

The Embodiment of Post-Concussion Syndrome:
Reflexive Research, Acting Athletes, Managing Medical
Professionals, and Moral Trepidation

by

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ABSTRACT

This thesis undertakes a phenomenological investigation to explore the embodied experience of the recovery from Mild Traumatic Brain Injury (mTBI) from the perspective of high-level athletes alongside the perspective of managing medical professionals. Semi-structured, one-on-one interviews were conducted with six athletes and five medical professionals to provide a partial actors-first perspective that seeks to begin to fill in the qualitative experience of post-concussion syndrome (PCS), which has been lacking within both the medical and social science literature to date. Supplementing this will be a brief consideration of how the media has driven public discourse on the prevalence of this injury (mTBI) and illness (PCS) in professional and high-level amateur athletics, instigating a *moral trepidation* crystallizing around the uncertainty of possible long-term health consequences of repeated mTBI. This moral trepidation is experienced most viscerally by the parents of Canadian athletes. Seeking to describe the embodied experience of others is understood to be partial within the phenomenological tradition. I hope to draw from my own experiences with mTBI as a means of providing an *experiential bridge of understanding* to an illness that is described by medical professionals as being especially ambiguous.

KEY TERMS:

Phenomenology, embodiment, lived experience, being in the world, intersubjectivity, intentionality, mTBI, PCS, moral panic.

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“This is my way of telling you that every day I’m loving you so much more.
Because you believed in me through my darkest night.
Put something better inside of me, you brought me into the light.
Threw away all those crazy dreams, I put them all behind and it was you.
Right down the line.”

Gerry Rafferty, *Right Down the Line*

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CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

I would like to begin by formally introducing myself to my informants, who graciously opened up to me (a perfect stranger) in a way that was honest and candid. I believe they did this for the same reason I conducted this research: we all feel an immense desire to communicate the nuances of the lived experience of post-concussion syndrome (PCS) and mild traumatic brain injury (mTBI).¹ For the benefit of the non-concussed reader, I will introduce these nuances through a reflexive account of my own experiences with mTBI and sustaining over a dozen concussions over the past 15 years. Following in the American anthropological tradition, since the 1980s reflexively accounting for the positionality of the researcher is seen as important for transparency but can also be used creatively as a research tool as a means of getting closer to the experience of another.

As an undergraduate anthropology student at the University of British Columbia (UBC), I was introduced to the work of anthropologist Renato Rosaldo and his influential book *Culture and Truth: The Remaking of Social Analysis* (1993[1989]), which signaled to me that a reflexive methodology can be a powerful tool for beginning to understand the emotional aspect of lived experience. Rosaldo speaks candidly about how the loss of his wife Michelle in a tragic accident while in the field gained him membership to “*the invisible community of the bereaved*,” as opposed to those who had suffered no major

¹ See Appendix 1 for medical definitions of mTBI and PCS.

loss” (Rosaldo 1993:29). Membership to this invisible community is exclusive and based on the “distinction” (29) of having experienced losing someone and consequently the lived experience of bereavement. Similarly, when an individual sustains a concussion, they join the invisible community of the *brain injured*. The athletes in my study struggled with coming to terms with their membership to this community and whether their membership would be permanent.

I will also introduce the stories of former professional hockey players and brothers Eric and Brett Lindros, whose careers were cut short by concussions at a time when mTBI was poorly understood, both medically and experientially. I believe there is value in showing how acceptance of the severity and even existence of PCS has rapidly changed over the past fifteen years to a point where the more recent experience of NHL superstar Sidney Crosby has triggered a *moral trepidation* among the public over the prevalence of concussions in sports.² Eric Lindros’ increasing propensity for getting concussions was a widespread topic of debate among sports fans and sports broadcasters. As a concussed athlete, I strongly identified with Eric Lindros and people would compare me to him in much the same way as the athletes in my study were compared to Sydney Crosby. The media has and continues to play a prominent role in informing the public about the nature of this murky and ambiguous injury.

1.2 MY FIRST TWO CONCUSSIONS

In the spring of 1996 I was 13 years old playing in my first year of organized hockey when I had my first contact with mTBI and PCS. I was skating up the left-wing

² This was confirmed by the responses of all my informants (both athletes and medical professionals [MPs]). See Appendix 2 for a listing of informants, their background information, and their pseudonyms.

boards and looking back for an outlet pass rather than watching the play develop in front of me. As the puck hit my stick, I turned my head to look up the ice and all I saw was a shoulder smashing into my upper chest and jaw. I remember letting out a hard exhale on contact, but what follows is a disembodied account largely based on the recollection of my mom who was in the stands and my dad who was behind the bench. I stumbled to my feet and have a vague recollection of feeling the need to draw a penalty as a way to stop play and get off the ice, so I clumsily started chasing the defenseman who hit me while wildly waving my stick above my head. My mother was the first to recognize I had sustained a concussion. She stood up in the stands and demanded the referees “go and ask my son if he knows where he is!” After dragging me to the penalty box because I was unable to skate on my own, the referee asked me where I was and I replied, “In Seattle, playing in a big tournament.” In fact, I was in my home rink in Surrey, British Columbia. I was taken to the hospital where my mom was told to attempt to wake me every two hours and if unable to do so, bring me back to the hospital.

I was fortunate to have a family physician who was an early proponent of concussion management protocols. In addition to his family practice, he was a consulting physician to the Surrey Minor Hockey Association and his son also played. This personal contact with mTBI in young athletes encouraged him to educate himself on the injury. He also formulated his own graduated return to play (GRTP) protocols and promoted the importance of immediate removal of play—both of which became key recommendations made by the International Conference on Concussion in Sports (ICCS) (2001–ongoing), which is recognized as a leading international consensus body on concussion

management policies for all levels of sport. I saw him three times before he allowed me to return to play after a recovery time of two to four weeks.

While playing a game of organized ball hockey in the summer of 1997, I was rushed by three forwards, knocked to the ground, and kicked in the jaw while I was on all fours. This was the first time I lost consciousness, which was then considered necessary for a concussion diagnosis.³ In the dressing room after the period ended, I started crying uncontrollably in front of all my teammates. This was my first experience of having an uncontrolled emotional outburst, which often accompanies an mTBI in the acute phase. I recovered relatively quickly from this concussion (ten days at the most) and this was my first self-managed recovery (the same physician essentially recommended I go home and take it easy, which was the only time he didn't fully monitor one of my concussions).

1.3 LINDROS' CONCUSSIONS

In March of 1998, Eric Lindros sustained his first public concussion from a hit similar to the one which gave me my first concussion⁴:

I don't recall the hit. I recall a lot of things after the hit. I'm tired, I have a headache, and things aren't as sharp as they could be. . . . The biggest thing is having a sense of when to come back, and making sure when you do come back you're not putting yourself in a position where you're much more susceptible to having the whole process re-occur.⁵

³ Today mTBI is typically associated with an alteration in consciousness, rather than a loss of consciousness.

⁴ "Kasparaitis Hit on Lindros." YouTube video, 0:26. Posted by "gbrendel," January 18, 2008, <http://www.youtube.com/watch?v=W61W4NZiRf4>.

⁵ The public statements used to describe Lindros' concussions in this section are taken from Sports Illustrated (2001).

Later that year, he was hit twice on the same shift. He was not removed from play and he ended up missing only two games. After the game, he said, “Helluva shift, ‘eh? I’ve had better days. It’s not anything as bad as what I have had before. It’s a bottom-level concussion. I’m not going to miss 19 or 20 games.” When I was growing up, a bottom-level concussion was called a “bell ringer”: a blow to the head that is not quite a concussion but also not incidental. It tends to heighten the somatically experienced symptoms already present in an athlete. Lindros sought to downplay the severity of his injury to the media: “Don’t make a big deal out of this injury. It’s not a big thing . . . We’ve got games to win.” Team doctor Gary Dorshimer made reference to an early form of baseline testing⁶ in reference to this hit: “He has no dizziness. His sleep has been good. He has no headaches, and on his exam, everything looked normal. He’s back to his baseline.” Lindros’ teammate John LeClair said, “You definitely worry about it. With it hitting so close to home with his brother [Brett], you really wonder about him and hope everything will be all right. He has always got a constant reminder of what could happen.”⁷

Over the course of four months in early 2000, Lindros received three more bottom-line concussions as a result of incidental contact (e.g. running into teammates or routine body checks). All of a sudden, these so-called bell ringers became career-threatening brain injuries: “You get to a point where you think you’ve got a shot at

⁶ This will be explained in more detail later in the thesis. In simple terms, baseline testing is a neuropsychological assessment typically conducted before an athlete’s season starts. Data is used as a baseline for monitoring concussions against what’s considered normal healthy functioning.

⁷ By this time Eric’s younger brother Brett had retired from the NHL (he retired in 1996 after sustaining two concussions over a one-year period). In the concluding chapter, I will discuss how medical research is looking at siblings like the Lindros brothers as possible test cases to explore genetic predispositions to sustaining mTBI and prolonged recoveries from PCS.

coming back real quick. Then . . . it knocks the wind out of your sails. It was supposed to be a really low-key pass-the-puck-around skate. There was a collision and he tried to go left–right, between my feet, and he just ran into me.”⁸ The day after Lindros received his third bottom-line concussion of the year, rival New Jersey Devils defenseman Scott Stevens delivered these prophetic words: “Yes, if I can hit him, I’m going to hit him when he’s got the puck. I’m not going to go out of my way, I’m not going to hit him dirty, but I have to finish checks, and I know that if he’s got a chance to hit me, he will.”

Just a few weeks later, Stevens delivered one of his “classic, open-ice body checks” knocking Lindros out of the playoffs and forcing him to the sidelines for the next year. The hit was replayed constantly on hockey broadcasts and became etched in the minds of many young fans, including myself and my male athlete informants. The concussed neuroscience student I interviewed mentioned how he can’t stand to watch violent sports anymore:

Neurosci: When I used to watch football and there would be a big hit I would be like, oh awesome hit. Now I physically cringe. You see them now and they are all messed up. It’s good that the culture is changing.

Lindros spoke about some of the key features of daily concussion symptoms, how PCS is a daily process of negotiation, and subsequent concussions would reset the recovery process: “I don’t know what the future holds. I haven’t thought about the future to the point I want to discuss it publicly. I love playing in this city. The fans in this city are spectacular. I’m tired of the whole grind of it all. It’s frustrating. It’s back to square one.”

Lindros’ parents played an active role in his public recovery from concussions, which

⁸ This concussion is similar to the one sustained by the athlete–physician (AP) during an adult recreational ice hockey practice.

was unique for a professional hockey player but was a prominent feature in all my athletes' recovery narratives. From 2001 until his retirement in 2007, Lindros publicly sustained several more concussions. On the day of his retirement, he donated \$5 million to the London Health Sciences Centre in London, Ontario—the same hospital where he was born and where he received concussion therapy.

1.4 MY SUBSEQUENT CONCUSSIONS

In 2001, I sustained my first concussion outside of the sporting field.⁹ I was in a car accident which also caused a major whiplash injury that never really cleared up. The concussion—my third—seemed to make me more susceptible to sustaining subsequent concussions. After this, I started having more foggy days than clear ones. I was referred to a neurologist after about six months. In the appointment, which my mom accompanied me to, the neurologist listed five things in the office and asked me to repeat as many as possible ten minutes later. I didn't get one right and in my mom's mind it was the first indication of lasting cognitive difficulties (memory primarily). A CAT scan was ordered and an EEG was conducted in the office. Nothing showed up on either test and I was told symptoms should recede in time. This was my first indication of the limits of medical imaging technologies in trying to diagnose mTBI.

In December 2002, I was referred to a rehabilitation clinic (occupational therapy) after a workplace concussion. I was put through a battery of tests and they also initiated a sort of graduated return to work (GRTW) protocol that was supposed to reflect the spatiotemporal conditions of an average eight-hour work day: I picked up blocks and put

⁹ The role of the sporting field will be covered in the last section of Chapter 3 through a consideration of P. David Howe's (2004) model of the socially situated injured athlete.

them on shelves until symptom threshold. The results of my neuropsychological testing were sent to my employer and I was cleared to return to work in a modified fashion (I was required to wear a hard hat in the warehouse). This was the first time I considered how others may potentially see me as brain injured.

I felt really out of place at the clinic. Most of the other patients had TBIs.¹⁰ I was the only one with a history of concussion and I felt like they didn't know what to do with me and that I was taking their valuable time away from people who were clearly far worse off than me. This was my first instance of questioning if I belonged to the community of the brain injured or if my symptoms would ever clear up. I started to notice that very few therapies and interventions exist for the concussed and I had already tried everything my family physician could think of at the time.

In another concussion sustained from a car accident in 2004, I was shocked to see the lack of knowledge displayed by the on-scene police officer, who left me alone in my car for what seemed an eternity as I drifted in and out of consciousness. This concussion had the longest window of memory loss (2–4 days before the accident and 10–14 days after) and it essentially marked the end of symptom-free days. Since this concussion, I have constantly had varying levels of symptoms, but I have also stopped trying to intervene so much medically and instead focused on making lifestyle changes. This includes eating better, becoming cognizant of my physical and mental thresholds or limits, and learning how concussion symptoms can build over days, weeks, or even a month (*sedimentation of concussions*). I took a medical leave from university after this accident and also experienced my first retirement from sport. When I returned to

¹⁰ In comparison to mTBI, Traumatic Brain Injury (TBI) is based on an organic pathology which is lacking in mTBI (SM1, SM2).

university over a year later, I chose to study archaeology, which was an interest of mine, because I thought an interesting degree might not be as mentally taxing.

Several years later, despite the persistence of symptoms, I resumed playing baseball (as back catcher) and roller hockey (as goalie) in casual recreational leagues.¹¹ During the first roller hockey playoff game, I was charged by a player and lost consciousness but remained in the game until the end of regulation time. This was my last hockey game as I retired for a second time a week later. In the summer of 2010 shortly after graduating from UBC, I was playing my second season of baseball. Sliding into second base, I was struck in the face by the glove of the second baseman when he was applying the tag. Despite this being my thirteenth concussion, I chose to play the next day and in the first inning I sustained a multi-ligament knee injury. It was clear to me this was a consequence of not staying out of the game and that I incurred the injury in part due to heightened vestibular disturbances (i.e. dizziness). This injury marked my permanent retirement from sports, although I hope to maintain an active lifestyle in the future.

As a master's student at Carleton University, I was introduced to phenomenology and in particular the work of Drew Leder (1990). As I began to acquaint myself with phenomenology, I found myself understanding it by constantly relating it to the dialectical and holistic experience of PCS recovery. I continued getting concussions from random incidents, which resulted in having to take another academic leave of absence after completing the first year of my master's program.

My most recent concussion came as I was beginning to write the theory section of this thesis. I have found that my visual disturbances have increased; light sensitivity and

¹¹ This unwillingness to leave sport and in particular competitive sport will be discussed in Chapter 5.5.

contrasts, the *tracers* are much more pronounced across my field of vision and I am finding that my eyes are darting around uncontrollably when I try to focus my sight. Intentional acts of agency are constricted; they take longer to accomplish with more pain acting them out. I have also noticed that I am starting to lose will-full (intentional) control over my hands (I have been dropping objects constantly) and my feet (I stumble because my feet are not where they are intended to be). I find that the *sedimentation of symptoms* is heightened; symptoms that are exacerbated by embodied engagement build up over days and even weeks culminating in days where I have been unable to function in any productive way. While writing this thesis I had to take five “concussion days” (days off due to somatic symptom intensity) but at no point did I think about retiring from this project, in fact the *presence* of these symptoms motivated me to use them as a means of reminding me of the original intention behind this project and introduction; to express the embodied perspective of the researcher/writer and also to ensure that these experiences and the experiences of the members of my brain injured community can be mobilized in a medically and personally valuable way. I am now at a point where the experience of PCS is so much a part of my everyday lived experience that I am resigned to the fact that I feel like I *know* what my *teleology* is that I will forever experience the cognitive, emotional, and physical symptoms of PCS. This has become the normal state in which I engage with the world and each concussion I sustain in the future will likely make that engagement more painful. Yet I have a strong desire to use my negative experiences with PCS in a positive way, this thesis is my attempt to do so.

1.5 THESIS STRUCTURE

While the introduction has presented key events and experiences from my past, the rest of the thesis will focus on the ethnographic present in which the paper was written. Like all ethnography, this is only meant to provide a partial snapshot of a particular reality, in this case an injury (mTBI) and illness (PCS) experienced by particular individuals (athletes) and some of the people who try to help them (medical professionals¹² [MPs]). I initially planned on focusing primarily on the perspective of athletes with a secondary focus on medical professionals' lived experience of treating concussions followed by a brief media analysis. However, I chose to give equal attention to both embodied perspectives for two reasons. When I began recruiting informants, I assumed I would have a 2:1 ratio of athletes to physicians. Contrary to my expectations, I interviewed an equal number of athletes and MPs. Secondly, the type of athletes I interviewed interacted with MPs more routinely than I had expected. As high-level athletes (see Appendix 2), the political and economic implications of their return to play are much more significant than for recreational athletes (Howe 2004). Their universities made substantial investments in them and MPs are tasked with facilitating athletes' return to work/play/school while also attempting to negate the risk of an early return.

In Chapter 2 (methods), I will further explore how I used my embodied positionality as a concussed researcher as an ethnographic tool to elicit detailed responses on the qualitative dimension of PCS and its management by medical professionals. I will outline the scope of the project, including how I identified each of my informants and the reasons behind withholding certain identifying information. I coded for three

¹² By medical professionals (MPs), I mean family physicians (general practitioners, sports medicine, etc.), therapists (occupational, athletic, etc.), and specialists (neurologist, physiatrist, psychiatrist, etc.).

methodological categories: contrasting analogies, moments of myself being reflexive, and repeating phrases.

Chapter 3 (theory) introduces the reader to Maurice Merleau-Ponty's style of phenomenological existentialism in *Phenomenology of Perception* (1962[1945]), which recognizes the primacy of the physical senses as the starting point of our ongoing embodied communication with the world. Drew Leder's *The Absent Body* (1990) will be introduced as a template from which a phenomenology informed by Merleau-Ponty can be applied to the investigation of chronic pain and illness. P. David Howe (2004) introduces the socially acting embodied athlete and is helpful because he conducts topical ethnographic research with injured high-level athletes. Judith Butler (1988) will be introduced alongside Howe as a means of illustrating the sedimenting nature of lived experience. I employ her work here for both its gendered focus and to recognize that social identities (in conjunction with the social expectations surrounding them) are learned and reinforced through the enactment of intentions within and outside a demarcated sporting field.

Chapter 4 will describe the sociocultural context in which my MPs and athletes found themselves embedded. The chapter is organized according to my informants' responses so as to make the analysis as much from the actor's point of view as possible and to help describe the structures they see as influencing their lives. Both groups were aware of the role that the historic sedimentation of cultural beliefs and practices had on the embodied experience of PCS and its medical management, although MPs by far had more to say about the sociocultural context and historical legacies and as such their responses will outweigh the athletes' in this chapter. MPs spoke about medical structures

with particular emphasis on medical sub-specialties, the education of young physicians and the reeducation of practicing physicians, as well as national and international organizing committees like the ICCS. Athletes tended to speak about academic structures and athletic structures such as accommodations, team dynamics, etc.

Chapter 5 will be devoted to describing the experiences of my athletes' journeys with PCS. I will first describe the primary sensorial "dys-appearances" experienced by these athletes (visual, auditory, communication, and cognition). I will then show how these sensorial disruptions provide the foundation on which engagement with the world (acting out intentions) and others (intersubjectivity) is constricted. This chapter will conclude with a look at how an athlete's playing career is cast into doubt and how the decision to retire is intersubjectively implicated (made by an athlete and informed by others' opinions, in particular their parents'). Due to the episodic nature of chronic pain, an athlete recovering from PCS will always have uncertainty over their condition as the somatically perceived symptoms can constantly ebb and flow from awareness in lived experience though situational engagement with the world. Their decision to retire is always a negotiated one that is always in doubt because of the unknown teleology of this injury.

Chapter 6 will highlight the experiences of MPs who diagnose mTBI and manage¹³ PCS. Due to a historic lack of attention to concussions within medical

¹³ I use the term "manage" over "treat" because there is no silver bullet for treating concussions, as no singular treatment or intervention exists and there is no clearly defined teleological end point (in medical terms you could say the prognosis is uncertain). Management is also the term used by medical professionals to describe the ongoing adjustments and interventions they make to a patient's ways of being in the world as a means of alleviating somatically expressed symptoms and recognizing the patient's active role in recovery in terms of both compliance and recognition of the many individualistic variables that impact recovery. Monitoring is done through a combination of consensus-based findings (e.g. SCAT2, baseline testing, GRTP protocols, etc.) and intuition or feel (termed by MPs as "knowing the patient").

academia and practice, MPs are confronted with an illness that lacks empirically defined interventions, resists what few interventions are available, and has a prognosis that is nearly impossible to determine (the unknowable teleology). Further compounding the MP's task is the fact that this illness is holistic and dialectical. To properly manage PCS, the MP must first attempt to disentangle symptoms through a process of symptom isolation, ranking, and intervention that is constantly revisited and adjusted. As SM2 said, "Treating concussions is more of an art form than a science" and as such managing medical professionals are compelled to approach the concussed athlete as a whole patient that requires the interventions of a phenomenological physician. They saw their patients as socioculturally embodied actors with a social role that informs recovery. Much of the physicians' actions were in direct response to the structures and organizational dynamics of the medical and sporting worlds. As such they actively sought out opportunities to creatively engage with the system as a means of better helping their patients. They stay up-to-date with the most recent research and consensus positions, and they often emphasize the need to better educate their colleagues on these findings. The MPs I spoke to were not the type that I encountered in the past: they were fully willing to admit that so much is partial with mTBI management and that one of their fullest descriptive resources is actually the subjective reports from their patients. Because empirical measures and interventions are particularly lacking with this injury and illness, managing medical professionals are compelled to become *phenomenological physicians* (Baron 1992).

Both groups of informants spoke at equal length about the mainstream media's recent extensive coverage of concussions in professional and amateur athletes and the effect this has had on public discourse and acceptance. Chapter 7 will explore the *moral*

trepidation that has recently emerged around the rates of mTBI in sport and how this anxiety about the future is uniquely felt by the parents of athletes. I employ a modified version of Stanley Cohen's (2002[1972]) *moral panic* model by arguing that when it comes to mTBIs, there is a palpable *moral trepidation* among the public that has not yet but has the potential to reach a state of panic. This trepidation can best be described as an anxiety about an unknown future, which I call the *unknowable teleology* of mTBI. The trepidation around mTBI in youth and professional sports has instigated a social push toward medical research and policy makers (*socially accredited experts*) to propose solutions to this problem. The concluding chapter will seek to highlight some of these solutions that are coming on the horizon that have the potential to spring to the forefront of both the management and monitoring of PCS symptoms in athletes.

The concluding chapter will explore some of the therapies, interventions, and concussion management tools that my MPs and athletes foresee on the horizon. I will explore some avenues where profit-driven actors might try to enter the "Wild West" of concussion treatment: pharmaceuticals, standardized testing equipment and monitoring tools, genetic and hormone testing, and the value of a multi-departmental mTBI rehabilitation centers. I will also highlight the techniques and interventions my MPs and athletes saw as helpful, which range from empirically based medical interventions to recognizing the importance of emotional socialization. Finally, I will raise some phenomenologically based suggestions for medical professionals who deal with concussed athletes.

CHAPTER 2

METHODS

Approaching the Post-Concussed, Encountering Medical Professionals

2.1 SCOPE

In mid-December 2012, I put out my call for participants. I was interested in finding “self-identified athletes over the age of 18 who had sustained two or more concussions.” I was also seeking physicians and medical researchers with an “expressed interest in the treatment of mTBI and PCS.” The interviews were digitally recorded and I transcribed them over a four-week period which included a week of coding for particular phenomenological categories related to the theoretical framework I employ.

In total I interviewed six athletes and five MPs for a total of ten one-on-one interviews (see Appendix 2). The incongruence in the number of interviews is because I interviewed a sports medicine (SM) physician who sustained her first concussion participating in an adult recreational hockey practice. This informant will be referred to as an athlete–physician (AP) and the description of her experiences should be paid special attention throughout the thesis given her dual perspectives. She occupies contrasting and mutually informing social identities as both a concussed athlete and an MP who actively manages concussions in other athletes. Prior to her concussion, she was an accomplished amateur athlete. She was named an All-American gymnast while in college, at which time she also played with a high-level women’s travelling soccer team and later “did some triathlons for fun.” She noted how as a physician, she drew on her experiences as a high-level athlete to better understand where her patients are coming

from. With the additional experience of her concussion, she gained an embodied perspective of an illness that she only understood theoretically before.

