All of them have had concussions

and we probably shared about 60 concussions between the 20 of us. So, to come to school concussed or complain of concussion symptoms was just another day at school.

The exception to the rule is my best friend of 13 years, Paige Horton, who is a professional hockey player. She won gold with Team Ontario and received a full ride scholarship to play in the United States where she captained her team to the Frozen Four of the National Collegiate Athletic Association (NCAA) Tournament and won the College Hockey America (CHA) Championship. She was constantly reminding us about how easy it is to get concussed, and even easier to be re-concussed. She was the first person I contacted when I got home from the hospital in 2013. Her, and my other best friend Zack Tosswill, immediately left class and walked 5 kilometers from school to my house to be with me, they kept me company as I stared blankly at a wall, not even able to speak. Not a day went by without her checking in on me, and not a day goes by I am not grateful for her unwavering support.

In 1991, Hughes & Coakley set out to understand the basis and construction of athletic identities. In essence, Hughes & Coakley found that many athletes exhibit positive deviance in the manner of over conformity to social norms and values. Hughes & Coakley (1991) use the term "positive deviance" to describe athlete's behaviour when they subscribe to dangerous norms and values within the sporting culture (such as those we have already explored like playing through pain). This is labelled as "positive deviance" because athletes are overconforming to the dangerous social norms set out by their sporting culture (positive), yet at a rate much higher than those in mainstream society which alienates them from mainstream society (deviance). Similar to Nixon (1992), Hughes & Coakley (1991), found key determinants in behaviour that are typically exhibited by athletes: being an athlete involves making sacrifices for The Game, being an athlete involves striving for distinction, being an athlete involves accepting risks and playing through
pain, and being an athlete involves refusing to accept limits in the pursuit of possibilities (p. 309 - 310). I believe these behaviours also impinge themselves onto injury recovery processes including concussive injuries.

Many similarities can be drawn between Nixon's findings and Hughes & Coakley. Both studies emphasize sporting culture's value of playing through injuries and the impact this has on the individual athlete, who is often striving towards distinction and heroism by sacrificing oneself for the good of the team. Additionally, sacrificing other values or interests is a key indicator of athlete culture run amok. What Nixon (1992) terms as "role engulfment," Hughes & Coakley (1991) eloquently describe as such: "real athletes must love The Game above all else and prove it by subordinating other interests for the sake of an exclusive commitment to their sport" (p. 309). Hughes & Coakley (1991) elaborate further by warning that when "selfidentification" becomes formed within sport, the individual is susceptible to internalizing norms and demands of sport into their identity; self-sacrifice and other potentially self-destructive behaviours take hold to demonstrate *worthiness* and earn their place in the group membership of the sporting culture. I believe this internalization of sport culture, especially sacrificing other interests in pursuit of an athletic identity, cannot be overlooked when discussing an athlete's desire to continue to play even while injured, even to such lengths where an athlete will choose *non-disclosure* of an injury over *non-playing*. An athlete believes it is their duty to play through injuries to conform to the sporting cultures norm of sacrifice, because without adhering to sporting culture norms, the athlete risks being alienated from the group, and therefore I believe, alienated from their own identity.

The reason I say, "alienated from their own identity" is because due to the positive deviance, an athlete that rejects sporting culture but still participates in sport creates a

juxtaposition where the athlete does not fully integrate into sporting culture, but still deviates from mainstream social expectations. Not fully integrating into sporting culture means the athlete will not progress further in their sporting career, while contrastingly but similarly, integrating fully into mainstream society means sacrificing their identity as an athlete... a tricky situation to find oneself in. Personally, the relationships I created within sport seemed more genuine than relationships I created outside of sport. I felt accepted more by my teammates and shared more in common with my teammates than I did my classmates, therefore, the relationships with my teammates were prioritized.

It has only been through consumption of studies such as Nixon (1992) and Hughes & Coakley (1991) that I have begun to understand why the relationships with my teammates felt more authentic and connective: because we were all conditioned with the same beliefs, norms, and values due to the sporting culture we were raised within. Comparatively, although a Western culture will inevitably socialize and condition us with similar values such as individualism or self-sufficiency, I do not believe that socialization within mainstream culture is as powerful as socialization within a closed sector such as a sporting culture. Additionally, values and norms within a sporting culture create an environment where all members of a group (team) are striving towards a shared common goal: winning a game, a tournament, or a season. Given the drastic difference within mainstream culture, like the individualism and self-sufficiency, I am not surprised that many athletes bond more closely with their athletic counterparts. I always found acceptance and belonging within my sporting culture, whereas within the mainstream Western culture, I found alienation and judgement. I believe the sociological implications and construction of an athlete's identity is crucial to understanding the reasons that athletes may choose not to disclose their injuries, and how to best support those that decide to disclose their

injuries. Upon seeing my doctor for my second concussion diagnosis, he looked at me and said, "if you come back to me with one more concussion, then I'm not clearing you to go back to play." He didn't understand the potency of my athletic identity and my desire to protect that identity at all costs; thus, he likely didn't understand that upon uttering those words to me, he was only ensuring that I didn't come see him for my third concussion. Which is exactly what happened, and although I have *certainly* sustained multiple concussions after my second, I never received another diagnosis. An ode to the overwhelming priority medical professionals place on physical health, often at the expense of mental, spiritual, or emotional health.

To summarize, culture plays a huge role when it comes to athletes disclosing or not disclosing their injuries. It would only be through a complete culture shift that change will come. Large scale corporations such as the NHL, NFL, or UFC have a responsibility to their athletes to inform them of the dangers of the sport that they are playing, and yet this is not being done. A culture of risk removes the responsibility from higher level positions such as management, general managers, or presidents of clubs from being responsible for athlete's injuries, as it is assumed that the risk is understood by an athlete upon entering the sport. And while yes, many of us are aware that we could become seriously injured playing our sport, it is the negligence from higher authorities in sport that continuously disappoint and endanger athlete's wellbeing, despite a plethora of studies and information released, especially surrounding head traumas such as concussions and long-term damages and illnesses such as CTE.

#### **Chapter Three: Design**

Through this chapter titled *Design* I walk my reader through the different approaches to inquiry I am utilizing to explore concussions and personal experiences with concussions. I explore the differences between quantitative and qualitative inquiry, as well as autoethnography and the reasons that I chose the approaches that I am going to use. From a Critical Disability Studies (CDS) perspective, I introduce my reader to a literature approach called "Disability Life Writing" and use Disability Life Writing to explore my own experiences with my concussions, rehabilitation, and the complications I faced through my recovery. I link main concepts in my thesis such as stigma and stereotypes, mental health complications, and physical consequences to concussions through an exploration of "Critical Incidents" that have happened in my own experience.

### Quantitative and Qualitative Inquiry & Autoethnography

## **Quantitative and Qualitative Inquiry**

Research often falls into one of two categories: quantitative or qualitative research. Quantitative research "require[s] the use of standardized measures so that the varying perspectives and experiences of people can be fit into a limited number of predetermined response categories to which numbers are assigned" (Quinn Patton, 2015, p. 22,). A quantitative method allows a large group of people's experiences to be generalized and applied to a larger population. Qualitative methods of inquiry aim to achieve a deeper understanding of a phenomena with a smaller group of participants (Quinn Patton, 2015). Qualitative inquiry will give a more personal account of *what* a phenomenon means to the person, or *how* a phenomenon affects them (Quinn Patton, 2015). Carolyn Ellis (2004) describes the goal of qualitative inquiry, and autoethnography in particular, as "trying to understand the complexities of the social world in which we live and how we go about thinking, acting, and making meaning in our lives" (p. 25).

Personally, *meaning making* has become the driving force behind a lot of my academic interests and largely informed my selection of qualitative inquiry for this thesis. I believe it is important to understand *how* a concussion, or the sporting culture surrounding concussions, can impact an individual's life far beyond the medical sequela. Qualitative inquiry will provide an important framework for exploring meaning making, as I can investigate more nuanced topics of the concussion experience. For example, a study I spoke about in my Literature Review titled *Qualitative Study of Barriers to Concussive Symptom Reporting in High School Athletics* by Chrisman, et al., (2012), aims to discover *why* students were hesitant to report concussive symptoms. If this study were conducted with a quantitative lens, perhaps they would be trying to see *how many* students withheld disclosing concussive symptoms to a coach or peer. I utilize this specific study by Chrisman, et al. (2012) multiple times through my thesis as I believe that uncovering the hidden "whys" of concussion disclosure (or non-disclosure) will begin to dismantle the stigma and isolation that have been constructed around concussions through a careful analysis of norms within sporting culture.

Some research can take a mixed methods approach where the researchers utilize aspects of both qualitative *and* quantitative inquiry to achieve their answers. In this approach, you get the benefits of each method and oftentimes they complement each other quite well as you get the depth of qualitative inquiry, and the breadth of quantitative inquiry. Parts of my paper are bolstered by quantitative studies, but qualitative studies give my reader the most information possible, while also exploring personal experiences and nuances of the concussion experience.

### Autoethnography

Autoethnography was created as a derivative of the earliest method of qualitative inquiry: ethnography. Ethnography is an observation method of inquiry that was typically used by anthropologists to study *other* cultures, subcultures, or groups (Ellis, 2004; Quinn Patton, 2015). Comparatively, autoethnography gives researchers a tool to study *their own* cultures, subcultures, or groups (Ellis, 2004: Quinn Patton, 2015). In this sense, autoethnography provides a platform to close the gap between social and cultural understanding and an often silenced or taboo personal experience. Personal experiences within marginalized communities, such as those with disabilities, have a unique opportunity to challenge normative cultural discourses and serve as a retort to traditional Western misrepresentation and stereotypes. When using autoethnography, researchers are often searing for the answer to the following question: "How does *my own* experiences of my culture offer insights about this culture, situation, event, and way of life?" (Quinn Patton, p. 101, 2015).

People with concussions have been silenced in sport for many years as we signify a direct challenge to traditional sporting rhetoric and beliefs. Athletes and people who develop further cognitive decline in the form of chronic traumatic encephalopathy (CTE) are telling their personal stories to confront the agonizing ignorance that many sporting bodies refuse to acknowledge brain health is holistic health, and many athletes are experiencing an infringement on their personal advocacy for health. This may not be outright, but tucked away in sinister, yet "harmless," beliefs and sayings such as "play through the pain," "sacrifice your body," or embedded sporting norms such as placing the team before oneself. I experienced these norms and beliefs. It was the ingestion and embodiment of "sacrifice your body" that became a dangerous cadence of solely viewing my body as a physical object to be used for the

achievement of a "greater good" such as trophies or medals. In this thesis, I aim to illuminate seemingly well-intentioned, yet dangerous, sporting values. For me, this means using my own experiences with concussions to gain insight into how Western culture or an athletic subculture will view and address concussions.

The difference between autoethnography and ethnography is that autoethnography requires the researcher to be self-aware about reporting their experiences and allows the researcher to use their own experiences as the primary data source (Ellis, 2004; Quinn Patton, 2015). Perhaps this is where the biggest critique of autoethnography comes from: blurred lines between social science and literary writing (Quinn Patton, 2015).

While I can see the perspective of critics, I have troubles understanding what makes my experience any less valid than experiences collected through quantitative methods of inquiry. Perhaps the nuanced differences that occur from person to person when talking about the same phenomenon make a singular truth impossible to determine. While this may be a possibility, I believe the opposite to be true: knowing people's individual accounts of their concussion experience will undoubtedly shine light on *similarities* between individual concussion experiences. Through my research I have found an overwhelming number of athletes that speak to the heavy and all-encompassing depression that accompanies the social and physical isolation we experience. *Why* do so many people with concussions, athletes and non-athletes alike, speak about depression and isolation? A question I am interested in that cannot be discovered through quantitative inquiry. Some aspects of another person's story will help me with my own, just as I hope some aspects of my story help my readers. This is where the impact of Western individualism becomes damaging compared to interdependent collectivism, as I outlined in my Literature Review.

On the other hand, I can assure you that autoethnography is not as simple as a diary entry outlining what happened to me. Autoethnography forces the researcher to confront and relive possibly traumatic experiences and be vulnerable enough to open these experiences to strangers. Autoethnographic researchers must be critical of their own motivations and actions, as well as analyzing how their motivations and actions have been (or have not been) impacted by larger social norms and ideations (Ellis, 2004). Throughout this thesis I attempt to connect my personal experiences and beliefs to larger social norms, specifically in an athletic subculture, which is situated within and influenced by a larger Western culture. I discuss my critical incidents in the section titled "Vignettes' and Discussions." I have divided these incidents into an overview of the incident in question, followed up by a discussion on social norms or ideologies that were at play during specific incidences. For example, I could not understand my willingness to succumb to an athlete's mindset while I was in the midst of it - I believed that being an athlete automatically meant I had to be self-sacrificial. Further investigation into the literature, specifically Nixon (1992) and his research on athlete culture, showed me how standards have been set by sporting culture, and every athlete "must" adhere to these standards in order to "succeed." For example, sporting standards equate self-sacrifice to nobility, and what teenageprofessional-wannabe doesn't want to be seen as noble? I know I did, and chances are you know someone (maybe it is yourself) that climbs exorbitant ladders to acquire external praise. These phenomena are not isolated to the sporting world, but are certainly exacerbated when the promise of fame and fortune is positioned at the top of that ladder. But in all honesty... the ladder is rickety and wooden, the fall can be long, and the impact can be catastrophic.

Finally, autoethnography requires a writing style that evokes emotions and is personal while also informative for the reader. For my thesis, I am utilizing an autoethnographic approach, while implementing a style of writing called "Disability Life Writing."

### **Disability Life Writing**

Oftentimes, cultural representations of disability are controlled and depicted by nondisabled people within cultures. This means that representations of disability are skewed to align with typical non-disabled stigma and rhetoric of what disability looks like: incapable and dependent, or as a "super-crip" – someone with a disability that is shown overcoming their disability to achieve non-disabled standards of success. To counteract these cultural misrepresentations, there has been an influx of writing and documentation by people with disabilities through autobiographies. I am using an article written by G. Thomas Couser (2017) to explore the concept of "disability life writing" and I explain how I intend to utilize the premises within disability life writing to structure and guide my thesis. Couser outlines six criteria for disability life writing, and it is important that through my paper I aim to achieve as many of these criteria as possible.

Firstly, Couser states that disability life writing is not simply "spontaneous selfexpression" but rather "a response – indeed a retort – to the traditional misrepresentation of disability in Western culture generally" (Couser, 2017, p. 452). As I write my thesis, I am not only writing to document my experience, rather I write my experience and document instances where cultural norms and values have failed me and many others in our concussion recovery. I aim to provide a more accurate representation of my experience to challenge mainstream discourses of concussions and concussion recovery.

. Oftentimes, it is expected that authors conform to a "cultural script" when speaking about their disability. Since we live in the Western world, as a disabled author I would be expected to reproduce an autobiography (or thesis) that aligns with Western ideologies such as the Personal Tragedy Model and take responsibility for my disability. Supposedly, disabled authors (and disabled people in general) are expected to make others comfortable when speaking about their disability. For example, within this mindset I may summarize my experiences with phrases such as "I brought this on myself" or "it's not as bad as other people make it out to be," or avoid talking about certain taboo topics such as mental health, plant medicine, or suicide, for example.

However, Couser advocates *against* this mindset and method of representation. In fact, Couser (2017) states that disability life writing will challenge the assumption that disabled people are responsible for making non-disabled people feel comfortable when presented with realities of our disablement. I am not shying away from talking about more culturally taboo subjects within concussion recovery, such as struggles with my own mental health, or topics such as suicidal ideation, or psychedelic research and usage.

Historically, as I stated earlier, representations of disability have been scripted and shown by non-disabled perspectives, and oftentimes, visual representations of disability are often portrayed by non-disabled actors. Additionally, disabled people are often written *about*. This could be from a medical standpoint – such as medical examinations, trials, or experimental treatments – or it could be from a literary standpoint, such as biographies about a disabled person without any input from the person of interest. Thus, Couser (2017) states that another requirement of disability life writing is for disabled people to assume the main subject position and write about themselves *by themselves*. This includes writing their own account of their

experiences without any outside interference or rewriting of experiences. As I have stated, my thesis is rooted in my own experiences with concussions and my own recovery, as well as instances where systems designed to help me have failed me. Writing as the main "character" or occupying the subject position, as called for by Couser (2017), also fulfills another aspect of disability life writing: allowing the public to view accounts from disabled people that may be changed, distorted, or simply falsified if provided by mainstream sources.

Couser (2017) advocates for disability life writers to write from a post-colonial, or anticolonial, perspective. Similarly to how life writing by other marginalized groups – such as the Black community, or the LGBTQ+ community – disability life writing "is a cultural manifestation of a human rights movement" (Couser, 2017, p. 532). Part of a human rights movement requires a critique on the current status of said human rights, which is often determined by the values of the broader culture. Disability Life Writing is also effectively utilizing post-colonial frameworks to critique larger social structures and ideologies that disable those who have impairments.

Within post-colonialism, or anti-colonialism, those oppressed by colonial practices and values critique oppressive structures and systems. One of the impacts of colonialism is that those who have been colonized may ultimately embody a "post-colonized" identity that typically aligns more with the values of the colonizer's culture rather than the person's individual culture or society. Post-colonialism theory provides a foundation to analyze and critique dominant cultures; the "dominant culture" that I am analyzing throughout this thesis is "athlete culture." For example, in my literature review I discussed values such as a *culture of risk in sport* (such as playing through pain, refusing to accept limits, pain/injuries as part of the experience, etc.). After being involved in an athlete culture, these values may overshadow or replace values that the

individual may have had before becoming indoctrinated within the dominant culture. As we progress through my critical incidents and further chapters of my thesis, my critiques of these values become more evident as I document how I believe these values have impacted my concussion experience and recovery. By utilizing a post-colonial framework, I can challenge normative ideologies held by the culture in question: an athlete culture. Additionally, in its essence, the use of autoethnography allows me to examine oppressive and invisible societal and cultural ideologies thus making it inherently post-colonial.

Finally, Couser (2017) wants disability life writing to counter "the too often moralizing, objectifying, pathologizing, and marginalizing representations of disability in contemporary culture" (p. 453). What this means is that disability life writing should counter traditional assumptions about disability and the author can illustrate their experiences outside of a traditional medical view. In my thesis I show you my experience. My name is Kylie Hamilton, and I am writing to you about the things that I experienced as Kylie Hamilton. Not as a number in a study, or a diagnosis in a medical textbook, but as a human being who lived through these experiences, and I am here to tell you what those experiences genuinely felt like. This qualitative and autoethnographic approach that I take throughout my thesis addresses a large gap in our current body of literature. Todd et al., (2018) state "little is known about the subjective experience, or the qualitative links between concussion and mental illness" (p. 2). While other researchers such as Bloom & Caron (2019) state "the role of psychology had largely been absent from the literature on the management of sport-related concussions" (p. 3). While my thesis does not *explicitly* focus on psychology or mental illness, these are important topics that I attempt to highlight from a qualitative and autoethnographic standpoint.

#### **Trustworthiness in Qualitative Inquiry**

Along with the ethical considerations, as a researcher I must also consider how I should approach the research process in a trustworthy manner. According to Lincoln and Guba (1985), the criteria for assessing trustworthiness are credibility, transferability, dependability, and confirmability. Credibility refers to whether the research findings represent a "credible" theoretical interpretation of the data drawn from the participants' original data, that is, the 'believability' of the findings. Credibility is improved through using verbatim transcripts, checking with informants, re-reading the data sets and providing clear descriptions of all steps of the analysis process along with examples of each step from the raw data. Using the language of the participants also increases credibility. To establish credibility, I use verbatim quotes wherever possible, I vigorously read and re-read my Critical Incidents to ensure that I was being as accurate as possible, while also adhering to the same three-steps to write each of my Critical Incidence chapters. We will explore the three-steps that I used in my next header titled: Critical Incidents.

Transferability refers to the degree to which the findings of an inquiry can pertain or transfer beyond the boundaries of the project. This is a practical question that cannot be answered by the researcher alone. Readers of the project, other than the researcher, make the determination about its transferability. Readers will be helped in a decision about transferability if they have access to the steps taken by the researcher and a rich description of all the processes involved in the inquiry. Also helpful will be a rich description of the informants/sample/data sets and their contexts so that other readers can decide if the participants/data sets and contexts are similar to their own, and whether the findings might be transferred to their own contexts. Again, the more transparent and robust the description of informants/sample/data sets, contexts and

research processes, the more likely it will be that the findings will be seen as useful in other contexts.

Dependability refers to the inquiry's strengths in internal design that allow readers to be confident that sufficient cross comparison mechanisms in data collection and data analyses were employed. Thus, the findings can be seen to be derived inductively from the original data sets and deductively from engagement with sensitizing concepts from the literature and theoretical frameworks as opposed to being based in my own assumptions about the question under study. Triangulation of data collection and/or levels of data analyses, and providing a research audit in the form of an ongoing researcher's journal, contribute to dependability, the ability to depend on the findings being derived from a rigorous process of data collection and analysis. The more clearly these processes are described, the more dependable is the study and its findings.

Confirmability refers to how well the inquiry's findings are supported by the data collected and analyzed. Using verbatim quotes, the language of the informants/sample/data sets, and providing access to the processes of recursive reduction, either in the body of the work or in appendices, adds to the confirmability. In any study, a researcher should have employed some or all of these aforementioned practices which contribute to trustworthiness and should be able to provide specific examples of how they did this from their own research process.

## **Critical Incidents**

I focus the bulk of my thesis on exploring five critical incidents within my concussion experience, all of which I organized under the general subject header of *Vignettes' and Discussions* and then further separated into the individual critical incidents. Within these five critical incidents, there is the opportunity to discuss the topics that were outlined in my Literature Review chapter: symptoms, stereotypes and stigma, mental health, culture (specifically athlete

culture), and long-term complications such as PCS. My critical incidents are in chronological order, mostly because this is the easiest way for me to recall my experience, and I believe it is the easiest order for my reader to follow along with. I unpack each of my critical incidents and explore them using the same steps to ensure that I complete an appropriate analysis of all key themes. Through implementing these steps, I explore the key concepts that are included in my chart, as well as any other pertinent themes or concepts that I uncover as I progress through my analysis. My steps are as follows:

Step 1: To begin my critical incidents I am writing each incident as I remember them. This includes many details to ensure that I am bringing my reader into my experience as much as possible. This includes people, places, objects, times, activities, and things that were said to me throughout my recovery.

Step 2: I then analyze each of these incidents in series of steps in order to achieve the following three objectives; making the obvious, obvious; making the obvious, dubious; and make the hidden, obvious. In order to accomplish these three objectives, I follow the steps listed below.

2a. I try to encompass the entire experience, which begins with noting salient features and powerful phrases that were said to me. For example, each critical incident is titled within quotation marks, indicating a verbatim phrase that was said to me and that I feel encompasses the topics that will be discussed within that incident.

2b. Re-read and note any manifest features of my experience. This includes details that *any* reader or person observing would be able to notice. This step accomplishes "making the obvious, obvious" objective listed above.

2c. Re-read and question the obviousness or assumptions of what is obvious. To do this I use Critical Disability Studies (CDS) concepts and frameworks (such as ableism, Personal Tragedy Model (PTM), mental health, etc.) to guide my analysis. This step accomplishes "making the obvious, dubious" objective listed.

2d. Finally, I re-read and make the hidden, obvious, to complete to final objective listed above. I use the CDS concepts and frameworks to draw plausible conclusions and explore my own interpretations of what factors may be operating on a latent or tacit level of awareness (such as hegemonic normalcy, culture, stigma, etc.).

Step 3: I provide a thematic summary of the events and note *how* these events may situations in recovery can be improved and reimagined to benefit young adults and athletes experiencing concussions themselves. These recommendations should be extended to people who have not experienced concussions in the hope that their reactions and interactions with people in concussion recovery and more empathetic and understanding. There would also be the opportunity for recommendations to be used as educational tools to raise awareness around concussions and concussion recovery. Included is a chart with the topics that I explored in each critical incident.

Throughout the completion of this thesis, many revisions and edits have been completed in order to fully encapsulate my concussion experience and link aspects of my experience to those of others. After many writes and rewrites, the creation of the *Vignette's and Discussion* section came to fruition as a guide to my reader. The *Vignette's and Discussion* section is where I explore my Critical Incidents. My Critical Incidents were chosen as they were the most salient memories in my concussion journey. My Critical Incidents were moments where I felt the most pain, the most confusion, the most loneliness, the most pressure, and the most transformation. Each Critical Incident is titled with a verbatim statement that someone said to me that I believe sets the scene for the upcoming vignette. With regards to the *"discussion"* part of *Vignette's and Discussion*, each of my vignette's provides the groundwork for us to explore what the literature says in regards to the topics that I believe are most salient in the vignette. For example, the vignette portion of "You Can All Thank Kylie" illustrates a negative experience I had with a coach as an athlete with a concussion which I believe leads perfectly into a discussion and exploration of literature surrounding athlete experiences and culture.

My Critical Incidents are not easy for me to write. They require appropriate amounts of transparency in order to establish trustworthiness with my reader, *as well as* a constant attention to detail, where I am able to fully immerse my reader into my experience. A couple of my Critical Incidence chapters (notably Incidents Three, Four, and Five) needed sections to be carefully rewritten as I became more aware of my biases and subjectivity, specifically in relation to my socialization into an athlete culture and athletic values. Admittedly, as I critique athlete culture, I feel as though I am picking at a wound not yet healed. There is a sense of heartache and disappointment as I illuminate the more sinister ways that athlete culture has been structured to keep athletes in a perpetual state of self-sacrificing. I often wonder as I write my Critical Incidents: *Am I being too harsh? Am I being too critical?* But what exactly is *too critical?* The research is sound (Nixon, 1991, 1992, 1992b. Hughes & Coakley, 1991. Chrisman et al., 2013. Bloom & Caron, 2019. Todd et al., 2018), there is something happening to our athletes at a sociological/cultural level that is indoctrinating them with values and ideologies that do not necessarily encourage them to be appropriate self-advocators for their own safety and wellbeing.