I was fortunate to also interview a number of elite athletes including a Paralympic and World Cup alpine (downhill) skier, who I will refer to as Olympian (or Oly).¹⁴ She competed on the Paralympic and World Cup circuit from 1995–2011 and represents the athlete who attained the highest level of competition that I interviewed (the most elite). This athlete has cerebral palsy (CP) and a physical therapist recommended downhill skiing to her at an early age as potentially beneficial for balance and coordination in her legs. While most of the athletes I talked to reported a number of preexisting injuries they saw as “maybe” interacting with their mTBI symptoms, her CP is something that very much interacts with her PCS (in particular vestibular disturbances and motility). She jokingly calls herself “doubly disabled” due to the interplay of her history of concussions with her CP.¹⁵ However, as with all the other athletes, the oft-repeated phrase “all concussions are unique” applies here as well. Her experience of concussions is as informed by her embodied experience, which includes having CP, as my concussions interact with my learning disability—both her CP and my learning disability partially inform the totality of our experiences with PCS.

¹⁴ I personally choose not to distinguish between Olympic and Paralympic. For me, both groups of athletes represent the highest level of amateur athletics and I choose not to make an arbitrary distinction based on the physical body.

¹⁵ The Olympian spoke about the visibility of her CP in that she walks with a very slight limp. I barely noticed this when she walked into the café, but it was one of the first things she drew my attention to. She proceeded to use it as a jumping off point to speak about her CP and skiing as therapy. She also used her visible CP as a contrasting analogy with the invisible nature of PCS. See Davis (2005:153) for a philosophical investigation of the nature of invisible illnesses and their intersubjective implications.

I named all my informants based on their various social *fields*.¹⁶ Athletes are distinguished by their particular sport, while medical professionals are distinguished by their specialization which is based on educational experience and their practical approach to managing mTBI.¹⁷ All my informants had varying levels of concern about anonymity and I confirmed with each of them how they would be identified. I will take a moment now to describe how I identified the remaining four of six athletes, while the MPs' identifiers will be explained in Chapter 4 when speaking about medical sub-specialties.

The Nordic skier (Nordic) competes in cross-country skiing as an undergraduate student in psychology. When I interviewed her she was sitting out in her third year of eligibility, she was motivated to return to her sport in her fourth and final year. In the summer she is an outdoors/rafting guide so she also had a motivation to return to that field of play. The hockey player (HP) played defence in a "rough and tumble style" his favorite contemporary hockey player and the one he models his own game around is Shea

¹⁶ The term *field* has particular connotations within the social theory inspired by Pierre Bourdieu and mobilized by P. David Howe in the sporting context (2004:62–66). This will be explained in greater detail in Chapter 3. For now, it should be noted that the organization of the social fields of different sports will have implications for the lived experience of PCS and the athlete's ability to return to play. For example, it is understood that the ice hockey field is characterized as violent and therefore carries a higher likelihood of players sustaining a subsequent concussion on return, which is made more likely depending on their position in the field (e.g. defence, goalie, etc.). However, for my athletes who ski, they must consider other factors such as glare of sunshine off the snow, and the Olympian runs the risk of crashing in a downhill event. Risk is always present but varies in intensity and form depending on the sporting field. Because I interviewed athletes with histories of concussions, their propensity to sustain subsequent concussions must be considered in relation to their specific sporting field. I wanted to emphasize the risky nature of playing sports and how social engagement with the world is implicated when we think about the embodied experience of chronic illness.

¹⁷ The MPs were comfortable with being designated by their medical specialization. If they were affiliated with a university, they requested this information be withheld. I had to be particularly cautious with identifying the specialization of the informant I call RCPS (Royal College of Physicians and Surgeons of Canada), which is rare enough to be identifiable.

Webber¹⁸ for both his physicality (aggressive but within the confines of the rules) and his leadership qualities (the hockey player is an alternate captain on his team and as such his intersubjective relations with his teammates takes particular significance for him). He had two years left in his eligibility. Before attending university, he played major junior hockey (Ontario Hockey League or OHL) where he sustained a herniated disc injury which he frequently used as a contrasting analogy to his recovery from 16 concussions, which is the most concussions sustained by any of my informants.

The rugby player (Rugby) has had a handful of concussions. He's in his early twenties and had to miss his final year of hockey because of concussions and in hopes of being healthy enough to play varsity rugby at a Canadian university. He didn't make this team and when I spoke to him he was still a university student but was not playing on a team. I still refer to him as Rugby because he still has aspirations to play and because it's his primary sport. Playing both hockey and rugby through his adolescence made him doubly susceptible to sustaining concussions. The neuroscience student (Neurosci) is not identified by his athletic field because like RCPS, his sport is so rare that identification would be very likely. I thought the environment in which his sport occurs would uniquely exacerbate his symptoms, but to my surprise he didn't see a correlation. Rather, he emphasized how his PCS inhibits his ability to do athletic training not specific to his sport. I found his undergraduate degree in neuroscience an interesting factor in his

¹⁸ I considered naming my athletes after their own favorite athletes. I thought this would encourage my athletes to draw metaphorical connections between the traits symbolically embodied by these professional athletes and how they sought to personify them in their athletic endeavors. However, I decided to switch my system of identification to the sports themselves as I realized their *fields* of play (what sport they play and the level of risk associated with engagement in that sport) and their spatiotemporal position (at what point are they in their academic and athletic careers) could be more clearly reflected if I utilized a sport-specific identification system.

recovery. I assumed that like the athlete–physician, he might have a deeper understanding of his brain injury because of his specific education.

2.2 INTERVIEW METHODS: CAPTURING EXPERIENCE

My interviews were semi-structured and open-ended, allowing for elaboration and connection-making between what the participants were saying at the moment and what they had said earlier in the interview. I entered each interview with a list of six to eight questions (one set for the athletes and one for the MPs) that would broadly touch on the following themes: intersubjectivity (parents, team, coaches, and MPs), emotions, retirement decisions, interventions and coping mechanisms, structures and organization (medical, academic, and also general social or cultural perceptions), and a question about the media. I wanted to ask similar questions in a thematic sense but phrased in a way that would be applicable to both sets of participants while also general enough to be able to be asked at different times and different ways in order to evoke elaboration, particularly with the athletes.

At the beginning of each interview I highlighted the need for qualitative research to address the gap in literature on mTBI and PCS in terms of the lived experience of sufferers and what it is like to medically manage mTBI and PCS symptoms. With my athletes, I noted the lack of case studies available to medicine and how for a long time our experiences were being shunted to the side in favour of the accumulation of

normative statistics.¹⁹ I told them I felt the personal experiences of individual sufferers were missing and it could help medicine to focus their research and practices around experientially based interventions and hopefully help others with PCS who might feel their condition is unique. With my MPs, I wanted to see how they creatively engaged with medical academia and structures as a means of exploring individual or group acts of agency.

I recognized that follow-up questions would be important in these interviews. In the athlete interviews I tried to note when their thoughts might have strayed in another direction or when they forgot what they were saying as short-term memory problems and communication difficulties commonly accompany mTBI. My follow-up questions for MPs were aimed at garnering more specific information or elaboration. The MPs were surprisingly candid about their opinions surrounding “medicine’s approach” to mTBI and PCS both currently and in terms of the historic legacy.²⁰ In reality most of this information emerged organically within the interviews and it should be noted for its perceived importance to the MPs that they would speak on these topics extensively.

I tried to arrange to meet with the MPs in a semi-private space in an effort to allow them to feel like they could open up about political and ethical dilemmas confronted when approaching mTBI and PCS. Two MPs (SM1 and AT) spoke to me in a

¹⁹ The notable exceptions to this lack of qualitative or experientially based accounts of mTBI sufferers are Echlin (2010:1–13) and Lindemann (2001). Echlin’s ten case studies and commentary were contained in the appendix to an article published in a special edition issue of a neurological journal. It signaled to me that qualitative research is possible and likely beneficial for medical practice. Kate Lindemann is a philosopher who speaks reflexively about her own experience acquiring what she called an adult-onset head injury (mTBI) and the lived experience implications (changes to life). This paper signaled to me the reflexive possibilities of my thesis.

²⁰ Often when speaking about the historic legacy of medicine, MPs would personalize it by relating it to what it was like for them in medical school or when they started their practice, and how they have seen attitudes change while they have been practicing medicine.

public space no more than thirty feet from their respective offices. SM2 met me in an empty pub, the AP interview was conducted over the phone, and the RCPS kindly invited me into his home. Regardless of where the interview took place, each of the MPs were surprisingly candid about their opinions on medical research and in particular the actions (or inaction) of their colleagues.

Interviewing athletes with somatically felt PCS symptoms presented a unique set of challenges in terms of accommodation. I tried to actively eliminate stimuli that I assumed, based on my own experiences, could precipitate their symptoms. I suggested quiet environments that were somewhat dimmed in lighting, but ironically it seemed each in-person interview I had was in a noisy, busy, and brightly lit space. I conducted two phone interviews (AP and Rugby), which in hindsight might have been a good option for my athletes who had particularly severe symptoms. Phone interviews allow each party to be in a space that is concussively comfortable.²¹

2.3 REFLEXIVITY, CONTRASTING ANALOGIES, AND REPEATS

As mentioned, I specifically coded for three methodological categories: moments where I was being reflexive in the interview (coded as “reflexivity”), analogies or hypothetical examples (coded as “contrasting analogies”), and repeated phrases or key words (coded as “repeats”).

Reflexivity should be seen as a theoretical orientation and as a method that can be selectively employed within ethnographic fieldwork as a means of both creating an

²¹ By this I mean free of incoming stimuli that exacerbates an individual’s symptoms in unique ways. Those with PCS know how and why a space is comfortable and a phone interview would have allowed more of my athletes some level of control over their sensorial environment.

affinity based on shared experience between the researcher and the informant and also as a means of eliciting responses that have more qualitative depth.²² Positing questions rooted in my own experiences was a means of gaining more depth and specificity.²³ Rosaldo (1993[1989]) opens each chapter of his book with a reflexive anecdote from his own life and throughout each chapter he continues to mobilize personal experiences as a means of critically engaging with sociocultural theory and for illustrative purposes. I hoped that my personal history with mTBI would quickly create a close affinity founded on shared embodied experiences between the athletes and myself, which was a similar process used by Rosaldo to get closer to his informants (“the Illongot headhunters” from the northern Philippines).

I was also aware that my extensive embodied knowledge coupled with my preliminary research on existing medical literature had the potential to create a communication barrier between myself and the MPs. I explicitly told the MPs that I was not trying to be an “overly critical social scientist.” I told them I knew about the historic lack of medical research but that I appreciated recent efforts among the medical community to correct this. I also communicated that I wanted to focus on what MPs do differently to help athletes with PCS as a means of contrasting their approach with the structural environment in which they find themselves embedded. The position of the

²² “Ethnography of course means many things. Minimally, however, it has always meant the attempt to understand another life world using the self—as much of it as possible—as the instrument of knowing. As is by now widely known, ethnography has come under a great deal of internal criticism within anthropology over the past decade or so, but this minimal definition has not for the most part been challenged . . . that the ethnographic stance (as we may call it) is as much an intellectual (and moral) positionality, a constructive and interpretive mode, as it is a bodily process in space and time” (Ortner 1995:173).

²³ Drawing from Arthur Kleinman, who spoke of the various informing aspects of verbalizing embodied illness experience and *performance theory*, Ong et al. argue that “interviews are performances and require an audience with whom a shared experience and understanding is created. In this sense, reflexivity allows a material presence to words and language, and as such they have an effect on people” (2004:534).

researcher in relation to the informant will necessarily influence findings: it is something that we need to remain cognizant of theoretically and is also a method that can be creatively deployed in the field.

The second methodological theme I coded for was contrasting analogies. These were most often used by the MPs as a means of striking a comparison between the nature of treating and experiencing PCS versus a more conventional sports injury such as broken limbs and ligament tears. These comparisons were meant to communicate the challenges MPs face in treating a subjective injury²⁴ with few objective or empirically supported interventions versus treating a well-researched injury with a clear pathology.²⁵ Contrasting analogies were also used by MPs to describe individual cases they have had in the past or are currently treating. These examples took a particular narrative form that reflected a medical case study in format and structure,²⁶ but would be used to describe some of the more embodied challenges of recovering and treating a concussion (e.g. emotions, interpersonal politics, lifestyle changes, and decisions about retirement). Each example given by a MP would quickly be checked with a counterexample, reflecting the personalized nature of PCS as well as the ongoing exploration and negotiation process

²⁴ The difference between subjective and objective injuries is based on available medical imaging technologies. For example, a broken limb can literally be seen on an X-ray, whereas mTBI and PCS are entirely based on subjective reporting (perspective-based on the patient's positionality). Attempts are underway to cast mTBI in a more objective manner; however, like most spectrum conditions, mTBI continues to resist empirically based medical imaging technologies (objectification).

²⁵ A clear pathology would include diagnostic categories and tools, generally agreed upon interventions that are empirically supported, and a prognosis that is made clear through normative statistics and medical imaging technologies (Davis 2005).

²⁶ See Good (1994) and Good and DeVecchio Good (2000) for their detailed ethnographic work on how physicians learn to speak about and envision the ill patient (mechanistic rendering, devoid of emotional attachment, socially and culturally unsituated, etc). My MPs often rendered a narration of a hypothetical case example in a similar way to the medical publications I encountered, but when speaking about their *actions* they often reflected a holistic dialectic approach. Athletes likewise delivered succinct renderings of injury histories (concussive events and symptoms) in a rapid, practiced, and medically relevant fashion.

undertaken by MPs seeking to understand the embodied experience of others. The AT, for instance, bemoaned the fact that “young typically male athletes” had a harder time coming to grips with the severity of concussions in the short- and long-term and were more likely to engage in reckless behavior that puts them at risk of either delaying recovery or sustaining additional concussions.²⁷ However, she immediately provided a counterexample of some “young female athletes” being just as reckless as their male counterparts. She also provided examples of both male and female athletes being really “smart” about their recovery and in some cases being “overly conservative” about their decision to return to play. Both groups of informants employed contrasting analogies as a descriptive method to help them elaborate on an illness that often defies our efforts at articulation due to its embodied and holistic nature.

The third methodological theme I coded for was repeated phrases or keywords (“repeats”). By coding for repeated phrases and keywords I was able to locate the “prevailing wisdom” among MPs and the extent to which athletes embodied this through their communicative acts (Ong et al. 2004). In another sense, repeated phrases and keywords signaled to me where the topical emphasis should be placed and how the thesis should be structured. “All concussions are unique” and “every recovery is different” were the two most commonly repeated phrases by the MPs and were echoed by most of the

²⁷ There is a palpable trepidation emerging over the health and safety of young people who the public sees as reckless for their sense of invincibility. This moralizing undercurrent is well-reflected in Sharon Kirkey’s (2013) article which reports on recent medical research by Dr. Gabriela Ilie and her colleagues (2013:2550–2552) that “finds” that young people after bouts of drinking or recreational drug use are more likely to sustain a brain injury. This is the closest reflection of a moral panic sub-group that would traditionally be covered by Stanley Cohen’s model; reckless young people engaging in destructive and violent actions in an uncontrollable fashion that has repercussions on social cohesion. In this thesis we will use his model as a means of exploring moral transgressions within the sporting field which carries its own set of culturally (historic) informed beliefs.

athletes. Athletes repeatedly described PCS recovery as frustrating, isolating, and fear-inducing (specifically anxiety of an unknown future in terms of health and functioning, which I will call trepidation). After my third interview (at that point SM1, SM2, and HP), I revisited my questions and formulated two additional questions that would further explore the above mentioned themes and keywords.²⁸ By intensely focusing on what was said by my informants, I was able to explicitly structure my thesis on what was communicated to me as being important to them, adding to the partial actors-first perspective that I was seeking to describe.

A dialectical orientation (reflexively accounting for positionality) established in ethnographic fieldwork is crucial to begin to account for the mutually informing intersubjective encounter between self (researcher) and others (informants) (Ong et al. 2004:534). Phenomenology is a descriptive philosophy that seeks to communicate the experience of others, which is a process that's always understood to be partial. It is further acknowledged that describing one's own lived experience is also partial due to the limited descriptive possibilities of language systems. The impetus of leaning on my own experience within the interview process was to begin to form an experiential bridge to aid in the communicative process. The interviews with the athletes in particular took a dialectical form where we both mobilized our own experiences and found moments that were largely shared and others that were personally unique. My presence will be backgrounded in the following descriptions, allowing the experiences of my participants (both MPs and athletes) to take the foreground. I seek to begin to fill the lack of

²⁸ The additional questions were about retirement from the athletes' perspectives and how MPs broach this subject and the role parents play within these decisions. Many athletes, myself included, experience a number of retirements and reentries to sport. This process is outlined in Chapter 5.

qualitative research on PCS, its management and the unique role that the media has played in fanning the flames of this *moral trepidation*. I hope that by providing a partial actor-first perspective (Ortner 1984), I will begin to crystallize some of the experiences of this so-called invisible injury so that MPs are presented with additional avenues of intervention and other concussed athletes don't feel like their experiences are singularly unique.

CHAPTER 3

THEORY

To Be in the World

The fact that mind and body are fully one while pain is present points to a fundamental issue: namely, that physical experience is inseparable from its cognitive and emotional significance. It is for this reason that pain can be used to describe not only physical agony but emotional turmoil and spiritual suffering.

P. David Howe (2004:69)

3.1 INTRODUCTION

mTBI is a dialectical illness, both for those who suffer from it and for the medical professionals who attempt to manage the myriad of somatically experienced symptoms of PCS.²⁹ Suffering an mTBI and the prolonged recovery that may accompany it represents an illness that seemingly affects all aspects of embodied lived experience and has symptoms that are worsened through engagement with the world. I see the concepts of dialectic and holism as being interwoven within phenomenology but also reflected in the lived experience of the athletes and MPs in my research. The responses I collected reveal

²⁹ The Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) published by the American Psychiatric Association has two different disorders classified: PCS and PCD (Postconcussional Disorder). See Appendix 1 for an overview of these disorders. McCauley et al. (2005) compared the two diagnostic criteria and found “no substantial pattern of differences between the DSM-IV and ICD-10 in the outcome domains of psychiatric symptoms and disorders, social and community integration, health-related quality of life, or global outcome as measured by the Glasgow Outcome Scale-Extended. In spite of significant differences between the two diagnostic criteria sets and different incidence rates for PCD/PCS, outcome in all measured domains was very similar at 3 months post-injury.” For the purposes of the thesis I will employ PCS as it is the acronym most commonly employed in everyday vernacular and by my informants.

this dialectic–holistic phenomenon that was conveyed in the specific language they used and in the connections they made across phenomenological categories.

This section will follow a three-fold progression from the embodied individual, to the individual in pain, and conclude with a description of the socioculturally enmeshed injured sporting actor. I will begin with a brief overview of phenomenology and how the concepts of embodiment and being in the world relate to the dialectic and holism through a reading of Maurice Merleau-Ponty's *Phenomenology of Perception* (1962[1945]). I will carry these concepts through to a topical application of this brand of phenomenology to pain and chronic pain with Drew Leder's *The Absent Body* (1990). Leder is a phenomenological philosopher and a medical doctor who applied Merleau-Ponty's work (among others) to the study of the experiential nature of chronic pain. As both Leder and Merleau-Ponty speak in general terms, I will introduce some of my ethnographic findings where helpful as a means of both grounding these philosophers and promoting the applicability of both writers in beginning to apprehend the experience of PCS. The third theorist I will introduce is P. David Howe and his book *Sport, Professionalism and Pain: Ethnographies of Injury and Risk* (2004). Howe is a social anthropologist who conducted ethnographic research with professional and elite amateur athletes from various sports. He has an expressed interest in examining the social forces that influence international high-level athletics through an application of Pierre Bourdieu's theory of practice, which he augments with Merleau-Ponty and Leder to show how the socioculturally situated "athletic body" is also a sensing body that is as much influenced by outside social forces as it is a generator of society and culture through intersubjective relations. The generative force of the socially embodied cultural body is a dialectical process between structure and

agency. Alongside Howe I will introduce Judith Butler (1988) to help reinforce the idea that injured athletes and their managing physicians are challenging and recasting social and cultural norms of behavior within intersubjective encounters. Butler evokes Simone de Beauvoir, a contemporary of Merleau-Ponty, who argues that socially enmeshed actors create and reinforce a particular type of identity through their actions out in the world (and in reaction to others), which is based on personal and cultural legacies that build up in a sedimenting fashion. The athlete's inability to enact their sedimented histories (*Hexis*³⁰) while somatically experiencing the problematic appearance of their bodies is existentially problematic to one's sense of self and place in the world.

3.2 MERLEAU-PONTY: EMBODIMENT AND LIVED EXPERIENCE

The body is the vehicle of being in the world, and having a body is, for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continually committed to them. In the self-evidence of this complete world in which manipulatable objects still figure, in the force of their movement which still flows towards him, and in which is still present the project of writing or playing the piano, the cripple still finds the guarantee of his wholeness. [Merleau-Ponty 1962(1945):94]

Maurice Merleau-Ponty (1908–1961) published *Phenomenology of Perception* in 1945. His philosophical influences included Karl Marx, Martin Heidegger, and Edmund

³⁰ “For Bourdieu, an agent’s habitus is the embodied sediment of every encounter they have had with the social world. It can be used, in the present, to mould perception, thought and action to the extent that it gains an important role that influences the decisions that an agent might make in future encounters. In this sense, actors can be seen not simply to follow rules but also to bend them much in the same way as is propounded in the work of Merleau-Ponty (1962 [1945]). Dispositions, or more generally forms of social competence, may be seen as a product of well-established social environments. In other words, while society may be seen as shaping agents, it needs the improvisations of the individual from time to time if it is going to evolve. Therefore, in the post-industrial society in which we live, it is important to see the body as much a product of the self as it is of society” (Howe 2004:59).

Husserl, and his two most prominent contemporaries were Jean-Paul Sartre and Simone de Beauvoir. Phenomenology is both a theoretical orientation and a method. The orientation is one that sees existence, having a sense of personal identity (self), as embodied. The method seeks to investigate embodied identity through an examination of sensorial perception (sight, hearing, taste, smell, touch, and motility) cast as the primary means through which we engage with the world.³¹ Our embodied sensorial communication with the world (material objects and the social or intersubjective world, i.e. our interactions with the people in it) and its communication with us is a *dialectic process* (it is ongoing and mutually informing). Our sense of being *embodied* (to both have a material body and to be able to exert control over it in acting out goals [*intentions*] and making adjustments) is used here to describe the holistic encapsulation of the dialectic processes that make up our sense of embodied self. We perceive the world through the physical senses and use our corporeal bodies³² to enact our intentions (goals or plans for the future). Enacting intentions involves moving through space over certain periods of time (space–time) and is dependent on our embodied pragmatic ability to do

³¹ “The difficulty of finding full, rich accounts of the experience of important forms of illness is startling . . . Research that attends only to semiotic structures or social processes seem to miss the essence of what gives illness its mystery and human suffering its potency.” (Good 1994: 117) While recognizing that the description of our own or others’ experiences is fragmentary and partial, as social scientists we can still strive toward providing experience rich accounts of illness and the meanings that are ascribed by individuals into their pragmatic actions, out I the world. This allows us to provide a partial, yet *thick*, actors-first perspective (Ortner 1984, Geertz 1973).

³² Thomas Ots employs two German terms: *Leib* (life, person, and self) and *Körper* (the material body, the corpse, or corporeal body). Ots describes what it means to be in the world: “it is through *my Leib* that I am inserted into this world; I am *Leib-in-the-world*” (Ots 1994:117). It is understood that to be embodied (to have *Leib*) is dependent on an ongoing and mutually informing communicative process between the *Körper* and intentions. The somatic body is a term I use to refer to the sensorial experience of having a body that is able to facilitate this communicative process between the self and the world.

so.³³ Our present context is understood to be informed by our own past experiences (memories) and our future goals. From completing a PhD to simply going to the grocery store, intentions big and small tend to inform one another in a holistic and dialectical fashion.

The key to understanding phenomenology and its applicability to a medical anthropological project of this nature is in understanding the notion of dialectics and the concept of holism. I tend to understand dialectics in the sense of the reciprocal exchange (communication) between two opposing extremes that are always and continuously communicating with one another. Mind–body³⁴ is a foundational dialectic in phenomenology:

The union of soul and body is not an amalgamation between two mutually external terms, subject and object, brought about by arbitrary decree. It is enacted at every instant in the movement of existence. [Merleau-Ponty 1962:102]

We are made up of the collection of dialectical relationships that is at times deeply sedimented and at others open to scrutiny and modification through thought and action (this is the process of identity formation taken up by Judith Butler in this chapter). Being embodied means that we are both constrained and free: we are constrained by our bodies but it is our bodies that are the vehicle of intentions. When the body is in pain, injured, or ill (dys-functional), our inability to enact our intentions in a way we feel we should

³³ Merleau-Ponty uses the example of the *phantom limb* phenomenon experienced by amputees. Not only do patients feel the presence (material) of the removed limb, but often they will reach for or step with a limb that is no longer there. This example is used to explain many aspects of his phenomenological method. Here it points to the how the state of our bodies will have a necessary impact on intentional possibility (*agency*).

³⁴ “Enter phenomenology, a discipline for which the relationship between body and self becomes a central and explicit problem. The body is not divorced from the self . . . rather, the body is considered in constant and intimate reciprocal relationship to the self” (Baron 1992:40).

(based on past experiences) is emotionally problematic. The body in illness and injury is compelled to engage with the world in a modified fashion that takes into consideration the changes to embodied engagement with the world going forward. The individual, often with the help of others, seeks to return to a pre-objective engagement with the world where one does not need to consider bodily functionality prior to intentional acts.

Rene Descartes (1596–1650) was a French philosopher who is largely responsible for the formulation and promotion of the scientific method. What would come to be known as Cartesian dualism is a rational organization of the world into contrasting oppositions that are cast in separate isolation from one another—they do not communicate. One of the central binary oppositions in this formulation is mind and body, where the mind is seen as immaterial and the body is seen as a material object:

Cartesian categories lead to systematic mis-description of human activity. Bodily acts are not merely mechanical. Nor are all acts with cognitional and volitional status truly “mental”, as Descartes envisioned them, arising out of explicit judgments and acts of will . . . Rather, an examination of experience reveals that it is the body which first “understands” the world, grasping its surroundings and moving to fulfill its goals. In phenomenological terms, the body is not just a caused mechanism, but an “intentional” entity always directed toward an object pole, a world. [Leder 1984:31]

This primary division allowed science (including medical science) to break from the church, which was seen as engaging with domain of the immaterial realm. Descartes’ scientific method of empirically investigating the material elements of the world utilizing the physical senses, coupled with a process where hypotheses could be proposed and revisited based on empirical findings, very much reflects the embodied process of being in the world; intentionally engaging with material objects, apprehending the results through the senses, and readjusting intentions going forward.

Merleau-Ponty's promotion of his dialectic–holistic philosophy (informed by Gestalt psychology³⁵) can be seen as his political project. He seeks to challenge the Cartesian legacy in medicine and by extension what he terms classical psychology:

Thus the permanence of one's own body, if only classical psychology had analysed it, might have led it to the body no longer conceived as an object of the world, but as our means of communication with it, to the world no longer conceived as a collection of determinate objects, but as the horizon latent in all our experience and itself ever-present and anterior to every determining thought. [Merleau-Ponty 1945(1962):106]

Merleau-Ponty instead wanted to encourage the promotion of a holistic rendering of the body as lived, allowing medicine and psychology to recognize that the individual is situated and informed by a specific sociocultural world that is simultaneously mental and physical, social and personal, structured and open-ended.

A long-standing critique of western medicine is that it's overly committed to the material or objective side of the illness experience, as opposed to psychology's commitment to the immaterial mind, which uses empirical measures and interventions with the aim of eliminating organic pathology in the material body. In the most extreme manifestation, treating physicians approach the ill patient in a hyper-materialistic fashion as broken machines in need of repair, with little to no consideration given to emotions, cultural norms, or simple manners. I would suggest this process of objectifying the ill as a means of empirically understanding disease pathology at the expense of subjective

³⁵ The background–foreground mutually informing nature of perception (and by extension embodiment) is derived from Gestalt psychology. It is the foundation of the dialectical nature of perception as embodiment. Merleau-Ponty uses an example of a painting to explain gestalt's figure–ground organization. A painting has a background and a foreground. If one is told to look at the background, the foreground becomes the background. The background and foreground are communicating with each other and they are intimately interwoven. We will see below how Leder (1990) employs this concept to speak of the ecstatic–recessive nature of the body in conscious perception—an ongoing dialectic process that informs the totality of being in the world.

considerations is a dialectical process. It is never the case that MPs are entirely objective or rely solely on empirical measures. Rather, it is always a blending process of subjective and objective approaches to patient care. With mTBI and PCS the managing MPs I spoke to were keenly aware of the dialectic approach demanded of them and the holistic embodied experience of disruptions to lived experience that is characteristic of PCS for athletes. My MPs are compelled to approach the concussed athlete in a *whole patient*, phenomenological manner due to a combination of a historic lack of attention devoted by medical research and academia to mTBIs and because the empirically based, at times technologically constrained, visually based diagnostic capacities are confounded by this allusive injury and illness.

3.3 THE SPATIOTEMPORAL MODE OF EXISTENCE

Within the concept of embodiment is an implied concern with understanding the relationship between space (your ability or agency to manipulate and travel through the world) and time (the length of time it takes to perform actions). Both our ability to physically move our bodies through space over time (motility) and the style in which we move our bodies is informed by the sedimentation of personal experience and the enactment of sociocultural norms (Butler 1988). The perception of the spatiotemporal landscape is dialectically informed by our embodied state of being. An ongoing manifestation of this is my athletes' desire to engage in activities previously considered normal and done with relative ease, such as playing competitive sports or studying for exams. Athletes with PCS typically undergo a process of sectioning off their days into manageable sections (based on space–time informed intentions that have been enacted in

the past while somatically experiencing PCS). Enacting more intentions (doing more things, performing more actions) or more strenuous actions tends to precipitate their somatically experienced symptoms. Figuring out “what makes things worse” and “what make things better” is an ongoing process that is continuously reflected on in an effort to exert some control over PCS’ somatic recurring presence.

Our perception of the spatiotemporal landscape and our ability to move through it is largely based on our sedimented memories of executing similar actions in the past and is driven by our goals for the future:

The fusion of soul and body in the act, the sublimation of biological into personal existence, and of the natural into the cultural world is made both possible and precarious by the temporal structure of our existence. Every present grasps, by stages, through its horizon of immediate past and near future, the totality of possible time. [Merleau-Ponty 1962:97]

One’s perceptions of the future are influenced by having a history of concussions and may be more pessimistic if PCS symptoms continue to be experienced during everyday engagement with the world. The number of mTBIs sustained, the time frame in which they occurred, and an athlete’s future plans are all considered when making RTP or retirement decisions. The MPs’ future intentions are also influenced by past actions at a more societal level (historical legacies) when they constantly raised the need to educate other physicians about the severity of mTBI. According to my MPs, there continues to be a high number of physicians without a personal interest in mTBI research or treatment of

PCS. This is due to physicians who are simply old fashioned, are too busy to educate themselves, or fear the perceived financial burden of treating mTBI.³⁶

3.4 DREW LEDER AND THE PROBLEMATIC APPEARANCE OF THE BODY

Drew Leder (1990) positions his investigation of the body in pain as a dialectic process that is organized around Gestalt psychology's figure-ground model of perception. The body (or parts) constantly fades in and out of conscious awareness through our healthy everyday engagement with the world: "As ecstatic, the body projects itself into the world. As recessive, the body falls back from its own conscious perception and control" (Leder 1990:69). At times regions of the body are backgrounded from our awareness, while at other times they spring to the forefront.³⁷ Our ability to largely background the totality of our corporeal body from active perception allows us to engage with the world in a pre-objective, unencumbered manner.

Leder points out that the regions of our body which recede furthest from our awareness tend to be some of the more crucial parts necessary for sustaining life and as such their appearance will be more troublesome the more deeply buried it is in everyday perception. The brain (as body part) is a perfect working example to explain this. Normally we do not think of how our brain is implicated in engaging with the world. We become aware of the presence of our material brain (the brain as an object open to our

³⁶ Many physicians shy away from mTBI cases due to financial and time burdens associated with its management. More on this highly personal barrier to wide-scale reeducation campaigns of physicians will follow in Chapters 4 and 6.

³⁷ Leder also uses this orientation as a means of describing our *from-to* communication with the world (Leder 1990:15): we communicate *from* the body *to* the world in "healthy functioning". In pain, illness, and disease the afflicted part or region presents itself to our awareness, inhibiting our pre-objective engagement with the world and demanding that we reorient our intentions toward making the part or region disappear.

perception and exploration) when it is in a dysfunctional state, such as after pulling an all-nighter writing a term paper). When our brain problematically “appears”³⁸ we attempt interventions to make it fade back; perhaps we go to bed early the next day or try or vow to get our writing done earlier in the future. Sometimes the brain is summoned to our awareness in a less problematic way, such as when we are trying to recall facts. If this inability to recall a memory persists over time, it will become increasingly emotionally problematic. When experiencing a brain injury many aspects of our embodied engagement with the world are disrupted due to the primacy of the brain to sensorial perception and the primacy of sensorial perception to embodied engagement with the world.

When the appearance of a body part or region is accompanied by pain, especially if it is a part that is typically deeply buried from our perception, it makes a *telic* demand for a reorientation of our intentions from the world onto our bodies:

The sensory intensification [pain] brings into play, combined with an episodic temporality and affective call establishes its particular hold upon our attention. Yet pain, like any other experiential mode, cannot be reduced to a set of immediate sensory qualities. It is ultimately a manner of being-in-the-world. As such, pain reorganizes our lived space and time, our relations with others and with ourselves. . . . Here pain effects what I will term an *intentional disruption* and a *spatiotemporal constriction*. Correlatively, the painful body emerges as an *alien presence* that exerts upon us a *telic demand* for its removal. [Leder 1990:73]

In Greek the prefix *dys* translates to “ill” or “bad”, whereas the Latin prefix *dis* means “away from”. When Leder speaks of the *dys*-appearing body he is emphasizing the

³⁸ Leder notes that the appearance of the body to our perception is *episodic* in presence, intensity, and duration. Even in chronic pain (or persistent PCS) the expression of symptoms tends to be episodic. Not only are they evoked through episodic engagement with the world, they also persist for variable lengths of time and seem to defy interventions (controlling the length and intensity).

emotionally aversive nature of pain that accompanies the episodic appearance of the corporeal body to our conscious awareness. It is pains' affective quality that elicits the telic demand on our attention, away from the world and toward the body, undergoing a *hermeneutic quest* for its source, meaning, and removal which is understood to be ongoing and marked by moments of regress from and progress toward a teleological end point.³⁹ Our intentions, which are generally organized in a from-to structure, become disrupted when the body is presented not as an incorporated holistic aspect of our sense of self but as an object presented to our intentional perception that can and needs to be scrutinized.

3.4.1 SPATIOTEMPORAL CONSTRICTION

In moments of bodily dys-appearance there is a constriction in how we experience the passage of time and how we negotiate space (motility) (Leder 1990:72). In chronic pain we experience a congealment toward the present of both our past (which includes remembrances of a pain-free past) and our future goals (both of which are informed by our perceived current embodied state). Our intentions, which are future-oriented, are reorganized closer to the present with the expressed goal of being free from pain, right now.

³⁹ Typically the teleological goal is bodily disappearance (removal of pain and illness). With many chronic conditions like chronic back pain (Jackson 1994) the persistent presence of the pain (over time, typically years) often mean that all viable medical interventions including many non-western practices (e.g. acupuncture was sought out by some of my informants) have been tried but have not succeeded in alleviating the pain or even empirically identifying its source. Chronic pain patients like my informants undergo a process over time of subjectifying their pain, making it part of themselves, their sense of self, in hopes of making sense of its continued existence. However, the episodic nature of chronic pain conditions and PCS means that our corporeal bodies are constantly being presented to conscious awareness reminding us of our emotionally problematic dysfunctional embodied state of communication with the world.

Leder suggests that chronic pain represents a holistically embodied mode of being in the world that is highlighted by moments of acute pain which spring from a background of general persistent pain.⁴⁰ The episodic nature of pain “is not a constant accompaniment of normal bodily activity but tends to arise at times of unusual stress or trauma. . . . Even relatively constant pains participate in this episodic temporality via their continual reassertion of presence” (Leder 1990:72). Living with chronic PCS is episodic in the sense that there are general background symptoms (e.g. headaches and feeling slowed down cognitively) from which acute symptoms emerge instigated by engagement with the world. The *hermeneutic quest* undergone by athletes with PCS and in other chronic pain sufferers is a continual process of seeking to identify the sources of episodic pain (i.e. what was it in the world that made my symptoms worse?) and a process attempting interventions toward the alleviation of bodily dys-appearance and a self-reflexive questioning process about how this chronic condition will impact your life (future plans).

Not only will episodic moments of dizziness, for example, trigger mini-hermeneutic moments of questioning the origin and meaning behind a felt symptom, but it also serves to remind us of our concussion history and how future engagement with the world needs to be adjusted so as to avoid the risk of sustaining another concussion and exacerbating symptoms. The condition makes this an existential question that reaches far beyond physically or cognitively experienced pain; it is a whole life situation where changes to lived experience are lasting as we go forward trying to engage with the world

⁴⁰ Leder utilizes the term pain to describe the presence of an emotionally aversive somatic experience. I utilize the same definition of pain and would add that pain should always be seen as synonymous with *symptoms* of PCS.

in a concussively safe manner. While the corporeal and cognitive dys-appearances figure prominently in mTBI recovery and treatment, it is the social ramifications of concussions that my athletes tended to raise with at least equal frequency as responses to questions about embodied symptoms. I will turn now to P. David Howe (2004) and Judith Butler (1988) for a consideration of how actors are socially informed.

3.5 THE SOCIALLY ACTING ATHLETE

P. David Howe (2004) is a British social anthropologist who situates his ethnographic analysis of the injured professional sporting body within the phenomenological frameworks of Pierre Bourdieu, Maurice Merleau-Ponty, Michel Foucault, and Drew Leder. He mobilizes these theorists to ethnographically investigate the embodied experience of being a high-level injured athlete (Howe 2004:55). Sports research within anthropology and sociology has traditionally been underdeveloped theoretically and topically (Howe 2004:55); however, Howe seeks to add in both aspects by situating the athlete as an embodied actor engaging in the structured world of high-level athletics:

I believe sporting culture to be somatic, or pertaining to the body in a corporeal sense. . . . In this way, the study of sporting bodies is rather an investigation of embodiment where the body becomes a social space that is transformed through its involvement in sporting practice. . . . the body is the primary tool with which elite sporting participants have to work in order to enhance their performance. . . . ultimately it is the body that performs in the sporting arena. [Howe 2004:55]

Instead of providing a complete overview of Howe, I will attempt to explain three aspects of his theoretical framework: how he employs Bourdieu's concept of habitus in relation to athletic practice, which I will extend to the MPs in my research and Judith

Butler's consideration of the sedimentation of past experience; his employment of the concept of being in the zone and how it relates to Leder's concept of the ecstatic disappearing body; and a brief consideration of risk within the high-level sporting context, which I will begin to extend to the context of the everyday world for athletes with a history of concussions.

3.5.1 HOWE, BOURDIEU, AND HABITUALLY ACTING IN THE FIELD

The habitus as the feel for the game is the social game embodied and turned into a second nature. Nothing is simultaneously freer and more constrained than the action of a good player. [Bourdieu 1990:63, in Howe 2004:63]

Pierre Bourdieu (1930–2002) was a social theorist who developed a theory of practice that “identifies the nexus between the body and the social environment surrounding it” (Howe 2004:62). His theory is used by Howe to locate the athlete's body within various social fields (both sport and non-sport). *Habitus* is a concept that was developed by Bourdieu and is meant to explain the combination of the habitual schema and dispositions that have been learned over time within a structured environment (Howe 2004:63). The structure of any one environment dictates how social actors are expected to execute their moves in a manner that is socioculturally acceptable. The structured environment (or *field*) in which athletes often find themselves is of course the sporting field, a site where coordinated intersubjective interactions are carried out in a fashion that has been habitually learned but is dependent on the ability to mobilize their embodied habits (hexis) without reflection (pre-objectively). The more seamless the enacting of these structured habits, the more social capital (“talent”) the performer can be said to

have: “In the particular environment of elite sport it is the embodied disposition⁴¹ or doxa that enables a social exploration of the distinctive character of sporting practice and body hexis (the performative aspect of habitus)” (Howe 2004:63).⁴²

Higher impact sports fields such as rugby and hockey are structured in a way that condones a certain level of controlled violence in the field of play. Athletes who play these sports have habitually embodied protective measures which mitigate some of the inherent risk involved in athletic engagement.⁴³ When athletes transgress these historically reinforced protective measures, as Eric Lindros did while skating through the middle of the ice with his head down, their transgressions carry a cultural connotation specific to the sporting field itself. Outsiders such as fans and sports commentators will have perceived justification to blame the transgressor for instigating their own injury, while players who deliver these so-called punishing hits are heralded for enforcing the cultural ethos of the sporting field.⁴⁴

⁴¹ “A disposition is an underlying tendency or propensity to act in a certain way and is therefore more flexible than a habit established through rudimentary drills, but is still achieved without conscious thought before the action. The disposition to fight is fundamental for a boxer, and requires more than technical skill and physical fitness. The disposition is the embodied ability to put the habitual training together in such a way that it can be quickly adapted to suit any fight situation” (Howe 2004:57).

⁴² *Doxa* (dispositions and orientations) + *bodily hexis* (performed habitus or competence) + *capital* (resources available) + *structure* (embodied relation to the structured environment) = *sporting potential* This represents Howe’s model of the sporting body in practice. Italicized text denotes Bourdieu(ian) language and non-italicized text is Howe’s words (Howe 2004:63).

⁴³ Two examples given by my athletes include not skating through the middle of the ice with your head down in hockey and not watching your pass for too long after you let it go in rugby. Player could also consider changing positions, as I did, as a protective measure. I also switched my sporting emphasis to a seemingly less violent sport (from hockey to baseball). However, the risk of injury is still present in baseball and was heightened due to my own history of mTBI.

⁴⁴ Many commentators likened Scott Stevens’ ability to hit players to an art form and blamed Lindros for not keeping his head up while skating through the middle. Stevens’ comments in his Hockey Hall of Fame acceptance speech on prematurely ending Lindros’ career show his lack of empathy and how he justifies the use of his “art form” (“2007 HHOF Fan Forum – Scott Stevens on Lindros hit,” YouTube video, 0:50, posted by Daniel Tolensky, November 13, 2007, http://www.youtube.com/watch?v=XeFvduxp_eM).

The sporting field is populated by other actors (teammates, coaches, trainers, fans, and in my research also parents) who figure into an athlete's decision to return to play after an injury. Athletes in my study who played team sports had trepidation that their play might be a little off when they returned and that their teammates would feel the need to play differently with them in the lineup to protect them from future injury. We see here the social element of athletic engagement. Across all sports, my athletes noted they would consider returning to play only when they had reached a point where they no longer felt they would be a burden on their teammates and coaching staff, so that all actors could engage in an embodied, pre-objective manner.

3.5.2 IDENTITY AND THE SEDIMENTATION OF EXPERIENCE

Social theorist and philosopher Judith Butler picks up on Simone De Beauvoir's assertion that "one is not born, but, rather, becomes a woman" (Butler 1988:519) as a means of showing how our understanding of our own identities is enacted and reinforced through social interaction (engaging with the material and intersubjective world). How these interactions are performed is informed, but not determined, by a sedimentation of past actions. All actions are socioculturally informed, yet actors have the capacity (*agency*) to choose to act in ways that differ from societal expectations. Choosing to act is a dialectic process in that agency is informed by social expectations and these expectations are developed over time through individual and group acts of agency. I employ Butler as a means of expressing the holistic nature of identity, where individual aspects of identity (e.g. gender) make up of a mutually informing unified whole.

I will also use Butler's performative gender theory to speak about the means through which conceptions of masculinity and femininity informs the medical context surrounding mTBI management, including the context of my informants' own lives.⁴⁵ Butler's social theory should be seen as applicable to gendered conceptions of identity specifically but also to the performative nature of identity in general. This is because when we follow a phenomenological tradition we always understand identity as both a continual negotiated process that is never determined and as a mutually informing process where conceptions of "gender" are just one aspect:

Consider that there is a sedimentation of gender norms that produces the peculiar phenomenon of a natural sex, or a real woman, or any number of prevalent and compelling *social fictions*, and that this is a sedimentation that over time has produced a set of corporeal styles which, in reified form, appear as the natural configuration of bodies into sexes which exist in a binary relation to one another. [Butler 1988:524]

Understandings of the social position and expected behaviors of athletes and physicians are likewise historically informed and constrained by a legacy that is lived by both groups.⁴⁶ MPs' expectations of athletes are informed by a historical understanding that athletes are "by nature" (or naturally) highly competitive and driven, and therefore will need to be constantly restrained from returning to play too early, where they risk hurting themselves further.⁴⁷ Athletes had expectations of medical professionals as

⁴⁵ I imagined questions of gender would emerge more prominently in the responses of my informants. However, gendered implications of living with PCS were often raised while discussing other aspects of lived experience.

⁴⁶ The sociocultural context will be considered in the next chapter. The context section is entirely derived from what both my MPs and athletes saw as the historically sedimented present context in which they find themselves. The concluding chapter will build on this notion with a projection based on what both groups saw as factors influencing the experience of PCS and treating it in the future, which is also based on their historical present and perceptions of the past.

⁴⁷ Athletes have the agency to act in a contrasting fashion to this stereotype by being cautious in their recoveries. Conservatism tended to be the norm in my cohort despite their strong desires to return to play.

providers of cures due to medicine's celebrated history of curing disease and illness. Both conceptions are "compelling social fictions" in that our attempts to strictly categorize social groups as fixed in practice transcend the very boundaries we attempt to construct. The athletes in my study were eager to get back to their sports but were also extremely cautious about the long-term consequences of their concussions. MPs do not have all the answers, but they are trying to help these athletes largely because of their stated love of sport and athleticism.⁴⁸ MPs assume a position that is less highly empirical, rational, and materialistic; instead they act more like a teammate or friend as a means of examining the interplay between emotions and physical symptoms.

When I entered the field, I assumed I would talk to highly empirical physicians and incredibly driven, irrational athletes. I confronted these compelling social fictions through seemingly contrary acts of agency that while constrained by social structures to a certain extent, defied simple categorization.⁴⁹ Through structured acts of agency, athletes and MPs in my study challenged social expectations and recast what it means to be a concussed athlete or a managing medical professional.

3.5.3 ECSTATIC BODY AND BEING IN THE ZONE

Howe (2004) mobilizes the well-known concept of "being in the zone" during athletic engagement as a means of explaining what it is that keeps athletes coming back to sports despite a history of injuries. Athletic injuries⁵⁰ inhibit an athlete's ability to enter

⁴⁸ All MPs spoke of their love of sport and athleticism as their primary motivation for pursuing and continuing to practice medicine with an expressed interest in treating athletic injuries.

⁴⁹ Identities are often cast along binary lines (athlete or non-athlete, physician or specialist, man or woman) but are lived dialectically (Butler 1988:524).

⁵⁰ Athletic injuries are injuries that have implications on one's ability to perform athletically within the sporting field.

into a pre-objective (seemingly disembodied) engagement with the sporting field, as the corporeal body is literally getting in the way of attaining this engagement. Like Leder's conception of the ecstatic-recessive nature of bodily disappearance, the time we occupy in the zone is fleeting. When an athlete becomes injured their ability to enter "the zone" is inhibited by the dys-appearance of the corporeal body. An injury that is considered permanent and potentially career-ending can be described as one where the athlete is permanently unable to ever enter the zone again (loss of dispositions). Like many other injuries, a history of concussions affects an athlete's ability to be comfortable enough with their structured embodied engagement with a sporting field to be able to attain this temporary higher level of embodied engagement. Yet the uniquely dialectic and holistic experience of this particular sporting injury make its recovery that much more problematic. Unlike the Hockey Player's herniated disk which is an injury that he can play through with maintenance therapy, PCS lacks both empirical measures and interventions coupled with the medical social norm of withholding players from play who are presenting symptoms. MPs quickly find themselves at a loss in terms of what to recommend to their athlete-patients besides waiting, resting, and most importantly not athletically engaging with the world until somatic symptoms resolve.

Those of my athletes who played individual sports (Nordic and AP when doing triathlons) missed the feeling of entering and being in the zone on an individual level, as well as its benefits (e.g. general stress levels recede). All of my athletes participated in athletic activities that were not directly related to their sports (e.g. jogging or cycling) and they gained a positive sensation similar to my athletes who played an individual sport.

One of the more emotionally problematic aspects of PCS for my athletes was the

distance it created between the sufferer and their team. Sitting in a dressing room with concussion symptoms creates an embodied distance between the concussed and their teammates based on the knowledge that the concussed athlete is restricted from play. Athletes would describe how they missed interacting in the dressing room, sharing in the punishments doled out by their coaches after a hard loss (HP), and the general family-like environment typical among organized high-level athletics (Rugby, Olympian, Neurosci, and HP). The other players in the room are preparing to undertake team-oriented tasks, and the inability to enter this structured social zone of team athletics is perhaps the most emotionally problematic aspect of having an mTBI.

3.5.4 RISKY SPORTS

Does one ever really recover from a concussion? If our intentions and our embodied actions to attain them are fundamentally altered in such a way as to guard against sustaining a subsequent concussion, then an athlete with a history of concussions can be thought to live in a perpetually risk-filled environment. The concept of risk is of central importance to Howe's study. Howe suggests that inherent in all sports is a risk of injury. This risk of injury is heightened as the competitive level of the sport increases; likewise, the incentive to conceal an injury from those who decide on your ability to participate (i.e. coaches and physicians) grows as the competitive stakes are raised.