The theories, methods, and approaches that I take with my research throughout this thesis (Disability Studies, Disability Life Writing, social constructionism, and qualitative inquiry)

allow me to properly traverse the juxtaposition that I feel when speaking about athlete culture: there is *no singular truth*; even in my own experience! The reality of my experience in athlete culture is not a binary one, it was not *all good* nor was it *all bad*. I had some of my greatest victories, healthiest habits, and best qualities come from my involvement in soccer, while simultaneously allowing for some of my hardest defeats, annoying routines, and harmful ideologies – and a whole plethora of days and games and practices and moments that were simply mediocre. As I edited my Critical Incidents, I often added more positive experiences in order to combat the negative experiences. This thesis is not aiming at scaring people out of playing sports, rather, this thesis aims to bring attention to the reasons *why* an athlete may not decide to disclose concussive injuries; and illuminate the lived experience of someone who (because of athlete culture socialization) sustained a concussion that resulted in years of rehabilitation, therapy, and healing.

| Critical Incident   | Topics to Discuss  |
|---|--|
| "Maybe You Have a Concussion"                               | <ul> <li>Main focus: Symptomology</li> <li>Main question: What is a concussion?</li> <li>Brief dialogue on concussion history<br/>(Meekosha &amp; Shuttleworth, 2017)<br/>(Bloom et al, 2019).</li> <li>First undiagnosed concussion</li> <li>First diagnosed concussion &amp; the<br/>barriers to reporting.</li> </ul> |
| "We Have to Re-Regulate Your Heart"                         | <ul> <li>Main focus: Prognosis &amp; Recovery</li> <li>Main question: What did my recovery look</li> <li>like? <ul> <li>Linking theory with praxis (Meekosha &amp; Shuttleworth, 2017)</li> <li>Anticipated recovery versus actual recovery</li> </ul> </li> </ul>   |
| "You Can All Thank Kylie"                                   | <ul> <li>Main focus: Athlete Culture</li> <li>Main question: What impact did an "athlete mindset" have on my experience?</li> <li>Ableism</li> <li>Stigma and Stereotypes</li> <li>Chrisman et al. (2012)</li> <li>Nixon (1992)</li> </ul>   |
| "Would You Like to Watch Some Fireworks?"                   | <ul> <li>Main focus: Post-Concussion Syndrome</li> <li>Main question: Who am I?</li> <li>Biopower</li> <li>Mental Health</li> <li>Dialogue Among Cultures (Meekosha<br/>&amp; Shuttleworth, 2017) (Lorenz, 2010)</li> </ul>  |
| "Tell Her to Call Me if She Needs to go to the<br>Hospital" | <ul> <li>Main focus: Reclaiming Identity</li> <li>Main question: How do I improve upon my recovery? <ul> <li>Most recent concussion</li> <li>Alternative therapies – psilocybin</li> <li>Life after my concussions</li> <li>No single truth (Meekosha &amp; Shuttleworth, 2017).</li> </ul> </li> </ul>                  |

My critical incidents unfold in the following order:

1. "Maybe You Have a Concussion!"

Within this section, I discuss the initial concussion event, which begins with an undiagnosed concussion that I didn't even recognize until years later as my "first" concussion. This section gives me the opportunity to discuss symptoms with you. We will then explore the catalyst for this entire thesis: my first diagnosed concussion. This section also gives me the opportunity to discuss some of the barriers to reporting and the hesitation I felt when reporting this concussion.

2. "We Have to Re-Regulate Your Heart"

I dedicate this section to my prognosis and the specific recovery schedule that I went through. Within this section I discuss more symptoms as they change frequently through my recovery. I outline my graduated Return-To-Learn program, and how this differed from my graduated Return-To-Play program. I discuss biological phenomena such as the Autonomous Nervous System. There is opportunity to speak on mental health, as my recovery prognosis was very ambiguous with many medical professionals unsure of what degree of recovery I would be able to achieve. I also discuss my second diagnosed concussion, and the impact this had on me.

3. "You Can All Thank Kylie"

I dedicate this section to a discussion on athlete culture and the stigma and stereotypes that may be experienced by athletes suffering with a concussion. In turn, in this section I outline some key phrases that I heard during my recovery, as well as other phrases that I have heard throughout my soccer career that impacted how I understood my role within a team setting. There will be the opportunity to talk about mental health and how necessary team support is while recovering from a concussion. This section illuminates the hidden ideologies of athlete culture that have the potential to structure an athlete's own moral code and decision making around the values of the sporting culture, even outside of sporting events or experiences.

4. "Would You Like to Watch Some Fireworks?"

I dedicate this section to my long-term complications that I have lived with and learned to manage... or not manage. I centre this within a discussion of Post-Concussion Syndrome (PCS). In this section I speak about mental health and mental health complications that I have experienced years after my concussion diagnoses. Additionally, I discuss how living with PCS has affected my life outside of sports and the barriers I have in my personal and working life due to stigma and stereotypes.

5. "Tell Her to Call Me if She Needs to Go to the Hospital"

In this section I talk about life after my concussions, and my personal experiences with trying to recover outside of medical professions advice. Most importantly, I talk about the fear I hold surrounding the possibility of another concussion. I talk about psychedelic medicine and research in this field, as well as other avenues of recovery that weren't available to me at the time of my concussions.

As I stated, this is not a comprehensive list of what I speak about through my critical incidents. Rather, my main objective when sharing my experience is to make information accessible to my readers. For example, when I talk about biomedical implications of concussions, such as the autonomic nervous system, I try to make these findings easy to read and understand. Ultimately, my thesis is to act as a cautionary tale. I do not search for pity from my reader, rather, I urge my reader to navigate my experiences as though I were their daughter, or their best friend, or their teammate. I urge my readers to reflect on how they could act differently when confronted with someone who has experienced a concussion or is going through

concussion recovery. Of course, everyone's concussion experience will be different, but I aim to illuminate the darker side of recovery, the side that many are too ashamed to speak about, because chances are, more people are suffering in silence than we are aware of.

#### Section Two: Vignettes and Discussion

In this section we explore the Critical Incidents that I believe provide the opportunity to explore crucial topics of conversation surrounding concussion education and knowledge. There are five different Critical Incidents titled: Maybe You Have a Concussion, We Have to Re-Regulate Your Heart, You Can All Thank Kylie, Would You Like to Watch Some Fireworks, and Call Me if She Needs to go to the Hospital. Each Critical Incident chapter will begin with a vignette recounting the event in question. These vignettes provide the opportunity for discussion and reflection, which I interweave within the vignette to educate my reader on varying conversation topics such as concussion symptoms, recovery process, athlete culture, or alternative methods of healing.

#### Incident One: Maybe You Have a Concussion

There is a reason that soccer is renowned worldwide as "the beautiful game." It can transcend language, and communicate through emotion and passion, binding players and fans together through an unspeakable sense of community. There is no doubt to me that soccer saved my life. It gave me teammates when I wanted friends, it gave me purpose when I felt lost, it gave me drive when I felt defeated. It gave me structure, peace, happiness, and joy. Lacing up my cleats and stepping onto the field filled me with empowerment and confidence. Having a ball at my feet was comforting, the hot sun on my face was better than any medication or drug I have ever been on. It became me. Soccer worked its way into every fibre of my being, wrapping itself around my psyche and molding me into the dedicated and driven woman I am today. It taught me patience, awareness, dependability, teamwork... the list feels endless. It also introduced me to some of the greatest disappointments and heartbreaks that I have ever been exposed to, and it felt as though all the lessons I had learned were ripped from me in a split second... the second I sustained my concussion.

My first concussion doesn't even start with a story about my *first* concussion. Rather, on a hot midsummer day, we were playing an away game in London, Ontario. I was playing in my position of centre-back, and the ball had been played to me. I turned to play it back to my keeper, knowing she had plenty of time to assess the field, find a player, and make a play. I had played with this keeper for many seasons, and I read something strange in her body language. *She's going to clear that ball*, I thought in my head. In a last-ditch effort to get out of the way, I bent at the waist and turned (mostly) away from her.

I saw the flash of light before I could process the impact of the ball, which had been kicked at full force by my keeper making contact with the side of my head from about 6 feet away. It all happened within seconds that felt like minutes. I tried to open my eyes, not sure if they were closed or if I temporarily lost my sight. Panic. I'm not sure if I'm falling over? The world is spinning, but where's the ball? I'm a defender I have to find my player. *FIGURE IT OUT KYLIE*. My eyes snap open, I'm still standing bent over, catching a glimpse of my player shoot the ball at our net and hit the crossbar before going out of play. I pull myself upright trying to steady myself, my ears are ringing, the field feels crooked and uneasy. I look around at the faces of my teammates, all trying to figure out if I'm okay. Dimly, "KYLIE. KYLIE. KYLIE ARE YOU OKAY?" from the sidelines. *Oh shit, my coach*. I struggle to place my eyes on him, so I shoot a thumbs up towards his voice coming from the sideline hoping that it will suffice. I shake my head and legs and roll my head around between my shoulders and take a breath to steady myself. I finish the game, but I have no idea what had happened to me. I wouldn't know what happened to me that day until many years later.

## Concussed.

Obviously, I was concussed. This was only a tiny teaser into the crystal ball that would become the next two years of my life.

### **Sub-Concussive Impacts**

2013 was the year that changed my life. It didn't start with a major catastrophe or accident. Rather, it started with sub-concussive impacts, which are defined as a force (contact or inertial) to the brain that does *not* result in acute morbidity or symptoms associated with a concussion (Moore, Lepine, & Ellemberg, 2016). With that being said... perhaps it's more accurate to say that as of the age of ten or so, sub-concussive impacts began to alter the structure and development of my brain.

For soccer players, the act of heading the ball often results in a sub-concussive impact, and many athletes sustain more than a dozen sub-concussive impacts in a single game, and hundreds over a season (Moore, Lepine, & Ellemberg, 2016). The effects of these sub-concussive impacts can be better understood using neuroimaging such as Magnetic Resonance Imaging (MRI). It is important to note that because a concussion is a *functional* injury (it changes the way our brain's function), neuroimaging such as MRIs can only detect *structural* alterations within the brain. In that sense, neuroimaging research is consistent in showing that cumulative sub-concussive impacts will lead to a change in neural structure and function within the brain, such as alterations in the dorsolateral prefrontal cortex (DLPFC) and the primary motor area; both are essential regions for higher cognition and voluntary control of behaviour (Moore, Lepine, & Ellemberg, 2016). With that said, it makes sense that someone that has sustained a concussion may report increased impulsivity, behavioural changes (mood swings), and/or brain fog as lingering symptoms (Schwarzbold et al., 2008).

Additionally, neuroimaging shows that repetition of sub-concussive impacts also changes the integrity of white matter in the brain (Moore, Lepine, & Ellemberg, 2016). White matter is comprised of myelinated axons, and these axons are responsible for carrying information between neurons; so when white matter becomes damaged by sub-concussive impacts, or concussions, our brain's ability to carry and transfer information between neurons becomes hindered (Technology Networks, 2019). Finally, neuroimaging also shows alterations, specifically decreased functional connectivity, within the Default Mode Network (DMN) in the brain following sub-concussive impacts (Moore, Lepine, & Ellemberg, 2016).

With a sound understanding of sub-concussive impacts, we can carry on with the series of unfortunate events that led me to my first diagnosed concussion. Within a week, I sustained three substantial sub-concussive impacts: an elbow to the cheekbone and a knee to the temple during one high school soccer game, followed a couple days later by an empty alcohol bottle (26oz) being thrown at my head during my high-school's post-graduation party. None of these resulted in any concussive symptoms, but I would be remiss not to consider these as significant precursors to the injury that followed shortly after.

## The Concussion

Let me take a moment to set the scene for you. It was early April 2013. My club team had just started pre-season training. We practiced on some derelict high school soccer/football field, still torn, rutted, bare, and miserable from a cold winter and what looked to be a rough and wet former football season. It had been a gloomy and overcast day, interspersed with rain and drizzle, which carried into the evening, and as it got later, it also got colder. I was bundled in sweater and sweatpants, some of my teammates had earmuffs on, some had gloves, some were a little weirder than others and showed up in shorts and a t-shirt as though it were a balmy 27 degrees outside, rather than the 6 or 7 it probably *really* was. Regardless of the weather's effect on my teammate's style choices, the cold and dampness had the same effect on each practice ball: the ball was harder than normal, slicker than normal, and carried more weight than normal. Passing the ball in this weather left a sweet sting on your ankle bone and getting hit on any exposed skin was akin to a free session at a cheap tattoo parlor as a red imprint reminded you of your sacrifice for days to come.

We had made it to the end of practice with little concern and decided to finish off with something fun: corner kicks. We were split into our positions: defenders, strikers, midfielders, and keepers. As a centre-back defensive player, I settled into my most defended spot, standing beside my keeper on the six-yard-line. My teammate played the ball in from the corner, a perfectly weighted floater that was about to drop right into my space. I quickly shoulder check my surroundings and turn my attention back to tracking the ball... slowly, slowly, adjusting my body to properly head the ball to safety out of the defending box. Quicker than I could even process, my foot stumbles over one of the many mounds of dirt on that awful field. *No problem, it's all good*. I catch myself from falling, but I was far too late... That tiny misstep, a fraction of a second, was enough to throw off my timing, simultaneous thoughts of *ABORT MISSION* and *all good we're still good* sang through my head. It was the former... I should have listened to the former.

The ball contacted the top of my head. That soft place on your head every parent tells you to be mindful of when holding a newborn baby. That place on your head that you are taught for years and years to *never* take the ball off of. Yeah... *that* place on my head. For the first time all practice, a warmth spread through my body. It started at the top of my head and worked its way into my eyes, down my neck, my arms, my torso, down my legs and into my feet. It felt like

being shocked by an electrical current (which I have done, minorly, while trying to plug my phone into a socket at night). My head filled with a thousand thoughts at once: *What the hell was THAT? That wasn't good. That was terrible. This feels terrible. Something bad has happened. This is weird.* My eyes dart from teammate to teammate, searching for some silent social queue that my outer world was exploding the same way as my inner world, like a child searching for a parent after they get hurt in order to gauge how to react.

Nothing. No reactions from anyone.

*I'm alright, I'm standing. It'll be fine. Wow that was weird, but I'm sure I'm fine.* Isn't it interesting how quickly we ignore our instincts based on queues from other people? With those thoughts comforting me into a false sense of security, I finished practice.

### The Symptoms

My parents picked me up from practice... or at least they dropped me off, so I assume they picked me up. Honestly, I don't remember getting home that night. Maybe because of the concussion, maybe because it's a boring and rudimentary 25-minute drive back home... who knows for sure. That night the Toronto Maple Leafs played, and I sat on the couch, no different than from any other night they played, except tonight *was* different. I caught myself just staring at the TV screen, zoned out. I never knew how long I had been "checked out" for, but I pulled myself back into my body and tried to follow the puck. No success, my eyes kept getting stuck in one spot, and as soon as that happened, I was gone, completely checked out again. *I'll shower, that was a tough practice, I'm tired. I'm just tired. I'll be fine in the morning.* So... I showered. But I was not fine in the morning.

My mom dropped me off to school the next morning because I "slept in" and missed the bus... truth is, I had forgotten to set my alarm on my phone the night prior. I turned to her as we pulled up to the front doors. I had my school bag and my soccer bag, as my high school team had a game later that afternoon. "My head is killing me," I said to her. Which was true. I rarely got headaches, but there was a dull, consistent, annoying, droning pain that felt like my entire brain was compressing inwards on itself from all angles. "Take an Advil or Tylenol and hopefully you'll feel better," my mom urged. I nodded blankly and she said, "maybe you have a concussion! I love you, have a good day at school." *Maybe I have a concussion*? Puzzled, I got out of the car, and she drove off. *Maybe I have a concussion*. I dragged myself into the building and forced my way through my day. And before you all leap at my mother for not knowing better, how could she? Her daughter was playing it off as though everything was fine because her daughter knew that if her mother knew something was wrong... then oh boy. No more soccer, and that was simply unacceptable, no matter the reason.

I don't remember anything about that day until I was sitting in biology class. I was cold, my eyes were half open, and I was catching myself staring at my teacher completely checked out... again. The throbbing in my head was relentless, the stupid lights were like a thousand suns. I was exhausted. My teacher put on a video and shut the lights off. *A couple minutes to rest*, I thought to myself as I set my head down on my desk. "Kylie, head up, pay attention." My eyes lolled in my head as I pulled myself upright, my hands gripping to the far edge of my desk to leverage myself back into position. *I can't watch this video*. The movement, the flashing, the lights, the sounds... the coordination required from my poor injured brain to match images to words to meaning proved to be too much for me. So, I sat staring blankly at the chalkboard, until my high school soccer coach came to get me for the game. He stood in the doorway, beckoning to me, and I stared at him confused. *Why the hell is he here? OH! We play tonight!* I don't remember if I even packed up my stuff, but I sauntered over to him and I remember the coolness

of the blue metal doorframe against my arm as I leaned against it for support. "I think I have a concussion," I said to him.

Commence my freefall into nothingness.

# Signs and Symptoms of a Concussion

My symptoms were not unlike the symptoms that many people experience when they sustain a concussion: headache, pressure in the head, dizziness, blurred vision, sensitivity to light and sound, ringing ears, balance problems, fatigue, drowsiness (Parachute, 2020). My ego is not so big that I believe that had I known the symptoms ahead of time then I would have told someone earlier. Nope, I am conscious enough to know that the stubborn, dedicated, "invincible" teenage athlete wouldn't have told anyone until she had to, even if she knew. While that all seems courageous and admirable in the moment, the twenty-seven-year-old writing this thesis with neck and back pain, an annoying headache, and short temper; longs for an opportunity to smack some sense into that young kid, or at the very least give her five minutes with the annoyance and pain that she will be living with. I can't do that. I can educate you, my reader, in hopes that somewhere this all helps at least one young athlete and keeps them from wanting to smack their seventeen-year-old self.

With that said, the following is a list of most reported **signs** of a concussion to look for in other people. Even if **one** of the following symptoms is present, the person should seek medical advice:

- Loss of consciousness (although a loss of consciousness is *not* the only way to sustain a concussion)
- Problems with balance
- Glazed look in the eyes
- o Amnesia
- Delayed responses to questions
- Forgetting instructions, confusion about assignment or position, game, score, opponent, etc.

- Inappropriate crying (crying without appropriate context)
- Inappropriate laughter (laughing without appropriate context)
- Vomiting

Concussion Legacy Foundation, n.d.

In addition, there are common symptoms that are typically reported by the concussed

person. These symptoms fall into four major categories, somatic (physical), cognitive, sleep, and

emotional symptoms:

# 1. Somatic (Physical) Symptoms

- o Headache
- Light-headedness
- o Dizziness
- o Nausea
- o Sensitivity to light
- o Sensitivity to noise

# 2. Cognitive Symptoms

- o Difficulties with attention
- Memory problems
- o Loss of focus
- Difficulty multitasking
- Difficulty completing mental tasks

### 3. Sleep Symptoms

- Sleeping more or less than usual
- Trouble falling asleep or staying asleep

# 4. Emotional Symptoms

- o Anxiety
- $\circ$  Depression
- Panic attacks

Concussion Legacy Foundation, n.d.

These lists are important and should be engrained into the minds of athletes, their

coaches, their trainers, their family, their friends, and their teammates. Honestly, anyone can

sustain a concussion at any point in their life, so these symptoms and signs should really be

known by everyone. It is important to know that these lists are not all encompassing.

Additionally, symptom expression may take days to appear after a concussion has been

sustained, and some people may experience all of the symptoms listed while others only have a couple. Others may only have somatic symptoms, or a mixture of some from one category and some from another. This is another reason that it is important to self-monitor after sustaining impact to the head.

## **My Diagnosis**

It's as though my brain was holding on for dear life and functioning for as long as it possibly could, because the second those words left my mouth to my coach, I do not remember a single thing. My brain had its reprieve and someone else knew I was injured, someone else could help, and that was the *exact* moment my brain began its hiatus. I thought I took the bus home and told my mom about the concussion myself. Years later I would learn that this couldn't be further from the truth. Turns out my school coach called my mom immediately and she left work to come and get me. The next thing I remember is being rolled in a wheelchair through the double wide automatic opening doors to my local emergency room at the St Thomas Elgin General Hospital. I sat waiting for my turn with the triage nurse, staring at the floor. *Ugly tile*. I struggled to keep my eyes open and my head upright.

I was irrefutably *exhausted*. An exhaustion unlike anything I had ever felt before. It seeped into my bones, latched onto my muscles and my tendons. Each breath felt shallow, surely there was a cow sitting on my stomach and chest. I took a moment to thank the internal workings of my body for self-regulatory tasks because surely, I would have died if I had to consciously breathe or beat my own heart. Cellular exhaustion is the closest description of "tiredness" that I can find. It felt like every part of my body no longer had the capabilities or functionality to do what it needed to do. As though my mitochondria itself was no longer the "powerhouse of my cells," but rather the eternal resting place for all my worries. I was wheeled over to the triage

nurse, and I sat in front of her with a blank stare. She was asking me questions, but I could only muster up enough energy to force out a quiet "yes" or "no." She kept repeating things; I figure she could barely hear me. She was in a glass box talking to me through an opening in the glass wall. My eyes traced along the navy-blue metal framing that attached the glass walls together. *An office and a window*, my brain reminded me.

I was promptly wheeled behind a big orange curtain with yellow hexagons covering it, and a nurse brought over a large contraption on wheels with wires and tubes and some pokey metal stick with a screen on it. A thermometer? They strapped my arm up to take my blood pressure. I wonder how they take the temperature. Does that go in everyone's mouth? God, I hope they disinfect that thing. Is it even clean then? How many mouths has that been in?! I don't remember what my blood pressure read, but I remember seeing gurneys and stretchers lined up along the hallway walls. Suddenly, I am in another room. I'm not in the wheelchair anymore, I'm in an uncomfortable waiting-room chair, my mom is sitting next to me. I. Am. Freezing. Cold. Why are there so many lights?! My face is wet. Oh God, I'm crying. Why am I crying? Nurses keep coming in and covering me with more and more heated blankets as I lay shivering (probably closer to convulsing) on my mom's lap. I've made a makeshift cave, covering my face and eyes from the light. There's a crying baby, I'm bawling my eyes out. Am I the crying baby? The mother with the crying baby stands up and leaves her child to turn the lights out for me. A small room of 15 or 20 of us sit in the dark, my entire world feels as though it's crashing down around me. I am in the dark, and I didn't mean physically. I tried to cry quieter, for the baby.

Brief side activity, remember the **signs** of a concussion to look for in a person after they have sustained a blow to the head or body? At this point I have clearly exhibited six of the nine

signs of a concussion: balance problems, glazed eyes, amnesia, delayed (almost non-existent) responses to questions, memory disturbances, and inappropriate crying.

The lights are on, it's bright again. I'm in a different room, sitting under blankets in a hospital bed. None of the other beds have any occupants, the room belongs to me and my mom. There are two doorways at either end of the longest wall, and large windows filled the space in between the two doorways. I watch countless doctors and nurses walk past the doors and windows before my doctor finally comes to see me. I only remember parts of what he said to my mom, not to me. "She has a concussion... Give her two Tylenol/Advil every two hours to help with the swelling and pain..." *Swelling? Am I swollen?* I don't remember seeing myself in any mirrors or reflections. *I must look terrible*.

"Keep her in a dark room for the next two weeks... No phone, no TV, no lights..." TWO WEEKS? What am I supposed to do? This doesn't feel right.

"I don't have any more answers... I'll write a recommendation for physiotherapy, they'll know more..."

I can't talk. He knows I can't talk, right? Why don't my eyes work? What does he mean he doesn't have answers? Why am I here if he doesn't know? Send me to someone who can help me. Why can't I talk? I'm staring at the ground and I'm panicking. Except, in the strangest way possible. I can't talk and my body isn't letting anyone know that I can't talk. My mind and thoughts know something is wrong, yet my body has no physiological response to this indication of danger. Months later I would learn about the Autonomic Nervous System (ANS), and this strange reaction of a "calm-panic" would make much more sense to me.

I left the hospital with more questions and less energy than I went in with. *What is wrong with me? What is happening?* Sure, I had a diagnosis. I was concussed, but what the hell does

that even mean? I don't remember going home after the hospital, and the next memories blend themselves into one: a dark room. My bedroom was in the basement of my parent's home, so even on the sunniest summer days, if the lights were off my room was akin to a damp cave. I lost all spatial awareness, the walls felt far away but also as though they were closing in around me. I spent most of my time down there crying. No one had prepared me for the emotions... and let me tell you, there was so much crying. I cried because I was scared, I cried out of pain, out of misery, out of despair. I cried out of worry and loneliness. I hysterically cried through an entire (unrelated) appointment with a nurse a couple of days after my ER trip, which I think scared the nurse. My mom gave an empathetic shrug to the nurses' panicked glance: "she has a concussion." I think I cried due to boredom and impatience. My mom would come into the basement and keep me company, sitting in my bed with me, reading her book with a clip-on reading light. Two Advil every two hours was the "solution" from the ER doctor, and dutifully my mom would bring them to me. I laid in my bed, my arms outstretched upwards, and I started bawling my eyes out. My mom, frantically, "what's wrong? Is everything okay? Can I help you?"

Through tears and hiccups, "you gave me baby fingers!" I proclaimed.

"... What?" Not the answer she was expecting, this much I knew.

More tears, more inappropriate crying, my hands shaking above my face, "YOU GAVE ME YOUR BABY FINGERS!" I was pissed, pissed at my short fingers, pissed at my mom for giving me her short fingers. I was *so*... *freaking*... *angry* (remember how no one prepared me for the emotions?). Also, disclaimer: my mother and I have perfectly normal hands. Sure, a little tinier than most, but nothing to be crying about, and *certainly* nothing to be angry about. Needless to say... I was not administered anymore Advil. I cried when my dad brought me white

cheddar popcorn, which I had requested with a whispering... "dad... dad... dad..." from the basement. This launched me into a self-idolizing frenzy when I heard his footsteps coming down the stairs. What I thought was magic telepathy was nothing more than an isolated coincidence. Dad entered my room with a quizzical look on his face, probably in response to my utter disbelief and awe that I summoned him with a whisper... which affirmed my mom's decision... no more drugs for Kylie. Realistically, I think I only made it through a couple days of my two-week sentence of solitary confinement before my mom made the decision to bring me into the living room. I was clearly losing grip on my sanity.

I made my new home in the corner of the living room couch, staring blankly at the yellow/beige wall. The TV was kept off because even the sound made me nauseous, so the only noise was the ticking of the clock. As the time passed, I felt everything shutting down. I laid on the couch, focusing on my breathing as everything else slowed to a stop.

## Tick tock.

Thoughts that raced through my mind quieted down to nothingness. My eyes locked on one spot on the wall, my eyelids barely open.

#### Tick tock.

My body felt as though it were melting into the couch beneath me. By this point my neck and upper back had completely seized up and the only way I could look at people was if I turned my entire body.

### Tick tock.

I didn't have any emotions anymore. Emotions meant energy, and frankly, any energy I did have needed to be saved for eating, drinking, or using the bathroom. I slept for hours upon hours with no relief when I woke, and no more energy than I had when I had gone to sleep. I
couldn't move, my eyes could barely scan the living room, I was alone with the walls and the clock, which sounded like some sick twisted countdown to doomsday. My arms felt heavy, like pool noodles with a cement filling. The stupid invisible cow was sitting on my chest again, there was an excavation crew digging through my brain. My legs... let's just say "I hope you're comfortable where you are, Ky." But I didn't care. I was apathetic, I had succumbed to the endless wait for my appointment with my physiotherapist. *I hope they have answers*...

Tick tock.

#### **Incident Two: We Have to Re-Regulate Your Heart**

The day had come: my appointment with my physiotherapist. I don't remember how I felt that day, but I'm sure there were no emotions as they had all shut down by this point. My mom took me to the hospital where the office was. It wasn't my first time in the office, I had been there before for a couple sprained ankles. To this day I remember how to get there... In through a set of side doors on the main floor of the hospital, through two sets of sliding doors, hang a left down a hallway, go to the end, hang a right, through a hallway with exposed red brick on the one side, take a left to go through an atrium-like area with staircases, follow that past a tiny food court and knick-knack stores that sold purses and sweaters. Then, there you had it: Woodland Physiotherapy<sup>\*</sup>. My body made that journey a couple times a week for almost two years through my concussion rehabilitation, who knows how many other times for my ankles.