Most athletes play with some low-level of "hurt" which can be thought of as preexisting injuries that inhibit their full engagement in a sporting field but are not so severe as to make engagement impossible.⁵¹ Playing hurt is celebrated as heroic and also

⁵¹ Here is where we should NOT think of the Olympian (while skiing) as having a "disability", in her own words: "When I was on my skies I looked like everyone else, I could ski like the dickens." Because she has

expected by the other subjects on the sporting field—this is one aspect of the morality surrounding organized sports. Athletes are assumed to routinely downplay or even hide an injury from their teammates, coaches, and trainers (or downplay an injury’s significance in their own thinking) as playing on is considered the morally righteous thing to do. For this reason athletes with concussions are compelled to explain the somatic details of their PCS and exactly why they are unable to play. In mTBI many of these reasons are very much informed by a trepidation of future health and functioning: I want to have a productive future career, want to be an active parent some day, etc.

The media coverage reflects this morality, reinforcing it through every account of a player shaking it off and getting back out there. Increased public awareness (especially among sports fans and participants) of mTBI and its long-term significance has enabled the casual fan (or parent of an athlete) to visually recognize when a concussion has occurred on the sporting field (e.g. wobbly legs, glazed look, erratic behavior). This recognition of when an injury has occurred has started to change the positive tone that “shaking (or walking) it off” used to carry, particularly around this injury.

MPs recognize the risk of athlete’s concealing brain injuries and have taken steps to ensure this risk is more widely recognized and hopefully mitigated. MPs will promote the findings of consensus forming groups to their colleagues and members of the sporting community to help educate them on the risks of *not* removing an athlete from play if a concussion is suspected, as well as the risks of a hasty return to play. According to my

always had CP, she has never known skiing without having CP, it is informing, but only one aspect of her holistic embodiment in the sporting field. Her concussions are different, they are *acquired* and demand incorporation into her embodied sense of self and place in the world.

MPs' responses, the decision to return to play is ultimately made by the athlete; however, the MPs I spoke with report strenuous efforts to educate athletes about the long-term risks of continued sports engagement while having a history of concussions. Athletes report hearing similar concerns from their parents, who often share news stories with them about professional athletes who have suffered long-term implications from repeated concussions. The emotionally problematic nature of the decision to permanently “hang-up the skates” is made worse when athletes feel the decision has been made for them. They may feel their last opportunity to play high-level athletics was taken from them because of mTBI, and the fact that nothing could be done to reverse this is difficult to reconcile for individuals who are used to playing hurt in a risky environment.

CHAPTER 4

THE SOCIOCULTURAL CONTEXT

Situating the Present Webs of Significance

Think about it, you wake up, go to work, you are tired, you drink some coffee. We have these coping strategies so that we can work hard and all that. I have patients who do work harder, so they extend their work day from eight to twelve hours in an effort at getting all their work done, which is counterproductive. I spend a lot of time telling them about how their brain is acting out. You need to hammer that home, [but] some people will still you know, push it. The more severe the injury and the greater the length of time, the more likely (it is that) you will be compliant.

RCPS

4.1 SITUATING THE PRESENT

This chapter is devoted to introducing the sociocultural context in which my informants saw themselves embedded. The content and structure of this section is guided by what informants said about society, social structures, culture, and historical legacies. While this section is about society and culture (the historical present), I will also highlight some of the individual acts of agency that my informants performed in response to: medical organization and sub-specialties, consensus positions (RTP, SCAT2⁵², and baseline testing), political–economic structures, and athletic and academic structures. I

⁵² SCAT2 (Sport Concussion Assessment Tool 2) is a “pencil and paper” neuropsychological test that has a topical application to sports-related concussions. The test has been updated at each meeting of the ICCS (International Conference on Concussion in Sport). The RTP (Return to Play) protocols, which are also put forth by the ICCS, are the recommendations for clinical practice and are updated every four years. This chapter will focus on the ICCS and this particular test due to its heavily informing nature on how concussions are managed in clinical settings for both my MPs and for the athletes who were subjected to them.

will add supporting material as a means of further situating informants' perceptions of the structures that inform their lived experiences.

I would like to introduce Sherry Ortner's (1984) theory of practice for its focus on the analysis of the dialectic relationship between structure and agency and for how she situates her own theoretical orientation within the American anthropological tradition.⁵³ Her practice theory understands agency to be *meaningful intentions* carried out *pragmatically* in the world in *response* to the sociocultural structures historically sedimented over time. The questions I posed to both groups of informants were intended to evoke descriptions of their sociocultural positions with emphasis on the meanings they ascribe to their position and the acts that reinforce or challenge it. On a more recent reading, perhaps informed by the contextual present in which I find myself writing this paper, I noticed quite a bit of language and theoretical formulations (the dialectic and holism primarily) which struck me as phenomenological. I am using her here as a means of situating my phenomenologically informed approach within the American pragmatist tradition of symbolic anthropology.

4.2 SHERRY ORTNER'S THEORY OF PRACTICE

I chose to utilize Sherry Ortner's outline of a theory of practice because of how she situates herself within larger theoretical trends and for its focus on the meanings behind the actions of socioculturally situated individuals (Ortner 1984). The dialectical relationship between agency and structure was "one of the central problems of modern

⁵³ This is the theoretical school of thought I was educated in at UBC. It has a stated interest in exploring the pragmatic meanings individuals ascribe to events and interactions. Since attending Carleton I have been introduced to phenomenology as a viable theory and method for ethnographic research. This thesis represents a blending of these two traditions.

social theory” (Ortner 1984:146–147, quoting Giddens 1979) at the time and continues to manifest itself in my research. Ortner’s paper is useful as it is meant to be read as a loose framework on which future projects can take shape.

Ortner follows in a pragmatist tradition augmented by symbolic anthropology, which has an expressed concern in exploring meaning from the actor’s point of view.

This can be traced through the writing of her teacher and mentor Clifford Geertz:

Geertz’s most radical theoretical move (1973b) was to argue that culture is not something locked inside people’s heads, but rather is embodied in public symbols, symbols through which the members of society communicate their world-view, value-orientations, ethos, and all the rest to one another, to future generations and to anthropologists. . . . Yet the point about symbols was that they were ultimately vehicles for meaning; the study of symbols as such was never an end in itself. [Ortner 1984:129]

This orientation agrees with Merleau-Ponty and Leder’s assertion that the nature of being in the world is to always be in an ongoing and continual communication with it. Existence exists in the perceived “real” world. Merleau-Ponty’s main criticism of classical psychology is that it is locked inside people’s heads and is unable to recognize the informing nature of one’s pragmatic engagement with the real (perceived) world. Within medical anthropology, one of main critiques of medical practice is that it does not take into consideration the ill body as lived, both socioculturally and emotionally. Medical anthropologist Byron Good is also informed by this symbolic–pragmatist–phenomenological tradition, as noted in the following passage from his study of the experience of chronic pain:

the body as creative source of experience. The relations among embodied experience, intersubjective meaning, narratives that reflect and rework illness experience, and the social practices that mediate illness behaviour. [Good 1994:118]

I see his approach as also being holistic, meaning centric and dialectical. His inclusion here is to note a continuum of this three-fold theoretical orientation from Merleau-Ponty's phenomenology to a symbolic medical anthropology informed by American pragmatism.

Ortner further suggests that the analysis of the structure–agency dialectic should be conducted from an “actor-first” perspective, which strikes me as a phenomenological and a reflexive goal:

The other major contribution of the Geertzian framework was the insistence on studying culture “from the actor’s point of view” . . . this does not imply that we must get “into people’s heads”. What it means . . . is that culture is a product of acting social beings trying to make sense of the world in which they find themselves in, and if we are to make sense of a culture, we must situate ourselves in the position from which it was constructed. [Ortner 1984:130]

Ortner also sees the aim of practice theory as holistic, describing as much as possible the system (structures) and acts of agency of individuals, understood to be historically situated and actively reproduced in a totality of experience: “What a practice theory seeks to explain, then, is the genesis, reproduction, and change of form and meaning of a given social/cultural whole, defined in more or less this sense” (Ortner 1984:149). Ortner sees intentionality as manifested in the actions performed by embodied actors in response to structure: “What is left, then, is a view of action largely in terms of pragmatic choice and decision-making, and/or active calculating and strategizing” (Ortner 1984:150). Ortner suggests, as do the four theorists discussed in the previous chapter, that embodied being in the world is largely pre-objective, freeing our intentions to be bigger and to reach further into the future.

Ortner encourages us to account for powerful forces that can compel actions in others however she recognizes that to challenge hegemonic power there is a need to understand where this system comes from and how it is reproduced:

At the core of the system, both forming it and deforming it, are the specific realities of asymmetry, inequality, and domination in a given time and place. [Ortner 1984:149]

The MPs in my study made self-reflexive inquiries into their own disciplines to understand why concussion cases are mismanaged. All my MPs seemed up-to-date with the most current protocols. In fact, some are directly involved in the development of future concussion guidelines (both ICCS and working groups associated with the Ontario Medical Association [OMA]). My MPs consistently pointed to the “under-education” of their colleagues as the leading cause of mismanaged cases they see and they hope to creatively engage their colleagues’ resistance to change.

Athletes also undergo a continual process of self-reflection, seeking meanings behind the experience of being a concussed athlete within this rapidly changing landscape of awareness, acceptance, as well as misconceptions that are played out in the media or through interactions with others. Leder uses the term hermeneutic quest as a means of describing this process of self-examination and the search for meanings. I believe it can be extended to begin to account for the sociocultural world that my athletes see themselves informed by. Both groups recognize themselves as embodied social actors grappling with historical legacies (both collective and personal) that can be objectively examined.

4.3 STRUCTURING MEDICINE: MEDICAL SUB-DISCIPLINES

Formal education on mTBI has historically been lacking in Canada: “I had zero training in concussions until I did my sports medicine certificate (around 2007–08). I could have been a family medicine practitioner with no formal training in concussion management” (SM1). Many of the medical professionals I talked to came into contact with concussions on the job and quickly found no clearly defined empirical basis:

SM2: Then you have to decide do I introduce exercise now or not, how quickly do I put them through this gradual protocol. There’s nothing there yet. That’s where it’s a bit of an art form in the sense that you do a little bit by knowing a patient, their past experience, but there is no hardcore science to back you on that. So it’s very experiential in that regard.

The recurring metaphor of concussion management⁵⁴ as an art form is based on the murky and unknown nature of this illness—its range of symptoms, lack of singular interventions, and unknowable prognosis—which is at least partially based on a historic lack of attention within medical research and practice until quite recently. Despite the newfound attention from medical research and practice, there are still many within medicine who continue to question the existence of short- and long-term health implications of a history of mTBI.

Anthony Giddens (1976) points our attention to understanding “historically located modes of activity” (232) when we consider how present actions are informed by

⁵⁴ My MPs used the term “management” of PCS instead of “treatment”, which is how I phrased this process in my letter of introduction. In using this term they are pointing to the dialectical, holistic nature of mTBI in the sense that “every concussion is different”. Managing concussions defies Cartesian-based dichotomies and also lacks singular interventions. They approach the management of concussions in a modified trial and error process (taking into account the lived experience of the sufferer), which they term their “artistic approach” (or the art form of managing concussions), which is informed by their empirical findings and subjective reporting.

historical legacies. The earliest mention of sport-related acquired brain injury that I was able to find dates to the 1850s, reporting on dementia in boxers post-retirement. From this point on we see sporadic publications which typically carry a social critique that medicine needs to pay closer attention to the prevalence and severity of mTBI. In 1954 Rowbotham et al. published an epidemiological study:

To set on record a statistical statement of the severity and the nature of the injuries sustained, to analyze the cause of death and to appraise methods of surgical treatment, to inquire into the long-term results with the object of discovering whether and how morbidity can be minimized and to bring to the notice of the surgical world *once again* the magnitude and importance of this branch of medicine. [Rowbotham et al. 1954:726]

This study was published in the *British Medical Journal*, the same publication that five decades later would publish (in open access format) the ICCS' consensus positions. Rowbotham et al.'s study was indicative of the medical culture surrounding mTBI in the 20th century. Acquired brain injuries (mTBI and TBI) were certainly considered real but their long-term implications have been murky partially due to a lack of longitudinal studies and limited empirically based monitoring tools that can be readily deployed in the clinical setting. For these reasons there persists an undercurrent of doubt within medical academia about the prevalence of long-term health implications from multiple mTBI:

Thirty-six papers had relevant extractable data (from a detailed evaluation of 93 studies of 943 identified from the initial search). *Quality of evidence was generally poor.* The best quality studies were those with a cohort design and those that used psychometric tests. These yielded the most negative results: only four of 17 (24%) better quality studies found *any indication of chronic traumatic brain injury in a minority of boxers studied.* Thus, *there is no strong evidence* to associate chronic traumatic brain injury with amateur boxing. [Losemore et al. 2007:809]

4.3.1 SPORTS MEDICINE

Sports medicine is a sub-discipline of family medicine and entails an additional year of specialized training that includes a practical component:

SM2: The Canadian Academy of Sport and Exercise Medicine (CASM) has been around since 1970, but not a lot of people knew about it at the time. There are upwards of six to seven hundred members now. It's not just about sport. It's sport, exercise, and activity. So I am a family physician. Sports medicine is my topical background. There hasn't been much in terms of designation for this, except for the diploma.

Sports medicine as a discipline seems to have largely spearheaded the move within medicine to refine understanding this illness and come to some agreement on medically valid interventions. The International Consensus on Concussion in Sport (ICCS) is the primary vehicle through which this small medical sub-discipline has been able to exert a disproportionately large influence on concussion management in general (not necessarily just sports-related). However, according to one of my informants, other physicians do not seem to fully understand what sports medicine practitioners actually do, which is detrimental to patient health as these practitioners tend to be on the cutting edge of education and treatment:

SM1: Of all the medical sub-specialties sports medicine is at the bottom. It's not funded [by] the feds. You can't roster patients . . . I think often people (other doctors) don't really know what we do. They think maybe we only work with high-level athletes and that's all we see . . . I see more weekend warriors with twisted ankles than I see high-level athletes. This is why we changed our name to "sport and exercise medicine"—to make ourselves sound a little less elitist. But people still don't seem to understand what we do.

4.3.2 ATHLETIC THERAPY

Athletic therapists (ATs) differ from physiotherapists in regards to the schooling they receive, which in turn informs how they approach injured athletes. Physiotherapists receive education in burn, cardiac, and neurological injuries, as well as orthotic, muscle, bone, and nerves; whereas ATs only receive schooling in the latter four fields. According to my informants, what makes ATs unique is that up-to-date concussion management protocols are central to their formal education:

AT: RTP criteria⁵⁵ is central to our training. The clinical setting for practical education plus on-sight field management gives us a good understanding of concussions.

Despite being a relatively small discipline, athletic therapy has been able to be dynamic (in much the same way as sports medicine) and has made strides in narrowing the treatment and research gap in mTBI:

AT: We are trying as a discipline to be ahead . . . we are trying to be a lead people.

Me: Was this because there was a gap?

AT: That and we are not a regulated health profession. There's no college of athletic therapy. So we are more flexible.

In the varsity environment where I spoke to this informant, she noted that her fellow sports medicine colleagues allowed her the opportunity to be the central person on RTP decisions due to her additional formal training and her personal skills development. She believes her knowledge base is augmented by the level of trust she has forged with the athletes, coaches, and physicians with whom she works. Typically the final RTP

⁵⁵ Return to play, learn, and work are interchangeable goals but the process is the same. RTP protocols are the stepwise process of introducing activity (motility and cognitive), progressively working toward pre-concussive levels.

decision is made by a physician, but in this case the AT has gained the trust of her physician colleagues to make this call on her own for the varsity athletes.

Speaking about the discipline of athletic therapy, the RCPS' statements seem to reflect a notion that only specialists can truly "cure" the most difficult cases, whereas less educated or less specialized MPs can handle the more simple cases. He noted this while at the same time recognizing the strides athletic therapy has made in concussion management "over the past 20 years":

RCPS: I think a lot of the [athletic therapists'] approach . . . is in-the-moment competition and athlete-focused. A lot of them are pretty good at dealing with the most common types of concussions (sporting event, then concussed). There have been great strides in [recent] decades when a concussion has occurred, and acknowledging that this is something needed to be taken seriously, not putting them back too soon and increasing their risks. For the people who don't follow that neat line of recovery is where they start to fall off the edge.

4.3.3 THE SPECIALISTS: NEUROSCIENCE, NEUROLOGY, PHYSIATRY, AND PSYCHOLOGY

When an individual "starts to fall off the edge" they are often referred to specialists like the RCPS. These referrals typically occur when recovery has plateaued or has remained constant for some length of time. Concussed athletes can expect to be referred to a neurologist, psychologist, psychiatrist, or physiatrist. Each of these designations involves a level of education beyond their general medical education. Within RCPS' discipline, formal education is devoted to mTBI.⁵⁶ In conjunction, he personally trained under a prominent physician who was a lead author of the Ontario

⁵⁶ Due to the specificity of his designation, this information has been withheld at his request.

guidelines, which lends him “an additional level of expertise” (RCPS) on this particular injury. Sports medicine students can expect to be referred to specialists like RCPS during the practical component of their education. This is often where they first come into direct contact with concussion treatment:

RCPS: Sports medicine physicians do two years of family medicine, where they deal with none of this, then a year in sports medicine. [The] majority of training comes from the year spent with other sports doctors, kind of on the job, at the whim of those who teach you.

An individual with persistent PCS that has defied medical interventions can use a diagnosis from a socially accredited professional like him to gain a level of acceptance about the validity of somatic experience.⁵⁷

The fact that “there is so much we don’t know about the brain” (Neurosci) is the symbolic origins of the troubling nature of this injury: it is an injury to the organ we know the least about and is typically deeply buried, absent, from our conscious perception (Leder 1990). According to SM2, for an injury to the brain, neurology has been surprisingly silent on mTBI⁵⁸:

⁵⁷ I see the management of chronic fatigue syndrome (CFS) as similar to the management of PCS: “The disturbances represented by this syndrome have been granted a medical diagnosis even though no pathology has yet been found. The diagnosis is based on negative findings . . . The definition of CFS stresses the appearance of somatic symptoms that have not been subject to objective measurements, that have only been reported by the patient . . . consensus was reached on what tests would be necessary before making a diagnosis” (Sachs 2010: 300).

⁵⁸ The RCPS suggested this vacancy is due to neurology’s traditional focus on TBI education, research, and practice.

SM2: It's really the sports medicine physicians who have an interest. Rarely will you see a neurologist, a few neurosurgeons, some physiatrists . . . they are into the TBIs as opposed to the mTBIs . . . The problem is that we are sport medicine physicians, we are not neurologists . . . who does it?⁵⁹

With mental health issues such as depression and anxiety⁶⁰ that often accompany a prolonged recovery from mTBIs⁶¹, the physicians in my study tended to manage these symptoms in much the same way as they would manage other symptoms. They prescribed medication where they thought helpful but would first suggest non-pharmacological interventions. The motivation to identify and actively treat mental health complications is based on the understanding that depression and anxiety symptoms can be masked in PCS or PCS can mask the manifestations of depression or anxiety, yet seeing a psychologist is expensive. Each of my physicians noted they would attempt to treat mental health issues themselves, not only because of the cost of specialists, but also because they felt both psychology and psychiatry lack knowledge of mTBI⁶²:

RCPS: In general, going to a psychiatrist, it's often not about consoling. It's more about the manipulation of medication . . . Generally I don't use a psychiatrist. In terms of concussions and medication, I feel pretty confident in treating this myself.

Me: Due to your background?

⁵⁹ We will see in both Chapters 7 and 8 how this lack of attention paid to mTBI is one of the reasons why a number of TBI rehabilitation centers exist but few mTBI ones exist.

⁶⁰ PTSD, which is sometimes associated with mTBI in soldiers (Kennedy et al. 2007), was not mentioned by any of my informants as a mental health concern they encountered.

⁶¹ See De Beaumont et al. (2009), Henry et al. (2010), and Mainwaring et al. (2010) for examples of neuropsychological research conducted on the numerous long-term, behavioral, cognitive, and emotional consequences of a history of mTBI. *The Handbook of Sport Neuropsychology* (Frank M. Webbe ed. 2011) is an interesting publication that emerged from attempts to approach mTBI management in a more holistic fashion while still retaining the ontological framework of Cartesian divisions (i.e. seeing the mind and body as separate entities).

⁶² Note the reference to a whole patient perspective in this passage, which harkens back to Merleau-Ponty's criticism of psychology 80 years ago.

RCPS: That's the thing [with] going just to a psychiatrist. They can help with mood, but the whole person interaction aspect will be a little lost, because they are not as comfortable with PCS . . . It's useful if you have money [as] psychiatrists are expensive. I will prescribe mood-stabilizing meds. With Concussions, think about it as homeostasis being off. Depression is an imbalance in neurotransmitters . . . Sometimes there is a medication that will treat a handful of symptoms, so I get into trying to manage these things myself, from a counselor's perspective.

PCS is listed in psychiatry's Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) as a different "mental disorder" known as PCD (Postconcussional Disorder).

McCauley and colleagues found that:

In spite of significant differences between the two diagnostic criteria sets and different incidence rates for PCD/PCS, outcome in all measured domains was very similar at 3 months post-injury. There is no compelling evidence, based on these outcome domains, to suggest which of the two diagnostic criteria sets should be clinically preferred. [McCauley et al. 2005:540]

The debate within psychology, psychiatry, and neuropsychology is currently centered on debates over diagnostic classification. While specialists like the RCPS, family physicians (SM1, SM2, AP), and therapists (AT) are seeking to actually manage the "mental disorders" associated with being a young person with a history of mTBI. Other disciplines are at variable stages of determining the etiology of this illness, debating their existence (Loosemore et al. 2007) and contesting the long-term repercussions to mental health (Mainwaring 2011:251–274).

4.4 REACHING A CONSENSUS EVERY FOUR YEARS

SM2: So the way we manage concussions is more consensus-based than evidence-based now. In medicine we always try to be, where possible, evidence-based. Randomized, controlled trials that tell us a certain treatment works this way—that’s the gold standard. In concussions we don’t have that, partially because of the nature of the injury. It’s very diverse. . . . To know what’s going on, we need to do brain biopsies on concussed people, which is not going to get past the ethics board . . . There’s lots we don’t know. It’s not new, but it’s new’ish. Interest in it is new. Having said all that, we have some consensus-based things that I am sure you heard about.

The “consensus-based things” that SM2 referred to are the consensus statements produced by the International Conference on Concussion in Sport (ICCS), a quadrennial international conference⁶³ organized by major international athletic bodies⁶⁴ and attended by leading figures in concussion research. While this conference is ostensibly about sports-related mTBI⁶⁵, their consensus statements are widely disseminated to medical professionals and serve as the standard for concussion management:

SM2: You have to think and adapt and innovate. With concussions there is a little bit of that because there is stuff we don’t know yet . . . Classic example of that: in 2004 in Prague, labeling concussion as simple or complex. Simple got better in seven days, complex not so much. So we used that, and I always had trouble with that . . . telling someone they have a simple concussion might be sending the wrong message, a complex one sure . . . I remember putting up my hand in

⁶³ Previous conferences include Vienna in 2001 (Aubry et al. 2002), Prague in 2004 (McCrory et al. 2005), Zurich in 2008 (McCrory et al. 2009), and Zurich in 2012 (McCrory et al. 2013).

⁶⁴ Organizers include the International Olympic Committee (IOC), the International Ice Hockey Federation (IIHF), the Fédération Internationale de Football Association (FIFA), the International Rugby Board (IRB), and the Fédération Equestre Internationale (FEI).

⁶⁵ From the 2008 consensus meeting in Zurich: “This document is developed for use by doctors, therapists, health professionals, coaches, and other people involved in the care of injured athletes, whether at the recreational, elite, or professional level . . . While agreement exists pertaining to principal messages conveyed within this document, the authors acknowledge that the science of concussion is evolving and therefore management and return to play decisions remain in the realm of clinical judgment on an individualized basis” (McCrory et al. 2009:76).

Zurich and asking, you know the treatment is the same, there was a whole pile of people saying yeah we don't use this . . . and it was decided to drop that criteria . . . so it's an evolving sort of thing . . . when we get more information and we learn more, we have to change within the concussion world.

An entire thesis could be devoted to analyzing the debates and decisions made on these consensus statements. However, I would instead like to highlight the three most important products of these meetings as they relate to the experience of my MPs in managing concussions and in how these structural decisions impact athletes' lived experience: the SCAT2 (SCAT3 was forthcoming as I was conducting the interviews), baseline testing, and RTP protocols.⁶⁶

4.4.1 SPORT CONCUSSION ASSESSMENT TOOL 2 (SCAT2)

Across the board, all my informants (athletes and MPs) agreed on the usefulness of the SCAT2 test as a diagnostic and monitoring tool. Its questions elicit responses on cognitive function, perception (balance, light sensitivity, and auditory processing), and physical and emotional symptoms. These are all given a numerical value and compared against future results to help chart recovery. The SCAT2 attempts to codify the phenomenological nature of this injury through subjective patient reporting. The SCAT tests represent attempts to objectify this dialectic illness and apprehend its holistic experience. The breadth of symptoms covered in the test allows the physician to identify the patient's worst symptoms, which can be confirmed by asking follow-up questions:

SM1: We can communicate through the SCAT2 . . . instead of "how did you feel this week?" they can just show me through the SCAT responses.