I was escorted to an area in the back corner of the physiotherapist office, where I sat and waited on one of the beds, staring at the floor. The bed was kind of like a bed in a doctor's office, no annoying parchment paper on it though. This area of the room was separated from the rest of it by thick beige sheets that hung from the ceiling to the floor. I don't remember much from that appointment, but I could never forget Liam<sup>\*</sup>. Dr. Liam was my assigned physiotherapist. A bald, average sized dude with glasses. He had bright cheery eyes and a big smile. He radiated a calm and reassuring energy and told me a little bit about himself. A licensed chiropractor, acupuncturist, and a specialist in concussions, specifically athlete concussions... specifically female athlete concussions. He mostly treated women and girls that played rugby but had also worked with soccer players. I sat and listened to him talk for a while realizing the guy had more

<sup>\*</sup> Name changed for confidentiality.

letters *after* his name than I did in my name. I couldn't recognize it in the moment, but I had been paired with the perfect fit.

I don't remember much from the initial consultation. I was given a test to complete. The Sport Concussion Assessment Tool (SCAT-2 at the time, the number refers to the edition) is a standardized test utilized to evaluate athletes 10 and older for a concussion. Basically, the SCAT is a symptom evaluation sheet that lists common symptoms of a concussion and asks the athlete to score each symptom on a scale of 0-6, with 0 being "none" to 6 qualifying as "severe." It lists 22 symptoms: headache, "pressure in head," neck pain, nausea or vomiting, dizziness, blurred vision, balance problems, sensitivity to light, sensitivity to noise, feeling slowed down, feeling like "in a fog," "don't feel right," difficulty concentrating, difficulty remembering, fatigue or low energy, confusion, drowsiness, more emotional, trouble falling asleep, irritability, sadness, and nervous or anxious. The SCAT test we currently use in 2022 is the fifth edition, SCAT-5, which lists the same symptoms. After completing the SCAT-2 Liam walked me through some assessment exercises.

Walk in a straight line. I tried.

Walk backwards. I tried.

Stand on one leg... okay, now the other. I tried.

Close your eyes and stand on one leg... and then the other. I tried. This one I failed, miserably.

Sit down, please follow my pen with your eyes. Side to side. I tried.

Continue to follow the pen. Far away... close up. I tried.

I must have failed the eye tests because Liam sent me home with two eye exercises that day. Print offs on standard printer paper, one with lines of random letters where I was to read the first letter in the line and the last letter in the line. The other sheet had numbers in circles, scattered randomly across the page and I had to let my eyes work their way around the sheet, finding the numbers in order. I remember explicitly being told "don't memorize anything, let your eyes work." As though memorization was something I was going to be excelling at...

Ocular dysfunction after a concussion is a relatively common symptom, with 69% of people with a concussion reporting eye movement complication (Gunasekaran et al., 2019). This is because over half of our brain is dedicated to vision and eye movement control (Gunasekaran et al., 2019). The most commonly reported oculomotor dysfunctions after a concussion are: loss of vision, blurred vision, double vision, reading difficulties, photophobia (sensitivity to light), headaches with visual tasks, and difficulty tracking fast objects (Gunasekaran et al., 2019). Liam completed his ocular diagnosis with the pen exercises which allowed him to assess the degree of ocular dysfunction that I was experiencing as the result of my concussion. My main problem was classified as a "saccadic dysfunction" which means that I had difficulty moving my eyes rapidly between objects, which occurs in up to 30% of concussion patients (Gunasekaran et al., 2019). The saccadic pathway in our brains involves "multiple cortical, cerebellar, and brainstem control areas... making it highly vulnerable to damage following mTBI" (Gunasekaran et al., 2019, p. 533).

I left that appointment with a couple different things that day. A formal diagnosis of a concussion, my eye exercises, an exemption from school for a couple weeks, and a lot of questions. My most burning question: when am I going to get better? Unfortunately, due to the unpredictable nature of concussions no one was able to give me an answer.

I need to be completely honest with you, I don't remember a lot of my initial appointments with Liam. I remember filling out the SCAT form and being annoyed every single

time with the "don't feel right" question. Of course, I don't feel right, my brain isn't working properly. Liam couldn't answer a lot of my questions about my progression, he would tell me to be patient and not get caught up in rushing to the result. He reminded me to focus on current tiny steps towards rehabilitation, one of those tiny steps was my Return-to-Learn program that he started for me after I had been away from school for almost a month.

#### **Return to Learn Programs**

The purpose of Return to Learn (RTL) programs is to ensure that the injured student has had an appropriate time *away* from stimulation, which allows the brain time to begin the healing process after sustaining a concussion. In Ontario, we have a consistent 6-step RTL program that has been developed by Parachute Canada (2019). Parachute Canada (2019) recommends a universal 24-48 hour "resting phase," which is characterized by *no* school, *no* physical activity, and *no* sports to allow the student an opportunity for physical and cognitive rest. Depending on the severity of the individual's symptoms, light cognitive stimulation (board games, crafts, light reading) may be permitted during the resting phase *if it does not exacerbate or induce concussion symptoms*. This resting phase is intended to be completed within a home setting until symptoms begin to improve, or the individual has rested for a maximum of 48 hours.

The remaining 6 stages outlined by Parachute Canada (2019) are outlined in the chart below (Table 1), with Stages 1-2 being completed at home, and Stages 3a to 4b being completed within a school setting. Parachute Canada (2019) indicates that each stage is *at least* 24 hours long, and you are only to move to the next stage if you can complete the current stage without new or worsening symptoms. If your symptoms re-appear, you are to return to the previous stage for at least 24 hours, and if symptoms worsen or don't improve, to seek medical assistance or contact your doctor.

| Stage 1<br>"Light Cognitive<br>Activity"•Easy reading<br>••School<br>•If you can tolerate<br>30 minutes of<br>cognitive activity at<br>home without<br>exacerbating<br>symptoms.••Easy reading<br>••School<br>•If you can tolerate<br>30 minutes of<br>cognitive activity at<br>home without<br>exacerbating<br>symptoms.••Easy reading<br>••School<br>•If you can tolerate<br>cognitive activity at<br>home without<br>exacerbating<br>symptoms.••Easy reading<br>•••Sports•••Easy reading<br>•••Sports•••Eimited screen<br>time••If you can tolerate••School-type•SchoolIf you can tolerate |
|---|
| Stage 1• Easy reading• SchoolIf you can tolerate"Light Cognitive<br>Activity"• Limited TV• Work30 minutes of• Drawing<br>• Limited peer<br>contact• Physical<br>exertioncognitive activity at• Limited peer<br>contact• Sportsexacerbating• Limited screen<br>time• SchoolIf you can tolerate   |
| "Light Cognitive<br>Activity"oLimited TV<br>ooWork<br>o30 minutes of<br>cognitive activity at<br>home without<br>exacerbating<br>symptoms.Activity"oDrawing<br>ooPhysical<br>exertion<br>ocognitive activity at<br>home withoutoLimited peer<br>contact<br>timeoSports<br>symptoms.exacerbating<br>symptoms.Stage 2oSchool-typeoSchoolIf you can tolerate   |
| Activity"oDrawingoPhysicalcognitive activity atoLimited peerexertionhome withoutcontactoSportsexacerbatingoLimited screensymptoms.timeoSchool-typeoStage 2oSchool-typeo   |
| o       Limited peer       exertion       home without         contact       o       Sports       exacerbating         o       Limited screen       symptoms.       symptoms.         time       o       School-type       o       School       If you can tolerate   |
| contact     o     Sports     exacerbating       o     Limited screen     symptoms.       time     o     School-type     o   |
| o     Limited screen     symptoms.       time     o     School-type     o       Stage 2     o     School-type     o     School  |
| time       Stage 2     O     School-type     O     School     If you can tolerate   |
| Stage 2 • School-type • School If you can tolerate  |
| G J1 J  |
| <b>"School-Type</b> work in 30 min. attendance 60 minutes of  |
| Work/LightchunksoWorkcognitive activity in  |
| Physical Activity"•Light physical•Physical2-3 chunks per day  |
| activity exertion without   |
| • Some peer • Sports exacerbating   |
| contact symptoms.   |
| Stage 3aoUp to 120oMusic or gymIf you can tolerate  |
| "Part-Time Schoolminutes ofclass/physicalschool work up to  |
| Light Load"cognitiveexertion120 mins. a day for   |
| activity in o Tests/exams 1-2 days per week   |
| chunks o Homework without   |
| • Half-days at • Heavy exacerbating   |
| school, 1-2 physical loads symptoms.  |
| times/week (ie,   |
| • Some light backpacks)   |
| physical activity o Sports  |
| Stage 3b • Limited testing • Gym If you can tolerate  |
| "Part-Time School o School work for class/physical school work 4-5  |
| Moderate Load" 4-5 hours/day exertion hours/day in chunks   |
| • Homework up to • Standardized for 2-4 days/week   |
| 30 mins./day tests/exams without  |
| • 3-5 days of • Sports exacerbating   |
| school/week symptoms.   |
| • Slow decrease   |
|   |
| accommodations       Stage 4a       Q       Nearly normal       Q       Gym       If you can talarata   |
| "Nearly Normal cognitive class/physical full time coordenie   |
| Workload? activities evertion workloads without   |
| • Pouting school of Standardized exact being  |
| work as tosta/avama symptoma  |
| tolerated - Full  |
| O Homework up to participation  |
| 60 mins /day in sports  |

# Table 1: Return to Learn Schedule

|                         | 0           | Minimal<br>learning<br>accommodations   |   |   |   |
|-------------------------|-------------|---|---|---|---|
| Stage 4b<br>"Full Time" | 0<br>0<br>0 | Normal<br>cognitive<br>activities<br>Routine<br>schoolwork<br>Full curriculum<br>load<br>No<br>accommodations | 0 | Full<br>participation<br>in sports/gym<br>class until<br>medically<br>cleared | Next stages are<br>Stages 5-6 of the<br><i>Return to Sport</i><br><i>Strategy (see Table</i><br>2, pg. 74). |

My RTL program followed Parachute Canada's guidelines and Liam promptly set me up to begin attending school on a part-time schedule. I was attending either morning, or afternoon classes, alternating the days that I attended each class. For example, I would attend morning classes (8:35am-11:45am) on Monday, Wednesday, and Friday, and then attend afternoon classes (12:15pm-2:45pm) on Tuesday and Thursday and switch those days each week. While on this part-time schedule, I was not to be participating in any tests, assignments, homework, or exams. Essentially, Liam explained that this routine was to acclimate my brain and body to the reality of in-class learning: bright lights, sounds, movement, socializing, etc., while also slowly coaxing my cognitive abilities back to where they were before my concussion. This all seemed straightforward to me, I was to report *any* symptoms to Liam, and if the symptoms became too much while at school, I was to return home. I felt confident in our plan, and Liam equipped me with a note to give to my teachers and principal which explained the terms of my RTL program, as well as an exemption from upcoming exams as I returned to school in the couple weeks prior to final exams. The next week, he sent me to school.

You know when you return home after a holiday, and you can smell your house? You're either pleasantly surprised, or you're faced with the realization of "that's what we smell like?!"

The first couple steps back into my high school felt like that, everything was novel and peculiar. My friends rushed to me, quickly giving me the nickname "Conky Ky." They helped me navigate and make sure I had everything I needed to attend my classes, and overall, my afternoon went smoothly, until I made it to biology class and presented my teacher with my RTL note. I stood beside him as he read over my note with a dull expression on his face, he looked up from the note and said "so… you won't be doing any class work or writing the exam?" His abruptness caught me off guard, and I slowly shook my head. He rolled his eyes, "you may as well hand in your textbook and don't bother coming back to my class," he put my note down, and turned away from me to indicate the conversation was over. I stood there for a couple moments, slowly turned, and walked out of the classroom doors. Liam didn't prepare me for that, and I didn't process the depth of my teacher's reaction until many years later.

## Normalcy and Ableism

I have spent a long time reliving and replaying certain aspects of my concussion recovery, and that moment standing in my biology class is one of those moments that I was unable to understand for a very long time. How is the *biology* teacher, who should have the most comprehensive idea of what happens inside our bodies, the *only* teacher that gave me a hard time with my exemptions? It wasn't until I got deep into my undergraduate studies in Disability Studies at King's University that I was introduced to concepts of "normalcy" and "ableism" within a Critical Disability Studies (CDS) framework.

I'm sure many of my readers could articulate what "normal" means to them – maybe it's a standard, or an average? Maybe it's not standing out in a crowd or having the ability to do things like other people do. "Normal" may not even be apparent to many people, until it is in direct contrast to the "abnormal," which is what you and I will be unpacking over the next couple

of pages. To truly understand the concept of normalcy within a CDS framework and apply it to our modern understanding and use of the word, we *must* be aware of the historicity of the word normal, and how the word normal manifested itself as a divisive tool within our societies. According to Merriam-Webster (2022) our modern definition of the word "normal" is "conforming to a type, standard, or regular pattern: characterized by that which is considered usual, typical, or routine." However, this was not the definition of "normal" prior to 1840, where previously, the word meant "perpendicular" and the word "normal" came from the root word of "norm" which was used to describe a carpenter's square – or a 90-degree angle (Davis, 2017). Words such as "normality" and "normalcy" as we currently understand them did not appear in the English language until 1849 and 1857, respectively (Davis, 2017).

Of course, there still needed to be a way of conceptualizing the human body prior to 1840. To do that, the concept of the "ideal" dates from the seventeenth century and was exemplified through devotions to the gods such as the nude Venus, for example (Davis, 2017). In essence, the word "ideal" was conceptualized to glorify the perfection of the gods, and this divine standard of "ideal" was not attainable by humans. Even in art form, "ideal" was unachievable. When the Greek artist Zeuxis tried to paint Aphrodite, the goddess of love, he used many beautiful models within Crotona and took an idyllic feature from each model in an attempt to construct the "ideal" that was Aphrodite (Davis, 2017). Clearly, the concept of "ideal" was unattainable within individualized members of the community, as the ideal could only be emulated by a divine (godly) body.

Umm, Kylie? Then how did we get to our current understanding of the word "normal?" Oh, I'm glad you asked. To understand our current verbiage of "normal," we must turn to statistics, which seeks to understand phenomena such as the "norm" or the "average" (Davis, 2017). A French statistician, Adolphe Quetelet (1796-1847) took the "law of error," which was used at the time by astronomers to plot star points and extrapolated the basic premises within the law of error and applied it to the human body and mind to create the "average" man, or *l'homme moyen* (Davis, 2017). Quetelet maintained that the average was determined using all human attributes within a given community or country, and with that thought, unlike the divine concept of "ideal," which was knowingly unattainable by humans, the "norm" or "average" became standard for the majority of people to strive for and conform to. Human traits and differences became standardized and could be thought of like a bell-curve, with average traits being plotted within the peak of the bell-curve and outliers were plotted amongst the downwards slope of the peak, or outside the slope entirely.

In the 1800s, the concept of a "norm" takes a dark turn, and many statisticians merged their rhetoric with eugenics in an attempt to remove outliers to "improve" the human race, this created a symbiotic relationship between statistics and eugenics (Davis, 2017). Eugenics became obsessed with eliminating these aforementioned outliers, which included traits such as "feeblemindedness, the deaf, the blind, the physically defective, and so on" (Davis, 2017, p. 4). Eugenicists such as Sir Francis Galton believed that inward (identity) defectiveness was identical to outward (bodily) defectiveness, which creates a binary system between a defective outside (body) equating to a defective inside (identity), and vice versa. The connection between inward and outward defects was unwavering and unchangeable.

Using this logic, many people with "undesirable" traits (that eugenicists believed were to be "weaned out" of the next generation) were lumped together, so people with disabilities were

lumped together with criminals, and the poor. Karl Pearson, a leader of the eugenicist movement described the "unfit" as: "the habitual criminal, the professional tramp, the tuberculous, the insane, the mentally defective, the alcoholic, the diseased from birth or from excess" (Davis, 2017, p. 6). Although not outright, it is these subtle concepts that still permeate many of our medical, political, and educational systems in place today. I believe this is the basis of justice systems based on punishment rather than rehabilitation, political entities that sterilized those that were deemed "unfit," education systems that assess children by IQ tests, and medical systems that identify health as a physical state of perfection. As a collective, we may forget that the atrocities committed by Hitler in the second world war were adopted and implemented based on the theories of British and American eugenicists.

One of the ways that the understanding of normalcy is perpetuated today is through a CDS concept termed "ableism." Ableism is defined as "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as perfect, species-typical, and therefore essential and fully human. Disability... is cast as a diminished state of being human" (Runswick-Cole & Goodley, 2014, p. 126). Before we dive into ableism, it is important that we link the fundamental aspects of ableism, such as the "particular kind of self and body that is projected as *perfect, species-typical and therefore essential and fully human*" to the discourse created by *normalcy*. The key indicator that links this definition of ableism to normalcy is *species-typical*, which is another way of saying "average," a concept idolized by the statisticians and eugenicists of the past. The connection between "species-typical" and "essential and fully human" creates a dangerous relationship between disability and humanness where the disabled, or people that do not conform to "perfect" and "species-typical," are deemed as non-essential and less than human. Once we deem people non-

essential or less than human, it is not long before we end up teetering on the precipice of a slippery slope that often justifies or enables the questioning of humanness through disruptive policies, dehumanizing experiments, and harmful discourses that perpetuate the ideology of "less-than."

It is this relationship between typicality and humanness that has laid the groundwork for some of the often-unconscious rhetoric that we engage with in our daily lives. If we deem someone, or a group of people, to be less than human (even on an unconscious level), we are less likely to bridge the gap that enables those groups to successfully integrate into our society in a meaningful way. This predicament often exacerbates itself when we are dealing with differences that are not outwardly apparent, or do not have any "outward markers" of difference. These differences are known as "invisible disabilities," and are often questioned more than visible disabilities. We are largely a society that holds true the idea of "if I can see it, I can believe it," which leaves many people with invisible disabilities cast to the sidelines, myself as one of them. For example, it was no problem for my classmate who broke both of his arms in grade 9 to get someone to write out his notes for him, or for the teacher to print out their notes for the student... but I was told not to come back to a class because of my inability to preform my full duties as a student. The concepts we have explored may help illuminate why I left that biology classroom that day confused and questioning the belongingness I held as a student within that community. The very essence of "worthiness" was tied to my ability to execute my "average" duties as a student, and once I deviated from the "norm," I was asked not to return.

My experience that day didn't only involve a discussion with my biology teacher, but with my other teachers as well, who were all happy to see me up and moving again. My final stop before heading home was to see my principal, which in hindsight should have been my first

stop but... live and learn. I walked in, hesitantly, and sat with him for a while slowly discussing the degree of my injury. He watched me closely, and I remember feeling anxious and recalling the interaction with my biology teacher just prior to this. But my principal smiled, leaned back in his chair and said, "I'm really happy you were able to get this accommodation. I had a couple concussions back in my day and no one took them seriously." He reassured me that my grades would be frozen at the current marks and not to worry about exams. To my principal, maybe this just felt like a natural human response to what I had told him, but I can assure you that to this day I still feel an immense amount of gratitude towards him.

# **Return to Play**

As an athlete, returning to soccer was high on my priority list. It's probably no shock to hear that returning to soccer was higher on that priority list than returning to school, and I impatiently fought my way through the necessary steps to get back onto the field. My return to school program went smoothly, and truthfully, I was expecting that my Return to Play schedule would follow just as quickly and smoothly. Unfortunately, that expectation was quickly shattered, and I began my year long journey to have a ball at my feet again.

My body was not cooperating in the way I had hoped it would. With the Return to Learn program stimulating my cognition, Liam focused extensively on restoring any mobility I had lost due to the injury. First matter at hand: my eyes and my neck. Liam and I worked through various treatments, I tried acupuncture, but sitting still for any duration of time with needles sticking out of me was repulsive. We tried chiropractic adjustments, which I endured for a couple of adjustments, but the adjustments were painful, not relieving. I was adamant no more adjustments, which Liam agreed to – not before bribing me with cupcakes on my birthday to squeeze in "one last adjustment." Liam knew me well and I obliged, but that ended up being my

most uncomfortable and painful adjustment so far. I felt defeated, but Liam never gave up: hot towels and massage therapy, coming right up! Week by week the mobility in my neck began to reappear, I could move my head and my eyes, so Liam and I began my Return to Sport program.

Like their RTL program, Parachute Canada (2018) created a Return to Sport (RTS) program that consists of 6 stages. The 6 stages are explained in the chart (Table 2) below and run seamlessly off the RTL chart on pages 66 - 67 (Table 1). The guidelines are similar to those in the RTL program: each stage is *a minimum of* 24 hours long; you can move onto the next stage when activities can be done without new or worsening symptoms. If symptoms worsen, return to the previous stage until your symptoms subside again.

| Stage Name  | Okay if tolerated  | Not Okay  |
|---|--|---|
| Stage 1<br>"Symptom-Limiting<br>Activities"   | <ul> <li>Light cognitive and physical<br/>activity</li> <li>Daily activities, moving around<br/>house, simple chores</li> </ul>  |   |
| Stage 2<br>"Light Aerobic<br>Activity"  | <ul> <li>Light exercise for 10-15 minutes</li> <li>Stationary cycling, walking</li> </ul>  | <ul><li>Resistance training</li><li>Heavy lifting</li></ul>   |
| Stage 3<br>"Individual Sport-<br>Specific Exercise,<br>No Contact"  | <ul> <li>Sport-specific exercise for 20-30 minutes</li> <li>Skating, running, throwing</li> </ul>  | <ul> <li>Resistance training</li> <li>Body contact</li> <li>Jarring motions such<br/>as: high speed stops,<br/>hitting a ball with a bat</li> </ul> |
| Stage 4<br>"Begin Training<br>Drills, No Contact"   | <ul> <li>More complex drills</li> <li>Passing drills</li> <li>Progressive resistance training</li> </ul>   | <ul> <li>Body contact</li> <li>Impact activities such<br/>as: checking, heading<br/>the ball</li> </ul>   |
| Stage 5<br>"Full Contact<br>Practice Following<br>Clearance by a<br>Doctor"<br>Stage 6<br>"Return to Sport" | <ul> <li>Normal practice activities</li> <li>Full contact</li> <li>Impact activities allowed</li> <li>Full game play or competition following Doctor's clearance*</li> </ul> | <ul> <li>Engaging in<br/>competitive game play.</li> </ul>  |

Table 2: Return to Play Schedule

\*If symptoms return after medical clearance, you should be re-assessed by your doctor

My RTS program was not smooth sailing. In fact, I bounced around from one stage to another for a couple months. We started with light aerobic exercise; I walked on a treadmill for 10 minutes every session. The heart monitor I was hooked up to beeped quietly in the background as I walked on the treadmill, staring out the floor to ceiling glass window that looked outside to a seating area of the hospital. A big wooden gazebo often distracted me as birds and squirrels ran around it. I remember asking Liam why he needed me hooked up to a heart monitor, and the answer took me by surprise: "we have to re-regulate your heart." I gave him a trademark teenage girl look that basically said, "what the hell are you talking about?" He was a patient man and directed my attention to the screen of the monitor. My heart rate bounced around erratically, I was walking but my heart rate was sitting around 120 beats per minute (BPM)... it would fall over the next couple of readings, as low as 58, before abruptly spiking back up into the 100s again. For reference, my resting heart rate sat around 80BPM before my concussion, and a normal resting heart rate for adults ranges between 60-100BPM. My snotty teenage derision quickly turned to panic, and the heart monitor reflected it. Hard to lie when you're hooked up to something that tattles on you. Liam then explained to me a thing in our bodies called the autonomic nervous system (ANS).

## The Autonomic Nervous System (ANS)

Our nervous system's main purpose is to gather and process information, create responses to stimuli, and coordinate the inner workings of our bodies, from our individual cells to the coordination of our major organs. Our nervous systems are broken up into two subcategories: the central nervous system and the peripheral nervous system. Our central nervous system comprises of the brain and the spinal cord and is responsible for interpreting incoming sensory information (Wade et al., 2015). Our peripheral nervous system is comprised of the

nervous system *outside* of the central nervous system and handles the input and output of our central nervous system through *sensory* nerves which carry information from the skin, muscles, and other sense organs; and *motor* nerves, which transmit information from the central nervous system to our muscles, glands, and other internal organs (Wade et al., 2015). Motor nerves also control the secretion of hormones (Wade et al., 2015). The peripheral nervous system is also categorized into two sub-categories: your *somatic* nervous system, and your *autonomic* nervous system. Your somatic nervous system is responsible for sensory information, while "the autonomic nervous system regulates the functioning of blood vessels, glands, and internal organs such as the bladder, stomach, and heart" (Wade et al., 2015, pg. 111).

The autonomic nervous system is again broken down to two main parts: the *sympathetic* nervous system and the *parasympathetic* nervous system. The sympathetic nervous system works like an accelerator that mobilizes the body for activity and energy output, this is also the part of our nervous systems that control our "fight, flight or freeze" response in times of high stress or danger. In contrast, the parasympathetic nervous system works like a brake intended to slow things down to conserve and store energy, the parasympathetic system is what regulates your body after it has experienced the uptake of energy through the sympathetic system. Think of the last high intensity moment you were in: the racing of your heart, the blush to your cheeks, the shaking in your hands, and the feeling of being ready to "burst" is all a product of your sympathetic nervous system priming you for energy output. After the moment has passed, your heart rate slows, your breathing returns to normal, the shaking may subside, and the feeling of being ready to "burst" will slowly dissipate as your parasympathetic nervous system takes over to still the body in an attempt to reach homeostasis and regulation. When these parts of the autonomic nervous system are out of regulation due to an injury such as a concussion, then the

body's innate ability to regulate itself as effectively as it did prior to the injury is hindered and may not function as efficiently. When I walked on the treadmill and my heartrate spiked and fell without any rhyme or reason, this was my body demonstrating an "exercise intolerance" which La Fountaine (2018) states, "may be clinically demonstrated as an abnormal heartrate or blood pressure response compared to controls for a given workload... should be considered as a symptom of CV-ANS (cardiovascular autonomic nervous system) dysfunction following concussion" (p. 156).

This exercise intolerance made my RTS plan difficult and frustrating. I couldn't move to the next stage in my program until my heartrate stayed steady through walking. After a couple weeks, my heartrate stayed steady, and I was able to progress to Stage 3: Individual Sport-Specific Exercise. I moved from walking on the treadmill to jogging. I began balance exercises on a Bosu ball and balance board. Liam tied up his running shoes and started passing exercises a couple weeks later. I was feeling optimistic when I was in rehab with him, it was a tiny slice of normal. I was laughing, jogging, and finally... finally... had a ball at my feet again. My time at home was spent the same way, I spent hours alone doing ball touches in an empty space in my room that probably measured 3ft by 4ft. Every morning I woke up I wanted to do more than I did the day before. A couple weeks before I was cleared to Return to Sport, I showed up to my physiotherapy appointment talking Liam's ear off for the entire hour we spent together. Liam smirked and turned to my mother and said, "wow, I think I liked it better when you couldn't talk." My mouth fell open and instead of anger or frustration, I laughed. Liam laughed and my mom agreed with him, "the house was definitely quieter for a long time..."

The end of my summer season was creeping up quick. I was registered with my team but was unable to play due to the concussion. I had hinted at Liam that I was eager to get back out

there, but the timing had to be right... and finally the time had come. After months and months, Liam cleared me to start practicing. No contact, no heading the ball, no scrimmaging just ball movement drills. I didn't even care what I wasn't allowed to do, I missed my team, I was ready to get out there and pretend to be a pylon for all I cared. The first practice back was clumsy and awkward, but I was overjoyed. My coach welcomed me back with open arms, my teammates were happy to see me. The grass seemed greener; the sky seemed bluer. The breeze and the smell of the dirt invigorated me. It was bliss. I was back. Kylie was back.

For a short while, anyways.

You see, the problem with a concussion is that you want to ensure you're completely healed before you go back to playing, or you are susceptible to sustaining another concussion easier than those who don't have a history of concussions. Even though I was only at one "diagnosed" concussion, as I said earlier, I was likely sitting around 4 or 5 at this point when I returned to play. The summer season ended, and I didn't play a single competitive game, I didn't play in my winter season, as Liam wasn't ready to clear me yet. So, over the winter we trained and rehabilitated twice a month, and he cleared me to play full contact for the upcoming summer season. My rehabilitation with Liam was "finished."

My "opening season" was with a new team moving from the Under-18 (U-18) league to the women's league, so we had to start at the lowest division, Third Division, and work our way up the divisions by finishing at the top of the table at the end of the season. Most of my games I stood at half kicking at the grass, my team was lightyears better than the other teams (having just moved up from a competitive teenage league) and my involvement wasn't needed very often as a centre-back. It didn't matter, I was happy to be here, and I was happy for about a month and a half of playing. My mom sat on the sidelines yelling at me whenever it looked like I was going to head a ball, and for the most part, I heeded to her worry and left well enough alone when a ball came buzzing towards my head. Until I didn't. The other team had a throw in, and I was marking my player. The ball was thrown, and it was coming right at my head. *It's a throw in, there's no power behind it, you can head this one.* Afterall, it was no different than the headers we do in practice.

I headed the ball. My mom yelled.

I was fine! Everything was cool. No buzzing, no ringing in my ears, I felt okay. We won the game; I went home and all was normal. My parents went to bed, I did too. But around 2am I was woken by a head-splitting, nauseating, repulsive migraine. The worst head pain I have ever felt – this coming from the girl who just rehabilitated from a year-long concussion! I slumped out of bed and dragged myself up the wooden basement stairs to the main floor. The pain intensifying to a degree I didn't even know was possible, as though every fibre inside my head was trying to escape through whatever hole it could find: my pores, my eyes, my ears, my nose, my hair follicles, my mouth, my *teeth*... the pressure was unbelievable, I was certain that my head was going to explode. I was crying and clutching to the sides of the toilet. I had never thrown up from pain before, but there's a first time for everything.

My dad came down the stairs. The funny thing about parents is that they almost sense when something is wrong with their children, and before I knew, he had scooped me up and put me on the couch with a warm cloth over my eyes. My father slept on the couch sitting up that night, my head on his lap, trying to keep me as calm as possible. When morning came, my mom booked me in to see Liam again...

No. No. No. <u>NO</u>.

Dread.

Disappointment.

I can't do this again.

But around we go again. I hate this stupid merry-go-round.

*Let me off.* 

That day I walked that stupid walk... In through a set of side doors on the main floor of the hospital, through two sets of sliding doors, hang a left down a hallway, go to the end, hang a right, through a hallway with exposed red brick on the one side, take a left to go through an atrium-like area with staircases, follow that past a tiny food court and knick-knack stores that sold purses and sweaters. Then, there you had it... again: Woodland Physiotherapy. I hung my head in shame as my mom talked to the receptionist. *Liam is going to kill me. Liam is going to kill me. Liam is going ... to kill me.* Mom came back to sit with me, "Liam doesn't work here anymore... they're setting you up with someone new."

Dread.

You see, while I was terrified of hearing what Liam was going to say... I was grateful to be seeing him again. Hearing that I was going to be under the care of someone else spiked my anxiety, and rightfully so. The details of the next 4 months of my life with this physiotherapist are barely worth recounting. She was not a concussion specialist, so I received a standardized RTS program. She was not a chiropractor, or an acupuncturist. My treatment was hot towels on my neck and electroshock therapy. Once a week I was hooked up to a big machine with two leads that attached to my earlobes, this machine generated an electric current that moved through my head to facilitate blood flow in the region, "aiding in a quicker recovery." It was far from the recovery process that I needed, especially so close to being cleared from my other concussion... Being cleared to play again didn't bring the same joy or happiness that it did the first time around. Yes, don't get me wrong I was happy. But I was scared. I wasn't sure if I would be able to head the ball again, I wasn't sure if I could go into a hard tackle, I wasn't sure if I could do it. My support system quickly dissipated as my friends all went to university and I had to stay to do a semester of fifth year in high school to bring up my marks from the semester I had lost due to the concussion. I had a new team, new teammates, save a couple who came with me. This was the first time I started to feel lost and confused coming out of my recovery. My memory was slipping, I felt confused as to who I was, my identity was so closely wrapped into soccer that if I couldn't play soccer *who was I*?

#### Who was I?

People don't warn you about the dangers of having your identity wrapped up into one thing. My "fact about me" was always that I've played soccer since I was 6 years old. If I didn't have that then what did I have? I didn't have the answer to that question, and that identity crisis led me to make dangerous choices time and time again. I didn't seek a second opinion or even further treatment after my second concussion because of a carefully worded warning from my family doctor: "if you sustain a third concussion, I'm not sure that I can clear you to play soccer again." Upon reflection, and re-reading of this thesis, I make one crucial edit to this paragraph: this statement from my Doctor, while I'm sure was well-intentioned, did not carry a cautionaryconcerned-weight to it, rather I understood it as a threat. "You come back here again, and I will take away the thing you love." What does this approach do to an athlete whose identity is the very thing being removed? Well, I never went to that Doctor for another concussion ever again, even though I sustained more after this warning. One misconception that many non-athletes have is that athletes play the game we play simply because we *like* the game we play. However, it's not that simple. Yes, we obviously love the game we play, but we *are* the game we play. We *are* our pre-game warm-ups. We *are* our game-day routines and superstitions. We *are* our chants and our pump-up songs. Our teammates are our families, not just "teammates." What do you do when you feel like you're at risk of losing pieces of yourself and pieces of your family? You do whatever you can to hold onto them. And foolishly, that's what I did because that is genuinely what it felt like: losing a part of myself. I believe this is partly due to a routine, but mostly this is due to athlete culture, which seems hearty and wholesome at a glance, but truthfully, athlete culture is a dark and insidious place to find yourself... especially if you don't know where you are.

#### Incident Three: You Can All Thank Kylie

Almost any conversation I have had with a fellow athlete makes its way to the topic of "gnarliest sports injury." Injuries ranging from purple and green bruises, to sprained ankles, torn muscles and ligaments, and broken bones. I've witnessed my fair share of injuries that weren't my own as well. I've heard the pop and ensuing scream from my teammate from across a soccer field when her ACL tore. I was a couple feet away from my teammate when she fell going into a challenge, immediately breaking her wrist. I pulled my shinpad out of my sock to use as a plate for her wet-noodle arm. I watched helplessly, tangled in my own player, as my goalie took two or three full-force kicks to the head as she tried to cover up a ball. She ended up done for the season with a concussion, a fractured cheek bone, and extensive nerve damage in her face. The next season (of course she came back to play) she told me that when she brushes her teeth, she can feel it in her eye. We had a game put on hold after the opponent's player lost a challenge and couldn't feel her legs. We waited on the sidelines for the ambulance, which had to drive out onto the field to tend to her. An opposing teams' goalie had to be pulled after she tried to stop one of my teammate's shots. The shot was too hard, and the goalie was making a reflex save... the force of the shot and the position of her arm resulted in her forearm snapping back on itself and breaking.

I always thought myself to be lucky. My injuries confined themselves to sprains and bruises, aside from my big toe on my right foot which broke during a playoff game while I was blocking a shot. I knew it was broken, but I didn't see my doctor until many months later when I realized I couldn't bend it. He sighed and shook his head at me when I went to see him and said, "you waited too long. You broke it, only way I can fix it is to break it and reset it." The thought turned my stomach. I said no thanks, only to accidentally catch my toe on a shag carpet one day

a couple weeks later and snap it myself. I've had multiple sprained ankles. Two deep bone bruises that kept me off my feet for a week or two at a time. I've had turf burn engulf the entirety of my knee, which had to be wrapped and bandaged to keep it from becoming infected. I have deep scars to remind me of the sweet bite of cleat studs on my right ankle from blocking a shot. My hands have been stepped on, my eyes have been elbowed, my shins have been bruised and bloody, my feet once had 27 blisters on them after a weekend tournament. Yes, twenty-seven. Of course, as you all know: two diagnosed concussions that had me miss a year and a half of soccer. And yet... perhaps the most interesting thing is that other athletes have similar stories. But I've never had my arm implode inwards on itself, snapped my leg, or needed surgery to fix any of my injuries. My concussions impacted my life in a different way: slowed speech, difficulty concentrating, daily headaches, but certainly no cast to sign or crutches to play with, just a dutiful internal reminder that I function much differently now.

If you, as my reader, are not an athlete you may be thinking "why would you still play?" or, "why would anyone ever put themselves into a situation like that?!" And that is what we are going to be unpacking throughout this chapter. What makes an athlete play through pain or injuries? Why do all athletes know the phrase "sacrifice your body!" so well? Is it a lack of information? Is it improper policies or procedures? We have many questions to unpack, so let's begin!

## Disclosing concussive injuries: Is it a lack of knowledge?

My first thought, prior to starting research for this thesis, was that there simply was not enough concussion education circulating within our young athletes to make them aware of the risks and dangers of concussions. Growing up in sport, I never had to do a pre-season concussion seminar. There was never a team meeting or chat from my coach. We weren't given any

handouts or information sheets, so logically I assumed that the concussion education sector is *greatly lacking*. I had a very rudimentary understanding of what a concussion was and what some of the symptoms were. Mostly, I understood a concussion as only occurring during a loss of consciousness, which we now know is not the truth. To understand what the barriers to reporting concussions are, I turned to a couple articles that asked that very question: what stops an estimated 20%-60% of athletes from reporting their concussions (Chrisman et al. 2013, p. 331)?

Clark & Stanfill (2019) completed a systematic review of barriers and facilitators for concussion reporting behaviour among student athletes by reviewing the current literature on the subject. Using key terms such as "concussion," "mild traumatic brain injury," "athlete," "self-report," "reporting," and/or "reporting behaviours," the researchers then decoded the relevant research articles and dissected the reasons that were cited for not reporting concussive symptoms. These key terms resulted in 878 articles, of which 24 met the criteria to be included in their review: they were published in English, preformed on human subjects, included a specific reason why the athlete did not disclose their injury, and the athletes in question were of high school or collegiate age. The 24 articles that were used in the review by Clark & Stanfill (2019) reported the following reasons that athletes gave for not reporting their symptoms: may lose current and future play time (16/24), did not feel injury was serious (15/24), do not want to let the team down (14/24), not sure it was a concussion (13/24), pressure (to not report) from teammates/coaches/parents/fans (9/24), and did not want to be seen as weak by coaches or teammates/embarrassing to report (7/24) (p. 304).

Outside of those top commonalities, other reasons for not reporting included: coaches' attitudes (being upset, angry), not wanting to risk future athletic opportunities/scholarships, not

wanting to upset/worry family, or the concussion happening during an important time of the season (playoffs or important games). Two of the top barriers *may* indicate the lack of concussion education in athletes: "did not feel injury was serious" and "not sure it was a concussion." The study does make clear that a myriad of factors may discourage an athlete from disclosing a concussive injury. Many of the reasons that were given can be applied to almost *any* injury, but the hidden nature of a concussion makes it easier for an athlete to play through a concussion in comparison to a broken bone or sprained ligament. So, we know some *reasons why* an athlete may not disclose a concussion, so let's turn to a study by Chrisman et al. (2013) to understand whether athletes understand concussive symptoms.

Chrisman et al. (2013) conducted a qualitative study with high school students to determine whether these athletes understood concussion symptoms, and if so, what barriers stop athletes from reporting their injuries. This study was comprised of 50 participants from three football, two boys' soccer teams, and four girls' soccer teams. There was varied socioeconomic representation of athletes from public and private schools, as well as one club team comprised of athletes from three different schools. The researchers decided to approach this subject *qualitatively* for the same reasons that I'm using a qualitative approach on my thesis: "qualitative methods allowed us to explore the richness of subjects' experience without predetermined hypothesis" (Chrisman et al., 2013, p. 331). These athletes were split into 9 groups, and each group was asked by the researchers to describe concussion symptoms.

*Every group* (9/9) mentioned: impaired mental status (loss of consciousness, difficulty concentrating, or seeming "out of it"). The majority (8/9) of groups were able to identify ocular impairments (dilated pupils, glassy eyes, eyes stuck, loss of vision, squinting), physical pain (headaches/throbbing, sensitivity to light/sound, tinnitus), as well as balance problems (loss of

balance, stumbling, dizziness). From there, 6/9 groups listed memory disturbances and nausea/vomiting, 2/9 groups mentioned motor control loss such as slurred words or inabilities to stand, and only 1/9 groups mentioned emotional and mood disturbances. Chrisman et al. (2013) state that "most groups also mentioned consequences of concussions, particularly the possibility of permanent injury or death" (p. 332).

Researchers then gave the groups hypothetical game-time situations where concussion symptoms would be incurred (without explicitly stating that it was a concussive situation) and asked the athletes to discuss whether they would continue to play within the hypothetical situation, or if they would stop playing and disclose their symptoms. 6/9 groups said they would keep playing while 3/9 groups said they would take a little break but would probably go back to play. Even after displaying an understanding of concussion symptoms (up to permanent injury or death) *no group* stated they would stop playing while experiencing the symptoms from the hypothetical situation (Chrisman et al., 2013). The researchers then coded several different themes that the athletes gave as reasons to why they would continue to play while experiencing concussion symptoms.

First, Chrisman et al. (2013) found that athletes *want to keep playing*. Athletes stated they loved their sport and may be pulled from the game if they disclosed their symptoms. A female soccer player stated: "... you just want to keep playing. You're always going to think it's something little and it will go away... like, can't you just *play through it* or something?" (Chrisman et al., 2013, p. 332, italics added).

Second, researchers found that it's hard for athletes to tell when they're injured due to the non-specific nature of concussion symptoms. A football player stated: "I'd just think I'm not drinking enough water or something... or like a migraine..." and a female soccer player said,

"[t]he first thing I think is 'I just got hit so something is wrong,' but then, "nothing is wrong I'm just *imagining it.* I'm fine. I'll keep playing" (Chrisman et al., 2013, p. 333, italics added).

Third, Chrisman et al., (2013) discovered that athletes believe you're *supposed to play injured*. The responses of the athletes display a deep-seeded warrior ethos that is embedded into an athlete culture, which we will explore in depth in the next section. For example, athletes stated:

- *Football player*: "It seems like a little punk thing to leave the game for... like 'ooh the lights hurt my eyes."
- Football player: "Got to look like a solider."
- o *Football player*: "You won't want to look like a baby."
- *Female soccer player*: "I HATE telling ANY coach that I'm tired or want to come out. It's embarrassing like, "Oh coach... I need a break."
- *Female soccer player*: "… I'd probably be like, 'I'm going to keep playing because I need to suck it up and show that I'm not a wuss."

- Chrisman et al., 2013, p. 333.

Fourth, athletes don't want to let their team down. Researchers found that athletes identified themselves very strongly with their team and want their teams to do well. These athletes felt as though it would be their fault, or their team would blame them, if their team lost a game because of an athlete being pulled due to concussion symptoms. Interestingly enough, I have a story to share about this very sentiment, which I will share at the beginning of our discussion on athlete culture.

The biggest differentiating factor that either discouraged or encouraged an athletes' disclosure of a concussion injury is the coach due to his or her reaction to the injury (Chrisman et al., 2013). A players' relationship with their coach needs to be built on trust, dependability, and respect. When these components of a relationship are missing, the athlete may feel uncomfortable disclosing an injury for fear of being ridiculed, centred out, losing playing time, or simply not believed. For example, when dealing with a coach that was unsupportive of their

athletes, those athletes stated: "the coaches call you bad words if you come out... they say, 'when you're hurt, come out,' but *they don't mean it*. If you say anything they just call you a wuss and tell you you're overreacting and that you can *play through it*..." (Football player, Chrisman et al., 2013, p. 333, italics added). A female soccer player said, "my coach doesn't want us to play when injured, but I kind of feel pressured because they will say... 'Well, are you sure, do you have to sit out, can you not *push through it*?" (Chrisman et al., 2013, p. 333, italics added).

This discrepancy between what a coach *says* they will do, and what a coach *actually* does when faced with a concussive injury quickly erodes athlete-coach trust, not only for the athlete *experiencing* the concussion, but for the entire team, as they see how the coach reacts when their teammate requires assistance. Let's compare those negative coach experiences with two athletes that have supportive coaches. A football player stated, "they always give us a little practice and we have to spend a whole day just learning concussions… learning how to hit right and stuff. This is why earlier we were saying that if we feel dizzy, we are supposed to tell them…" and a female soccer player said, "I think that from previous incidents that I've known what our coach expects of us… I'd tell him right away because I know what he wants us to do with injuries, because I've been out for a long time" (Chrisman et al., 2013, p. 333). These healthy athlete-coach relationships insulate the athlete with support and trust which facilitates a safer environment for the entire team.

Concussion education programs have been passed into law in Ontario after the passing of Rowan Stringer, a seventeen-year-old rugby player who died from second impact syndrome, a rare but deadly complication which causes swelling of the brain after sustaining too many head injuries within a short period of time. After her passing in 2013, Ontario passed "Rowan's Law"

in 2018, which requires all officials, coaches, and team trainers, as well as athletes under the age of 26 and parents with athletes under the age of 18, review the government approved concussion awareness resources every year before engaging in sports. This law came into effect on July 1, 2019. I have not participated in organized sport since August 2019, so I do not know if the club I played for is implementing their concussion education properly.

In March of 2022 I was given the opportunity to speak to a group of Grade 7/8 students about concussions. I started my discussion by asking about concussion symptoms, much to my surprise about 15 hands shot straight up into the air. They rang off concussion symptoms such as: dizziness, blurred vision, problems sleeping, irritability, headaches, nausea, vomiting, eye impairments, balance issues, loss of consciousness, not feeling right, difficulty concentrating, and memory loss. Their teacher, a dear friend of mine from university, had conducted a lesson on concussion education the week prior. She has heard my story and said that she wanted to make sure her students were well equipped to protect themselves and make the proper decisions for their future. Concussion education does not simply take place on the side of a field or within sport settings, rather this education should be conducted within all spaces such as schools and workspaces as well. This ensures that concussion education is reaching student athletes, but also reaching *all students* who may experience a concussion outside of sport. In addition, I believe everyone, especially those in "carer" positions such as teachers, coaches, personal support workers, nurses, early childhood educators, etc., should be equipped with the knowledge of the common signs of a concussion to ensure the proper care and due diligence is done when a suspected concussive injury is incurred.

Between the articles explored, we can come to understand that many athletes understand concussion symptoms. Other articles state similar findings, such as a study conducted by

Delaney et al. (2015), who found out of 469 athletes, 92 had suffered a concussion in the past year and 72 of these 92 athletes did not disclose their concussion symptoms to anyone. Delaney et al. (2015) found that many athletes understood concussion symptomology, however, the researchers stated that *more* concussion education is needed on the importance of the possible long-term complications of a concussion as well as the seriousness of the injury. So, we lay at cross-roads, where many athletes understand concussion symptoms, perhaps less understanding of long-term complications, but still continue to make decisions to *not* disclose concussive injuries. I believe we must turn to athlete culture to answer the *why* of the question: why do athletes not disclose their concussions even if they know the symptoms?

## Athlete Culture

Only a couple days after my initial concussion diagnosis in 2013, my school soccer team was competing in a tournament qualifier game. The "tournament" in question was OFSAA – Ontario Federation of School Athletic Association. Basically, OFSAA is like the World Cup of high school athletics in Ontario. It was a big game and I wanted to show up to support my team. My mom agreed to let me go so long as I wore sunglasses and a hat to protect my eyes from the sun and promised to tell her if I started to have any worsening symptoms. I donned a large fluffy blanket, as my body was still having difficulty regulating my temperature, and I went to the game. I sat next to my teammates and anxiously watched, it was an even match between the two teams, which resulted in a 1-1 tie going into the final 10 minutes of the game. The other team had the ball in our 18-yard box, a couple shots ended up blocked by the legs of my teammates, it seemed as though all 11 of us were standing in front of our net, throwing our bodies haphazardly in front of shots in a desperation attempt to clear our box. *Clear the ball, clear the ball, someone clear the ball.* Typically, those large clearances were brought to the team by the tiny legs of

yours truly (me)... but without me on the field the clearance never came, and the other team was able to breach our defensive line. The ball trickled over our goal line and into the back of our net, 2-1. I hung my head, and the heads of others followed.

The game ended 2-1. We lost our qualifier game, and therefore, our season was over. Our coach huddled us all in a circle to give us a post-game speech. We were sitting on the grass, some of my teammates were stretching, most of them were sitting in an angry silence, absentmindedly braiding blades of grass together. I was still bundled in my blanket, my sunglassed eyes all they could see of me. Our coach stood at the helm of the circle and paced with his arms crossed as we all waited to see what he would say. "Well..." he started, "I guess you can all thank Kylie for that." I looked around at the faces of my teammates to try and figure out who the hell this Kylie chick was that he was blaming, until my brain connected the dots, and I was filled with ice cold dread. *He means you.* 

At the time, I internalized that statement heavily. I mean yeah, as a centre back defender, I ran my teams 18-yard box tightly, and odds are that I would have cleared that scramble play that put the other team ahead by a goal. As a 16-year-old girl, I was full of shame. I let my team down. They lost because of me. I should have been playing. He's right, it's all my fault. On a deep unconscious level, he validated the nonsensical belief I already held within myself, and a sentiment many injured athletes can likely relate to: if I don't play, then we won't win. I tightened the blanket around myself and sat quietly, staring at the blades of grass in front of me. Our coach carried on, but I had retreated into the safety of my own mind. Whatever he had to say next was meaningless to me. He dismissed us, no one said anything to me. I was exhausted, mentally and emotionally. I was embarrassed and ashamed. I was angry and disappointed. *Mom, home*, the only two words that steered me towards the blackers and away from the soccer field. I briefly explored the article by Nixon (1992) in my literature review chapter, and even though the article is now two decades old, I find that Nixon is concise and accurate with his analysis on sport culture. Before we get to the meat of his article, we must understand a couple of key terms that Nixon defines. Before this study, Nixon (1991) had conducted a content analysis of major sports magazine articles and found recurrent themes about risk, pain and injury. Nixon (1992) states that the themes formed a coherent cultural belief system which was termed the "culture of risk." To apply the culture of risk to his current work on why athletes play through pain, Nixon uses a social network analysis. Nixon (1992) defines a social network as "a set of relations among persons, positions, roles or social units... a social network analysis of sport focuses on webs of interaction that directly or indirectly link members of social networks in a particular sport or sports-related setting" (p. 128). Nixon uses the word *sportsnet* to describe these webs of interaction within sports. These *sportsnets* can be compared to "athletic subcultures" which Nixon (1992) defines as "groups or categories of people in sport who share a distinctive culture" (p. 128).

In this article, Nixon uses a social network analysis on *sportsnets* to focus on who interacts with whom, how they interact, what kinds of messages, resources, and influences flow through this interaction; as well as how these forms of interactions influence the people or social units within the *sportsnet*. Then, Nixon (1992) focuses on athletic subcultures to understand meaning-making, symbols, clothing, values, beliefs, norms, attitudes, identities, language, rituals, and ways of acting that connect people within a subculture to one another and differentiates them from other members of society or other areas of sport (p. 128). In essence, a *sportsnet* emphasizes patterns and structures of interaction that link people together, while an athletic subculture highlights shared culture and identity groups of people within sport. The

intertwining of these two concepts is important, because we can understand the shared "culture of risk" in *sportsnets* through athletic subculture. This culture of risk leads to what Nixon (1992) terms a "rationalization of risk" for athletes, which often occurs in a "risk transfer" (p. 128). This risk transfer takes the risk off high-level members of the *sportsnet*, and places it onto the athletes. These athletes are not in a position of power in their *sportsnet*, and therefore have limited autonomy to decide their *own* boundaries for acceptable risk taking. This creates a *sportsnet* with insulated and protected high-level members who (because the risk lies on the athletes) are less likely to be questioned on the legitimacy and safety of sport roles and practices (Nixon, 1992). Nixon calls this the "institutional rationalization process" (p. 129).

A prime example of this institutional rationalization process is how the NHL responded to a lawsuit launched against them on behalf of Steve Montador, a former player who died at the age of 35 after his 14-year long career in the NHL. Upon Montador's death, he was diagnosed with a degenerative brain condition *chronic traumatic encephalopathy* (CTE). The NHL's response to the lawsuit argued that Montador's head injuries were "caused, in whole or in part, by [Montador's] own lack of care and fault, and/or by pre-existing conditions; and/or the lack of due care of others for whom the NHL has no responsibility or control" (Official W5, 2020). In one quick statement, the NHL places blame on Montador for his own death, and the high-level members of the *sportsnet* are insulated from outside scrutiny. However, I would argue that the NHL failed Montador on multiple occasions. Montador sustained 19 concussions within his hockey career, 11 of which were in the NHL, 4 of which were sustained *within a 12-week period*. It was the NHL's *own lack of due care* that perpetuated an unsaid message that the head traumas being sustained by Montador were not concerning. If the head traumas were viewed as concerning by the NHL, Montador *never* would have been cleared for play 4 times in 12 weeks.

These silent messages are all directly related to a *sportsnet* that is rationalizing the risk of pain and injury in sport and are indicative of the values and norms held by the *sportsnet*.

A lot of the values and norms of a *sportsnet* can be discovered by analyzing the messages that permeate *sportsnet* communication networks. A study of cultural scripts, or common phrases, that athletes are faced with when they reach out for support when experiencing pain or injury show us that the messages that athletes receive are conducive to upholding and maintaining the culture of risk and rationalize risk taking for athletes. Such scripts may sound like phrases from the Chrisman et al. (2013) study such as: "can't you just *play through it* or something? (p. 332)," "[i]f you say anything [the coaches] just call you a wuss and tell you you're overreacting and that you can *play through it*... (p. 333)," or "[w]ell are you sure, do you have to sit out, can you not *push through it*? (p. 333)." The general statement made by Chrisman et al. (2013) that athletes believe they must play injured or play through pain or injuries is a direct reflection of the culture of risk in sport.