⁶⁶ Each of these could be modified to the non-sporting concussed community, but for our purposes we will focus on how they are used by MPs to treat athletes.

The SCAT2 can also be used as a comparative diagnostic tool in pre-season baseline testing: “the SCAT2 can be helpful for interpreting post-injury test scores” (SCAT2:1).

Another key aspect of the SCAT2 is that it was designed to be administered by medical professionals who may not know about mTBI, how to recognize it, or how to treat it.⁶⁷ The consensus statements (including the SCAT tests) are made widely available in open access format⁶⁸, which is meant to encourage widespread distribution. Still physicians seem slow to adapt to these consensus positions:

SM2: Doctors have been so slow to adapt with such old information. “He’s second degree”—we haven’t used these classification schemes since Vienna 2001 . . . what’s the problem? Maybe because concussion is sport-related, some consider that not worthy of study. They feel what we do is not really medicine and that we don’t deal with real people.

For the general public, the Sport Concussion Recognition Tool (SCRT) is promoted for use among parents and coaches. Similar to the SCAT2, the SCRT is available in various formats and is intended for widespread distribution. It is designed as more of an awareness tool for the sporting public than a diagnostic tool. It advises readers on recognizing the signs of an mTBI and knowing that the appropriate response to a suspected concussion is immediately removing the athlete from play. It also states that a

⁶⁷ SM1 cited a survey conducted among physicians in Alberta on their comfort level in treating mTBI which showed “essentially that they were not educated and do a poor job overall in management . . . this is slowly changing. I just heard they put some slides together for medical students . . . But everyone has to buy into it, that it affects them and is important to them . . . but we still have a long way to go, and it’s a sad thing that the thing we need to do is actually educate physicians. People say to me, ‘I went and saw my doctor and I knew more about concussions than they did!’” (SM1).

⁶⁸ It is published in the *British Medical Journal* but is also publicly available for download on the Internet. The most recent consensus’ preamble states, “Readers are encouraged to copy and distribute freely the Zurich (2012) Consensus document, the Concussion Recognition Tool (CRT), the Sports Concussion Assessment Tool V.3 (SCAT3), and/or the Child SCAT3 card and none are subject to any restrictions.”

medical professional should be consulted as opposed to trying to manage a concussion by oneself.

4.4.2 BASELINE TESTING

Pre-season baseline testing for anyone playing organized sports was recommended by all my MPs. As noted above, baseline data can be ascertained through the use of the SCAT2 or computerized systems like ImPACT.⁶⁹ My MPs preferred these methods over neuropsychological testing as the latter can cost around CAN\$1500 (according to Nordic), while an ImPACT test costs around CAN\$15 (according to AT). Furthermore, the SCAT2 and ImPACT tests can be done relatively quickly within the clinical encounter. Readings from baseline testing is meant to reflect normal functioning. The ideal time to conduct a baseline test is therefore when a patient is fully healthy (i.e. not experiencing a concussion or other complicating factors, such as a hang-over) and before the start of the season (typically in early September for varsity athletes). Normative (objective) data like the SCAT2 is meant to represent a picture of the athlete's normal embodied state of being in the world, the return to which is seen as the teleological end point in the hermeneutic process of recovery. However, complicating factors must be considered when attempting to cast such a normative picture of health:

SM1: With computer systems, if you have a learning disability or ADHD it will take that into account, normative data there are

⁶⁹ The ImPACT test is a computerized concussion assessment tool that is found in well over 1000 medical offices and is regularly used by professional sports teams. As with all attempts at objectifying this illness, there is much debate over the veracity of ImPACT's findings and as such the MPs I spoke to note using it occasionally but rely more so on a dialectic approach termed "knowing the patient". ImPACT will be brought up again in the concluding chapter where I will speak about its developer's connections to the development of a possible pharmaceutical intervention for PCS.

so many more variables⁷⁰. ImPACT gives us objective information as to when they get back to baseline, but I encourage doctors to use it as a tool not for diagnostics. I will return athletes to play when not quite normal or pull them back when they are, because I take into consideration how they are doing in school, physically, emotionally. I don't care what the IMPACT says. It's a tool that can help but it's not the be all and end all.

According to AT, participants in most Canadian university “collision sports” (e.g. hockey, football, rugby) do a baseline test (ImPACT) prior to the season starting, while athletes in other sports (e.g. fencing, Nordic skiing) will only do the baseline test if they have a history of concussion. The symptom part of the SCAT2 is where RTP is determined. The double-edged sword of baseline testing is that if the teleological end point is unattainable (i.e. if recovery has leveled off to a point where symptoms persist continuously) it will serve as a reminder to the recovering athlete of their past functioning or *old-self*. HP and Olympian specifically asked the question, “Is this my new normal?” It is clear that questions of the permanence of illness elicit strong emotions and the use of baseline data as a comparative tool reminds athletes about their old abilities to engage with the world. Furthermore, each new mTBI sustained will likely reset the recovery process in such a way that a new baseline number will be needed.

While these tools are valuable and certainly necessary for giving MPs objective information on athletes' baseline measures, according to SM1, “I encourage doctors not to use [SCAT2] as a tool for diagnostic purposes.” If the SCAT2 and baseline testing are to be used as a tool, then perhaps it should be valued for showing improvements in other aspects of embodied functioning. If short-term memory is shown to be difficult but long-

⁷⁰ This is why I have chosen to only include incident rates of concussions (number of concussions reported in Canada to medical professionals) rather than statistics of recovery rates which are highly variable (see Appendix 1.5).

term memory is improving, treating physicians can perhaps highlight emotionally positive findings rather than focusing on embodied dys-appearance.

4.4.3 GRTP PROTOCOLS

Graduated return to play (GRTP) protocols is the monitored process of returning to everyday functioning. In the context of athletes this is represented in a return to their sport, and if they are a student–athlete there will be an added educational focus:

SM1: I love athletes for so many reasons, but one of them is their desire to get better. But with a concussion you need to hold them back. [You] need to be specific, also get into cognitive things as well. For example, at computer for no more than one hour per week, and no more than two hours of “screen time”, then work your way up. I do this with adults who are working too.

GRTP protocols involve a stepwise progression of cognitive and physical activity on a “sub-threshold” level (carried out until just before you feel symptoms).⁷¹ Much of the information used by MPs when establishing these steps is based on subjective reporting from the patient on when they felt their symptoms and what activities elicited them. This is why the SCAT test is used in conjunction with GRTP to provide physicians with a more objective and empirical reading of the patient’s progress. Ultimately the decision to return to play is made by the athletes themselves, although the MPs within varsity contexts wield much more influence in these decisions than they would with so-called weekend warriors. Much of the basis for the return to play decision is garnered through a

⁷¹ The sub-threshold component of RTP, which was an addition to the 2012 consensus statements out of Zurich, seems logically well-founded. Physicians want to promote a conservative recovery process as overexertion leads directly to worsening symptoms. From my experience, which was also reflected in what athletes told me, when you start to feel symptoms, it is too late. The somatic symptoms will persist for the rest of the day.

mixture of objective (i.e. test scores) and subjective opinion, which is often based on intersubjectively knowing the patient:

SM1: Deciding not to play is extremely difficult. There are no guidelines on that either. It used to be that three concussions and you are out . . . quickly with the past few guidelines we eliminated that, because concussions are so individual. Some can get three and return, some get one and it's over. It's very subjective, which why I think (lowers her voice) family physicians might be concerned with liability issues and have difficulty making that decision. I rely on knowing the patient, but you need to be able to support this decision medically.

In part to avoid liability issues stemming from an early RTP decision, medical professionals go to great lengths to educate their athletes about the long-term implications of an early return to play as opposed to the short-term gains (the chance to win a championship or being able to play in one's last year of eligibility were both cited by my informants as factors motivating an early return). The decision to return to play or work is made even more complicated due to an absence of evidence:

Neurosci: There is an art to medicine. It's very individual—not cookie cutter. [You] have to be creative. [It's determined by] what the patient wants to do. What do they do at school, sports, life, and most importantly what are their priorities?

4.5 BILL 39

In 2012, Ontario's Minister of Education introduced Bill 39, an Act to amend the Education Act with respect to concussions. The bill proposes a new section to be added to the Education Act which:

Authorizes the Minister to make policies and guidelines respecting head injuries and concussions and sets out a list of matters that this power includes. The section requires [school] boards to establish policies and guidelines respecting head

injuries and concussions and requires boards to address the specified matters. The Minister is also given authority to make regulations about the same matters. The section describes when board employees or volunteers will not be liable in a civil proceeding for their acts or omissions.⁷²

Essentially this legislation would codify into law the consensus statements agreed to at the International Conference on Concussion in Sport. Emphasis is placed on immediate removal from play and the GRTP protocols (and in this case specifically RTLearn is emphasized), with an added emphasis on concussion management education and recognition.⁷³ With Bill 39, Ontario became the first Canadian province to introduce comprehensive legislation on concussion management.⁷⁴ The status of the bill remains to be seen; at the time of writing, the bill's sponsor has resigned as an MLA and the bill has yet to be re-introduced in the most recent Parliamentary session.

Nevertheless, jurisdictions as well as the medical community will continue to closely follow any progress of the bill as it is one of the first pieces of legislation compelling physicians to become educated on concussion management:

⁷² "Bill 39, Education Amendment Act (Concussions), 2012," *Legislative Assembly of Ontario*, accessed June 22, 2012, http://www.ontla.on.ca/bills/bills-files/40_Parliament/Session1/b039.pdf.

⁷³ Two sub-amendments in the Bill legislate RTP and RTL criteria: "Respecting the return of a pupil who has or may have sustained a concussion to intramural or inter-school athletics or to any part of the health and physical education curriculum, or his or her return to learning" and "Respecting when a pupil who is suspected of having sustained a concussion is to be removed from or prevented from further participating in intramural or inter-school athletics or any part of the health and physical education curriculum."

There is also an interesting liability exemption built into this bill: "A board employee or volunteer who is involved in intramural or inter-school athletics or any part of the health and physical education curriculum is not personally liable in a civil proceeding for an act or omission if the person acts reasonably in the circumstances, in good faith and in accordance with the Act, regulations and with any policies and guidelines made under this section."

⁷⁴ In November 2011, British Columbian MLA Dr. Moira Stilwell introduced a member's bill (M 206) titled "Concussions in Youth Sport Safety Act." The bill would have required youth sports organizations to develop and adopt guidelines on the risks of concussions. It also would have required immediate removal from play of an athlete suspected of sustaining a concussion and it would have mandated RTP decisions be made by a licensed health care professional trained in the evaluation and management of concussions. Like Ontario's Bill 39, M 206 has yet to be reintroduced in the most recent parliamentary session.

SM1: If every time a kid bumps their head they are going to a doctor, these physicians are going to see a lot more concussions, and their lack of education will become public knowledge because parents and coaches will also become more educated . . . we will also have to develop a specific concussion code for billing purposes to account for the extra time needed with these cases . . . It's a public health issue now with this legislation.

If the lack of education among physicians persists, there is a strong likelihood that medical malpractice suits may follow. I believe this is partially why my medical professionals are motivated to ensure their fellow physicians improve their knowledge of concussion management protocols. Legislation like Bill 39 has the potential to expose the lack of training that is endemic in concussion management both in Ontario and across the country. If this is to be a test case for future legislative acts, my MPs do not want to have the national spotlight directed on them as the province that was unable to effectively manage concussions in young people.

4.6 ECONOMIC IMPLICATIONS OF CARE

The most common economic aspect of concussion management from a structural perspective that my MPs raised was changes they would like to see to the health care system's billing structure. While the structure of medical billing is fixed in Ontario (15-minute windows for family medicine practitioners and 30-minute windows for specialists like RCPS and therapists like AT), my physicians continually highlighted how they creatively engaged with medical billing structures. The most explicit instances of this were found in how my sports medicine physicians (SM1, SM2, and AP) reported that they would double-book concussion patients, especially in the early stages of recovery, as a means of giving them additional time for articulation. The Olympian acknowledged

how helpful this extra time was in allowing her to fully describe her somatic experience, as well as the emotional and intersubjective challenges she was experiencing during the process of retiring for the second time and challenges she faced with teammates and coaches. RCPS typically sees patients for 30 minutes, but he tends to book a double consultation window for certain concussion cases. His intentions are the same as the SM doctors (to allow patients time to fully articulate themselves), but his motivations differ, he feels like because he is financially compensated at a higher rate than his sports medicine colleagues he is financially compelled to spend more time with his athletes:

RCPS: We would love to say we are all doing it to help people at any cost, but unfortunately there is also a certain income that people want to make. And so you are paid by OHIP, and they dictate what a visit makes. I make more than twice what a family physician makes for a clinical encounter. Okay I make more money, I can spend more time with them—with concussion management you need to. If you are rushing them in and out you are not managing them well. I have the luxury to take more time . . . a typical consultation with me is 30 minutes (60 minutes for concussions). Around the city a typical consultation with a sport med doc is 15 minutes on average, some less than five. I do screen and look at my referrals before they come in. Seven months out, they can't do anything and it's their eighth concussion, sometimes I slide them in for an hour . . . I can do this . . . if a family physician did this they wouldn't make any money at all.

My MPs generally point to the lack of singular interventions as an appealing opportunity for economically motivated actors. Concussion management in the current context reflects:

SM2: Kind of like the Wild West, because concussion research is a great way to get in the news as it is not something we know everything we need to know about. For treatment all we got is don't do anything to provokes your symptoms, so we don't have anything dramatic, so it is a great place for research . . . It's good that [increasing media coverage] causes people to do studies, but also there is a lot of money to be made, promoting neuropsychological testing when it's

not necessary, new types of equipment like hamlets we know do nothing . . . Every so often you get groups that will say, “We are going to do something about concussions.” They feel like they are inventing the wheel, the wheel has already been invented but they don’t bother to look into it.

4.7 VARSITY AND ATHLETIC STRUCTURES

Canadian Interuniversity Sport (CIS) is the governing body for university sports in Canada. It actively promotes academic excellence in student–athletes, including through initiatives such as its annual Academic All-Canadian awards.⁷⁵ CIS emphasizes that student–athletes should be considered students first and as athletes second. My MPs noted how varsity athletes constantly reminded them that they are “students first, athletes second” (AT). As such, they tended to give cognitive recovery stronger consideration in making decisions about returning to sport. This was reflected in the responses of Neurosci (who recently graduated from university), Nordic, as well as HP:

Me: Did you have moments of clarity? Random days where you have been symptom-free?

HP: Umm no actually I think that’s the most frustrating part. I have had days where I feel like a million bucks. The other day I felt great, came in had a hard workout, went for a run, and felt great, I felt normal. Then you open up a textbook and it all comes crashing down . . . Have I had days where all day I’m smiling thinking I am getting better? Then no. I mean I have skated a couple times . . . and then you can’t open a book. You start to realize that you know what, are you going to jeopardize being able to come to the rink every day or do you want to be able to read a book and graduate? That’s when it becomes so clear as to what you have to do. It’s just doing it that’s hard.

⁷⁵ “CIS Academic All-Canadians,” Canadian Interuniversity Sport, accessed June 22, 2013, <http://english.cis-sic.ca/academicAllCanadians/allcdns>.

Academic accommodations for my varsity athletes were relatively easy to obtain. Much of this is attributed to the large number of requests for accommodations various university learning centers receive, especially between September and November (according to SM1 and AT). It seems the athletes I talked to were more pragmatically concerned with their post-sporting life and how cognitive difficulties will impact their plans than with their inability to play the sport they love. SM1 and AT's university has a well-integrated system where the medical, academic, and sporting structures communicate effectively with one another and as a result they are able to deliver a high level of integrate care:

AT: Our athletes have an advantage to be in this [integrated] environment. In other universities there is not that great connection. When I started, I feel like over the years the relationship between athletic therapists and physicians has integrated. Coming in I wanted the "full varsity experience". There was always a struggle between physicians and ATs, but now we are becoming more like a big family. [Athletes] are really lucky and sometimes they don't realize how lucky they are.

The hockey player echoed these sentiments. Apparently he is aware of how lucky he is in his particular environment:

HP: I'm fortunate to have the training staff that we do because they are so considerate and cautious. Sometimes it's frustrating because I have to do things I don't want to do but I know it's for my own good and they have my best interests for the future [at heart]. Especially because of the added research, doctors now know to be more cautious.

The varsity athletes appear to be in an ideal, supportive environment where their medical and academic needs are adequately addressed. They each noted that they

received academic accommodation specifically geared to students with PCS⁷⁶ on the same day they reported their most recent concussion. The one instance where this level of support was not provided to an athlete is in the Olympian's account of the aftermath of her concussion in the early 2000s. Reflected in this account is how "times have changed" in the appreciation of the severity of mTBI and the long-lasting implications of PCS and also how some things remain the same:

Oly: I hadn't recovered from my crash in [early 2000s] and had no idea what to expect or what I should do. With this one [early 2010s] I had excellent immediate care, saw a neurologist in Calgary when I got home from the event but there was no follow-up, just told me to not be active for 30 days . . . didn't tell me any of the stuff I have since learned. What do you think I did on day 30? I jumped on my bike, rode around the city. I got home and my head was killing me.⁷⁷ I got into grad school the same day of my crash [early 2000s]. Had I known then what I do now I wouldn't have gone. I went though, this is my joke: I did a master's degree at [a prestigious Ivy League school] and was totally concussed the whole time! It seems like I know more now than I did back then. I learned from this most recent one . . . I was sensitive to noises, kind of antisocial, had memory issues . . . Nothing was going into my brain. I made it though and I don't think anyone was the wiser . . . There have been so many advancements made even between my two concussions. People today seem like they get more medical attention and the injury itself seems to be taken more seriously.

⁷⁶ For example, note takers, deferred exam dates, and most importantly the athletes' professors were made aware of their students' mTBI. They were told what to expect and suggestions on how to accommodate and support them academically. This academic accommodation, in conjunction with restricted and medically monitored activity (motility and academically) and the support of their coaching staff allowed these three athletes to "focus on their recovery" (AT, SM1) rather than navigating bureaucratic channels in search of accommodation.

⁷⁷ This is an example of the issue with "sub-threshold exercise" that was previously discussed. This informant didn't "feel" the symptoms of her concussion during her bike ride, but when she got home and sat down on her couch, a barrage of severe symptoms were somatically experienced.

CHAPTER 5

ATHLETES

The Emotional Experience of PCS

With a concussion it's like your brain is functioning like a Commodore 64, structurally it's intact but compared to a new Mac, it's like night and day. The 64 is intact but processing speed, memory, and ability to do things is lessened. But there is also not anything that can be fixed or upgraded . . . it forces you to become much more introspective, puts you in closer touch with your body, become in tuned. Every little thing that you do you analyze, whereas normally you go through life just sort of doing what you do without thinking about it.

SM1

5.1 INTRODUCTION

PCS denotes a temporally lengthy and spatially constricting brain injury that is uniquely experienced. The questions I posed to my athletes and what I made specific at the outset was that I was interested in the qualitative side of concussions (i.e. their perceptions of how PCS influenced their lived experience). Because I was only conducting one interview with each informant, the interview process relied on quickly developing a trusting intersubjective relationship, allowing me to elicit responses from them that spoke to what PCS feels like somatically to them and how they describe these feelings to others. I was also specifically interested in how PCS influences goals or plans (both sport- and life-related) for the future and what emotions are associated with looking toward a future that is unknowable. This line of questioning was aimed at eliciting

qualitative description infused with personal perspective that had the unintended consequence of producing thick descriptions.⁷⁸

I will describe the somatic experience of PCS by beginning with a focus on the primacy of the physical senses for embodied engagement with the world and how the symptoms of PCS uniquely evoke a sensorial dys-appearance⁷⁹ in my athletes. Because of the primacy of these senses for being in the world, the effect PCS has on the physical senses is where the often repeated phrase “concussions seemingly affect all aspects of your life” first takes root. We will then move from the senses to thought and language, where we will see how sensorial dys-appearance provides the foundation on which cognitive and communication difficulties arise. The level of thinking (planning, intentions, and strategies) and expression of these thoughts uniquely affects the student-side of the varsity athlete as their ability to return to play is dependent on both physical and mental recovery as determined through medical screening technologies and the more subjective opinions of their own MPs. I will use examples from the athlete–physician (AP) and Neurosci to show how cognitive difficulties and the difficulty in expressing ideas (communication, verbalization) hamper the intersubjective process inherent in the enacting of intentions out in the world.⁸⁰

⁷⁸ To do so, I organize this chapter around what my informants spoke about most frequently and I strive to stay close to the phenomenological model proposed by Merleau-Ponty and applied to pain by Leder. I attempt to make numerous connections between various phenomenological themes and concepts, and to provide a partial description of the lived experience of a concussed athlete in Canada, with the implied disclaimer that the description of one’s own experience is partial, made even more fragmented when twice removed in ethnographic writing.

⁷⁹ *Dys* will be employed in the same fashion as Leder (1990), which is outlined in Chapter 3 as an emotionally aversive appearance of our body to our conscious perception, demanding removal.

⁸⁰ Because engagement with the world is always holistic, continuously ongoing, and dialectically variable, the reader should direct their attention toward the interview excerpts contained in this chapter to see how the athletes raise implications of bodily dys-appearance, which touches on many phenomenological levels and concepts simultaneously. Rather than artificially breaking up their interviews, I left them more intact so as to reflect these mutually informing and multidimensional aspects of lived experience.

As I had hoped, the athletes spoke freely about their emotions surrounding PCS. I would like to explore the emotional side of embodied dys-appearance throughout this chapter. To do so I will actively link phenomenological concepts derived from Merleau-Ponty (1962) via Leder (1990) to illustrate some of PCS' affective nature. Frustration is felt (somatically) through how athletes' intentions are impacted by their experienced symptoms. Trepidation or anxiety about an uncertain future is implicated when athletes consider how actions performed now are informed by past actions and hoped for futures (three-fold sedimentation of time). The trepidation arises from the uncertain sedimentation of these temporally informed experiences which reflects an ongoing negotiation rather than certainty. Social isolation is emotionally experienced when spatiotemporal and intersubjective constriction occurs. I will situate this analysis of the phenomenology of emotions through the understanding that emotions are somatically experienced through an individual's engagement with the world, making engagement memorable. I was personally encouraged to see in the responses of all the medical professionals I interviewed that they explicitly focused on the emotions surrounding mTBI and plan to continue to do so because they see how emotions are manifested through the body and have implications on health. For their part, the athletes all seemed cognizant of the emotional ramifications of PCS; however, this does not forestall the emotional experiences they have in coming to terms with their new post-concussed selves.

The final section will be devoted to exploring how these athletes are coming to terms with their concussion histories and how the sedimentation of their concussions is compelling them to make a decision about retirement, sometimes not their first such

decision. The number of concussions sustained, when, how, and at what age all inform how each of my athletes pragmatically approached the decision of retirement from high-level athletics. However, it was the ongoing and episodic nature of PCS that threw this decision into doubt with each presence and recession of their dys-appearing concussed bodies. Either because the athlete has aged out (as was the case with Neurosci who graduated, which is more of a fixed retirement date) or because they want to enjoy a more active future, these athletes approach the decision to retire as a future-looking intentional one: hopes to become an active parent, holding down a challenging career (mentally more so than physically), and aging with dignity (fears of developing early onset dementia, clinical depression, or abusive tendencies). The sedimentation of concussions tended to constrict their futures by throwing into question how their engagement with the world might be altered through actions performed in the present context (e.g. the decision to return to high-level athletics). As they were speaking to me about retirement, they often had a sheepish grin on their face as they spoke about how they still hope to play in competitive recreational leagues in the future. The social role of “athlete” and especially “high-level athlete” is a sticky one that is built on hundreds of hours of sedimented experiences (training, practice, and successful execution of skills) and the emotion-filled memories of going through this process lends a level of permanence to this social identity.

In much the same way as these informants interrogated their potential membership in the invisible community of the brain injured, their selves are also composed of contesting social identities (student, athlete, teammate, competitor, son or daughter, etc) whose borders run up against each other and demand negotiation. The act

of retiring carries a permanence that seems to be incompatible with this illness' dialectic composition, which carries the promise that one day symptoms may clear up. This is why the decision to quit sports is a relative one that needs qualification, as it did in my own case. Even though I know I will not play sports again at a competitive level, I'm confident I can still enjoy an active lifestyle and perhaps remain involved in coaching. My athletes are also making these sorts of compromises, undergoing decisions of partial retirement and searching for opportunities to remain involved in sports. Their decisions about retirement are dependent on how they feel now and their assumptions about future possibilities which are informed by memories of past functionality. The decision to retire is intersubjectively reached. My athletes spoke of their parents urging them to retire but ultimately the final decision must be made by athletes themselves. Looking forward my athletes were fearful that deciding to retire now will be looked back on as a mistake and a missed opportunity that is unable to be relived.

5.2 EMBODIED EMOTIONS AND WORLD ENGAGEMENT

I would like to position the somatic experience of PCS as an emotional one. Emotions arise through dys-engagement with the world. Margot L. Lyon and Jack M. Barbalet (1994) recognize that emotions are first embodied experienced somatically

within the individual.⁸¹ One of the major functions of emotion consists of the constant evaluation of external and internal stimuli in terms of their relevance for the organism and the preparation of behavioral reactions which may be required as a response to stimuli. Emotions are felt “inside” but are always the result of our interactions with the “outside” intersubjective world. Lyon and Barbalet write:

An adequate understanding of social agency requires a concept of embodied agency. Emotion has a role in social agency as it significantly guides and prepares the organism for social action through which social relations are generated . . . the emotions which move the person through bodily processes must be understood as a source of agency. . . . It is important to conceptualize the body in a manner which directly refers to the interactive and relational, and therefore social. Instead of conceptualizing the bodies of individual persons in terms of the social constraints to which they are subjected . . . it is more appropriate to emphasize the active bases of the embodied agent in relational and social forms. [50–55]

I see this article as a potential adjunct to Ortner (1984) in that emotions are seen as generating the course of social interaction. In the case of mTBI the assumed emotional accompaniments of future social activities often motivates athletes to avoid them. I would like to argue that emotions are *situationally derived* in that they are derived from situational embodied engagement with the world rather than a result of a chemical imbalance of neurotransmitters or something that can be graphed and quantified

⁸¹ S. Kay Toombs (1995) reflexively uses her own embodied experience of living with multiple sclerosis as her reason for becoming interested in phenomenology. She sees its potential value in helping other sufferers in particular with the emotional ramifications and its holistic embodied experience. She also hopes that these experience-rich accounts could be an invaluable information source for MPs. She uses phenomenological analysis to “illuminate the human experience of loss of mobility—a bodily dysfunction that is common in neurological and other degenerative diseases . . . a phenomenological account of bodily disorder discloses the emotional dimension of physical dysfunction. In providing a window into lived experience, phenomenology gives invaluable information about the everyday world of those who live with disabilities. Such information is of enormous practical significance when devising effective therapies in the clinical setting and in determining how best to address the personal, social and emotional challenges posed by chronic disabling diseases” (Toombs 1995:10).

(Mainwaring 2011:256–265). If managing medical professionals are interested in attuning their interventions to the emotional correlates of concussion, it should be done in a manner that investigates possible medically sound adjustments to the means by which concussed athletes engage with the world. Throughout this chapter I will draw attention to the emotional ramifications of my athletes’ disrupted engagement with the world because of PCS.

5.3 WHAT’S IT LIKE TO BE CONCUSSED? EMBODIED DYS-APPEARANCE

Somatically experienced symptoms (symptoms experienced through the sensorial body) arise and also get progressively worse in direct correlation to the amount and type of embodied engagement with the world undertaken by athletes with PCS. The type of engagement and the threshold (how much engagement can be handled) varies according to concussed athletes and individual athletes’ day-to-day (and moment-to-moment) experiences.⁸² Athletes (or anyone with a prolonged recovery from PCS) undertake a process of scrutinizing somatically experienced symptoms in an effort to ascertain the meaning behind these felt symptoms and how they figure into their life and future plans—a process Leder refers to as a hermeneutic quest. Efforts are undertaken to avoid whatever it was in the world that made symptoms more severe. The dys-appearance of various body parts (eyes, ears, and the collective bodily movements involved in motility)

⁸² The day-to-day variation within an individual athlete speaks to the episodic nature of this illness. Symptoms can also sometimes appear for no discernible reason and cannot be immediately linked to past embodied engagements.

and functions⁸³ uniquely affects the lived experience of my athletes. When experiencing PCS, not only is your brain presented to your awareness but you also become aware of the primacy the brain has for seemingly all aspects of engagement with the world. This is due to how the physical senses are uniquely implicated in this illness and inform all aspects of embodied lived experience. The precipitators of mTBI symptoms exist in the world and it is through engagement with the world (via the senses) that the somatic experience of symptoms is heightened.

5.3.1 SENSORIAL DYS-APPEARANCE: SEEING

In the realm of visual experience the athletes seemed to collectively struggle with bright lights. Typically they would describe their light sensitivities in reference to things they couldn't do now in comparison to a state prior to their concussions. For the varsity athletes (and the athlete–physician), a projector in a classroom setting was a common precipitator of heightened symptoms. The rugby player provided another instance of this type of visual dys-appearance and he illustrated how he attempts some interventions based on questioning his own engagement with the world:

Rugby: One thing that really bothered me and still does is oncoming headlights at night—really irritating. Sometimes I turn on the overhead lights to block it out and sometimes I have to look away from oncoming headlights.

My interviews were conducted in the wintertime and in Ontario that means perpetual snow cover. The glare of the sun against the snow was noted as an irritant for

⁸³ The sensory symptoms of PCS include: seeing (tracking motions, apprehending brightness); hearing (focused hearing, noise sensitivity, painful hearing); and motility (limits to the extent of motility, inability to control motility, tracking motions as one is moving). These dys-appearances can present themselves to our conscious awareness in isolation but more often in mutually informing bundles.

the rugby player and of course the Nordic skier, whose sport is played on a snowy mountain. I was able to evoke a peculiar visual dys-appearance from her, based on my own experiences, which I call tracers:

Me: What were your symptoms? What precipitated them?

Nordic: Headaches . . . I would get agitated because I would want to do work but my head would just start throbbing. But it wasn't that bad. Lights outside, bright snow, and bright sun is really bad. I try to wear sunglasses, but I also try to avoid it as well.

Me: Do you see dots in your vision when you look at snow?

Nordic: Yes! Oh you too?! I thought I was dehydrated. So weird. What is that?

Visually, athletes also noted the difficulty they had with tracking motion—both tracking with their eyes and turning their head to look at something. Difficulty in reading tended to be the most common manifestation of tracking motion sensitivity. The hockey player noted he would get spatially located headaches above his eyes through the unique combination of cognitive precipitators (sustained thought), visual precipitators (light–dark contrasts of black and white typeface), and motility precipitators (moving the eyes over a page). The usage of “we” in the following quote indicates the intersubjective nature of dealing with these complex symptoms:

HP: When you read a piece of paper, say if you're reading a book. You're trying to basically read that in your head. You may not notice it but when we're reading something, we're talking in our heads. When I do that, I become blurry (visually and cognitively). I become nauseous. And I get a pulsating headache right above the eyes. And it becomes where it's unbearable. We don't know why. We don't know if there's damage. We don't know if it's just a symptom and we don't know if it is permanent.

The AP also identified experiencing this type of spatially located headache but because she is “more somatically aware than others” (AP), she was able to lean on her education as a means of explaining their origins and possible interventions (both medical and non-medical). The knowledge she brings to her PCS experience is helpful, but dominant in this passage is the unavoidable nature of PCS; it is impossible to retreat from the world and our embodied engagement with it:

AP: I know a temporal headache is related to motion sensitivity, so if I have done a long walk, I know it gives me a headache in that one location. I get a cognitive headache when I read that is more in between the eyes. I can describe the symptoms pretty well and I usually have an explanation for it too (*laughs*) . . . I’m definitely not functioning well now. I have a five-year-old daughter. I had to drop her off at daycare and I could barely drop her off, walking through the center with all the kids running around, and their voices. To drive her there and pick her up was all I could do in a day. It was even pushing it. The drive is only eight minutes. Then I would try to do laundry and dishes, just trying to make supper, looking down, trying to chop carrots, for example. The motion of just putting my head down trying to do that would just make the room spin. Trying to prepare things for a meal I would probably have two hours of a flare-up trying to do that. Trying to do things around the house I realized there are a lot of things that really don’t need to get done.

5.3.2 SENSORIAL DYS-APPEARANCE: HEARING

Auditory sensitivity was noted by the Olympic athlete and the hockey player in different ways. The Olympian described her post-concussion hearing as supersonic. She not only has hearing that is more sensitive in that she literally hears things louder now than she did before, but she also now “hyperfocuses” on distant (spatial) sounds that are

episodic (spring forth from general background noise) in distracting ways.⁸⁴ We had our interview at a fairly busy coffee shop and when she mentioned this problematic auditory focusing, I exclaimed, “Oh I get that too!” and together we picked out specific sounds we found distracting at that point in the interview (e.g. clinking sound of teaspoon on saucers).

The hockey player noted how he actively tried to not be distracted by his auditory environment.⁸⁵ He makes his auditory sensitivity an “object” of his scrutiny and avoids it or undergoes a process of subjectification until it is “unnoticed”—a process outlined in other ethnographies of people with chronic pain (Jackson 1994). To illustrate his point, he pointed out a young woman sitting at the table next to us whose music we could hear through her earphones. He said, “See? That right there—doesn’t distract me anymore. I have learned to tune it out.”

Neurosci and I had the most noisy interview environment and over the course of the interview I noted his shoulders rounding, his right hand rubbing the back of his neck and side of his head, and his speech getting slower and more labored:

Me: What are your concussion symptoms right now?

Neurosci: Headaches every day, low grade and in the background,
 always running, always on the right side of my head, sharp

⁸⁴ The Nordic skier echoed the distracting, hyperfocusing nature of episodic sound: “I used to be able to study with music on in the background. Now I can’t have any. I can’t concentrate.” The episodic nature of distracting sound here is in the presence of music itself against a possible backdrop of near silence. During the composition of this thesis I have been able to listen to music without being distracted. I think this is because the music itself (which is more constant and less episodic classical or electronic music) has distracted me from both the pain associated with cognitive output and the frustrating sensation of not being able to find a word (aphasia). It seems as though the sound type and composition has implications in sensorial dys-appearance.

⁸⁵ After 12 concussions over nine or ten years, the hockey player was able to actively attempt (and sometimes succeed) in forcibly backgrounding symptoms or skillfully avoiding them. This is not a total process but reflected in his descriptions of his coping mechanisms. They tend to be geared toward distraction and avoidance in a process toward *subjectification* (Jackson 1994:203) in an intentional fashion.

pain behind right eye, neck stiffness, always pulling my neck to release it. My biggest complaint is noise sensitivity. It's been over a year so I have learned to get used to it. Unloading my dishwasher might as well be setting off fire crackers, it's like a high frequency or pitch thing, like I don't just hear the sound, I feel the physical sound wave sensation on the eardrum. Even quiet things—if they are sharp, I feel that sensation too.

This passage reflects a blending of the subjectifying process described by the hockey player (trying to ignore the sound)⁸⁶ and the particular sensitivity to piercing sounds described by the Olympian. It also reflects the troublesome and unique somatic experience of PCS. “Feeling” sound would make Neurosci’s background headaches more severe). He has also been able to specifically locate the origin of his pain as being in his eardrum (dys-appearance) and identified specific tasks he could attempt to avoid in the future.⁸⁷ This passage also reflects the episodic nature⁸⁸ of chronic pain as cast by Leder (1990), where pain springs forth from a background of continuous, ongoing pain through enacting intentions.

5.3.3 COMMUNICATION BREAKDOWN

The communication of embodied lived experience will always be limited by language; the breadth and depth of the phenomena that make up lived experience is too

⁸⁶ Later in the interview Neurosci spoke explicitly about how his persistent headaches have fallen into a background awareness that is constantly painful: “I have had headaches for so long now that I kind of forget what it’s like to not have them. They just become your way of life.”

⁸⁷ In mTBI recovery, because there is little that can be done to reduce somatically experienced symptoms, often the only intervention is to avoid certain engagement(s) with the world that have been identified as being something that precipitates symptoms. This is why Neurosci, in describing his somatic experience of painful sound waves, linked it to an everyday action from his lived experience (emptying the dishwasher), which he will actively try to avoid in the future.

⁸⁸ “Even pain of a more chronic nature are often marked with an episodic nature, changing in their character and intensity according to ones activity or position. Feelings of general neutrality (well being) are not marked by abrupt beginnings and ends but a unthematized flow of time, not in pain. Constant pain is like this, reasserting its presence at various times. Normally awareness of stimuli recede over time, this is why pain constantly needs to re-assert its presence” (Leder 1990:72–73).

profound to be captured completely in partial language systems. This is made more difficult when a member of the brain injured community is trying to communicate to someone who has never suffered an mTBI or experienced PCS. The somatic experience of PCS is also uniquely strange⁸⁹ with symptoms that manifest to our conscious awareness which had never been experienced in association with particular actions. Here too athletes will employ comparative devices to aid intersubjective understanding (e.g. nausea when reading [HP], balance issues [RP]⁹⁰, or out-of-body experiences where they are not themselves [Oly]⁹¹):

HP: That's one of the main frustrations. To a doctor maybe it's different, because they know what to look for, sort of. It's very hard to explain your symptoms, what works, what doesn't work. Nine times out of ten it makes zero sense. Why can I go for a run and push through a two-hour workout and not be able to open a book? Why can I go out and play hockey, but can't turn on lights or sit in a room with bright lights? It's something so simple that becomes so complicated, something so complicated becomes so simple.

Aphasia is often associated with mTBI⁹² but has been poorly documented clinically. This spectrum disorder lacks a clear etiology and is often cast as a symptom of

⁸⁹ The medical professionals and athletes were unable to make a positive comparison between the experience of mTBI recovery and any other illness or injury. They instead provided contrasting examples as to what makes PCS and mTBI unique. Athletes often contrasted recoveries from preexisting injuries with recovery from mTBI (the hockey player often cited a herniated disk injury as a comparative device).

⁹⁰ Rugby player: "After a shower I shake my hair out. I have to hold on to something to steady myself. It's like when you lie down and stand up quickly. Everyone gets that. I get it worse. My mom's always on my case about it."

⁹¹ Oly: "I went to work and made tons of driving mistakes. I could have killed someone. Nothing was connecting. It was like Charlie Brown's teacher: whaa whaa whaa." Me: "Like detached?" Oly: "Out of body, totally."

⁹² See Appendix 1.4 for a medical definition of aphasia. Nordic: "Following a conversation is difficult. Communication like finding a word or a memory recall. The 'tip of the tongue' phenomenon." In the interviews with Nordic and Olympian, I talked about aphasia after they described it in their own words when speaking about communication issues. In both instances they said, "Oh that's what that's called. I didn't know it had a name." The Nordic skier specifically thought that she "was just getting dumber" when she had difficulty with word recall and articulation.

brain injury and is also under-researched (Kavanagh et al. 2010). I can note instances of aphasia in my own life, particularly in verbalizing my thoughts but typing does not seem to be affected to the same extent.

It would be assumed that communicating with another person who has had a brain injury would provide some shared experiential ground of understanding. However, the rugby player resisted a simple classification of intersubjective communicative encounters (even between concussed teammates):

Rugby: I offer advice to people when I find out they have a concussion. I think there is only so much you can do for someone. I have a friend who has been through the same thing. I remember talking to him about it, what he might miss out on. They were very similar experiences. It sounds weird but I felt a similar connection with him. Dealing with teammates, some people understand and appreciate what you are going through, based on personal experience or people around them. Then there are people who are completely ignorant about it, whether it's cracking jokes or calling you a pussy for not playing. But it seems like nowadays lots of people have some sort of knowledge on it, more so I think if I tell someone they seem to be interested in asking about your symptoms. Just what it's like if they haven't been through it themselves. But I have also met people who have had one or two and it's just something you can talk about, right? Then there people who have had a few and really don't get it.

The rugby player was the only athlete to be treated by a concussed physician. His physician was able to mobilize her own embodied experiences as an aid in facilitating communication within the medical encounter:

Rugby: My cranial sacral therapist was a university soccer player who sustained concussions herself. Describing my symptoms she would say "I have been through that" and describe symptoms in detail, giving her own take on it. She would say, "Has this ever happened because it's happened to me?" I was able to talk to someone who has been through it. Once you experience it, it's a whole different perspective you have.

I find this passage illuminating as to the communicative potential of the AP, who is planning on utilizing her own experiences with PCS within the clinical encounter.

5.3.4 COGNITIVE DYS-APPEARANCE

Oly: Nothing was going into my brain, I made it through the program and I don't think anyone was the wiser, but I can't remember any of it.

The dys-appearance of cognition (cognitive processing potential) is a terrifying prospect that is uniquely experienced by each of my informants. Short-term memory recall was problematic for these athletes and was often experienced through tasks that they used to perform with ease:

Neurosci: Even now, I started to work in a medical clinic, look up a number to call—ten digits—have to check it twice to make sure. Absent-mindedness. You don't trust yourself at all because you don't know what you are doing.

Current cognitive functioning is compared in reference to past functioning. Often intellectual milestones or accomplishments will be pointed to as a comparative device:

Oly: In [the early 2000s], I was an undergrad student in history and poli sci. I wouldn't make this statement now, but pre-2000s concussion I was confident in my cognitive abilities. I could study a variety of subjects. I don't feel that way about cognitive abilities at all anymore. Now I can barely do my job as a public servant, and in all honesty it's not that hard. You wouldn't know that I had a graduate degree. I don't remember things. If I was blond I would have the perfect out! If I can't remember things I will just joke. Inside though I know, shit, I should know this.

Often the slow recovery of cognitive symptoms is pointed to by athletes as a possible indication of a permanent change in how they engage with the world:

Oly: I started to notice cognitive issues so I went to see a neuropsychologist . . . well-known in the literature but didn't

have the best bedside manner. Hurtful when she said then, but I cling to it now, “Well you need to understand that this is the way you are now. Turn the page. This is the new you, your new baseline and you need to accept that. If you haven’t gained what you lost a year later, then this is your new normal now. It’s more about accepting it.” I know my cognitive abilities are not going to come back, people close to me don’t notice it. I can tell how much mental energy it used to take me in the past compared to now. If I look at it that way then I have PCS till the day I die. I haven’t been able to talk to anyone else about this stuff. I was hoping that your research would be helpful in having someone to talk to. I didn’t have it. I was trapped in my head.

5.4 INTENTIONAL CONSTRICTION AND INTERSUBJECTIVE RELATIONS

What has been discussed in this chapter so far is meant to provide some background on the embodied foundation from which these athletes now engage differently with the world. This section will look at how the dys-appearances presented thus far have implications for how athletes enact their intentions differently and how they interact with different groups of people. The enactment of intentions out in the world is dependent on one’s ability to compel their somatic body toward their achievement. Due to both the episodic nature of chronic pain in general and PCS specifically, the experience is one of constant revisiting and adjustment of intentions. According to Leder, it is the disrupted flow of pre-objective intentionality that occurs when the body dys-appears:

A landscape is viewed not as a field of possibility but of difficulties to negotiate. The ordinary sense of free and spontaneous movement is now replaced by calculated effort; one does not want to take chances . . . This experience of world-as-opportunity is precisely what dis-ease calls into question.
[Leder 1990:81]

[When in pain] a phenomenologically centripetal force is experienced, gathering space and time inward to the center. We are ceaselessly reminded of the here-and-now body . . . we seek

to escape this hold of pain by focusing outward upon the world, or dwelling in our past or our hoped for future. Yet even such a move outwards bears witness to the original constrictiveness of pain. The body is no longer a null point but an active presence we must resist. [Leder 1990:76]

Intentional constriction is the bringing near of space and time, where a consideration has to be made of the collection of micro-moves needed to enact longer-range goals:

HP: And the frustrating thing too is, especially in a situation like myself now, I know that it seems like physically I can do everything. I have no pains in my body. Do I get headaches when I read? Yeah. But I just don't read then and everything's fine. It's hard mentally to convince yourself you can't do it.

With PCS, micro-moves⁹³ are symbolically magnified for the sufferer, each move representing a depletion of available intentional resources. Not only does it take more effort and more time to accomplish tasks that in the past were considered simple, but the actual enactment can make symptoms worse. Athletes feel isolated from the world because of their inability to pragmatically engage with it in a fully integrated (holistically embodied) way, where sensorial stimuli and movements through space and time become progressively more intolerable. Because it is impossible to completely isolate oneself from the world, they became constantly cognizant of how they spatially and temporally structure their days:

AP: My anxiety was going into places that I knew were going to aggravate my symptoms . . . I would get anxious because I would be getting out of my car knowing that I had to go into a store that I *knew* was going to make my head hurt. Even a coffee date with a girlfriend, that should be a good

⁹³ The understanding that micro-moves taken together are the means through which we mobilize intentions is foundational in Pierre Bourdieu's social theory. Ortner (1984) recognizes (as does Merleau-Ponty and Leder) that our intentions are made up of micro-moves, but that because the conscious intention devoted to executing these moves is largely pre-objective, we should instead direct our analytical focus toward how individuals cast temporally further reaching intentions rather than focusing on the small moves necessary to enact them.

experience, I would get anxious. I knew that just the drive there would not make me feel good and going into a setting like a coffee shop I knew within a half hour my head would hurt. Eventually you run out of that and there's to eliminate from your life. And I would push myself longer than I should, talk for an hour. I knew I would feel awful afterward so I would get this anxiety going. Or having kids over at the house. My daughter having friends over. I would get anxious. I knew that the extra noise would bother me. Family functions, I knew it would trigger me in a really bad way. The anxiety, people have a hard time explaining why they are anxious . . . I knew it was a "trigger dependent anxiety" but for awhile I didn't know where that anxiety was coming from. I didn't know whether I should go on an SSRI (*selective serotonin re-uptake inhibitor*—an "antidepressant") because I kept having anxiety-related issues. To tease that out is hard to articulate. Maybe you could ask more questions, to kind of tease it out of them.

The somatic experience of anxiety is evoked by fears about the future (trepidation) and also from just knowing based on past experience that environments and engagements are certain to make symptoms worse (but we often do them anyway as a means of maintaining our ongoing engagement with the world). The AP talked about how she broke her day down into manageable "chunks" and would organize her activities according to how she was feeling at the time and her experience of how she handled certain activities in the past. She also, especially early on in her recovery, invested a great deal of meaning in the accomplishment of small goals. A particular instance she gave was the first time she was able to drive to the bank across town and back on her own. Not only was this important to get done in terms of paying the bills but it also helped her feel that she was not dependent on others and, even more importantly, that she was doing things that she felt a mother should do. Conceptions of gender were not explicitly brought up by my athletes but when it was it is often conflated with their inability to fully enact intentions:

AP: Then little things, like day-to-day functions. I couldn't read a story to my daughter, my head would just kill. Just trying to tuck her in bed at night, I could barely do it. Even phone calls I just couldn't do it . . . everything in my day was affected. You couldn't even socialize or go run an errand because just going to run that errand caused many symptoms. I figured that I couldn't run errands without having problems, so I would just slow myself down and do maybe one or two only. Certain things still bother me, like taking my daughter to hockey today, just driving to the rink trying to watch the motion on the ice, putting her equipment on . . . I gave myself an hour to make my symptoms calm down before I talked to you on the phone, though to do something like that I need to give myself an hour of downtime to make the symptoms go away before I can do the next thing.

The Olympian spoke about being sent to the London Summer Games for a work assignment as a turning point in her recovery from her most recent concussion. She unwittingly underwent a process of subjectifying symptoms that made them invisible to her perception and in so doing enabled her to accomplish a meaningful goal:

Oly: At home things were crazy. I was still constantly checking in with myself: how's the head, mood, balance. In London I was so busy I didn't have time to do this and I made it through! I was really proud of myself. I was so out of my element. If I could do that, I think I'm okay, am I okay? I think I'm okay. Since that point I have been treating myself as normal, except I can't get over the hurdle of exercise . . . I'm still able to ride my bike. I have a hard time shoulder checking and moving the head, but a mellow bike ride I can do it.

The male athletes in my study (Rugby, Neurosci, and Hockey) all pointed to their unwillingness to go to bars and clubs as a problematic example of the social constriction of intentions. The act of going to a bar or club as a young athletic male carries gendered connotations of what is expected in terms of conduct and what could happen if there is an aggressive confrontation:

Neurosci: When I walk around I am so much more careful now. Even if I bump my head like a tiny bit it is a headache for the rest of the day. I don't go to bars downtown anymore. Sometimes I will go if I know it's a safer crowd. I would never step foot in a club. Blaring music is one thing, but also the unpredictability. You never know what someone might do. I am a lot less confident now. I am more turned inside. If there is ever a confrontation, even bordering on it, my heart starts racing and I just take off.

The Olympian connected the experience of intentional constriction with gaining weight.

Not only did gaining weight alter her conception of her body, she went on to tell me how others saw her as a “non-athlete”, reporting surprise to learn that she has competed at multiple Olympics:

Oly: The concussion [in early 2010s] caused me to not want to do things anymore . . . During this recovery, because I was not on the national team anymore, I focused on GRTW protocols, which didn't leave me with the energy to exercise. Being proactive is the opposite. The prescription is to be conservative. This is why it's interesting to talk to you. So much has changed in the last two years. My coping mechanism has been: I will just accept this; it is how things are now. Accept the fact that I gained 40 pounds and gone from a national team athlete to sedentary person. I accepted it, but it sucks. I had to buy a new wardrobe. I don't want to buy fat people pants. I know I'm being a girl right now but it's true. I said to someone recently, I am only now relating to the body that I have now, because for me, I'm not morbidly obese but I have never been like this before. I was muscular. I don't relate to this body. That's been really challenging.