Unfortunately, athletes often find themselves on the receiving-end of these messages, which means they have little hierarchical authority within the *sportsnet* to challenge these messages. Due to this hierarchy, these messages such as "play through the pain" or "sacrifice your body" seem *very* "supportive," however, they actually perpetuate the culture of risk. So as long as replacement athletes exist to fill the void within the *sportsnet*, then "the network can afford to continue encouraging risk and *supporting* injured or at-risk athletes with messages and other resources that encourage their future risk-taking" (Nixon, 1992, p. 130). The closed nature of a *sportsnet* system also ensures that the athlete continually turns back to people within the *sportsnet* (and therefore, the *sportsnets* ideologies). An athlete that reaches outside of the *sportsnet* for support may be met with sympathy from outsiders, but little connection if said

outsider does not understand the athletes' interest in participating in an activity that places them at risk. Rather than risk that alienation, the athlete turns back to their *sportsnet* for support, where the beliefs about risk, pain, and injury within the culture of risk engrain themselves within the athletes' *identity*.

However, *sportsnets* are not just comprised of athletes and upper-level management. There are a plethora of roles within a *sportsnet* that contribute to the culture of risk in sport. Take coaches for example. We know from the Chrisman et al. (2013) study that the relationship between coaches and athletes is a major deciding factor between whether an athlete discloses their injury or chooses not to. Athletes from the Chrisman et al. (2013) study displayed a correlation between a coach's openness and positive support to a more open and forthcoming athlete when it comes to injuries or concussion symptoms. Additionally, there was a correlation displayed between a coach's negativity and harshness to a shut off and closed off athlete, where the athlete does not feel comfortable or able to disclose their symptoms or injuries to said coach (Chrisman et al., 2013). The latter may not be a conscious decision on behalf of the coaches, in fact, Nixon conducted a study prior to the one we are analyzing now, where he discovered that many coaches do not choose to exploit their players in this manner, but rather, their "support" has an exploitative effect due to the hierarchy between player and coach (Nixon, 1992b).

You can probably relate. If your boss asks you to perform a work duty, I'm sure you would complete that task. Especially if you believe that you either must complete the task as part of your job duties, or if you believe that the completion of this task is tied to your employment with your company. This is likely due to the hierarchy that is at play, your boss is higher on the hierarchy scale than you within that company, and therefore you, as the employee, may find little autonomy or support if you were to question your bosses' directives. This rhetoric may also be
utilized by parents when raising their children: "I'm the adult and you do as I say." Again, this is the power of a hierarchy. Athletes may find themselves in situations similar to this when it comes to a coach cajoling them to continue to play, especially if an athlete believes that they are required to play through pain and injury, or if that athlete believes they must play injured or lose their spot on the team, similar to the young athletes in the Chrisman et al. (2013) study.

If we turn back to the findings within the Nixon (1992b) study, Nixon claims that coaches often do not consciously exploit their athletes, rather the messages that the coach relays to the athlete are a product of the culture of risk within sport. The hierarchy within sport does not stop after the coach, but the coach is part of the hierarchy as well, and therefore, the coach will often circulate the deep cultural norms and values of the *sportsnet*. We know that these cultural norms within the *sportsnet* encourage risk as a necessary component of participating within the *sportsnet*, therefore coaches often exploit, encourage, or push athletes in ways that will normalize and glorify risk-taking, simply by repeating cultural scripts such as: sacrifice your body, play through the pain, no risk no reward, it's all part of the game, etc. etc...

Around age 15, I had a coach with this mindset. He cared deeply for us, but he often utilized cultural sport norms to condition the team. "Sacrifice your body" was drilled into the minds of my defensive linemates and myself. I can recall a practice session after a particularly pitiful and poorly defended loss. My coach at the time lined all the defenders up on the 6-yard line, our goalie stood behind us, and the midfielders and strikers lined up outside the 18-yard line. As the defenders, we were instructed to get used to "sacrificing our bodies" to protect our goalie and the net, and with that, the midfielders and strikers took turns shooting the ball on net, and every ball that made it past our defensive line equaled another round of "suicide" sprints for the defenders to run. My coach was a kind, funny, and caring coach... but he subscribed to the

athlete culture mindset and instilled in us a hierarchy of importance where the outcome of a game was higher than the importance of keeping our bodies and minds safe. I wasn't playing professional sports, heck, I wasn't even playing semi-professional sports. This is the danger of athletic culture, especially as it becomes engrained into the minds of our young generations. Our safety becomes secondary to the goals and achievements of a larger population, our bodily autonomy comes secondary to the values of our cultures... neither of which are conducive to rearing a responsible, mindful, and conscious athlete and young adult.

In fact, Nixon (1992) references an article done by Adler & Adler in 1991, where they note that young athletes often fall into a term called "role engulfment" (Nixon, 1992, p. 132). This role engulfment happens when the athletic role, and all that comes with it, encroaches itself on other aspects of the person's life. This person then begins to act as an athlete outside of sports settings, and is discouraged from acting in a way that would bring negative attention to their teammates, their club, their coaches, their university, etc. This athletic role begins to engulf other aspects of the person. Interests and abilities outside of athletics such as academics, non-athlete friends, hobbies like art, reading, music, etc., are abandoned in favour of a full embodiment, and identity, of being "an athlete" (Nixon, 1992).

If we place this "role engulfment" within the larger context of a *sportsnet*, this role engulfment ensures that athletes seek support and encouragement from others *within* their *sportsnet*... essentially insulating the athlete with mutually reinforcing ideologies about pain and injuries being a natural part of sport. This very concept of "role engulfment" becomes increasingly dangerous when we look at what happens to an athlete when they do suffer a "nonplayable injury" such as a concussion and are *unable* to return to their sport. I believe that full role engulfment creates the perfect storm for mental health complications and identity crises, which we will explore in our next chapter.

Like any good researcher, Nixon (1992) provides his reader with structural remedies that can be incorporated in sportsnets to lessen the impact of cultural scripts and norms like those we have explored through this chapter. Two of the recommendations are directly tied to an athlete's medical diagnosis. First, medical decisions should be done by independent networks where the positions of doctors and trainers are not connected to coaches, teams, directors, or any other members of a *sportsnet* that may indirectly or directly sacrifice the athletes' welfare for the "good of the team" (Nixon, 1992). Second, for athletes who are experiencing consistent nondisabling problems or disabling injuries, they must attain a medical opinion from a medical practitioner outside of the *sportsnet*, and this medical opinion *cannot* be vetoed or ignored by members within the sportsnet. (Nixon, 1992). Finally, Nixon (1992) recommends that there is a loosening of *sportsnet* ties. This will ideally stave off, or prevent altogether, the creation of "role engulfment." The loosening of *sportsnet* ties could be done in many ways, such as phasing out athlete-athlete roommates in college/university levels, encouraging participation in non-athlete activities, or an emphasis on academic achievements and commitment (Nixon, 1992). Going to these lengths hardly seems difficult when we are considering the welfare of our young athletes and encouraging interaction with those outside of a *sportsnet* will help a young athlete question athletic culture norms surrounding the risk and rationalization of pain and injury.

The study conducted by Chrisman et al., (2013), as well as the studies we explored by Nixon (1991, 1992, 1992b) share many commonalities with another study that we will explore by Hughes & Coakley (1991). The goal of the study conducted by Hughes & Coakley in 1991 was to analyze athlete behaviour, particularly how athletes are socialized within an athlete

culture. The researchers term the norms and values engrained by sport cultures as "sport ethic" which encompasses four commonly held beliefs which I will list below, and attempt to connect to how these beliefs may create an environment or identity that is hesitant or reluctant to disclose a concussive injury:

1. Being an athlete involves making sacrifices for *The Game*.

This standard encompasses the belief that athletes must love The Game above any other interest or hobby, and adherence to this belief means sacrificing other interests to exclusively commit to their sport and their role as an athlete. Like Adler & Adler's (1991) term of "role engulfment" where an individual's role as an athlete gradually encroaches itself upon other aspects of the individual's life until ultimately the individual fully identifies as an athlete without external interests. While this may not seem like a terrible thing, because dedication to one's craft seems to be a commonly accepted and valued trait within sporting culture *and* mainstream culture, I believe that the abandonment of outside interests can exacerbate complicated recovery trajectories where the Return to Play may not be a possibility and lead to a feeling of loss or grief over the death of being an athlete.

I fell fully into role engulfment, I abandoned my other interests such as writing, art, music, or reading to fully adhere and commit myself to my athletic identity. My identity as an athlete had become my master status, and when that identity was put at risk, I was overwhelmed with anxiety and panic over the possibility of never being an athlete again. Even once I "overcame" that possibility and returned to play, I had to do so with stricter rules, such as not heading the ball. Can I fully be accepted into a sporting culture when I am not adhering to the basic premises of the culture? Outwardly, yeah... I was. I am conscious enough to know that I may have been an anomaly in the manner with which my teammates accepted and supported me.

My team was very understanding that I was not going to head the ball any longer – yet the internal struggle that I had with the voices in my own head (internalized sport culture values) sought to make me feel guilty that I could no longer sacrifice myself in the manner that I was used to. I felt like a lesser teammate, or that I wasn't "doing my part" because I placed my own interests (safety) above the good of the team and The Game. I caught a glimpse of the added guilt and pressure that come with a team that places The Game above individual autonomy over health. "You can all thank Kylie." Ugh.

## 2. Being an athlete involves striving for distinction.

Any athlete you meet will probably hold some value of overachievement. Whether it's arguing about who has the best 6-pack, who scored the best goal, who made the best play, or who had the worst injury. As Hughes & Coakley (1991) found, "true athletes seek to improve, to get better, to come closer to perfection... real athletes are a special group dedicated to climbing the pyramid, reaching for the top, pushing limits, excelling, and exceeding or dominating others" (p. 309). Hughes & Coakley (1991) make the key distinction that athletes striving for distinction often do so to validate one's own identity as an athlete, rather than for external praise or rewards. Athletes are constantly looking for new ways to improve upon themselves to become better athletes, which you would think would mean taking care of one's body and taking the appropriate time to rest and recuperate to ensure that one is staying at peak physical fitness after pushing one's limits. I would argue, however, that this understanding of improvement, like proper rest and recuperation, is one presented by mainstream sources, like media, of what the mainstream media wants outsiders to believe about athletes. But athletes are bombarded with silent messaging that upholds dangerous sporting culture values like pain and risk as normal. For example, in preparation for the 1992 Olympic Games held in Barcelona, the U.S. Olympic

Training Centre had "No Pain, No Spain" emblazoned upon the shirts their athletes wore (Hughes & Coakley, 1991, p. 310). That's right folks, if you're not in pain, you don't get to achieve the highest honours that the sporting world has to offer you. I feel as though the connection to injury non-disclosure is clear here, but if not... an athlete believes they must be in pain to be successful or be rewarded. Injuries, *especially invisible or playable injuries*, get pushed to the side because being in pain is normal! Just another day at work.

3. Being an athlete involves accepting risks and playing through pain.

Well. It's right there in the title. An athlete "does not give in to pressure, pain, or fear... voluntarily accepting the possibility of injury is a sign of courage and dedication among athletes" (Hughes & Coakley, 1991, p. 309). I believe this ideology has been engrained into sporting culture from the very birth of sport itself. In fact, this warrior-like ethos is deeply rooted in sport and is reflected in Greek legends like that of Pheidippides, a Greek soldier who collapsed and died after running a long distance to Athens to deliver news from the battle of Marathon (Bloom & Caron, 2018). Marathon... well, now you can be a marathon runner! Named after a soldier who died from exhaustion but was idolized due to his commitment to complete his task. Additionally, neatly wrapped up under this third belief is the value of "moral courage," where athletes are expected to sustain high performance levels while under extreme social or psychological pressure. This understanding by Hughes & Coakley (1991) mirrors a finding in Todd et al.'s (2018) study where mental toughness is a defining feature of whether you will be a successful athlete, or unsuccessful. Athletes must never back down from challenges, and must remain level-headed, "cool and composed," when faced with fears or challenges (Hughes & Coakley, 1991). I believe this need to be cool and composed coupled with the acknowledgement that mental weakness equals unsuccess may create a personality that is hesitant to confide in

people when they are experiencing adversity or fear, both emotions that may be very salient during an ambiguous concussion recovery process, especially because we know that anxiety and depression are commonly experienced throughout the concussion recovery process.

4. Being an athlete involves refusing to accept limits in the pursuit of possibilities.

Hughes & Coakley (1991) describe this perfectly, so I won't even try to paraphrase: "[a]n athlete does not accept a situation without trying to change it, overcome it, turn the scales... sport is a sphere of life in which anything is possible, *if* a person lives by the sport ethic... external limits are not recognized as valid" (p. 310). WOW. Yeah, tell me about it. So, in order to live by the sport ethic, the person will adhere to these 4 premises we just explored, which ultimately means that you need to make sacrifices, you need to set yourself apart from others, pain is normal and expected, and you had better persevere! How does that intersect with concussion recovery? Likely this means that athletes will try to return to play so they will be viewed as successful even if they're still in pain because external limits do not matter!

Hughes & Coakley (1991) determined that athletes display "positive deviance" to the sport ethic; stating that positive deviance occurs when the athlete "positively adheres" to the conditions (sport ethic) created by the sporting culture, including potentially dangerous norms and ideologies, at a rate much higher than mainstream society which "deviates" them from mainstream culture.

For example, as a soccer player, I hit my head (head the ball) much more frequently than the majority of people that are not soccer players. What is seen as "positive" within my sporting culture (the act of hitting a projectile with my head), is seen as "deviant" to those outside of the sporting culture... sorry, but I don't see many people on the street stopping things with their head, in fact, they usually try to move their head out of the way. This positive deviance will find

the athlete being accepted into the sporting culture, so long as the athlete overconforms to the sport ethic, while simultaneously alienating the athlete from mainstream culture. This is similar to Nixon's (1992) findings, where the athlete will continually turn to their *sportsnet* for support, even when the *sportsnet* has dangerous self-sacrificial ideologies, rather than risking alienation from outsiders who cannot understand the athlete's decision to participate in self-endangering activities.

Hughes & Coakley (1991) not only set out to term positive deviance, but also to understand how and why athletes overconform to dangerous ideologies that place the athlete into realms of risk or danger. The researchers found that:

"[U]ncritical acceptance of and commitment to" repetitive signalling of certain behaviours such as "[being] dedicated, to set goals, to persevere until goals are achieved, to define adversity as a challenge, and to be willing to make sacrifices and subjugate other experiences generally associated with "growing up" all for the sake of their quest to become all they can be in sport" (Hughes & Coakley, 1991, p. 308).

Being surrounded by these values may result in these behaviours becoming engrained into the athlete's identity, and the athlete will use the behaviours as the standards to evaluate themselves and others as "real athletes." In other words, adherence and over-conformity to the social standards set in place by the sport ethic will make you a real athlete. Athletes do not find their behaviour to be "deviant" or "out of place" because an athlete that is conforming to sport ethic is simply affirming their identity as athletes. Therefore, in order to reconfirm their identity as an athlete they will likely behave with positive deviance and possibly unknowingly "do harmful things to themselves and perhaps others while motivated by a sense of duty and honour" (Hughes & Coakley, 1991, p. 311).

After reading through the various studies, I obviously had to sit and reflect on where these ideologies took a foothold in my own personal experience. I mulled over this reflection for a while and discovered that there wasn't a single incident or experience that suddenly "created" these values in me. Now, I don't like to place blame on the coaches, but coaches have a massive role in how they shape their athletes and how their athletes will behave, as we read in the Chrisman et al. (2013). Athletes receive most of their cultural scripts and values from their coaches, as the coach is there to guide the athlete and help them grow into the best possible version of themselves. Hughes & Coakley (1991) posit that one quality of a great coach is to keep their athletes in a state of perpetual adolescence, even once the athlete matures past adolescence. Why adolescence? Although not explicitly stated by Hughes & Coakley, I believe it is because adolescence is when we are most desperate for approval and identity confirmation from our peers. If this is to be the motivator, then yes, keeping athletes in a state of constantly seeking approval from their peer group will ensure the athlete constantly places themselves into situations where they can "prove their worthiness" to the group and gain acceptance. These situations can mean playing through pain or injuries to not be seen as weak, or non-disclosure of injuries so that their spot on the team (and therefore their belongingness to said team) is not jeopardized (Chrisman et al., 2013., Hughes & Coakley, 1991., Clark & Stanfill, 2019).

To summarize, there is a plethora of different factors that may prevent an athlete from disclosing their concussive injuries. Clark & Stanfill (2019) has shown that there are many different reasons that athletes say influence their decision such as loss of spot on the team, not knowing the severity of the injury, or wanting to continue to play. This study alludes to minor flaws within the concussion education sector where athletes are unaware of the severity of concussions, or are unaware of concussive symptoms, but largely corroborates the findings of

Nixon (1992) and Hughes & Coakley (1991) who both believe that socialization from a sporting culture massively impacts how an athlete prioritizes different decisions in their life. Oftentimes, an athlete will choose to continue to play with injuries because the athlete has been socialized to believe that playing with injuries is a necessary component of being a "real athlete," and keeping silent about the injury or, in more serious situations, outright denial of being injured is the only way that athletes believe they can be recognized as a "real athlete" and therefore, affirm their identity as an athlete.

I can reflect and understand that I deeply believed that injuries were just a part of the game. To come home with a black eye after *practice* was not an unusual event. To sprain an ankle, break a toe, tear an ACL, or even sustain a concussion were all expected as part of the game. In fact, you're even warned about these possibilities from very young childhood. Although I did not find a study on this, and this is purely my own speculation, but I believe that with the key formative years in childhood being between the ages of birth to seven years old, integration into sporting culture in this age span may mean that the values and ideologies of said sporting culture can actually be seeded much deeper into the individual's psyche than someone introduced into sport at a later age. Again, pure speculation but I would be interested to understand this on a deeper level. Ultimately, the only way that sporting culture is going to change is to change the sporting culture. Implementing proper concussion education and fostering a team where the athletes understand that while injuries will likely occur, the coach and other club members care about the athlete's wellbeing over the wellbeing of the team. Afterall, the athlete will go on to live a life outside of sport, while the club is a perpetuality. If the club's wellbeing deteriorates, there is chance to recuperate through means of faculty changes, new coaches, new training programs, or different athletes. However, if an athlete's wellbeing

deteriorates, the chance of healing and recuperating isn't as simple as changing a coach. It could be weeks, to months, to years, to permanently altering and seeking different ways of living, and alternate modalities of healing to restore oneself to a pre-injured state of being. Otherwise, we must find a way of living that coincides with the consequences of the actions we performed for a fleeting opportunity to glorify ourselves, our sport, and our teams.

#### **Incident Four: Would You Like to Watch Some Fireworks?**

July 1<sup>st</sup>, 2013. Canada Day. I was approximately 3 months into my concussion recovery. I was taking things day by day, trying to navigate the turbulent storm of emotions, headaches, exhaustion, and confusion. A couple years prior, my family and a couple other houses on our street began a tradition of pooling money and buying a bunch of fireworks to set off in the field across the road from all our houses. This year was no different, aside from my concussion, so instead of watching the fireworks, I cozied up in my bedroom in the basement. My dog, Piper, has always been terrified of fireworks so she snuggled right in next to me. It was almost dark when a light knocking sound came from my bedroom door. My mom walked in and invited me out to watch the fireworks with everyone. I had been in isolation for most of this 3-month period, not speaking to many people outside of my household. I declined, as I wasn't sure if I should be around loud noises. My mom asked again, and I paused to reconsider... My recovery was going well, my sensitivities were less and less, so hesitantly, I agreed.

I sat down on the concrete stairs that lead up to my parents' porch and sat waiting for the show to start. My dad, and our neighbour from down the street were setting up the fireworks. My mom and our neighbours' wife were chatting over a glass of wine. Everything seemed normal and the familiarity lulled me into a safe surrender. Life, for the first time in many months, seemed normal. A faint, tiny flame could be seen from across the road. The fireworks began...

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You know those "screamer" fireworks that don't explode? They're just a flame with this stupidly incessant, high-pitched squealing? Well, those. But 4 or 5 of them all at the same time. The entire earth seemed to shake and tilt. The edges of my vision darkened. My ears were ringing so badly that it felt as though a thousand angry bees were swarming in my brain...

Stinging. The ground seemed to come rushing up to meet me. I closed my eyes; the world was swimming. When I opened my eyes next, my hands were clasped to both sides of my head, tears were pooling in my eyes, my jaw was clenched so tightly I thought my teeth would crack. I stood to turn to the door of the house. *Get the hell out of here*. I don't remember if anyone spoke to me, I don't remember what I even did next... but in an instant, a small slice of normalcy turned into a fiery reminder that I wasn't ready. I had never lost consciousness before in my life, and if I did that night, it was only for a brief couple of seconds, but the reality of the situation plunged me into a deeper recognition of all the ways that my life had changed, and a growing anxiety of all the ways my life *will* change.

# **Post-Concussion Syndrome (PCS)**

I included a brief statistic in my Literature Review chapter on the prognosis of concussions. Overall, the recovery prognosis for concussions is a positive one, with most concussion cases resolving themselves within 3 months. However, approximately 10-20% of concussions do not fully resolve themselves and patients may end up with a prolonged and complex recovery (Todd et al., 2018). Those of us who fall into the 10-20% of complex concussion recovery paths are often diagnosed with post-concussion syndrome/post-concussion symptoms (PCS).

I believe that the *possibility* of this prognosis should be given to everyone that is in concussion recovery, as there is no definitive cause that researchers have been able to find to indicate a certain person will develop PCS. Certain factors have been isolated to be a "red flag" for the development of PCS such as: neurologic factors such as a previous history of brain injuries, previous diagnosis of depression or anxiety, or significant substance abuse (Broshek et al., 2015). Broshek et al. (2015) also cite personality variables such as high achievement goals,

or a dependent/insecure personality may also contribute to post-concussion symptoms. The researchers also addressed psychosocial factors including work and school demands, or pressure from teammates or coaches to return to play before they are ready (Broshek et al., 2015). Situational factors such as environments with rapid processing demands or the need for complex cognitive attention can also exacerbate and prolong concussion symptomology (Broshek et al., 2015). I feel as though the vast majority of us will find ourselves in one of those situations, and therefore I reiterate, *every* person with a concussion should be educated on post-concussion symptoms, even solely as a way of marking their own progression and recovery progress.

I know that if I had even *heard* of PCS, I would have been a little easier on myself in the recovery process. However, it wasn't until many years into my recovery and living with the accompanying complications of my recovery that I stumbled upon the term "post-concussion syndrome" and the symptoms that came with it.

Post-concussion syndrome is a collection of symptoms that follow a mTBI/concussion. These symptoms include headaches, dizziness, irritability, difficulty concentrating, memory problems, fatigue, visual disturbances, sensitivity to noise, lowered impulsivity control, depression, and anxiety (Ryan & Warden, 2003). These symptoms may last for months or continue into years following recovery. Ryan & Warden (2003) state that these symptoms may even be permanent or cause disability (p. 310). There are essentially two different "camps" that form when speaking about PCS: those that believe it is a real syndrome, and those that believe, due to the non-specific nature of concussion and PCS symptoms, that there is no way of linking PCS symptoms to the occurrence of a concussion. Often, the most compelling links made between concussions and PCS revolve around mental health and attention.

## **Concussion Mental Health 101**

The beginning months of my concussion recovery can be summarized in two words: black hole. I developed an annoying new dynamic with the voice inside my head. Typically, the voice was nonchalant. I was easy-going, always up for an impromptu journey at 2am with my friends. School came easily to me, reading was second nature. Over the course of my recovery, the voice in my head became less easy-going and more high-wired-coffee-driven anxiety broken up by periods of extended silence. The quiet moments may seem like a nice break from the chaos of our world, and yeah, I could argue that it is. But I could also argue that due to the chaos and constant "presence" required to function in our society, that the moments of quiet were almost debilitating. During those quiet moments I must move my body to keep myself preoccupied and "present." Otherwise, my eyes get stuck on some random object and before you know, I've wasted 5 minutes just staring at it completely checked out from the rest of the world.

As I said, there are different "camps" when it comes to PCS, and I have delicately walked the thin line of conversation that rears its ugly head when talking about PCS with healthcare professionals. In the latter half of May 2022, I participated in the first ever (in the World) Concussion Research Partnership where clinicians and patients gather to discuss what questions should lead the next round of research in the concussion field. We took 17 un-researched questions that had been submitted and ranked them from 1-17 with 1 being the highest priority for research and 17 being the lowest. In one of my "consulting groups," I was paired with a physiotherapist who spent most of their day addressing people's physical symptoms postconcussion and helping them return to sport/work/activity. One of the questions that was presented to us posed whether a prior diagnosis of a mental health condition will impact concussion recovery or influence the severity of concussion symptoms. I advocated for this to be

in our Top-10 most important questions, while the physiotherapist thought that it was in the bottom 5. His reasoning was along the lines of: "Access to mental health supports are robust and I don't see how implementing them into a concussion recovery plan would benefit anyone at all. All we would do is stigmatize the mentally ill by telling them they're more at risk for a complicated recovery due to their mental condition."

My heart sank as I saw the other members of my group start to slowly nod their head in agreeance. I raised my hand, and with my heart beating about a thousand miles a minute (I hate any form of confrontation), I laid out a couple of key factors that people with concussions face post diagnosis:

In relation to depression, at least 35% of people that sustain a concussive injury will experience a Major Depressive Episode (Todd et al., 2018). A study of retired football players conducted in 2007 found that people with a history of 3 or more concussions are 24.4% more likely to develop clinical depression (Todd et al., 2018). Another study conducted in 2007 focused on veterans and found that there was a 78% increased risk of depression with a concussion in their focus group (Todd et al., 2018). Furthermore, a more recent study in 2015 found that 20% of collegiate level athletes experienced an increase in depressive symptoms after a concussion, compared to just 5% of non-concussed control groups.

My point in raising all these statistics is... these are the numbers that we *already* know, and these are fairly high numbers when discussing the prevalence of an often-debilitating mental health diagnosis such as depression. What if a diagnosis of a prior mental health condition only *exacerbates* the numbers listed above? Are those people not worthy of knowing whether their recovery will be harder or more challenging than others? There is no stigma in spreading awareness of the possibilities of these complications... And if their recovery will be harder

because of a mental health diagnosis, then as clinicians and healthcare providers, there is a duty to be upheld by connecting this group of people to the *proper* concussion specialist team, such as one fitted with mental health providers, therapists, and mental health rehabilitators to ensure that these diagnoses do not slip through the cracks.

This becomes *even more important* when faced with the stark reality that suicide is the leading cause of death after a TBI, and people with a history of concussions are three-times more likely to die by suicide compared to the general population (Fralick, Thiruchelvam, Tien & Redelmeier, 2016. Teasdale & Engberg, 2001. Wasserman et al., 2009). A study conducted by Fralick et al., (2015) followed concussion patients over a 10-year period and out of 235,110 participants with a concussion, 667 suicides occurred over this 10-year period, which is equivalent to 31 deaths per 100,000 patients annually... 3 times the population norm. While this doesn't seem like a huge number, a hard pit in my stomach forms when Fralick et al., (2015) state that 50% of these patients visited a healthcare provider within the last week of their life. We can speculate that the healthcare providers maybe shared the same sentiments as the physiotherapist in my consulting group. Could those 334 people have been saved with better intervention, more mental health supports, or a proper concussion specialist team? After talking to other healthcare professionals in my consulting group... this question appears to be on the backburner of many of their concerns. Even after presenting my consulting group with the statistics I laid out for you, their opinion was made up and the question about a prior mental health diagnosis fell outside of the Top-10 questions.