5.4.1 RELATIONS WITH THE NON-CONCUSSED

Intersubjective relations depend on a shared understanding of experience. With PCS the intersubjective encounter itself can precipitate symptoms (e.g. talking, following conversation, traveling to meet someone, doing an activity together). Also, trying to explain why all these things are hard and how they uniquely exacerbate individual

symptoms adds to a sense of social isolation that is balanced against a desire to both be understood and to be socially active. Athletes experience an intersubjective and a social constriction where they are compelled to be selective about sensorially experiencing this aspect of the world, both for fear of making symptoms worse and so that further in the future they are able to continue to engage with the world (i.e. so that they don't expend their intentional resources). Athletes in my study tried to explain in various ways why and how people in their lives struggled to understand what they were experiencing somatically and why they couldn't do the things that people in their lives were used to seeing them do:

Neurosci: Across the board I have less contact with everyone. When I do though it's like old times, but they are pretty good. If I have to say I'm going to sit this one out, they are pretty good about understanding . . . just little things like having my friends over all the time. You turn them down enough, eventually they stop calling.

The hockey player used his family relations as a therapeutic tool to help distract him from his somatically experienced symptoms:

HP: Will the headaches be there? Yeah, but they kind of go to the back of your mind. It becomes more of an everyday thing where you expect them, so they become less noticeable. Spending time with family or friends, you know I might not be able to have a beer ever again. It doesn't mean I can't spend time with family and friends and to cherish them, because regardless of hockey they will be there. You know, I have had to stay away. I can't go everyday and see your teammates going to work and if they had a bad game before and get bag-skated. I want to be part of that, even the punishment, you hate seeing that.

Despite his best efforts to intentionally background his symptoms, the hockey player still is intersubjectively disrupted and finds that he has to justify how he feels to the non-concussed community:

HP: To explain to a teammate who has no idea at all, not comfortable at all, they look at me like I'm crazy. This is not always, even people without concussions come into contact with them. They hear it all, they try to find, I don't want to say the lies, but maybe the contradictions. They might look at me, because I am a university student, like maybe this guy is just trying to get an easy grade. I would love to be able to do my exams this term, just to get back into the rhythm. People start to think that maybe you are just trying to get through a loophole. It's frustrating when people question you. Pardon my French, it's bullshit. That's probably the part that hurts the most. The other day I pulled out my phone to read some texts and I put it away and said I can't read to a teammate. He said, "What do you mean? I just saw you." It's tough; he should be able to sympathize.

The Neurosci student voiced a strategy that is often employed by my athletes: sometimes it is just easier to fake being healthy to people rather than trying to explain the minutia. He recently started a job in a medical clinic, despite having aspirations of pursuing medicine. He decided to selectively disclose his symptoms to only a select number of physicians at the clinic after acquiring the job, but during the interview he did not tell them of his mTBI history as he feared he would not get the job:

Neurosci: When I applied for my job I didn't tell them, just because I thought it would severely limit my abilities. Why would they hire someone who they need to make accommodations for? The nature of the job I can mostly get by. It's pretty quiet. Good thing is that I am around doctors all day

Me: Do you talk to them about it? Ask them general questions about treatments as a roundabout way of asking questions about yourself?

Neurosci: Some know I'm asking about myself.

Me: Have you consciously made the decision who to reveal to or not?

Neurosci: Yeah, I don't bring it up much. I told the manager when asking for less closing shifts. Figuring out the billing is raging headaches. I make a lot of mistakes with stuff like that, stapling wrong papers . . . just little mistakes, it's so frustrating.

5.5 RETIREMENT AND STICKY HABITUS

AP: I would just change sports based on my injuries . . . I think I'm going to stick to the stationary bike and yoga for now.

As noted in my own experiences with PCS, I had to retire multiple times from sports because I kept returning. There is a palpable sense of “home-ness” when engaging with a sport where one has a well-developed skill set; it literally feels natural. Howe (2004) classifies this higher level, pre-objective engagement with the sporting field as “being in the zone”. This fleeting pre-objective engagement is what draws athletes back to their sports despite the increased chance of sustaining a subsequent brain injury and it is the intersubjective relationships that is often missed most. The rugby player spoke about his first retirement from organized hockey:

Rugby: Having a conversation with parents, they never made me quit but asked me to think about everything. They said it is in my best interest to not play hockey. I very well remember it, very emotional, both parents crying. I didn't want to accept it but I did. They were very happy and emotional. That was with hockey. It had a part to do with my doctor. He hinted that I should think about this. I was going into grade 12, planned on playing rugby in university. He said if I was serious about this I had to be ready. If I got another one in summer, I wouldn't be able to play. He recommended that I take longer. It was that moment where my mom said, “You only have one brain.”

While the hockey player does not reveal who “we” are in describing the process of coming to terms with the possibility of an early retirement, we see the emotionally aversive nature of his decision to quit the sport he has been playing for over fifteen years. The following passage illustrates how he wavers between quitting and continuing to play, seeking to strike a middle ground where he is still involved in hockey but in a non-player

role. Yet being a spectator instead of a player is a difficult transition to make, and the decision to do so is made even more reluctantly in the absence of a clear prognosis:

HP: Don't know how long it will be. Like I said, it's not my first and if I keep playing it probably won't be my last. So we have to consider some things, what route to take. And if that means to move on in life, then that's what we do. If it's to play and keep risking it, then we'll do that too. So we got to assess some things. Not something that will be decided overnight. I've done some things and some rehab that I've felt good, and some I haven't felt good. So until everything's perfect, I won't play. Right now, heaven forbid, but if it happens where this is the last one, I think I might have to take a break from sports in general. Personal lifestyle I think you can say is a different thing, and I'm lucky that I can do that and not experience the symptoms. But as far as staying in hockey, it's something I do intend on doing, whether it's immediate is a different story. Just because it might be too painful right now, but down the road, absolutely. You want to participate. You want to do it yourself. So if let's say in the situation we're at, where I have to stop playing and I keep myself in shape, I can think to myself, you know I can still do this. It's hard because your brain doesn't all of a sudden hurt. You get a trigger.

The Nordic skier sustained a concussion in a non-sport related biking accident, but it of course still detracted from her ability to engage and potentially forced her into an early retirement. In this passage we see her desire to remain involved in sports and how it is uniquely intensely felt by athletes who have been forced into retirement due to injury:

Me: When you think to the future . . .

Nordic: Surprised that I am still having effects. Surprised I'm not racing yet. I'm still feeling effects from it. It's mind-boggling trying to make realistic goals. I don't really know. Mostly it will recover I hope, but there will be a little bit that's not perfect.

Me: Do you think it's going to detract from future athletics?

Nordic: No, I'll definitely stay involved, might have to do something first then come back. I was looking forward to a full career.

Earlier in the interview she spoke about a “wax tech” award she recently won at one of her team’s racing tournaments. Athletes are driven by success and even a small award directly tied to athletic activities can help to tangibly remind them that participation in sports has the potential to reach beyond the deeply sedimented role of student–athlete, despite their voracious desire to continue to engage in the sporting field in a manner they have grown accustomed to.

CHAPTER 6

MEDICAL PROFESSIONALS

Managing Holism

The big thing is it does not just effect your ability to play, it effects your ability to go to class, study, socialize, party, drink, maintain relationships . . . being in university these are the concerns. Concussions are also incredibly isolating. I try to get coaches on board so that if a player is out they can keep them involved in the team somehow, whatever their brain can tolerate. Their social world is their team. Take away their ability to play, socialize, go out and stay late, work twice as hard in school—you are taking away a major part of themselves. These changes can develop into developmental disorders, depression, and anxiety primarily. Not situational anxiety, its deeper . . . it's the changes in their lives that are causing these other issues.

SM1

6.1 INTRODUCTION

Medical professionals in my research have been presented with an illness that is ambiguous both in its treatment and prognosis. Attempts are underway among researchers and practitioners to refine their understanding of mTBI and PCS' etiology within a medical framework (objectively and empirically through the collection of normative data). Due to both a historic lack of attention within medicine itself and concussions' dialectic–holistic nature, MPs are faced with an illness that demands they approach the concussed athlete in a phenomenologically oriented manner. The actions of this phenomenological approach are geared toward fulfilling an intense desire on the part of MPs to help the athletes whom they hold in such high regard in any way they can (both traditional western medical approaches and others). They recognize that athletes are

socially and culturally situated actors influenced by the intersubjective relations in their lives, the larger changes in society's acceptance of the severity of mTBIs and the long-term ramifications of multiple concussions. These factors influence the medical professionals' rendering of the concussed athlete as an integrated whole that is situated within a sociopolitical field.

It falls on the managing medical professional to disentangle the concussed athlete's lived experience and impose some order on this murky condition through the manipulation of the athlete's physiological body and their future actions. Medical professionals employ the limited tools at their disposal to manage concussions but rely more on their ability to creatively devise and employ an individual concussion recovery plan for each of their patients, made possible by being attuned to the embodied holistic context in which each of their patients are embedded. To gain access to this context, a relationship of trust must be quickly established within a spatiotemporally confined medical encounter. MPs undertake a rapid process of symptom isolation and treatment, which they note is both efficient in its ability to quickly help individuals and more importantly gives both the MP and the athlete the feeling that active steps are being taken toward recovery.⁹⁴ This approach is the foundation of campaigns underway to educate MPs' fellow colleagues in an effort to correct the historical legacy of a lack of attention.

This chapter will discuss how the concussed athlete is envisioned by MPs. mTBI demands that managing medical professionals see these athletes as holistic beings whose health is impacted by aspects of their lived experience. By assuming a holistic

⁹⁴ This process also importantly contrasts the old medical advice of: go home and rest until symptoms dissipate. Like back injuries my MPs recognize that the introduction of early exercise is key for both recovery and mental health concerns. The approach of ranking and isolation follows this same trajectory of actively engaging in recovery, which was not the approach in the past in mTBI management

perspective, my MPs are well-positioned to be attuned to the informing aspects of health that have traditionally been disregarded within medicine's tendency to cast the ill as broken machines in need of repair.

The chapter will conclude by showing how this new approach to medical thought and practice is being lived by the athlete–physician (AP). Her own embodied (pragmatic) experience of sustaining her first concussion instigated an existential shift in her perspective on the management of concussions, which is reflective of a more deeply entrenched version of her colleagues' whole patient approach. What she experienced was essentially a process of understanding the Other, undertaken through years of practical experience managing concussions within a clinical encounter and then suddenly being thrust into the community of the brain injured. Her prolonged recovery has made her membership in this community more permanent for the time being. When she returns to her practice, she plans on approaching concussion management in a fundamentally different way as she feels she has gained an invaluable depth of empathy for the plight of her patients' embodied lived experience.

6.2 PHENOMENOLOGICAL PHYSICIANS

mTBI challenges physicians to become the phenomenologists that Richard Baron (1992) advocated for in an essay entitled *Why Aren't More Doctors Phenomenologists?* Baron points to the historical legacy of Cartesian thinking and practice as the main culprit in seeing the self as composed of two separate entities, mind and body:

Generally speaking, the relationship between body and self is invisible in the traditional orientation.⁹⁵ People either are their bodies with no distinction made at all, or the self is seen as completely independent of the body, the body being a servant of the self. The texture and complexity of the relationship is not a subject for medical scrutiny, being taken for granted as identity some of the time, or master–servant most of the time . . . The traditional view deprives us of a point of view from which overall human purposes and goals might be incorporated into our approach to patients and leaves us no way to conceive of body and self as being related in any meaningful way.
[Baron 1992:39–40]

Baron advocates that physicians assume a phenomenological approach, one that views the patient as being a holistic, embodied amalgamation of dialectical processes. The approach that he advocates for in clinical practice is holistic in its rendering of the ill patient as emotive, cultured, socialized, having a personal history, and maintaining individual goals and aspirations beyond simply getting well. His hope is for a modified medical practice that takes these lived implications into account as they have ramifications on illness experience and recovery, meaning that they should fall within the domain of medical theorizing, research, and practice. In so doing he hopes to introduce the medical reader to the possibilities of a phenomenological medicine:

Enter phenomenology, a discipline for which the relationship between body and self becomes a central and explicit problem. The body is not divorced from the self to be studied with a series of abstract technical manipulations (autopsies, pathology slides, CT scans); rather, the body is considered in constant and intimate reciprocal relationship to the self. [Baron 1992:40]

The MPs in my study were emotionally expressive, speaking in general about a “love and respect” they have toward their patients, which is situated in witnessing an

⁹⁵ Critiquing the “traditional orientation” of medicine (lack of a dialectical rendering of the lived body) is done in the same spirit as Merleau-Ponty’s criticism of classical psychology and its tendency to analyze the mind in isolation from the body; he advocated that psychology should take a dialectic perspective in its practice (see Chapter 3).

athlete's competitive drive manifested in the clinical encounter with intentions to get well. My MPs expressed concern that this desire to get well can prove to be problematic in mTBI recovery as patients risk doing too much, which can set them back in their recovery. They also felt a sense of helplessness at not being able to assist athletes more, watching them suffer through their recovery while running out of possible interventions to suggest.

Chronic pain as a phenomenon has been extensively researched within medical anthropology because it confounds the historically sedimented approach that is characteristic of the "expert knowledge model" of western medical thought and practice:

Pain is subjective, not objective; the causal basis of pain is often poorly understood; pain is often regarded as a "mere" symptom, not as a disease; there often are no "magic bullets" for pain; pain does not fit the expert knowledge model. In order for health care professionals to do a better job of treating pain, some changes need to occur in medical philosophy, education, and practice. [Resnik, Rehm, and Minard 2001:278]

The nature of chronic pain, which is associated with PCS, demands that physicians and therapists approach its management in a phenomenologically oriented way. This would entail a blending process, one that draws from empirically based scientific interventions and more subjective approaches. The stance of the objective and subjective Cartesian divide is arbitrary and fictitious. I do not believe that it is possible to be entirely a "materialist" or "empiricist" in medical practice. The MPs in my research bore this out with particular clarity. Lived experience is characterized as dialectical and as such medical practice is also relative and dialectical. The MPs in my study are educated in the medical scientific method and practice, but they also recognize that science has yet to master every domain of the human body, which is even more so the

case with the brain and brain injuries (both mTBI and TBI). Yet there is a teleological goal reflected in the interviews I conducted with the MPs, which was geared toward a desire to make mTBI and PCS more objective with more empirically based interventions. My MPs expressed a desire to move toward objectification⁹⁶ as it agrees with their medical training. Because mTBI is often not taught in medical school, my MPs learned how to manage them on the job and as such the approach they learned and deploy is phenomenological (dialectic). Prior to the breakthrough on Chronic Traumatic Encephalopathy (CTE) research⁹⁷, subjective reporting was the only evidence that PCS existed. Despite this breakthrough, a lack of objective (visual) measures of concussions in living patients persists.

MPs treating concussions are compelled to manufacture an adaptable framework that is attuned to the individual context of each patient's *Leib*. All my physicians assumed cross-disciplinary positions, taking on the role of psychologist, psychiatrist, physiologist, pharmacist, and nutritionist in order to meet patients' needs. They also freely admitted that much remains unknown within medicine about mTBI. As noted in the context chapter some physicians actively avoid taking concussion cases, or if they do take them, "they do not do a good job in managing them" (RCPS). What I garnered from my MPs' responses is that they actively embrace the holistic, phenomenological role of a medical professional, and their main criticisms of medicine in general and individual physicians specifically is that they resist becoming phenomenological themselves.

⁹⁶ Some of these attempts to confine mTBI and PCS to a medical framework will be discussed in the following chapter.

⁹⁷ CTE research will be discussed in more detail in Chapter 7.2.

Of all the medical professionals I spoke to, the AT was the most explicitly phenomenological in her orientation and it was this statement (coming in my last interview) that indicated to me this trend (an embodied holistic approach that was latent in all the interviews I had conducted):

AT: As soon as you are putting your hands on someone, there is that . . . connection established . . . I can almost communicate through my hands, asking them “does it hurt here?” and being able to say “yes I feel that injury there”. The power of touch is an important aspect of athletic therapy . . . Maybe it’s the type of person that the therapist is. Others maybe don’t ask those types of questions. Some [patients] will confide in me without even knowing me. It’s like getting to know someone when you are dating them. It’s a “personal relationship” that you form and it’s an advantage that we have. Physicians only see them for like 20 minutes then they just get referred . . . The time we spend with them is an advantage because we get to know them better, ask about “subjective stuff”. We know them better which aids in assessing their honesty. If you rehab a knee you can see how swollen it is. Concussions are not like that. You need their trust to get the information needed to help them.

6.3 CONTACTING CONCUSSIONS

My medical professionals cited their own personal experiences engaging in the sporting community as athletes (usually as adolescents) and seeing sports injuries in others as the main reason why they chose medicine as a career with a topical application of sport. Of the MPs I spoke to, the AP had the most experience playing highly competitive sports. The rest of the MPs’ athletic histories more closely reflect my own: they were average athletes (would not consider themselves “naturals”) who enjoyed playing and watching sports but had no aspirations of playing elite-level sports. Because of the increased risk of injury correlated with increased competitive levels of sport, the

AP, as the highest level athlete of my medical cohort, personally experienced a number of sports injuries which added an embodied motivation to get into sports medicine that predated her concussion.

All MPs reported knowing that concussions existed before their medical education, but they tended to point to the time they spent within the practical component of their educations as being their first intersubjective interactions with concussed athletes.⁹⁸ This is when they realized their lack of formal education on the illness and also the lack of available interventions in a practical sense. Through these encounters with concussed athletes, my MPs became interested in their treatment. The collective pragmatic experiences of practicing MPs stand in the place of normative statistics as PCS seems to actively defy normatization due to its variable and individual nature. These collective histories congregate at international, national, and provincial consensus meetings where working groups collectively debate the veracity of personal findings and clinical trials.⁹⁹ On occasion politicians like former NHL goaltender Ken Dryden attend these meetings, which is a further indication of the desire to come into contact with concussions so as to better understand them. The MPs in my study seemed to enjoy “the challenge of managing concussions”, which requires unique skill sets and nuanced understandings. In fact, for these reasons both RCPS and SM2 maintain side practices in sports medicine despite working in related medical fields.

⁹⁸ See Appendix 1.5 for incident rates of concussions in Ontario and Rowbotham et al. (1957) for a sense of how acquired mTBI and TBI has been present in medical awareness for some time despite receiving little focused attention until recently.

⁹⁹ Throughout the remainder of the thesis, findings of the recently released SCAT3 will be used to support the notion that findings from groups like these tend to touch on a number of the phenomenological themes discussed thus far.

6.4 INTERVENTIONS?

An offshoot of the lack of medical research and formal education in mTBI is the lack of generally agreed upon interventions. In an ideal situation, objective (typically visually based) empirical measures, normative statistics, and agreed upon empirical interventions would be available. Medical research and refinement of treatments are geared toward approaching a level of certainty in the etiology and prognosis of illness and disease. On a practical level, for treating physicians the lack of agreed upon empirical interventions with documented efficacy (cause and effect measurable through the empirical senses of the medical professional) presents a dilemma that was articulated well by the athlete–physician¹⁰⁰:

AT: There is this big gray box in medicine, like “we don’t know how to treat them.” I think with all the emerging research coming out that is trying to figure out what the best ways to treat them are, I think everyone is kind of scratching their heads . . . It’s just that . . . he did some blood work on me, and my thyroid is off. I have never had a thyroid problem before . . . So it’s like what do you do with this kind of information. There is not a standard that we are testing for . . . what things do we replace? There are a lot of gray box areas with not a lot of research yet, so you get a lot of physicians who are like “I’m going to hold off because there is not a lot of research yet.” But then people are like “show me the evidence.” So it becomes a thing where I’m not going to try something there is no evidence for. It’s a gray box but there are a few things.

The phrase “there are a few things” articulates well the desire within medical research to refine mTBI etiology and prognosis because science tends not to like gray.

¹⁰⁰ This was also hinted at by my other MPs, who had varying opinions on the efficacy of interventions and therapies like acupuncture, cranial sacral therapy, and chiropractics (which seemed to work for no one). My athletes also had varying opinions of these, but their opinions were entirely based on their personal experiences with them and as such they tended not to rule anything out in the spirit of “all concussions are unique” and if it didn’t work for them, it doesn’t mean it won’t work for others.

Since the Cartesian division, the refinement of methods was desired to articulate a world that could be divided into black and white oppositions. This is the root of an mTBI's challenging nature—why it can't be treated but only managed. MPs are presented with a condition that resists categorization and defies interventions. SM1 described how she found it helpful to track patients' SCAT2 numbers in a small booklet, an idea brought to her by a patient's father. This method has the potential to impose some normative order on an illness that tends to resist quantification¹⁰¹:

SM1: We can communicate through the SCAT2. Instead of “how did you feel this week?” they can just show me the book and we work off of that. Then I ask the questions based on the responses. That's an easy way to communicate, makes it a little more objective, and they don't need to get too deep into explaining deficits and difficulties.

Me: But there is a lack of language to describe the weird symptoms of PCS.

SM1: It's very true, especially with the visual disturbances.

Me: [I described my “tracers” to her]

SM1: Yeah they will say, “I got this freaky thing in my eye. I mean what does that mean? How significant is it?”

Me: I have transparent hexagons in the center of my vision, like a honeycomb, all the time. I mean what is that?

SM1: It's difficult. Vision problems on the SCAT too are sort of vague, but with this book I can go into details. It's hard to describe how you feel, especially when we are making medical decisions based on those descriptions.

¹⁰¹ SM1: “I had a patient's dad print a small booklet to chart SCAT2 numbers as opposed to writing down how you are feeling. A bit stereotypical but males struggle with that more and it doesn't give good info anyway . . . using the symptoms on SCAT they can communicate with a number. This allows them to not have to get into details with their parents and it is more clear for the parents. Tracking with that is a way of communicating how symptoms are without details, and it's quick. Early concussion has them do a SCAT2 every day. If it's high one day, write in the column what you did that day.”

The lived experience itself is lost in converting *Leib* to numerical values. SM1 hinted at this when speaking about her patients experiencing visual disturbances and how she wants to see how these disturbances figure into one's lived experience. By converting *Leib* into a number, she is seeking out an ease of communication, but in doing so she loses the richness of lived experience. That is why she and the other MPs note that the SCAT2 and similar tests are not meant as a simple diagnostic tool but as a tool to elicit more explanation. To make medical decisions based on the sometimes poorly articulated responses of brain injured athletes is difficult for this physician, who is used to making "medically sound" decisions supported with quantifiable statistics. While she recognizes that the reported symptoms and responses she uses are subjectively based (from the patient's interpretive perspective), by assigning a numerical value to the embodied experience of a variety of symptoms she is able to add a level of objectivity to managing the symptoms of PCS.

The most common way that medical professionals brought up the embodiment of gendered ideals was in the difficulty that male athletes had in talking about how they are feeling, as SM1 noted. This is one of the rare mentions of gender¹⁰² as a complicating factor in managing concussions with varsity athletes.¹⁰³ Although the AT made the same

¹⁰² I utilize the notion of gender here in the same ways as I did in Chapter 5. Judith Butler's (1988) notion of the sedimentation and enacting of past experiences in an intersubjective communication with the world is the same that was used to understand the social role of "athlete". Here I use Butler's theory in its original purpose to investigate gender.

¹⁰³ The most recent findings from ICCS (Zurich 2012) removed gender as a complicating factor in mTBI recovery. This is contested by Moser et al. (2011), who offer the following reasons for why women sustain more concussions than men: "hormonal differences render women's brains more sensitive to concussions, and women's brains are anatomically *different*" (Moser et al. 2011:197). The gendered connotations of this statement are deep and historically informed, which are beyond the scope here, but we will see in Chapter 8 how hormone replacement therapy is an emerging treatment for repetitive mTBI.

generalization as SM1¹⁰⁴, she quickly checked her statement and provided counterexamples. She did the same thing in reference to “young male college student–athletes” as a group that has to be constantly reminded to not drink, get sleep, and eat right. She then provided a counterexample of a female patient being “reckless” and how female collage students tend to eat just as poorly as their male counterparts. She reemphasized the importance of both males and females being overly cautious in their recoveries. While it seems that gendered notions of identity informed how MPs communicated with their patients, the trusting relationship that had been developed over time had the greatest impact on the communicative potential of medically encountering the concussed athlete.

6.5 TRUST ME, I TRUST YOU

The MPs all pointed to the importance of quickly developing an intersubjective relationship based on trust. Trust is key in RTP decisions and even more so in discussing the possibility of retirement. Because athletes are socially enmeshed in a political field¹⁰⁵, the trust developed between a physician and an athlete is crucial in allowing the athlete to open up and even discuss any pressures they might be experiencing for an early return.

¹⁰⁴ AT: “The difference between males and females? The females can be cattier. It’s something that we take into consideration . . . because changes in behavior are so drastic. They are fighting depression anyway and you don’t want drama and name-calling making it worse.” The AT brought up “the difference between males and females” on her own. At the time in the interview she had just explained the psychological merits and somatic drawbacks of social isolation versus inclusion, which seems unconnected topically but speaks to the mutually informing holistic nature of this illness.