# The Myth of Control

Years went by, and yeah, I went back to soccer, much to my mom's unhappiness and disapproval. I was happy on the field, but when I was off the field, I was still unsettled by the

fact that my cognitive symptoms weren't alleviating themselves as much as I wanted them to. My memory is still greatly lacking, plans and meetings get forgotten, assignments throughout university were late. "You need to be more organized, Kylie." I'm not actually unorganized. I can stare at a calendar for 10 minutes straight and within 5 minutes I wouldn't be able to answer if you asked me about a due date. I forget my own sentences halfway through. Forgetting due dates or plans didn't worry me, I had a very understanding support system and honestly, wonderful and accommodating professors throughout my university and post-graduate education. Despite the wonderful support system I had, I could not shake the unrelenting feeling that I was *unfinished*. I felt unsettled in my own body, nervous about the future and what it had in store for me. I fought relentlessly against my own progression in a desperate attempt to become who I used to be before my concussions, because during it all, it didn't feel like *any* progression at all. I had idealized the recovery process, I felt as though if I checked all the boxes and did all of the recovery activities, I would go back to who I used to be. I fell into what is termed "the myth of control," which Wendell (1996) defines as "the belief that it is possible, by means of human actions, to have the bodies we want and to prevent illness, disability, and death" (p. 94).

The myth of control is just that, a *myth*. A myth that is strengthened by a whole host of interactions in our societies, especially in Western societies, which Wendell (1996) attributes to the greater Western project of "controlling nature" (p. 94). If we look at Western medicine for example, it is largely focused on cures and lifesaving medical interventions rather than focusing on pain management, patient's quality of life, or rehabilitation. Comparatively, what Western medicine would call "alternative therapies," often focus on pain relief, pain management, a greater range of movement, or other ways of alleviating physical discomfort, rather than an absolute cure for the ailment in question (Wendell, 1996). In the Western world, we accept the

premise that medicine is there as an absolute cure, and that our doctors are capable of curing whatever ailment we present with. However, practitioners within the medical space *are not gods*. They are not perfect or omnipotent, but we as society, hold them to that standard. We expect answers, we expect progress, we expect *cures*. We hold doctors and surgeons and nurses to this unattainable standard because, as human begins, we have an innate need to believe someone out there can *fix us* when we are broken, sick, or unwell. When the medical system cannot make us well again, we are faced with the very real truth that disability or sickness can happen to any of us at any time – an uncomfortable reality check for those that operate under the myth of control: if I take care of myself and do everything I'm supposed to be doing, then I will be okay.

The existence of people with chronic uncurable illnesses or disabilities is perceived as a full-frontal attack and insult on the pristine standard that we hold our medical system to. Rather than relinquish control (or the "myth" of it), society flips the script, and places the blame on the unwell *individual*. This is often when cultural scripts such as "it's all in your head," "you're just imagining it," or "you just need to try harder," enter the play. All to sustain the myth of control, for *surely* if the perfect medical interventions don't work, then it *must* be because of the patient receiving the intervention. Concussions present an interesting framework for the myth of control to operate within. I believe this is due to the broad spectrum that concussive injuries may encompass, while some people may feel completely okay and "normal" within a couple of days, there are others like myself, who find themselves reeling from chronic and long-term post-concussive symptoms. Let's combine the radical differences in healing trajectories (such as healing duration, physiotherapy required/not required, necessity of Return to Play/Learn/Work, etc.) and the "success" of healing, with a currently unknown reason for *why* some people develop PCS and others do not… The ambiguity fosters an environment where many people with

concussions will be compared to each other – "so and so healed within 2 weeks... there's no way you did everything they did or else you would be better too…" Or if you're dealing with someone from the "PCS doesn't exist" camp (unfortunately there are people that will deny the realities of all different experiences, this is not isolated to PCS or concussions) then the PCS will be "all in your head" or your lack of progress was your own fault: "you should have listened to your rehabilitator."

Unfortunately, it is not only ableist society that tells those of us with unrelenting physical ailments that it is all in our head. Our medical system sees "the unknown" as unacceptable, and sometimes our own doctors or caregivers will tell us that there is nothing wrong with us and that we are imagining things. A well-known doctor within the concussion sphere (who literally calls himself Concussion Doc) denies the existence of PCS and attributes it to outside forces: your headaches aren't because of your concussion, they're because you're stressed, your brain fog isn't because of your concussion, it's because you think you're unorganized, the light sensitivity is because you kept yourself inside too long. While all of those reasons may be a *contributing* factor to PCS symptoms, there is a dangerous rhetoric being portrayed in his messages: it's not your injury, it's you and your mind. What happens when we're told we are the faulty mechanism stifling our own progression? Guilt. Doubt. Self-blame. This guilt, doubt, and self-blame often lead to a hopelessness – I can't even help myself; no one understands. Cue the isolation. If we can't even understand ourselves, then how the heck are we going to find connection with someone else? In the next section, we will explore the Cognitive and Social Authority of Medicine where Wendell (1996) explores how the authority we cede to our medical professionals can lead to alienation from our own bodies and experiences - a term that I believe fits in perfectly with the consequences of the myth of control.

That is the importance of education. To know that you are not alone, to know that the myth of control is firing on all cylinders to protect the integrity of medical institutions, to know that there are other people who are sharing your experience and that *you are not alone;* yes, I said it twice. It's the importance of validation and an understanding support system. Todd et al. (2018) found that "individuals who had validation, proper medical care, and support were able to describe a process of reconstruction of their identity" (p. 11). A reconstruction of their identity... in the depths of a confusing and lonely journey. That is the importance of connection.

### **Identity Reconstruction After Concussion**

How do we understand ourselves? If you were asked "who are you" what would your answer be? For a very, very, very long time, my answer was: a soccer player. Secondary to that, I was a teammate, a student, a daughter, a sister, a friend... but my primary identity was always closely intertwined with that black and white ball. If I went to bed early, it wasn't because I had an important test or plans with a friend, it was only because I had a game the next day. In fact, often I didn't have plans with friends because, "sorry... I can't. I have soccer." Growing up, I thought my interests were boring and I cringed at the idea of someone listening to me for more than a couple minutes drone on and on about the things I was interested in, so instead, I poured myself into soccer. Then, when people asked what I was "good at" or "interested in," I didn't have to tell them, I could just *show them*. Watch me go.

The bulk of the depression and anxiety that I fought with post-concussion surrounded "what if I can't go back to soccer?" Remember Nixon's (1992) analysis on athlete culture and sportsnets? I had become fully engulfed in my role as a soccer player, and when faced with the possibility of never playing again, I struggled to conceptualize myself in any role *other than* a soccer player. Who am I? Who will I be? What am I going to do? What are my hobbies? What

are my interests? Who... Am... I? The thought of redefining myself and having such a radical identity switch scared the shit out of me. To top it off, the involuntary nature of such a drastic change in my being seemed cruel and unfair. If I was going to stop playing soccer, I wanted it to be *on my own terms*, not because some fluke header at a practice or some idiot at a house party throwing a bottle at my head. *This isn't fair*. You're right Kylie, and it sucks too.

I sat in that confused refusal for years. Years... I fought tooth and nail against myself, idolizing pre-concussion Kylie, striving to be her again. Many athletes fall into the same depressive limbo, not quite our old selves, but certainly not anything that we felt *whole enough* to become the "new us." Todd et al., (2018) conducted a qualitative study to learn more about the psychiatric effects of concussion on constructed identity in hockey players. They interviewed 20 ice hockey players ranging from minor to professional levels in an attempt to understand how a concussion impacted their mental health and their sense of identity. The researchers analyzed these interviews and described a process of "biographical construction, biographical disruption, biographical deconstruction, and biographical reconstruction" that athletes undertake during concussion recovery (p. 11).

Biographical construction is understood by Todd et al., (2018) as the construction of the individual's identity. Oftentimes, this construction of identity is closely formed with traits and values of a sport culture, as well as the importance of a sport in the athlete's life. This means that personality traits and ideologies perpetuated *outside of sport* can be formed and morphed by values of the sporting culture. The participants in their research described this cultural construction as taking place early in life, oftentimes being "immersed" in the sport culture: "[t]he culture of hockey is, you have it at the beginning of school, you have it at the end of school, you spend winters doing it. You're uh... immersed in the culture because it's around you" (p. 7).

Other players described the significance of mental strength and toughness as the defining feature of whether you are a "good" hockey player or a "bad" hockey player (p. 7). According to one participant, a hockey coach: "guys, that don't succeed are seen as, you know, a mental flaw," and many players noted that their "mental strength was an important part of their hockey identity" (Todd et al., 2018, p. 7).

The ability to persevere when faced with anxiety-inducing situations or high-pressure moments was touted as a highly prized trait in a hockey player, oftentimes, being seen as the defining feature of success. Sometimes these traits such as perseverance under intense pressure or heightened mental strength can be bolstered by an individual's participation in sports. Contrastingly... individuals may also *pretend* that they have mental strength when they actually do not, because they are fearful of how they will be perceived by other people within the sporting world, or how the perceived "weakness" will affect their sporting career. I don't believe the totality of the term "mental strength" limits itself to mental health such as depression or anxiety. I believe mental strength will also contribute to how an athlete or individual will navigate different aspects of their concussion recovery such as removal from sport or isolation from teammates, as well as the healing of the concussion itself.

The second step in the concussion progress as defined by Todd et al., (2018) is biographical disruption, otherwise known as: the concussive injury. Many participants in the study described this period as "muti-faceted difficulty and resultant isolation" and "the difficulty of conducting basic life functions when they experienced a concussion" (Todd et al., 2018, p. 8). Participants described the psychological state of social reclusion due to their concussive symptoms with one minor hockey player recounting:

I didn't have anybody really that would understand what I was going through, so even when I was around people, like I said, I just felt by myself and so it just got worse and I felt terrible, I didn't wanna move, there are some days I didn't wanna get out of bed, and I just didn't wanna face... what... my life had come to pretty much. (Todd et al., 2018, p. 8)

This sentiment was echoed by a professional hockey player who described the isolation: "it was hard even going to the rink 'cuz you didn't really feel part of the team. Because you weren't on the ice" (p. 8). The effects of isolation aren't restricted to ice hockey players, a study done by Gould et al., (1997) found that 66% of US national team skiers with season-ending injuries reported isolation as their major source of distress. This isolation is described as being exacerbated due to the "invisibility" of a concussive injury: "it just doesn't make sense when you can't actually physically see it" (Todd et al., 2018, p. 9) stated a professional hockey player, which was echoed by a retired professional player who said "... With a concussion you got no signs at all, you look as normal as everyone else" (Todd et al., 2018, p. 9).

Five of the participants voiced that the isolation, concussion, and invisible injury all contributed to a change in self-image and how they envisioned their lives and voiced a "struggle in coming to terms with a new me" (Todd et al., 2018, p. 9). One retired professional player recounted this storm of cause and effect to be distressing to the point of suicidal ideations:

It was probably at that point that the suicidal thought came to my head. That was like rock bottom... you feel like you have nothing. Like to even have a thought like that you feel like you don't have anything anymore. Everything I'd ever worked for and everything I ever wanted to do was gone and my life had changed. (Todd et al., 2018, p. 9)

Biographical deconstruction is next in the process where players begin to unravel their identities that are closely enmeshed with that of hockey culture. Many players in the Todd et al.,

(2018) study said they were able to overcome the physical aspects of concussions, but the mental aspect was challenging, especially when dealing with post-concussive depression and anxiety. This may largely be in part that there is still a lot of stigma in hockey culture (and our larger societal culture) surrounding mental illness and equating it to mental weakness. Todd et al., (2018) described a binary system where mental toughness is equated to a successful hockey player, and mental weakness was seen as failure and marked these players as unsuccessful in their endeavours to become a "hockey player."

This binary system means that there is no "middle-ground" to find yourself in when you are a hockey player, you can't be a good and successful hockey player while having a mental illness, as mental illness equates to mental weakness, and the main marker of a successful hockey player, if you can recall, is *mental strength*. This binary system will further isolate individuals that are struggling to cope with their mental health. If these players reach out for help, they have essentially "marked" themselves as mentally weak. This marking is stigma at work, as we discussed in Chapter Two. If we can recall the defining points of stigma by Coleman-Brown (2017) and Goffman (2017), it will illuminate how a cultural value (mental strength) has defined what the stigmatizing trait will be (mental weakness). Therefore, those within sporting cultures that still hold this value will be outcast, "marked," or stigmatized as having an undesirable difference. Rather than risk the rejection and associated consequences of rejection (such as impact to professional careers, or personal sporting development), athletes will try to hide their injuries, or the lasting effects of said injuries such as depression or anxiety, in a bid to remain "untainted" by the stigma of mental weakness. However, trying to work through depression or anxiety with little-to-no support further intensifies the isolation already felt due to

the concussive injury. This aversion to speaking about, or recognizing, mental health in sport is mirrored by a larger cultural and societal stigma about mental illness and weakness.

Finally, the last step is biographical reconstruction, and it is at this stage of the recovery process that athletes begin to reconstruct their identity, their understanding of self, and reassess the role that sport plays in their life and consequently, their being. Many athletes in the Todd et al., (2018) study expressed the importance of having an honest and understanding support system. Some athletes noted that they felt frustrated with the invalidation and misunderstanding they received from their healthcare providers, some of which manifested itself as unrealistic timelines or expectations. When healthcare providers set standardized times to achieve a certain progression, athletes felt disappointed and guilty if they were unable to reach the standards set out by their healthcare practitioners. Conversely, when supported and understood by their healthcare team, athletes were able to successfully reconstruct their identities outside of hockey, or sport. One athlete described the importance of an understanding practitioner as: "it was good that finally felt like somebody believed me; they weren't gonna shove me aside, say 'oh you're fine' and that felt amazing, that I was finally heard" (Todd et al., 2018, p. 10). The athletes that received this kind of support were able to change themselves, their activity patterns, and how they perceived themselves. Many of these athletes with a good support system were able to fully reintegrate a new identity noted they were able to learn important life lessons, and had a perception of being stronger in themselves due to the experiences. A sentiment I hold dear to my heart, as I have learned a lot about myself and the strength of my perseverance in the almost 10 years of my concussion recovery.

I believe that there is a necessity to integrate a holistic approach to concussion recovery, especially when the individual's identity is closely intertwined with the sport that they are connected to. Todd et al., (2018) summarize by saying:

When treating athletes with mental illness, it is ever important to understand the identity that has been formed around the sport that they play. Health care providers must remember the potency in this identity and that it often endures above all other identities. The athletes' identity as athletes is indeed their master status. (p. 11)

Essentially, if we combine the information laid out by Nixon (1992) about the potency of sporting culture and the concept of "role engulfment" with the qualitative interviews conducted by Todd et al., (2018) we can clearly see the necessity for encouraging identities *outside* of sport. The necessity of a strong and understanding support system can alleviate the isolation and frustration experienced by many people (athletes and non-athletes alike) that have sustained a concussive injury. Connection and understanding can foster growth and achievements even in a radical time such as identity reconstruction. This identity reconstruction isn't isolated to *only* athletes, either.

Laura S. Lorenz is a researcher studying the implications of identity reconstruction after brain injuries. In a study conducted in 2010, Lorenz states that there are two issues of importance when working with brain injury survivors of any degree: "learning the new post-injury self and building a new identity with multiple partial identities consisting of: the new brain injured self, an old self, and a self who does meaningful activities" (p. 863). People across all areas of brain injury can learn something from other areas. We do not only need to learn from others with concussion, we can also learn and find comfort and insight from people within the broader "brain injury community." For example, Lorenz (2010) conducts an interview with a woman named

Judy who sustained her brain injury due to complications that ensued after having a tumor removed. Lorenz and Judy used photo-elicitation to help Judy explore aspects of her brain injury journey, Judy would take pictures of things that are salient to living with a brain injury in her daily life. One such picture was a freezer, with a pair of car keys sitting inside.

Upon reading the article, my eyes widened as I recalled the first months of my concussion recovery where I had developed an annoying habit of putting the milk away in the kitchen cupboard. Eager to learn more, I delved into Judy's understanding of her photo titled "keys in the freezer." Judy's words are in the normal font, while Lorenz's prompts are italicized:

We as brain injured people put things in weird places. It's just this bizarre thing, that we as brain injured people put things in weird places. It's just not things that connect. It shows the disconnectedness of brain injury that why would you do that? It doesn't make any sense. It makes absolutely no sense. *But yet, if you have a brain injury* – It makes sense (Lorenz, 2010, p. 871).

Such a trivial photo to those who have not experienced a brain injury. But with the qualitative inquiry as to "why did Judy take that picture" shows the disunion that people with brain injuries may experience. I know I certainly experienced this. Upon reading Judy's recollection, I was overcome with a wave of relief. Again, such a trivial moment for those who have not experienced brain injury was received as a moment of acceptance and understanding by others (myself) in the community. I reiterate, this is the importance of connection. This is the importance of education.

#### **Incident Five: Call Me if She Needs to go to the Hospital**

We've gone on a long journey, you and I. You've read my story since 2013. After the years of rehabilitation, mental health struggles, lots of tears, lots of anger, lots of confusion, I stepped back out onto the one place I have ever known peace: the soccer field.

Like I said, we've gone on a long journey, and to hear that I stepped back out onto that field after everything I went through may fill your head with all sorts of questions, or you may find yourself with a sympathetic nod of understanding. I stepped out onto that field at least twice a week, every year from 2015 – 2020, summer or winter. I stepped out onto that field with a hesitant mother on the sidelines who set a very firm rule: you do not head that ball. Which I adhered to. Once a leaping and wild defender throwing my head behind anything it could reach, I committed to keeping my feet on the ground and my head away from the ball. But as we have learned... that isn't the only way you can sustain a concussion.

In the winters I played indoor soccer. Indoor soccer rules are like the rules of outdoor, but it's played inside on a turf field about a quarter of the size of an outdoor field. In indoor, it's very rare that a ball makes its way to head-level, as most of the game is played on the ground with sharp passes and quick plays. There aren't throw-ins, rather the ball is played in with a kick from the sideline. I excelled at indoor soccer. I was fast, my brain processed plays quickly, and my passing was crisp and clean. The stress of constantly wondering if a ball was coming at my head allowed me to relax and feel safe... until it happened.

It was 2018, just an average league game. I was playing defender, marking a woman who towered above me. I'm 5'6", while my opponent probably topped off around 6'2". She had the ball, and both of us were racing down the sideline towards my net. She touched the ball a tad too far away from her, I recognized my opportunity to capitalize, and I swooped in front of her to

take possession of the ball. However, upon touching the ball, she came at me with a shoulder check and knocked me clean off my feet. I was on the ground before I could process the impact, leaving me no time to protect my head. It whipped erratically during the fall, smashing hard to the turf floor. The spongy turf offered no protection, the impact was too great, and I felt the hardness of the concrete floor on my skull. Immediately, the metallic taste of blood filled my mouth. Pain radiated from my nose, into my jaw, into my eyes, ripping and clawing its way into the back of my head where the impact happened. I half opened my eyes, rolled onto my side to try and get up, but the world was lurching uncontrollably: crooked, sideways, upside-down. My coach was sprinting off the bench towards me. It looked like he was running on the walls instead of the ground. I closed my eyes as his voice echoed around distantly, "KYLIE DO NOT GET UP, DO NOT MOVE!" He knew my concussion history. My groans of pain escalated to tears. I laid on the turf pleading internally, *please not again. Please not again. Please not again. Please not again. Please Not. Again.* 

With the help of my coach, I slowly sat up. Tears streaming from my eyes, which had already dulled. He walked me to the sideline and sat me on the bench. My teammates hovered around for a few minutes before turning their attention back to the game. A couple of teammates with whom I had played with back in 2013 when I was originally concussed peered at me with anxious eyes. I was sobbing uncontrollably. "You must be in so much pain, Ky." One of my teammates offered an icepack.

No, actually. The pain was the least of my concerns, I'm accustomed to the dull, throbbing annoyance of a headache or head pain. Rather, it was the absolute terror that had me paralyzed this time. I did not have tears of pain; they were tears of fear. How long before my eyes stop working? How long before I can't speak anymore? How long before I become hollowed out again? How long until it all... Happens... Again? I thought about how

disappointed my mom was going to be. I thought about the burden I was about to become to my roommates, as I lived away from home. I thought about possibly having to miss school, the possibility of dropping out of university, the possibility of having to reroute my entire life plan... yet again. I thought and thought on that blue metal bench, only a couple of feet away from the playing field. I gazed at it, my heart full of betrayal and yearning.

I didn't drive at the time, rather I hitched a ride to and from games with a teammate of mine who lived around the corner. My coach offered to bring me to the hospital multiple times, but the thought of sitting in a cold, florescent-lit, loud, and busy waiting room alone for hours on end filled me with dread. I refused, and my teammate assured my coach that she would get me back to my house. I don't remember the car ride home, but I remember my teammate walking me up the stairs of my house and knocking on the door. My roommate greeted us, and my teammate filled her in on what happened. I stood in the doorway like a child being dropped off with a progress report from a babysitter. I hung my head in shame, guilt, and fear. My teammate left with one final parting statement: "call me immediately if she needs to go to the hospital, no matter what time it is."

# The Cognitive and Social Authority of Medicine

You may be wondering if I went to the hospital. I did not. You might be wondering why the heck not. Frankly, I knew what was happening to me. I knew I was concussed, and I knew the limits of my exertion. The hospital was of little-to-no use to me in 2013, they prescribed (way too much) Tylenol and (way too much) rest and sent me on my way. I took the tools I gained from my two-year stint in rehabilitation, and I set myself to work. (Not something I recommend, please get a diagnosis). I refused to argue and drain myself trying to entertain the medical system in something termed "the cognitive and social authority of medicine."

Wendell (1996) succinctly describes the Western medical system as suffering from cognitive and social authority, where we hold doctors and nurses and the entire Western medical system to a much higher intellectual and societal standard than they are often able to reach, mostly due to their status in the medical field. In this, we allow medical professionals to describe our experiences and our bodies to us. Sounds backwards, doesn't it? Within a CDS framework, we operate under the assumption that there is an *irreducibility of complex human phenomena to objective facts* – in other words, people do not equal their label, and therefore we cannot treat each person with said label in the same manner as one another, due to external forces that inevitably impact an individual. In the concussion experience, medical professionals will often try to overgeneralize the concussed individual's experience with broad assumptions such as a "standardized" three-month recovery period, or quantitative methods of recording symptomology such as the SCAT forms. This is an inappropriate method of diagnosing concussions due to the vast nuances within symptom expression, and functional differences in which each person's concussion may present themselves (vestibular, ocular, motor functioning, etc). Unfortunately, the cognitive and social authority of medicine affects how we understand our own bodies and our own experiences. Wendell (1996) summarizes it as such:

The authority of medicine tends to delegitimize our experiences of our bodies as sources of knowledge about them, because the authoritative, that is, the medical and scientific, descriptions of our bodies are third-person descriptions of physical conditions... our own phenomenological descriptions are at best treated as weak evidence for the truth of medical and scientific descriptions. They are almost never treated as even weak evidence *against* a medical or scientific description of our bodies. (p. 119)

The dynamic between medical professionals and their patients that is created by the authority of scientific medicine can result in unfortunate consequences for the patient. In this section we will explore the implications of the authority of medicine as defined by Wendell (1996).

# Alienation

The cognitive and social authority of medicine can lead to alienation from our own bodies and experiences. This alienation is not only created by a medical institution, but rather, it also garners momentum from larger social ideals and values such as the need to "perfect" the human body. If you can recall the conversation we had about eugenics and the term "normal," that may help you understand what I mean by the need to "perfect the human body." In this mission to perfect the human body, our bodies are often objectified and treated as material possessions. When our bodies are treated or understood as "possessions" or "objects" this diminishes our personhood and humanness. We begin to ignore our bodies urges and needs in order to adhere to modern medical descriptions of what our bodies should look like, act like, and function like. This often happens in regard to (but is not isolated to) chronic illnesses or disability, where someone's body is labelled as faulty by modern medicine, and in turn, may result in a cataclysmic avalanche of one's own self-esteem, connection, and understanding of one's body. Alienation.

The cognitive authority of medicine will often give more weight and value to a medical professional's "objective" stance or understanding of an illness or injury. This can undermine the subjective experience of the patient and diminish the patient's connection to their body and their confidence in understanding their body. Without acknowledgement of the patient's experience, the patient may feel isolated and hesitate or refuse to reach out to medical professionals in the

future. If you can recall the Todd et al. (2018) study, participants described the importance of a supportive and validating health care provider. In fact, Todd et al. (2018) state, "[s]imply being 'believed' was shown to be a therapeutic intervention" (p. 12) and "[participants] felt most comfortable and taken care of by those care providers who validated their suffering and normalized their concussion recovery process" (p. 10).

In the previous section, we discussed "the myth of control" and I mentioned how the myth of control can lead to alienation from our bodies if we fall outside of the medical systems' healing trajectories or develop unwarranted side effects or symptoms that the medical system cannot explain. We can marry the effects of the myth of control with the cognitive and social authority of medical systems to come to a conclusion that when we outsource the knowledge of our bodies to medical institutions, we become an entity on a bell curve on what are "normal" effects for said injury (such as a concussion in the case of this thesis), and if we fall outside of normal effects, we are effectively, *abnormal*. This is also an example of how normalcy functions hegemonically. Abnormalities that cannot be explained by medical institutions mean that the medical institution is *not* omnipotent, like we believe. Rather than begin to open the door to "what the medical system doesn't have answers to," the blame can be placed on individuals, and the blame has been placed on individuals' own lack of due care - rather than a failure on the medical systems' behalf. When this happens, there are no answers (because medicine cannot give them to us) and we are told that the problem is with ourselves. Oftentimes, this leads to a disconnect between a person's bodily complaints and discredits the lived experience of these individuals who are told that nothing is wrong, or that the steps we take toward health "aren't good enough" or "we didn't do enough." The myth of control and alienation often lead to

epistemic invalidation: the alienation from our own sense of being and a compromised sense of our own abilities to know *what* we know and know *how* we know.

# **Epistemic Invalidation**

I believe one of the most important ways of knowing is the knowing of *our own selves*. Unfortunately, the cognitive and social authority of medicine undermines our ability to intimately know ourselves, thus leading to epistemic invalidation (Wendell, 1996). Modern medicine's purpose is to describe our bodily ailments to us, and oftentimes, when modern medicine is unable to pinpoint or explain an ailment to us, they will deny that the ailment exists, or minimize and downplay the extent to which this ailment impacts us. This is acceptable to society because of the social authority we give to medicine. We believe a third person and scientific understanding of our bodies has more weight and importance, therefore believability, than our own subjective experience.

Let's unpack this epistemic invalidation in respect to concussions. Firstly, as we have learned together, concussions are a functional injury *not* a structural injury which means that concussions are not diagnosable with conventional methods such as MRI's, rather they are often diagnosed based off symptom expression. The problem with symptom expression is that many people will have different symptom "profiles" encapsulating an ever-changing combination of concussion symptoms. One person may experience headaches and nausea, while another has ocular fatigue and confusion, and another with sleep disturbances and a loss of consciousness.

In the case of CTE, the symptom expression is very present and lucid, but if we image someone's brain who has CTE symptomology, their scan will come back normal – as CTE is a cellular degeneration that cannot be identified by CT scans or MRIs. Therefore, before CTE was discovered, these athletes, often suffering with impulse control, irritability, extreme bouts of

anger, depression, addiction (gambling, drugs, alcohol, shopping), violence, and suicidal ideation were shoved to the side and told there was nothing wrong with them – their brains were "fine." Personally, I don't struggle to understand why so many athletes suffering from CTE die by suicide. Can you imagine slowly slipping down a slope, picking up speed, becoming more angry, more impulsive, more hopeless... and the medical system designed to help you tells you there is nothing wrong with you? You know deep down that something is *absolutely wrong*. Scan after scan comes back negative. There are no answers as to why you feel the way you feel, there is no timeline for when these for when these symptoms dissipate *or even if they will*... and this medical system is *supposed to have the answers*... Your life experience is no longer valid, no matter how much you know something is wrong. You are an abnormality. Your experience is buried in the medical system. You don't resonate with the person you are now, rather you are clinging desperately to the person you used to be. Your impulse control is gone, and in the blink of an eye, in the clutches of the deepest pit you could find yourself, irreparable decisions are made.

Unfortunately, due to the subjective/symptomatic method of diagnosis, and the generally well accepted three-month recovery trajectory, those who experience prolonged symptom expression (Post-Concussion Syndrome) may be told that this is "all in our heads" or that it's not a by-product of our concussions, but rather the result of external forces such as stress or other life events. This rhetoric is upheld by some "significant" members of the concussion community (as I have said earlier in my thesis) and has profound implications on the future of concussion care. Invalidating or denying a patient's lived experience may result in the patient directly questioning their relationship with their body, their experience, and their understanding of the symptoms and pains they live with. I feel obligated to state that no one likes feeling this way... no one opens
themselves up and becomes vulnerable to be told that there is nothing wrong with them when they *feel* the pain and are *living with* the consequences of that pain. I believe this stops people from reaching out and seeking help when needed, further strengthening the medical system's invalidation of an ailment. This feeds into isolation, which leads us to our next consequence of the cognitive and social authority of medicine.

# **Social Abandonment**

I mean it was, it was hard even going to the rink 'cuz you didn't really feel part of the team. Because you weren't on the ice, like I... I would go to the rink. I mean, and I could sit there. But I'd just sit there, you know, and just sit there. (Todd et al., 2018, p. 8)

Wendell (1996) lists social abandonment as the third consequence of the cognitive and social authority of medicine. Wendell speaks about the necessity of a diagnosis to receive social supports (federal or provincial financial support systems, physiotherapist appointments, etc.) in the bulk of her analysis on social abandonment, but I believe the social abandonment permeates many different levels of concussion recovery. I agree wholeheartedly with Wendell, diagnosis is necessary for many aspects of concussion recovery. Without a diagnosis I wouldn't have any school accommodations and I wouldn't have access to my physiotherapy. However, the invisible nature of concussions (and by extension, other invisible disabilities or illnesses) makes social abandonment possible even when a medical diagnosis has been made.

I began this section with a quote from a former hockey player participating in the Todd et al., (2018) study. He alludes to the social isolation and abandonment felt by many people during their concussion recovery. Even with a known diagnosis, people assume that because we are present, then we are able to participate. Another hockey player in the study described his experience:

I couldn't do the work, and so I was trying so hard not to cry because my head hurt and I was dizzy, the room was spinning, and so I... we were supposed to be working in

a group, and so I told them I can't do this I need a break, and so I was almost crying at that point and he came up to me and he said, "I bet you're fine, you're just a big baby that you can't handle this". (Todd et al., 2018, p. 9)

This isn't necessarily an isolated experience. I can recall my high school coach uttering, "you can all thank Kylie," even though he was fully aware that I was concussed. The same goes for my biology teacher who told me to not bother returning to his class, even though he knew I had a concussion. I often wonder what spurs people to ignore the wellbeing of others with invisible injuries/disabilities/illnesses, and honestly, I always get turned back to the medical system. Priorities are given to those with visible injuries, and sadly, the priorities are given to those whose medical diagnoses can be made unequivocally and without question through means of objective medical tests. Of course, this rhetoric trickles into our society. Visible injuries/disabilities/illnesses are more "understandable" because we can see them, and it has become commonplace for those invisible ailments to be questioned or even vilified because we cannot see them with our eyes.

# Failures of Communication and Gaps in Knowledge

Wendell (1996) lists the final consequence of the cognitive and social authority of medicine as failures of communication and gaps in knowledge. Due to the hierarchy between doctor/practitioner and patient, it is very possible that information does not flow properly between practitioner and patient. The patient may try to describe their symptoms and pain in a way that is easily diagnosable or accepted by the practitioner and/or the practitioner may ignore symptoms described by the patient if they do not fit into an accepted medical diagnosis. I think

back to the SCAT-2 form that was given to me at the beginning of my physiotherapy appointments. It lists concussion symptoms and asks the patient to rank each symptom from a 0 - 6 severity rating (0 being none and 6 being severe). There was one "symptom" that lit an angry burning inferno inside of me: "don't feel right." Yes, that's the symptom they want you to grade: don't feel right. Of course, I don't feel right... but what is this quantifying? What is my physiotherapist interpreting this as meaning? What am *I* supposed to interpret this to mean? Oftentimes I ranked this at a 6 because... what else am I supposed to rank this as? If I have the other symptoms on the list then obviously I do not feel right. The ambiguity of the symptom leaves room for *too much* practitioner interpretation, and *too little* patient experience.

This is just one example of how a failure of communication can be experienced during concussion recovery. Unfortunately, this failure of communication leads to gaps in knowledge. If the practitioner does not know what I mean when I list "don't feel right" as my most severe symptom, then how are they supposed to understand this symptom and how to rectify it? For me, I understood "don't feel right" as a culmination of all of my symptoms and their impact on my wellbeing. For someone else, they may interpret "don't feel right" as the spaced-out and "floaty" state of consciousness that many people experience after a concussion – where we are "present" but also slightly removed from our bodies. This description alone may cause practitioners to raise their eyebrow and question our capabilities. The gaps in knowledge occur because Western medicine is very unlikely to address or attempt to rectify that which it cannot understand.

Wendell (1996) states that she believes Western medicine is terrible at dealing with chronic pain due to its obsession with the myth of control and its desire to control the body. Our Western medical system is largely geared towards life-saving interventions, leaving it relatively

unequipped to handle patient's quality of life and wellbeing *while living with* chronic pain or illness. This leads us nicely into my next talking point: alternative healing.

# **Alternative Methods of Healing**

Since I did not visit a healthcare provider for my most recent concussion that I shared at the beginning of this chapter, I did not receive any physiotherapy or rehabilitation for the symptoms that I was experiencing. I kept my eyes moving with the eye exercise sheets that my old physiotherapist had given me. I kept my body moving with light aerobic exercise. I monitored my screen time in relation to my symptoms, and I successfully reached a point where the *physical* symptoms of my concussion (headaches, dizziness) greatly improved and I was left with the tiresome cognitive symptoms like confusion, difficulty concentrating, and memory loss. I managed these symptoms as best as I could; my desk was littered with sticky notes or my phone constantly dinged from a reminder, I always kept a bottle of water with me and when I felt my concentration slipping, I would take a sip of water to "bring myself back" to the real world. However, the bulk of my progress did not occur until the Winter of 2019.

It didn't seem like progress at first. I left my parent's house on Boxing Day of 2019 to begin my 2-hour drive back to St. Catharines. I mentioned to my mom about these intense stabbing headaches (ice-pick headaches) that I had been feeling for a couple of days. She hugged me and told me to text her when I made it home. I stopped at Tim Horton's for a coffee on the way back, and when I took my first sip, I was startled... I had no idea what I was drinking. I thought it tasted like coffee, but suddenly I was unable to remember what coffee tasted like. I took sip after sip trying to calm my mind and reassure myself that indeed, I was drinking coffee, but each sip was strange and alien. I had an hour and a half left in my drive home, which I spent teetering on the fine line that separates an anxiety attack from a panic attack. I made it home, and

immediately went to the bathroom and laid on the cold tile hoping the cold would calm my body and mind, but instead I disassociated. I knew that I was in my bathroom, and I was safe, but my body believed that this bathroom was a stranger's bathroom. I laid there for probably 10 minutes, I had no thoughts, only the ravenous feeling of hunger. I knew I wouldn't remember to take food out of the oven, so I set a timer on my phone, put my food in, and stared at the wall waiting for the *ding*.

I booked a session with a therapist in the weeks coming, and in the meantime, I spent hours and hours and hours of my time researching alternative ways that I could begin to improve my mental health. One evening I was watching a concussion webinar through a local concussion advocacy agency at Brock University called HeadsUpCAN. The webinar was host to four athletes who were addressing the stigma of concussions in sport: Molly Tissenbaum, Paul Rosen, Ian McCall, and Daniel Carcillo. The bulk of the conversation was dedicated to ensuring that you take care of *yourself first* and acknowledging concussion symptoms and the stigma that surrounds those symptoms within the sporting world. Then, the conversation shifted to something I wasn't expecting: the healing properties of plant medicine... specifically psychedelic medicine.

# **Potential of Psychedelic Healing**

Daniel Carcillo is a former National Hockey League player who most recently hoisted two Stanley Cup's above his head for the Chicago Blackhawks in 2013 and 2015. He earned his reputation as a "league enforcer," AKA the guy that does all the fighting, and his aggressive onice presence awarded him the nickname of "Car Bomb." Carcillo retired in 2015 and he lists a couple defining reasons for his retirement: the death of his friend Steve Montador whom we discussed a little in an earlier section, the birth of his son, the symptoms from his 7<sup>th</sup> concussion (light sensitivity, slurred speech, impulse control issues, headaches/head pressure, anxiety, depression, suicidal ideation), and the resulting cascade of his mental health and the impact that had on his ability to be a father, husband, and fulfilled human (Habs Tonight, 2021). Upon his retirement, Carcillo underwent many years of mainstream rehabilitation to improve his concussion symptoms and attempt to regain his quality of life such as MRI's, CT scans, fMRI's, neurofeedback, etc (Complete Concussion Management, 2021). Ultimately, the biggest strides in Carcillo's concussion recovery began once he discovered the healing properties of psilocybin (the active agent in "magic mushrooms") and cannabinoids. I want to preface the following information by saying that I am not a doctor, and this is not medical advice. I am sharing the experiences of other people, and how their stories steered me in the direction *I chose* for my concussion rehabilitation. My methods may not work for you, just like mainstream methods did not work for me. Trial and error, and be responsible, my friends.

# Cannabinoids

Cannabinoids are naturally occurring structural compounds that are found within the cannabis plant. The most known cannabinoid is delta-9-tetrahydrocannabinol (THC) which is the psychoactive component of the cannabis plant. Yeah, the part that gets you high. However, there are other *non-psychoactive* cannabinoids such as cannabigerol (CBG) and cannabidiol (CBD), both of which are the only currently-known neuroprotectants on Earth and have the potential to treat neurodegenerative diseases such as Parkinson's and Alzheimer's – both of which people with 3 or more concussions are 80% more likely to develop than the general population. (Players' Tribune, 2018. Complete Concussion Management, 2021). After a TBI, there are certain substances that are produced that are known to cause neuronal damage: tumour necrosis factor (TNF)-a and reactive oxygen species (ROS) (Mechoulam et al., 2002). A study conducted

by Mechoulam et al., in 2002 showed that after a TBI the endocannabinoid system in our brain kicks into gear and creates two endogenous cannabinoids: anandamide and 2-arachidonogyl glycerol (2-AG), both of which inhibit the production of the TNF-a and ROS substances that cause neuronal damage. In short, our endocannabinoid system creates neuroprotectants, when necessary, to mitigate damage to our neurons. Mechoulam et al., (2002) detailed a study where anandamide and 2-AG was administered to mice and rats with TBI, and it was discovered that when both compounds are administered the extent of brain injury is diminished by reducing swelling, tissue necrosis, and hippocampal cell death. In relation to self-administered or medicinal cannabis, CBD has been discovered to *increase levels of anandamide*, therefore reducing ROS and TNF-a (Mechoulam et al., 2002).

Cannabinoids can also be beneficial in regulating glutamate signalling in the brain. Glutamate is a neurotransmitter in the brain that encourages synaptic plasticity (the ability for synapses to expand and change) and is vital for learning and memory (Mechoulam et al., 2002). When glutamate levels climb too high, this induces neurotoxicity and can lead to the development of the damage causing compounds we explored above (ROS and TNF-a). Glutamate levels can be reduced by an effective antioxidant... enter in CBD and THC, both of which have strong anti-oxidative properties, with CBD exhibiting superior antioxidant qualities and preventing glutamate toxicity and in turn, reducing or preventing the creation of ROS and TNF-a (Mechoulam et al., 2002).

In addition to the wonderful neuroprotectant qualities that cannabinoids possess, they can also help with the management of other symptoms commonly associated with concussions. Research at this time is limited on the exact benefits of CBD, however preliminary research has posited that CBD could be used to relieve anxiety and depression, chronic pain, and may even

have potential to treat addiction (Silva, 2022). Although studies are limited, many athletes such as: Daniel Carcillo, Ian McCall, Riley Cote, Mike Tyson, Conor McGregor, Marshawn Lynch, Kareem Abdul-Jabbar, and Megan Rapinoe, for example, all have placed high value on the healing properties of cannabis or cannabinoids, even using the plant medicine throughout their professional career. These high-level voices of advocacy have prompted mega-corporations such as the NFL to invest money into research of cannabinoids in hopes to replace highly addictive and dangerous pain killers such as Toradol, with a more holistic option such as CBD. In recent years, this holistic mindset has started to garner momentum even further, with the NFL reducing the punishments for players who test positive for cannabis, while the NBA stopped testing for cannabis altogether (Thompson, 2021. Reynolds, 2021).

I was the teammate that had the "value pack" of Tylenol rattling in her soccer bag, and before my concussions, I regularly used Tylenol after a game to combat any pain or stiffness that I was feeling. After my concussions, the relentless throbbing pain of my headaches was barely touched from three extra strength Tylenol's. A cousin of mine suggested cannabis to alleviate some of the discomfort that I was experiencing, but due to previous not-so-great experiences with cannabis, I declined. Many years of suffering passed and come 2019 I decided that I had had enough. Enough pain, enough sleepless nights, enough classes and shifts for work being missed, enough irritability – because WOW, constant pain in your head makes you a really, *really*, miserable person, and for the first time in many years, I smoked a joint by myself in the cold mid-winter air.\* Within minutes the throbbing sensation in my head was gone, the elephant that usually sat on the top of my skull went for a walk, no feeling of pressure or pain. My anxiety

<sup>\*</sup> Please adhere to all Provincial or Federal regulations and laws on age and cannabis consumption. Start slow and find your appropriate tolerance window when using cannabis.

grinded to a halt. *Holy shit*. I threw out the expired bottles of Tylenol and Advil, I slept like a baby, I woke up the following morning for the *first time in years* without a headache, and I haven't looked back since. Rather, I was intrigued. I wanted to know more. *What else is out there that I haven't been told about?* I scoured hours and hours of media, publications, and testimonies, but Dan Carcillo's story rattled around in my mind. *Psilocybin*. The next step in my healing journey.

# Psilocybin

Before we begin, I feel obligated to say that my knowledge of psilocybin was initially formed in my teenage years where many of my friends were "tripping" on magic mushrooms and telling me all sorts of strange stories. Even to this day, with my new knowledge on the potential of psilocybin, when I tell people I am treating my brain injury this way, I am *still* met with stories of bad trips and hallucinations. So, I'd like for you and me to start on a clean slate. Try to forget the horror stories and whatever preconceived notions that you may hold and come in with an open mind. I know I had to.

Psilocybin is not the name of magic mushrooms, rather, psilocybin is a compound found within some mushroom species such as those hallucinogenic magic mushrooms. When our body is introduced to psilocybin, it converts the psilocybin molecule into a *psilocin* molecule (SciShow Psych, 2022). This psilocin molecule binds to one of the same receptors (the 5HT2A receptor) as serotonin, "which is the molecule involved in things from sleep and blood pressure to mood regulation and depression" (SciShow Psych, 2022, 1:01). Although, due to the novelty of psilocybin research, scientists are unsure if binding to the 5HT2A receptor leads to hallucinations, they are fairly certain that this binding is linked to how different parts of our brain communicate with one another (SciShow Psych, 2022). It is posited that psilocybin increases

brain connectivity between networks, even when those networks hadn't *previously* been strongly connected – meaning the psilocybin fosters neurogenesis, in other words, psilocybin can create new neural connections (SciShow Psych, 2022). Interestingly enough, the psilocybin alters the way in which we perceive our world and our understanding of the senses which we come to know our reality, this is what makes psilocybin a promising treatment possibility for depression (SciShow Psych, 2022). Studies have been conducted that show promising results in alleviating depression symptoms within treatment resistant populations (Erritzoe et al., 2018. Carhart-Harris et al., 2017), and unlike traditional antidepressants which require a daily intake, psychedelic modalities such as psilocybin show months of benefit after a single dosage (SciShow Psych, 2022).

Let's reel it in a bit, because you may be thinking "yeah that's all wonderful, but I don't want to 'trip' to get the benefits of psilocybin." I agree wholeheartedly with you there, that was the major drawback for me when I first started researching psilocybin, but I stumbled across a method that you may have heard about but not yet familiarized yourself with: microdosing. Microdosing is when you take sub-perceptual (non-hallucinogenic) levels of psilocybin, at this level, psilocybin still holds the potential to reduce anxiety and irritability, enhance cognitive functions and creativity, increase socializing, and provide a greater sense of well-being (Microdosing Institute, retrieved 2022).

Personally, I follow Stamet's Stack – a microdosing protocol consisting of psilocybin, Vitamin B3, and Lion's Mane. Lion's Mane is a non-psychoactive mushroom commonly known for its brain boosting abilities, specifically, Lion's Mane stimulates the brain's nerve growth factors which are responsible for myelin sheath production (remember the shield around the axons?), as well as production, growth, and maintenance of neurons in the brain (Microdosing

Institute, retrieved 2022). The potential benefits of Lion's Mane include: increased memory, increased focus and concentration, anti-inflammatory, supports gut health, improves mood, increases energy levels, supports insulin sensitivity, and Lion's Mane is a powerful antioxidant (Microdose Institute, retrieved 2022). Lion's Mane is safe and effective as an everyday supplement and does not need to be taken with psilocybin. Stamet's Stack also comes with a regimen where Days 1 - 4 are days where you take the psilocybin *and* Lion's Mane, and Days 5 - 7 are "break days" where you can continue with Lion's Mane, but no psilocybin. After a 4-week period, you "reset" your body and take a 2 - 4 week break from the psilocybin but can continue with the Lion's Mane indefinitely (Micro-dosing Institute, retrieved 2022).

I was initially weary of the promises of psilocybin at such low doses as the bulk of scientific research indicates that the most benefits are seen after taking a large dose of psilocybin. However, while I am micro-dosing, I am certainly more in control of my emotions. My irritability which was typically a police-siege-battering-ram hammering through my front door eases into a persistent knocking – annoying, yet manageable, and not coming out with aggression and force. I feel calmer and happier. Not an over-the-top giddy and laughing high, just a quiet peace that inevitably leads to an elevated mood. My focus improves, my jittering legs stop moving so much, and overall, I am a more productive and rational human being; two things I majorly struggled with post-concussion. It is recommended that while micro-dosing, you engage in mind-body connecting activities such as meditation, yoga, journaling, art/creation, or being in nature. All these activities have their own cognitive benefits. We will briefly explore some in our next section.

### **Additional Ways of Healing Concussions**

### Movement

Not so long ago in the concussion community, recovery from concussions meant an absolute removal from physical activity. This is what I was "prescribed" in 2013 following my concussion: rest for weeks in a dark room, no physical activity whatsoever. Emerging evidence in the concussion field is showing that this sedentary approach to healing actually resulted in more harm than good. The Consensus Statement on Concussion in Sport in 2016 changed its recommendations on rest after a concussion, recommending that rest be prescribed for the "acute" stage of concussion recovery which is typically understood as the first 24 - 48 hours after sustaining a concussion (McCrory et al., 2017). This is a big difference from their 2012 publication which recommended complete and total isolation and rest until all concussion symptoms had subsided and did not return. The initial thought behind complete removal from all physical activity was to decrease energy demands on the brain, allowing all energy reserves to be used for concussion recovery. Although the research is still emerging, the 2016 Consensus Statement acknowledged that there is currently insufficient evidence that complete abstinence from physical activity provides any benefits to the concussed person, rather light aerobic activity that does not exacerbate concussion symptoms is the new recommendation.

It comes to no surprise to me that light exercise is now recommended after a concussion. Proper blood flow is an integral part of the bodies healing process, and light exercise helps move the blood around the body, ensuring that the healing process takes place. The brain is no exception in this scenario. Personally, the weeks of isolation away from friends, family, and teammates drastically impacted my mental health. I became lethargic and introverted; I had little motivation or desire to participate in anything that I was once interested in. At times like this I'm

thankful for my tiny acts of rebellion that urged me to listen to my body and pick up a soccer ball to do tiny ball handling exercises in my room. In fact, Leddy et al., (2016) state that there is a therapeutic window of approximately 2 weeks post-concussion where *voluntary exercise* proves to have positive effects on brain-derived neurotrophic factor (BDNF) levels in the brain. BDNF is a key molecule that is involved in plasticity changes in the brain that are related to learning and memory (Miranda et al., 2019).

It is also important to note how the body in general responds to movement and exercise. Immediate benefits after exercise include increased focus and cognition, as well as decreased feelings of anxiety (Centres for Disease Control and Prevention, 2022). When we exercise, our body releases chemicals that are called endorphins (Bruce, 2022). Endorphins, affectionally termed the "feel-good" chemical, are our bodies natural painkillers. Endorphins also relieve stress and create a positive and uplifted mood – take the term "runner's high" for example, that is a result of the bodies creation of endorphins (Bruce, 2022).

# **Meditation and Mindfulness**

Mindfulness has become somewhat of a hot topic in the recent years, especially throughout the COVID-19 pandemic many people have begun to focus on this term: mindfulness. But what exactly is mindfulness? In short, mindfulness is careful awareness of our thoughts, feelings, and environment and how those aspects can impact our bodily presence. Mindfulness exercises are typically done for short periods in a day, sometimes 10 – 15 minutes long, in a meditative or meditative-like nature, or in other mind-body connecting modalities such as yoga. Mindfulness has become an accessible and practical way for many people to calm their minds and explore the deeper connections between their body and mind. Online apps such as "HeadSpace," "CALM," or "Insight Timer" even provide free mindfulness meditations to ease beginners into the newfound territory. So, we know what mindfulness is, but why the heck would we want to try it out?

Dr. Sara Lazar is a neuroscientist at Harvard University who set herself out to discover what happens to our brains when we employ mindfulness based meditative practices into our lives. During a TEDTalk, Dr. Lazar illustrates scientifically validated benefits of mindfulness practices including decreased stress, reduced symptoms associated with depression, anxiety disorders, pain, and insomnia, an enhanced ability to pay attention, and an increased quality of life (TEDxTalks, 2011). When we perform a task or habit repeatedly, this leads to structural and functional changes in the brain which is termed *neuroplasticity*.

Dr. Lazar utilizes MRI brain scanning to see if implementing a practice such as mindfulness has any lasting or important changes in brain structure and matter – in other words, she wanted to see if implementing mindfulness could contribute to neuroplasticity and *what* those changes would be (TEDxTalks, 2011). To do this, Lazar recruited people who averaged about 30 – 40 minutes of mindfulness practice in a week and compiled a control group of people who did not do any mindfulness practices (TEDxTalks, 2011). Lazar found that compared to the control group, people who practiced mindfulness had increased gray matter in certain areas of their brain such as the prefrontal cortex which is responsible for working memory and executive decision making (TEDxTalks, 2011). Remarkably, in relation to an aging brain, Lazar found that 50-year-old meditators had the same prefrontal cortex thickness (which naturally thins as we age) as 25-year-olds – yes, their brains were comparable to the brains of someone half their age, suggesting that mindfulness-based practices slowed age related cortical decline (TEDxTalks, 2011).

Lazar furthered her study by recruiting non-meditators, scanning their brains, and then enrolling them into an 8-week long mindfulness retreat. Upon completion of the 8-week retreat, their brains were scanned again. The results showed increased activity in the left hippocampus which assists in learning, memory, and emotional regulation; additionally, the results showed more connectivity in the tempo-parietal junction which assists in perspective taking as well as empathy and compassion (TEDxTalks, 2011). Lazar also noted changes in the amygdala, which controls our body's natural fight-flight-fawn response to threatening or dangerous situations. The changes in the amygdala showed a decrease in gray matter – which is directly related to feeling less stress or being able to handle stress with less amygdala (fight-fight-freeze) activation (TEDxTalks, 2011). Lazar concludes her TEDTalk by stating meditation isn't a placebo response, rather, meditation can directly change our brains. Better memory, better emotional regulation, better ability to tolerate stress, more compassion, more empathy, more connection, and a younger brain... all seem like pretty substantial benefits to me.

### **Parting Words**

It has been two years since I have played soccer. I moved to Saint Catharines to pursue my master's degree in Applied Disability Studies, and intended to find a team once I moved here; however, the COVID-19 pandemic brought organized sports and many other aspects of our daily lives to a grinding halt. These past two years have introduced me to newfound frustrations in my concussion recovery, and no outlet to put them into. Instead, I have been forced to find new ways to cope with the ebbs and flows of symptoms and how to navigate the fluctuations of my mental health. As a collective, we have all been struggling to keep our heads above water through this pandemic, and ironically, many of you are experiencing the same things I did during my concussion recovery... shut in our homes, kept away from people, with no clear end in sight, just a dutiful reminder that "we will get through this one day." I believe that sentiment is the hope we cling to, and that hope isn't given to us by a government organization, or a scholarly institution, or a medical practitioner... the hope that we will get through this must come from each other – a collective agreement to care for our neighbours and help our friends.

Throughout this thesis we have travelled through many different aspects of concussions, such as general concussion education, mental health implications, the connections between repetitive head trauma and degenerative diseases, the impact of cultural socialization on an athlete's decision to play with injuries, as well as long term complications such as post-concussion syndrome, and alternative modalities for healing concussive injuries. I attempted to present all these important areas of information in a new manner, with a first-hand autoethnographic, qualitative method of exploring the nuances and experience of navigating through these topics as an athlete deeply socialized in the values of sporting culture. As a young

girl, I found what I believed to be immense acceptance and belongingness with my teammates. However, 2 years out of play, and none of my relationships with my teammates have endured.

Prior to writing this thesis and understanding the plethora of studies and information that we have explored together, it deeply hurt that I lost those relationships that I thought could withstand any trial – after all, we had figuratively been to "war" together. But that's truly the crux. We never went through war, we never fought triumphant battles in the way that the Greek soldier Pheidippides did, or in the same life-or-death fuelled fury of ancient Roman gladiators. We were just told that we did. Consequently... we sought praise and valour in the same manner that many soldiers do - sacrificing ourselves to protect our team, to protect our triumph, to protect our identities, no matter what it meant to our bodies or our sanity. Without the shared illusion of wartime and the consequent bond that comes with sharing such experiences with a closed group of people, all fighting to achieve the same goal... without the illusion it becomes nothing. There is no shared goal, there is no shared experience, there is no commonality between us as we move past the confines of our sport and into the realities of our lives. Some teammates are nurses, some are massage therapists, one is a psychedelic therapist, another is a pharmacist. One is a world-travelling hiker, while another works from home with her dog. And here I am, writing to you about what the heck has happened over the past 20 years of my life. In that manner, we are more different than we are alike – a reality that was never presented that starkly when we gathered on the soccer pitch, and we were one. As one of my teammates captioned her Instagram photo of one of our end of year photos together: 1 ball, 2 cleats, 16 bestfriends.\* I can live with knowing that the relationships with my teammates were incredibly special, and I

<sup>\*</sup> I am not saying that all athlete relationships erode once the shared experience of sport is gone. Many athletes build strong, enduring, life-long friendships with their teammates. I am simply sharing that this was not the case in my situation.

*positively and adamantly know that without them I would not be who I am today*. A weird juxtaposition to grapple with: they're not here anymore, but without them I wouldn't be the me that is here right now.

My teammates were a second family, a haven where I didn't have to put on a mask or hide who I was. I didn't have to uphold the role of a sister, daughter, scholar, or girlfriend. I didn't have to be anything other than who I was. My role was clear-cut and precise, I never had to guess at what my objective was when I stepped onto the field. As a defender, my job was to protect my net and my goalie. That was all people expected of me, and I happened to be pretty darn good at it. I have never received praise in the same way I did when I would clear the ball off of our goal line at the last possible second, securing victory for my team. A glimpse at "true heroism," I believed. The duties in that role as a defender never changed, unlike the everchanging and never-ending to-do list of being a daughter, sister, scholar, or girlfriend. Soccer was a gratifying and weight-lifting release from the many different roles I assumed throughout the day, a sentiment I'm sure many fellow athletes can attest to. Now, 2 years without soccer, I am finding a fatigue in constantly assuming role after role after role... I yearn for the simplicity that once gave me solace. Truly, stepping out onto the soccer field and breathing in the smell of clumped dirt, and torn grass blades brings me peace. Feeling my cleat studs bite into the ground and hearing the grass rip under the weight and intensity of my sprinting take-off is cathartic. The adrenaline pumping through my body was warm and comforting. The pain of muscles screaming from the potency of a well-fought 90 minutes relaxed me. As I fondly reminisce on these little physical-feeling aspects of being an athlete, my stomach tightens and drops.

I miss it.

We discussed Nixon's (1992) article on athlete culture in depth. I gave caution to the potential dangers of becoming immersed in an "athlete role," and yet, I still stop to wonder if it's an "athlete role" we become so addicted to – or is it the simple release of all other roles expected of us? Maybe the engulfment of being an athlete is really simply comfort in authenticity. For many of us, being an athlete isn't a bad thing. We have teammates who care for us and provide us with a feeling of belongingness. We participate in tournaments and community fundraisers. We exercise or train on a regular basis. We have structure and routine. We collaborate, we learn problem solving, we practice conflict resolution... all these things are *integral* in the wellbeing of a human.

However, it is the culture in which we are conditioned and the ways we are taught how to be a "real athlete" like sacrificing our bodies, playing through pain, or blindly accepting risks without questioning dominant cultural ideologies, that is where the danger lies. And unfortunately, the culture is insidious in the way with which these norms and values are idolized and seen as "requirements for success." I didn't know that I was being indoctrinated with values that used my innate desire for safety and security and turned them into a way of constantly seeking safety in the form of companionship and security in the form of acceptance, and then leveraging those needs against me when I needed safety and security *the most*. I bought into the belief that "getting hurt" meant weakness, and proclamation of your injuries in any manner other than pride indicated that an athlete wasn't ready for the reality of what it meant to be a true athlete. So, I hid my injuries or played them out with a false sense of bravado. I've been called many things in my life but "weak?" I haven't had a single person in my life call me weak, and I'd be damned if my only weakness was tied to the part of me that believed it was the strongest. I

felt the same pull towards the game as millions of other athletes feel – you don't want to be away from playing.

Reader, my dear sweet reader... a couple months away from play to ensure you are fully equipped to safely return to play will always be the smarter move than decades of headaches, daily anxiety, fatigue, eyes that don't work properly, or a temper that is frequently mismanaged – all resultant from repetitive head injuries that I allowed to get away from me by keeping it a secret for as long as I physically could. I kept my concussions to myself until my body shut down and I was forced by a fear greater than fear of not playing to disclose to someone, anyone, that something seriously wrong was happening to me. It didn't need to get to that point – but alas, I didn't know signs of a concussion, I didn't know the severity of a concussion, I thought that the headache would last a couple hours and go away like it usually did. Instead, my body transitioned into survival mode, siphoning energy away from the "less necessary" bodily functions like speech and movement to ensure life-sustaining bodily functions had enough energy to continue. A couple of months away from play turned into a year and a half away from play. My prize for such insolence in protecting my body? Well, we've explored them throughout this thesis.

My parting words aren't "don't play sports or you'll hit your head and mess everything up." Kids are going to play sports, teenagers are going to play sports, adults are going to play sports. I believe it is what we do *outside of sport* that can mark our success. The danger in being an athlete is *only* being an athlete and *only* being able to know yourself or "feel like yourself" while you are in sport. I truly and loudly advocate for immersing yourself in all your interests. Paint, write, draw, dance, learn an instrument, take up crochet, try to meditate, do yoga, train dogs, finish your degree... whatever it is that you want to do – do it, even when you're an

athlete. Although we may be caught up in the adrenaline and routine of competition and challenge, it is important that we all remain mindful of the many years of our life that will happen outside of sport.

Intimately coupled with cultivating your interests outside of sport, there have been studies that we have assessed such as Clark & Stanfill (2019) that indicate *more* must be done on the level of concussion education. With the rise in concussion knowledge and research, and the growing number of studies linking multiple head traumas to the development of chronic traumatic encephalopathy or other degenerative brain diseases like Alzheimer's or Parkinson's, the importance and *duty* to educate our young athletes is paramount. We cannot sit idly by and watch as our youth incur damage to their developing brains while the adults in charge of their safety and wellbeing pretend like there is no cause for concern. The implementation of various concussion education laws such as Rowan's Law in Ontario, or Zach Lystedt Law passed by Washington State in 2009 attempt to underline the importance and severity of concussive injuries and highlight the importance, nay, *necessity*, to remove oneself from play (or be removed by a coach, trainer, or parent) upon the suspicion of a concussive injury. These laws are in place to ensure that no other athletes die prematurely like Rowan Stringer, or become disabled in the case of Zach Lystedt, due to improper handling of concussion protocols.

We can no longer stand by and let major corporations such as that of the NHL tell us that there is no link between repetitive head injuries and brain deteriorating diseases. **Because there are.** We cannot continue to mitigate concussions as a minor knock to the head, or "getting your bell rung" or "punch drunk" or any other cute misnomers that downplay the seriousness of the injury. Concussion education should be taught in all school health classes, concussion education should happen before the start of every sport season, concussion education should happen within

workplace health and safety meetings, within retirement homes and hospitals, during first aid courses and babysitting courses. The dangers of second impact syndrome need to be well known, the possibility of post-concussion syndrome, anxiety or depression, the feelings of isolation and loneliness should be communicated in every check-up, the percentages and likelihood of developing brain degenerative diseases should be shared. Instead, we shine a flashlight in a concussed player's eye and tell them to "get back out there, kid! Take their number." Redemption is the sweetest reward, right?

The basis of this thesis has been concussion education. There have been pro-level athletes (Daniel Carcillo for example) who have said that they received zero concussion education at the professional level (Complete Concussion Management, 2021). This is unacceptable. Not only is the absence of proper concussion education greatly disturbing within professional sports but becomes all the more dangerous when we place these elite level athletes in the realm of idols for our younger athletes. If our young athletes watch a player take repeated hits, showing visible disorientation, and continue to play in the game as though this is normal, then of course the upcoming generation will be conditioned with the same attitudes. Especially if that athlete receives praise from other teammates, sports broadcasters, members of media, or society at large. To a young athlete, praise is praise! They are in no position to question dominant cultural discourses any more readily than you were before this thesis, or before your own research on sport culture. An illumination of our culture at work is the foundation required to begin a careful reassessment of all values and ideologies engrained in us, who were treated as extensions of that culture. We, athletes, are the tools used for the culture's success and proliferation; and as we would question the environment of actual handyman tools that constantly break under the

pressure of the duties expected of it, we should question the environment that the athletes are constantly breaking under.

As part of completion of this master's degree, we were given an assignment in class to write a letter or rant to an institution or person about something we were passionate about. I wrote to the NHL and titled my letter: The NHL and it's Terrible, Horrible, No Good, Very Bad Concussion Protocol. I addressed the various ways that the NHL has failed to protect its players by implementing proper concussion protocols, rehabilitation, and education. I am sharing a piece of my writing here, because I feel as though it is pertinent for *all* major organizations, as well as *all* minor organizations:

The National Hockey League is watched by millions of people. The players within your organization are hometown heroes, childhood idols, and idealized futures. The NHL is in a unique position to start concussion awareness from childhood through its association with Timbits Hockey, but this ideal has yet to be fully realized. You perpetuate dangerous standards of what it "takes" to be a professional athlete. Perhaps I am most angry because I fell prey to it.

In 2013, I found it hard to believe I could have sustained such a life changing injury. Within 24 hours I could not speak. I could not walk. I could not move. Now I cope with post-concussive depression and anxiety, memory loss, persistent headaches, and migraines. Had there been awareness about concussions, had there been education around concussion symptoms, had any of my childhood idols spoke out, perhaps I would have stopped after the first blow to the head. I share a bit of my life, my experiences, my struggles, in hopes to combat the cowardice and neglect displayed by major organizations such as

your own. I write to you to end the trickle-down of a toxic mindset that becomes engrained within the morale of our Nation's youngest athletes.

You can raise awareness and to make this a serious conversation.

You have the chance to change lives.

You have the chance to save lives.

Please, do not continue to make the choice that ends lives."

Truly, that is what it is about – our Nation's youngest athletes. If we can have a generation of athletes who recognize concussion symptoms and fully understand the potential implications of concussions, I believe that we can make great strides in the prevention and treatment of concussive injuries. If we have a generation of athletes who uplift each other, as my Club team uplifted me through my concussions, I believe we will have a more inclusive sporting world. With a wider and broader understanding and acceptance of invisible injuries and disabilities we become more cohesive and less divisive. If there is anything I have learned through my concussion recovery, and now through a pandemic, is that unity, support, and community are fundamental to human wellness. I leave you with one final, parting quote from Malcolm X, one you have probably heard but honestly... what else is there to say?

"When I is replaced by We, Illness becomes Wellness"

Much love, much kindness, and truly yours...

Kylie J Hamilton

# References

Blaine, B. (2013). Understanding the psychology of diversity (2<sup>nd</sup> edition). Sage.

- Bloom, A. G., & Caron, G. J. (2019). *Psychological aspects of sport related concussions*. Routledge.
- Broshek, D. K., De Marco, A. P., & Freeman, J. R. (2015). A review of post-concussion syndrome and psychological factors associated with concussion. *Brain Injury*, 29:2, 228-237. DOI: 10.3109/02699052.2014.974674
- Bruce, D.F. (2022, April 1). *Exercise and depression*. WebMD. https://www.webmd.com/depression/guide/exercise-depression#:~:text =When%20you%20exercise%2C%20your%20body,similar%20to% 20that%20of%20morphine.
- Busch, C. R., & Alpern, H. P. (1998). Depression after mild traumatic brain injury: A review of current research. *Neuropsychology Review*, 8:2, 95-108.
- Cameron, C. (2014). Impairment. In C. Cameron (Eds.), *Disability studies: A student's guide* (pp. 75-78). Sage.
- Cameron, C. (2014). The personal tragedy model. In C. Cameron (Eds.), *Disability studies: A student's guide* (116-119). Sage.
- Cameron, C., & Moore, M. (2014). Disability studies. In Cameron, C. (Eds.), *Disability studies: A student's guide* (pp. 37-40). SAGE Publications.
- Campbell, C. (2010, November 15). *Flat affect and brain injury*. BrainLine. https://www.brainline.org/author/celeste-campbell/qa/flat-affect-and-braininjury#:~:text=Answer%3A,reflect%20what%20we%20are%20feeling
- Carhart-Harris, R.L., Roseman, L., Bolstridge, M., Demetriou, L., Pannekoek, J.N., Wall, M.B., Tanner, M., Kaelen, M., McGonigle, J., Murphy, K., Leech, R., Curran, H.V. & Nutt, D.J. (2017). Psilocybin for treatment-resistant depression: fMRI-measured brain mechanisms. *Scientific Reports*, 7(13187), 1 – 11. DOI: 10.1038/s41598-017-13282-7
- Centers for Disease Control and Prevention. (2022, April 27). *Benefits of physical activity*. https://www.cdc.gov/physicalactivity/basics/pa-health/index.htm#:~ :text=Being%20physically%20active%20can%20improve,activity%20gain%20some%20 health%20benefits.
- Centres for Disease Control and Prevention. (2019, February 12). *What is a concussion?* https://www.cdc.gov/headsup/basics/concussion\_whatis.html

Chrisman, S. P., Quitiquit, C., & Rivara, F. P. (2013). Qualitative study of barriers to concussive

symptom reporting in high school athletics. *Journal of Adolescent Health*, *52*, *330-335*. http://dx.doi.org/10/1016/j.jadohealth.2012.10.271

- Clark, R. & Stanfill, A.G. (2019). A systematic review of barriers and facilitators for concussion reporting behaviour among student athletes. *Journal of Trauma Nursing*, *26*(6), 297-311
- Coleman-Brown, L. M. (2017). Stigma: An enigma demystified. In L. Davis (Eds.), *The disability studies reader* (5<sup>th</sup> ed., pp. 145-159). Routledge.
- Complete Concussion Management. (2021, February 17). *Magic mushrooms: Using psilocybin to treat concussion symptoms with Daniel Carcillo* [Video]. Youtube. https://www.youtube.com/watch?v=hLCVGRnEk9c
- Concussion Legacy Foundation. (n.d). *What is a concussion?* Retrieved August 23, 2021, from https://concussionfoundation.org/concussion-resources/what-is-concussion
- Concussion Legacy Foundation. (n.d). *What is PCS*? Retrieved March 13, 2023, from https://concussionfoundation.org/PCS-resources/what-is-PCS
- Couser, G. T. (2017). Disability, life narrative, and representation. In L. Davis (Eds.), *The disability studies reader* (5<sup>th</sup> ed., pp. 450-453). Routledge.
- Davis, L. J. (2017). Introduction: Disability, normality, and power. In L.J. Davis (Eds.), *The disability studies reader* (5<sup>th</sup> ed., pp. 1-14). Routledge.
- Delaney, J. S., Lamfookon, C., Bloom, G. A., Al-Kashmiri, A., & Correa, J. A. (2015). Why university athletes choose not to reveal their concussion symptoms during a practice or game. *Clinical Journal of Sport Medicine*, *25*(2), 113-125.
- Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. Altamira Press.
- Erritzoe, D., Roseman, L., Nour, M.M., MacLean, K., Kaelen, M., Nutt, D.J. &Carhart-Harris, R.L. (2018). Effects of psilocybin therapy on personality structure. *Acta Psychiatrica Scandinavica*, 138, 368 – 378. DOI: 10.1111/acps.12904
- Feschuk, D. (2020, November 28). 'I was lost.' Ex-NHL enforcer Daniel Carcillo says magic mushrooms saved his life and offer real hope for mental health treatment. *TheStar*. https://www.thestar.com/sports/hockey/opinion/2020/11/28/i-was-lost-ex-nhl-enforcer-daniel-carcillo-says-magic-mushrooms-saved-his-life-and-offer-real-hope-for-mental-health-treatment.html
- Fralick, M., & Thiruchelvam, D., & Tien, H. C. (2016). Risk of suicide after a concussion. *CMAJ*, 188:7, 497-504. DOI: 10.1503/cmaj.150790
- Goffman, E. (2017). Selections from *stigma*. In L. J. Davis (Eds.), *The disability studies reader* (5<sup>th</sup> ed., pp. 133-144). Routledge

- Gould, D., Udry, E., Bridges, D., & Beck, L. (1997). Stress encountered when rehabilitating from season ending ski injuries. *Sport Psychology*, 11, 361-378. https://www.cabdirect.org/cabdirect/abstract/19981803595;jsessionid=B0E25402BECF4 FA007F8DAE29C607578
- Grue, J. (2016). The problem with inspiration porn: A tentative definition and provisional critique. *Disability & Society*, 31:6, 838-849. DOI: 10.1080/09687599.2016.1205473
- Gunasekaran, P., Hodge, C., Rose, K., & Fraser, C. L. (2019). Persistent visual disturbances after concussion. *AJGP*, 48(8), 531-536. DOI: 10.31128/AJGP-03-19-4876.
- Habs Tonight. (2021, April 27). *Why Daniel Carcillo retired from the NHL: Habs tonight ep 8* [Video]. Youtube. https://www.youtube.com/watch?v=LWH0BB\_WYs0
- Hughes, R., & Coakley, J. (1991). Positive deviance among athletes: The implications of overconformity to the sport ethic. *Sociology of sport, 8:4, 307-325*.
- La Fountaine, M. F. (2018). An anatomical and physiological basis for the cardiovascular autonomic nervous system consequences of sport-related brain injury. *International journal of psychophysiology*, *132*, 155-166. DOI: 10.1016/j.ijpsycho.2017.11.016.
- Leddy, J., Hinds, A., Sirica, D. & Willer, B. (2016). The role of controlled exercise in concussion management. *Advanced Sports Medicine Concepts and Controversies*, 8, 91 – 100. DOI: 10.1016/j.pmrj.2015.10.017
- Lincoln, Y.S., & Guba, E.G. (1985) Naturalistic Inquiry. Beverly Hills, CA.: Sage
- Lincoln, Y.S. & Guba, E.G. (1986) But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. In D.D. Williams (Ed.), Naturalistic evaluation (New Directions for Evaluation, No. 30, pp.73-84), San Francisco, CA.: Jossey-Bass.
- Lorenz, S, L. (2010). Discovering new identity after brain injury. *Sociology of Health and Illness, 32:6,* 862-879. DOI: 10.1111/j.1467-9566.2010.01244.x
- Ly, C., et al. (2018). Psychedelics promote structural and functional neural plasticity. *Cell Rep,* 23:11, 3170-3182. DOI: 10.1016/j.celrep.2018.05.022
- Mackenzie, R.J. (2019, August 20). *Gray matter vs white matter*. Technology Networks. https://www.technologynetworks.com/neuroscience/articles/gray-matter-vs-white-matter-322973
- McCroy, P., Meeuwisse, W., Dvorak, J., Aubry, M., Bailes, J., Broglio, S., Cantu, R.C., Cassidy, D., Echemendia, R.J., Castellani, R.J., Davis, G.A., Ellenbogen, R., Emery, C., Engebretsen, L., Feddermann-Demont, N., Giza, C.C., Guskiewicz, K.M., Herring, S., Iverson, G.L., Johnston, K.M., Kissick, J., ... Vos, P.E. (2017). Consensus statement on

concussion in sport – the 5<sup>th</sup> international conference on concussion in sport held in Berlin, October 2016. *J Sports Med*, 1 - 10. DOI: 10.1136/bjsports-2017-097699

- McKee, A. C., Stein, T. D., Kiernan, P. T., Alvarez, V. E. (2015). The neuropathology of chronic traumatic encephalopathy. *Brain Pathol*, 25:3, 350-364. DOI: 10.1111/bpa.12248
- McKee, A. C., et al. (2009). Chronic traumatic encephalopathy in athletes: Progressive tauopathy after repetitive head injury. *J Neuropathol Exp Neurol*, 68:7, 709-735.
- Meaney, D. F., & Smith, D. H. (2011). Biomechanics of concussion. *Clin Sports Med, 30, 19-31*. DOI: 10.1016/j.csm.2010.08.009
- Mechoulam, R., Panikashvilli, D. & Shohami, E. (2002). Cannabinoids and brain injury: Therapeutic implications. *TRENDS in Molecular Medicine*, 8(2), 58 – 61.
- Meekosha, H. & Shuttleworth, R. (2017). What's so "critical" about critical disability studies? In L. J. Davis (Eds.), *The disability studies reader* (5<sup>th</sup> ed., pp. 175-194). Routledge.
- Microdosing Institute. *Stamets stack (stacking Lion's Mane and psilocybin mushrooms)*. Retrieved July 9, 2022, from https://microdosinginstitute.com/microdosing-101/substances/lions-mane-stacking/
- Miranda, M., Morici, J.F., Zanoni, M.B. & Bekinschtein, P. (2019). Brain-derived neurotrophic factor: A key molecule for memory in the healthy and the pathological brain. *Cellular Neurophysiology*, 13(363), 1 25. DOI: 10.3389/fncel.2019.00363
- Mooney, G., & Speed, J. (2001). The association between mild traumatic brain injury and psychiatric conditions. *Brain Injury*, 15:10, 865-877. DOI: 10.1080/02699050110065286
- Moore, R. D., Lepine, J., & Ellemberg, D. (2016). The independent influence of concussive and sub-concussive impacts on soccer players' neurophysiological and neuropsychological function. *International Journal of Psychophysiology*, *112*, *22-30*. http://dx.doi.org/10.1016/j.ijpsycho.2016.11.0110167-8760/
- Nixon, H. L. II. (1992). A social network analysis of influences on athletes to play with pain and injuries. *Journal of Sport & Social Issues, 16:2, 127-135.*
- Nixon, H. L. II. (1991). Accepting the risks of pain of sports injuries: Understanding the nature of 'consent' to play. Paper presented at the North American Society for the Sociology of Sport annual meeting, Milwaukee, WI.
- Nixon, H. L. II. (1992b). Coaches' views of risk, pain, and injury in sport. Paper presented at the North American Society for the Sociology of Sport annual meeting, Toledo, OH.
- Official W5. (2020). *W5: The high cost of painkiller abuse in professional hockey* [Video]. Youtube. https://www.youtube.com/watch?v=s\_Sb664bCYU

- Parachute Canada. (2018, June 3). After a concussion: Return-to-sport strategy. Parachute Canada. https://parachute.ca/wp-content/uploads/2019/06/Return-to-Sport-Strategy.pdf
- Parachute Canada. (2020, October 20). Concussion. https://parachute.ca/en/injury-topic/concussion/
- Parachute Canada. (2019, June). Strategy for return to school after a concussion. Parachute Canada. https://parachute.ca/wp-content/uploads/2019/06/Return-to-School-Strategy.pdf
- Public Health Agency of Canada. (2020). *Injury in review 2020 edition: Spotlight on traumatic brain injuries across the life course*. Public Health Agency of Canada.
- Quinn Patton, M. (2015). Chapter 1: The nature, niche, value, and fruit of qualitative inquiry. *Qualitative research & evaluation methods* (4<sup>th</sup> ed., pp. 2-45). SAGE.
- Quinn Patton, M. (2015). *Qualitative research & evaluation methods* (4<sup>th</sup> edition). SAGE Publications.
- Reynolds, T. (2021, October 6). *NBA will not randomly test players for marijuana again this season*. NBA. https://www.nba.com/news/nba-will-not-randomly-test-players-for-marijuana-again-this-season
- Runswick-Cole, K., & Goodley, D. (2014). Resilience. In C. Cameron (Eds.), *Disability studies* (pp. 125-128). Sage.
- Ryan, L, M,. & Warden, D. L. (2003). Post concussion syndrome. *International Review of Psychiatry*, *15*, *310-316*. DOI: 10.1080/09540260310001606692
- Samuels, E. (2017). My body, my closet: Invisible disability and the limits of coming out. In L. J. Davis (Eds.), *The disability studies reader* (5<sup>th</sup> ed., pp. 343-359). Routledge.
- Sandel, L., Reynolds, E., Cohen, P. E., Gillie, B. L., & Kontos, A. P. (2017). Anxiety and mood clinical profile following sport-related concussion: From risk factors to treatment. Sport Exerc Perform Psychol, 6:3, 304-323. DOI: 10.1037/spy0000098
- Schwarzbold, M., Diaz, A., Martins, E. T., Rufino, A., Thais, M. E., Quevedo, J., Hohl, A., Linhares, M. N., & Walz, R. (2008). Psychiatric disorders and traumatic brain injury. *Neuropsychiatric Disease and Treatment*, 4(4), 797-816.
- SciShow Psych. (2022, January). *Your brain on psilocybin* [Video]. Youtube. https://www.youtube.com/watch?v=27Rlcu1C9HE
- Silva, L. (2022, June 7). *CBD oil: 9 science-backed benefits*. Forbes Health. https://www.forbes.com/health/body/cbd-oil-benefits/

- Teasdale, T. W., & Engberg, A. W. (2001). Suicide after traumatic brain injury: A population study. *J Neurol Neurosurg Psychiatry*, 71, 436-440.
- TED-Ed. (2017). *What happens when you have a concussion? Clifford Robbins* [Video]. Youtube. https://www.youtube.com/watch?v=xvjK-4NXRsM&t=90s
- TEDx Talks. Retrieved July 9<sup>th</sup>, 2022. *How meditation can reshape our brains: Sara Lazar at TEDxCambridge 2011* [Video]. Youtube. https://www.youtube.com/watch?v=m8rRzTtP7Tc
- The Players' Tribune. (2018, June 14). Former NHL player Daniel Carcillo discusses head trauma and treatment: The Players' Tribune [Video]. Youtube. https://www.youtube.com/watch?v=K4BySsH6FgQ
- Thompson, J. (2021, April 20). NFL players can smoke marijuana for the first time during the offseason and the window opened on 4/20. Insider. https://www.insider.com/nfl-players-can-smoke-marijuana-without-discipline-starting-420-2021-4
- Todd, R., Bhalerao, S., Vu, M. T., Soklaridis, S., Cusimano, M. D. (2018). Understanding the psychiatric effects of concussion on constructed identity in hockey players: Implications for health professionals. *PLOS ONE*, 13:2, 1-16. DOI: https://doi.org/10.1371/journal.pone.0192125
- van Middendorp, J.J., Sanchez, G.M., & Burridge, A.L. (2010). The Edwin smith papyrus: A clinical reappraisal of the oldest known document on spinal injuries. *Eur Spine J*, *19*, *1815-1823*. DOI 10.1007/s00586-010-1523-6
- Wade, C., Tavris, C., Saucier, D., & Elias, L. (2015). The brain: Source of mind and self. Psychology (4<sup>th</sup> ed., pp. 109-147). Pearson.
- Wasserman, L., Shaw, T., Vu, M., Ko, C., Bollegala, D., & Bhalerao, S. (2009). An overview of traumatic brain injury and suicide. *Brain Injury*, 22:11, 811-819. DOI: 10.1080/02699050802372166
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. Routledge.
- Whyno, S. (2019, May 23). Concussions in the NHL: Former and current players speak out. *Global News*. https://globalnews.ca/news/5307081/nhl-concussions-players/