¹⁰⁵ Coaches, parents, and teammates all have a stake in the athlete’s return. Pressure to return to play tends to grow as the playing season progresses (e.g. the playoffs are right around the corner).

Trust is also needed in recognizing if an athlete is seeking what SM1 and SM2 called “a graceful exit” from the game.¹⁰⁶

The trusting intersubjective relationship is developed over time through repeated encounters. As a specialist, the RCPS tends to see patients the least often, so for him he noted how establishing a trusting relationship quickly is a priority. He leaned on the fact that he was a “specialist”, which denotes extra education and experience to his patients. On the other hand, the AT spends the most time with patients, noting an advantage in having treated concussed athletes in the past for other injuries. She is able to delve deeper into the emotional, social, and interpersonal dynamics of her patients’ concussions. As described at the beginning of the chapter, she noted that the sensation of touch is another way she communicates with patients as it aids in getting closer to them emotionally. Being able to literally feel past injuries and use those as a jumping-off point in garnering background information is one of the unique tools she employs.

More than any formal concussion assessment tool, my MPs relied on their intuition and feel in determining RTP and in accounting for the progression of a patient’s recovery. For the first consultation with a first-time patient, they employ the typical measures available, but through these tools they seek to fill out the qualitative side of the picture. SM1 suggested that sometimes RTP determinations are made earlier than what would be by the book, and sometimes she would hold players back when they were otherwise considered physically and cognitively recovered. These determinations, she noted, were based on “knowing the player” in a holistically embodied sense that is only possible in a trusting, time-established relationship. MPs’ recognition of the importance

¹⁰⁶ An exit that is socially accepted by athletes and the other actors of the sporting field: a retirement due to an “unrecoverable” injury.

of “just being there” may also help stymie any feelings of isolation and loneliness experienced by the athlete, who is socially isolated from their team during their recovery. This extra time can also be seen as a possible intervention against the development of depression and other mental health complications which could mask as PCS symptoms and also inhibit healing. Thus we see how an intersubjective process of “being there” takes on a medical overtone when being done by a doctor to a patient. However, the process itself is an ongoing communicative one that is mutually informing and emotional for both sides even though it is spatially and temporally constricted.

6.6 SPACE AND TIME IN THE MEDICAL ENCOUNTER

All of my medical professionals were aware of the spatiotemporal constraints of the medical encounter, which occurs within a spatially demarcated zone where a particular type of encounter is expected and enacted within a codified, i.e. legislated time frame. The degree to which both actors (patient and MP) communicate within the medical encounter, in general, is dependent on the amount of objective measures available to the MP which are then supplemented by subjective patient reporting. On the surface there appears to be a lack of objective measures for mTBI and PCS. However, my MPs had a range of tools they used to garner information quickly from their patients in as short a time as possible. This is one aspect of the “art form” they spoke about. The artistic approach of my MPs was confirmed by some of the athletes who were their patients, echoing sentiments that “[he or she] really listened or seemed to care” or “was the first physician who really seemed to understand what I was saying.”

The MPs recognized that they were embodied actors existing within a spatially and temporally informed environment that was open to their intentional acts. It seemed their actions were independently derived (or formulated) but they did reflect some commonality. SM1, SM2, and AP all reported double-booking consultations (30 minutes instead of the standard 15 minutes, while the RCPS would book a 60 minute consultation for first-time patients and “difficult cases”). This was specifically done to give athletes time to articulate how they are feeling.¹⁰⁷ SM1 and SM2 also noted how they would schedule particular cases at the end of the day so as to give patients extra (unbilled) time for articulation. SM1 schedules all her concussion cases on one day, which she finds enables her to “get into the mindset” of treating concussions. She said jumping from one illness to a concussion “throws you off a little”.

Additional consultation time is meant to enable athletes to speak about broader issues of how concussions have changed their lives. Signs of depression (which they saw as possibly biochemical or situational-based), as well as stress, anxiety, and disrupted sleep patterns are some of the more prominent issues the physicians look for. Because these issues are more qualitative in nature, more time is needed to tease them out. SM1 and SM2 specifically noted that often when they ask a patient “how are you feeling?”, the answer is vague: “my head hurts.” To help speed up the process of specifying reported information, they employ tools like the one developed by SM1 (the small booklet) and rely on the trusting relationship that has been developed over time. Within a temporally restricted situation, skill is needed to make the most of a consultation. This is part of the artistic deployment of skills and observational techniques that MPs employ. To further

¹⁰⁷ They also noted in hushed or guarded tones that athletes don’t tend to be the most talkative people in the world to begin with, which is compounded by communication issues that often accompany concussions.

accelerate this process MPs engage in a process of symptom isolation, ranking, and treatment.

6.7 SYMPTOM ISOLATION, RANKING, AND TREATMENT

If mTBI symptoms do not resolve after 10 to 14 days, medical professionals shift into a process of monitoring and adjustments. The SCAT2 test was utilized to provide a general picture of the progression of recovery. The medical professionals in my study, however, sought to develop a relationship with their patients that would allow them to operate on intuition and feeling more than on the strictly normative process of conducting a standardized test. Rather than relying on the SCAT2 as a diagnostic tool to prove concussion symptoms are present, they use it as a means of focusing attention on the process of symptom isolation and treatment. The medical professionals direct their questions to evoke a ranking process by their patients of felt symptoms. This ranking allows the MPs to target their interventions and more importantly start to formulate an individual treatment plan, which seems to be required in concussion management because “all concussions are unique”.

The adage that all concussions are unique points to two important aspects of their embodied experience and consequently their management: symptoms will arise through various forms of engagement with the world which differ day to day for each patient, and what makes symptoms recede (i.e. interventions) tends to be geared toward the modification of future activities. In other words, they are prevention-based because of the lack of immediate symptom reduction technologies. One of the foundational practices used by my MPs was a process of figuring out what actions and styles of engagement

with the world (Butler 1988) made their concussed patients' symptoms worse. Once identified, steps can be taken to modify the athlete's process of being in the world.

This process of isolation also gives MPs the sense that something can actually be pragmatically and actively done, that medically informed interventions actually exist for this injury, and that they no longer need to tell their patients to simply "go home and rest, there is nothing that can be done." The most prominent symptom and effect of mTBI that all the physicians recognized as being easily controlled was the regulation of sleep. Sleep is the closest we come to being disembodied while still being in the world, so if it is found that rest and the elimination of sensorial stimuli is empirically beneficial to the concussed patient, than promoting sleep regulation should be seen as the best possible site for sensorial stimuli restriction. A low dosage of the antidepressant amitriptyline is frequently prescribed as a sleep aid.¹⁰⁸ In conjunction with educating patients on the importance of sleep, MPs advise their patients on how drugs and alcohol, stress from exam times, and just being a young university student in general can all have ramifications on sleep frequency and quality.

Social isolation was a prominent feature of concussed athletes' lived experiences, which my medical professionals pointed to as having the potential to develop into mental health concerns. The "treatment" of mTBI is isolation from external stimuli and sometimes the source of these stimuli can be the interactions we have with other people. Therefore, athletes often will say no to social engagements for fear of worsening their

¹⁰⁸ Originally prescribed as an antidepressant in the 1960s (typical daily dosage of 100 to 200 mg), it is frequently prescribed today to encourage stage 4 REM sleep (typical daily dosage of 10 to 25 mg). This is how it was described to me by two of my own prescribing physicians. Few clinical trials exist to prove the efficacy of amitriptyline on sleep patterns. It seems to be an instance of an intervention that gained steam "unofficially" through clinical practice and word of mouth.

symptoms and for a feeling of being a burden on others, the result being a sense of social isolation. To help stave this off MPs often encourage concussed athletes to remain involved with the team (e.g. attending practices and games, going on road trips). However, they also recognize that this seemingly positive act could precipitate other symptoms. Thus they go through a dialectical process of weighing the pros and cons:¹⁰⁹

AT: You don't want them at practice, but it's good for psychology. But with concussions there are more stimuli typically at practices. Psychologically being part of team and psychologically ready to play are both different things but are both important to consider. Attention to social isolation is especially key for out-of-town athletes . . . [gives example of a young, female, varsity athlete from out of town who had a high symptom score so they didn't want her to travel] . . . We [physician, player, coach, and therapist] weighed the pros and cons in terms of psychological and physical implications.

Another seemingly obvious intervention¹¹⁰ that SM1, SM2, AT, and AP all mentioned is how they encourage their patients to wear sunglasses as a means of reducing light sensitivity, in conjunction with recommending reduced “screen time” (also referred to as “unplugging”). Here we can see the MPs running through a process of eliminating precipitating factors that concussed patients typically encounter in their general lived experiences. Providing “real world” examples to their concussed patients of things they could modify or eliminate altogether from their lives as a means of accelerating their recovery:

¹⁰⁹ This is especially the case in a fully integrated, multi-departmental university environment. This process is also an intersubjective one between team personnel, the player, and various medical professionals (and occasionally parents).

¹¹⁰ I say seemingly obvious because I have always had light sensitivity and didn't think to wear sunglasses more often. This strikes me as a seemingly obvious answer that I somehow missed. I now wear sunglasses often when I write on my laptop.

SM1: I love athletes for so many reasons, but one of them is their desire to get better, but with a concussion you need to hold them back. You really need to be specific, also get into cognitive things as well, for example: at computer for no more than one hour in a week, and no more than two hours of “screen time”, then work your way up. I do this with adults who are working as well.

6.8 PREVENTION, COMPLIANCE, AND THE RTP DECISION

The physicians in my study recognize that the only way to cure concussions is to prevent them from happening in the first place or to take steps to prevent subsequent concussions in the future. The medical professionals generally said that the athletes they treat recognize the dangers of an early return and have concerns about the long-term implications of multiple concussions, both of which tended to supersede their desire to return to play early. On the other hand, the MPs also noted that on occasion, athletes (typically varsity athletes) will attempt to deceive them with the aim of an early return. To combat this they rely on “knowing the patient” as their screener:

AT: You constantly ask questions. In a caring profession, you do this then you can determine honesty.

The MPs acknowledged that the ultimate decision to return to play belongs to the athletes, and I believe this is why there is such an emphasis by MPs on educating their patients of the dangers of early RTP and on the importance of monitoring the progression of symptom intensity (as this is an indicator of recovery).

Besides educating other physicians, MPs pointed to parents of athletes (especially young athletes) as the main group requiring education on preventative measures. The AT has an ImPACT testing computer in her consultation room and as such comes into

contact with members of the general public. She sees these moments as opportunities to “do a little education” with both parents and their children:

AT: It’s important to get them to understand that it is different than a regular injury in that if you don’t move, that body part will get better on its own. Little things like any thinking you are doing, any focus you will be doing is going to influence and prolong your recovery . . . What is complete rest? No computer, texting, reading, or television. You basically need to lay there and not do anything in a dark room. Don’t think. It’s hard not to think . . . There are some with more than one concussion that still don’t get it . . . Outside people will come in to do the testing. I talk to parents of people coming in. Parents say “they got hit and you know, they got up and then later they complained about headaches. But I don’t think it’s anything.” They are not my patients, not coming to see me as a health professional, just coming to use my computer. I try to do a little bit of education without being aggressive. I refer them to SCAT2 and RTP and symptoms. Education is difficult . . . it’s getting better because you have the Sidney Crosby’s getting concussions and Eric Lindros—he got his concussions far too early on before he was such a big star. Now it’s getting the recognition it deserves, but it’s surprising how parents still don’t seem to get it.

6.9 CORRECTING HISTORY: EDUCATING PHYSICIANS

Due to the historic lack of mTBI research within medicine and the limits of readily available advanced medical imaging technologies, the normative grounding to concussion management is provided by consensus groups, i.e. is based on the collected experiences of treating physicians and augmented by what new scientific data is available. In Ontario, the Ontario Neurotrauma Foundation (ONF) leads a collaboration of partner organizations in implementing an mTBI strategy. In 2011 they produced a document titled *Guidelines for Mild Traumatic Brain Injury and Persistent Symptoms*:

[ONF] initiated this project with the overall objective to create a set of guidelines that can be used by healthcare professionals to implement evidence-based, best practice care of individuals who

incur a mild traumatic brain injury (mTBI) and experience persistent symptoms . . . Currently, the best practice for treatment of those who do not experience spontaneous recovery is not clearly defined . . . the purpose of developing the clinical guidelines is to improve patient care by creating a framework that can be implemented by health professionals to effectively identify and treat individuals who manifest persistent symptoms following mTBI.¹¹¹

Groups organize to reach consensus-based positions where scientifically based interventions and techniques can be widely disseminated to other physicians as a referential framework, language, and setting they are familiar with (both format of the publication and the environment of an academic conference). In Ontario, the introduction of Bill 39 elicited an urgency to educate other physicians “right now” or “soon” and the passage of time is putting increasing pressure on them to do so (it was assumed by my medical informants that the bill would swiftly pass into law without opposition). Physicians in our society have a great deal of formal education that is recognized as technical and advanced, so to have the spotlight placed on their lack of education of this illness will likely bring about improvements based on social shaming.

Besides the historical legacy, some of the blockages my MPs saw in the education of other physicians were both personal and structural:

SM1: Concussions should be able to be managed by emergency doctors and family physicians. When they are complex, get sport medicine and neuropsych involved. Simple ones they should know how to manage themselves . . . The Alberta survey asked as well how were they educated in the past and how would they like to be educated in the future? Giving a half day conference on concussion management protocols is step one. We had a group of 60 physicians on Saturday morning, which tells us there is a need. Is a webinar a better resource? Video webcast? Social media? It would be ideal to

¹¹¹ “Guidelines for Mild Traumatic Brian Injury and Persistent Symptoms,” *Ontario Neurotrauma Foundation*, accessed July 19, 2013, <http://www.concussionsontario.org/linkedfiles/Complete-mTBI-Guidelines-Mar2011.pdf>.

have data on how physicians want to learn and how do you reach them. A lot of the research now is how do we educate? It's funny, physicians are sort of old school and traditional. They like the face-to-face interaction. They like a facilitator. Charles Tator tried to do those. Three in the past year, poorly attended. Saying to physicians be online at 2:00 pm is not going to get people. Family doctors need to know about everything so there is also a prioritizing.

They recognized that physicians work long hours and are typically unwilling to attend an information session at the end of the day. The information sessions organized for midday times were poorly attended due to the difficulties physicians had in scheduling. The location of these meetings was also seen as an issue, so online meetings were scheduled for midday but these were also poorly frequented. Steps have been taken to make the education of physicians on the updated protocols quite easy;¹¹² however, a “slow uptake” still persists (SM1, SM2, RCPS, and AP).

This slow uptake in the willingness to become reeducated is largely a blend of structural reasons. One element of this is that for a family physician, there “is so much to know” (SM2, SM1) in general that devoting additional time to becoming educated on concussion management is prioritized against other ongoing training opportunities.

The RCPS suggested that perhaps mTBI education is given low priority by other physicians due to the fact that concussed patients are “problematic”. He noted the wide range of physical, cognitive, and emotional symptoms coupled with the lack of direct interventions and the amount of time generally needed to get concussed patients to articulate their issues within the medical encounter as factoring into the tendency for physicians to screen incoming patients to avoid those with concussions. The RCPS also

¹¹² Stated in the new SCAT3: “The full details of the conference outcomes and the authors of the tool are published in the BJSM (British Journal of Sports Medicine) Injury Prevention and Health Protection (IPHP), 2013, volume 47, issue 5 . . . and allow unrestricted distribution, providing no alterations are made.” Each of the previous consensus positions had a similar statement to encourage its distribution.

admitted to screening his patients before they arrived as a means of ascertaining his own ability to treat individual cases. He did not admit to outright denial of service, but he did note that he was cautious of patients who have plateaued or whose symptoms had worsened over time (which is taken as an indication of other “complicating factors”). He also noted some apprehension when reading the medical chart of an incoming patient “who has a long history of being told to go home and rest, with few interventions attempted, because over time these symptoms build on themselves. It can be like starting from scratch sometimes” (RCPS).

The other barrier to education noted by my medical informants was that mTBI management involves continual consultations that often result in no clearly defined resolution. Concussion management can be a frustrating endeavor and it seems this is a motivating factor by disengaged physicians to avoid coming into contact with them. Promoting the need for modifications to medical billing codes will hopefully stem this trend. Such changes would reflect the longer time needed in concussions consultation (30 minutes have been proposed). The MPs I spoke to hoped that a development of this kind would remove the financial and temporal motivation that physicians currently have in avoiding concussed patients.

6.10 THE WHOLE PATIENT DOCTOR

Recovery from an mTBI will manifest symptoms that can be categorized in “typological” groups that we would be familiar with and recognize as “different” from each other, but are mutually informing in complex ways that need to be accounted for and disentangled by MPs who typically lack an experiential ground of lived experience to

draw on, i.e. actually having sustained a concussion themselves. Similar to the Gestalt framework, which informed this thesis, my MPs seek to identify the backgrounded precipitators and interventions that permeate the athlete's experience of PCS. Elements of embodied lived experience can both worsen and help the somatic experience of PCS. As such the MP must consider all aspects of this lived experience (physical pain, cognitive dysfunction, emotional and mental health concerns, and social interactions all inform the holistic experience of PCS):

SM2: Every athlete is different, different triggers, thresholds . . . What can we do for them? The only treatment is mental and physical rest. Then we add on the adjuncts. Sunglasses, earplugs . . . sleep disorders, too much or too little, "sleep hygiene", wake and sleep at same time. If still struggling think about adding medication . . . it's a physical injury that also affects behavior, mood, personality, socialization . . . sometimes you have to weigh the pros and cons, so it's also not cookie-cutter because everyone is different.

The concussion history itself is the most sought after medical information but MPs also pay special attention to other injuries that might inform an athlete's larger PCS experience. Neck injuries (in particular whiplash) were often pointed to as the most common non-concussion injury that was either sustained at the time of injury or continues to inform it. The physicians I talked to claimed a certain competence in managing all of these symptoms, which is largely because they feel that specialists (e.g. psychologists and psychiatrists) do not have an understanding of how to manage a concussion or that, if they do, their knowledge base is woefully outdated.¹¹³

¹¹³ Signoretti et al. (2010) published findings that suggest emotional correlates of mTBI are biochemical in nature rather than a result of embodied engagement with the world. Therefore interventions should take place by biochemical means not at the level of lived experience.

6.11 THE CONCUSSED PHYSICIAN

I see my AP as representing a unique perspective shift that was based on the real embodied experience of sustaining her first concussion and the lengthy recovery that it entailed (and at the time of writing is still ongoing, unfortunately):

AP: I am a lot more somatically aware than most people. I can say I have a headache here. Unfortunately, or fortunately, I maybe have more insight as to why I have that symptom . . . I know a temporal headache is related to the motion sensitivity, so if I have done a long walk, I know it gives me a headache in that one location. I get a cognitive headache when I read. That is more in between the eyes. I can describe the symptoms pretty well and I usually have an explanation for it too.

She has a physician colleague following her case who she described in the following manner:

AP: He's very traditional. He's like, "You know what, there's nothing you can do, but I'm here to support you. I know you are having symptoms and I feel really bad that this has happened to you." I have that support, but it's also not . . . he's kind of the "do nothing, it's just going to be time, and I'm going to support you" school. Where I'm kind of like a carrot directing him, saying I'm doing this and that, you know I've spoke to these people would you want to try me on this medicine? So he is following me like a carrot through, what I am doing. But I am directing my own approach really, and I'm trying everything out, and because of it I have learned, you know what, this works for these symptoms. This doesn't work as well on these symptoms. You know, little things like threshold exercises. Getting a little heart rate monitor wristwatch has been really helpful. See what your heart rate is, trying to figure out what your heart rate can be where you won't have headaches for the rest of the day. I definitely put myself in the test pilot role, but I'm also teaching my colleagues around me who are following my progress. Some are even using A-Team.¹¹⁴ A

¹¹⁴ This unique pharmaceutical intervention (combination of the antiviral amandine and amitriptyline) has been developed at the University of Pittsburg. Further discussion follows in Chapter 8.

couple have been doing vestibular assessment, a couple of them are doing cranial sacral.

She extends this embodied perspective to help physicians she knows with individual cases. AP has also tried a new pharmaceutical being developed at the University of Pittsburg and she found it really helped her cognitive issues (clarity and processing speed). She also recognizes the complex ways in which mTBI can detract from enacting one's intentions and the emotions associated with having to say no to obligations.¹¹⁵ Our perceived ability to actually enact our intentions in the future is informed by our present context, which is informed by our memories of past functionality:

AP: It was hard initially because I didn't know how long I would be gone for. I kept saying two weeks, so patients would be waiting to see me and I would just push dates back. Meanwhile I'm feeling awful, where I can't even multitask at a level to take care of this kind of stuff. I did have a colleague who came up and is kind of filling in at my practice. It is hard. I'm a physician for a pro team and I missed the whole season. The season started right before the concussion, but I couldn't do anything for them. I couldn't drive the hour to where the game was, so I had to find another doctor to take over the team. And then the next season is starting up again—the first home game is tonight—I missed all the team physicals. You kind of feel like your brain wants to do these kind of things, I love doing those things, and I'm feeling like I'm missing out because I can't do them, only because my head is telling me that I am not well enough to do them. My head tells me that if I go I'm going to feel horrible, like I can't put myself in that situation. I'm organizing a big conference and am on the exec. I have been planning this for the last year. I still can't sit through a lecture. I can last maybe 20 minutes. You add a PowerPoint to the presentation and it's too much stimuli. I have had to call and say, you know what I may not sit through any of the

¹¹⁵ Obligations can be more sizeable and long-term (e.g. organizing an academic conference) or smaller and more immediate (e.g. AP noted having to decline going for coffee with a friend as being too much of an emotionally problematic ordeal). The difficulty in denying obligations is that it reminds one of their dysfunctional state (Leder 1990).

sessions. I might just show up and do some of the social stuff, like the chatting, but I can't. I'm still not there. I had to cancel the research session that I was supposed to moderate, and that's hard. I had two different speakers that I will introduce, and that's just the limit that I will be able to do. I feel professionally, I have taken a hiatus. I haven't been able to be involved in the committee like I should. I haven't been able to participate like I should. I couldn't go to Toronto for meetings that I should have gone to. I feel like the world is moving on without me . . . I feel like I'm not able to do what I should be doing.

An understanding of concussions in terms of organic pathology is helpful in explaining physiologically what is happening within the heads of athletes; however, an appreciation of the explanations provided by the concussed athletes themselves largely informs the approach taken by my MPs. Based on a trusting relationship that is developed over time, medical professionals are able to work off of what patients say and tailor treatments that are largely based on how each athlete engages differently with the world.

CHAPTER 7

MORAL TREPIDATION: PCS, THE MEDIA, AND AN EMERGING PUBLIC HEALTH DEBATE

7.1 INTRODUCTION

This chapter will be devoted to an analysis of the substantial and unique role the media has played in driving the narrative on concussion in sport, helping turn this sports injury into a public health concern that is emotionally felt on a social level as a *moral trepidation*. My informants talked at length about their perceptions of how the media has covered concussions and PCS, discussing positive influences such as increasing awareness and negative influences such as their sensationalizing tendencies and the implications for future athletic participation. Over the past three years, professional hockey player Sidney Crosby has emerged as the key symbol for the concussion debate in Canada. All my informants focused on Sidney Crosby and his apparent “recovery” from three concussions suffered over a one-year period as the catalyst for bringing widespread public attention to the severity of multiple mTBI. The RCPS describes how it also helped concussed athletes acknowledge their condition:

RCPS: I love it. A few years ago I was trying to get people to recognize their concussion. Now you can point to Sidney Crosby and say, look he is still not playing, nine months later, and it's not because he is faking it or a wimp. [It's] that he needs to look after his brain. People can self-identify with that. Before I don't think people had someone. People need to have someone they know who they admire and respect who has this condition where they can say it's okay for them to also have it . . . celebrities like Sidney Crosby.

Sidney Crosby's celebrity and his extensive public media presence made him the driving force in instigating a moral trepidation¹¹⁶ among the sporting and non-sporting Canadian public, propelling this sports injury into the public consciousness as a public health concern¹¹⁷. But this begs the question, why now? And why not in the late 1990s when Eric Lindros was sustaining his concussions? By mobilizing the experiences of these two professional hockey players, which are played out in the media and supported by the perspective of my athletes, we can begin to answer why Crosby and not Lindros was the catalyst for this moral trepidation.

The social theory I use to look at the role the media and public figures like Crosby play in public health concerns is outlined in Stanley Cohen's *Folk Devils and Moral Panics* (2002[1972]). Social scientists have widely applied Cohen's model to examine how events, people, or single key figures emerge to challenge socially sedimented values (e.g. moral, ethics, and ways of life), depicted through sensationalistic and biased media coverage. This model is typically used to examine problematic groups of actors (typically young people and subcultures) that are seen as a threat to social values, instigating a panic among the general public who call on policy makers to instigate corrective

¹¹⁶ I evoke this term in this context as it denotes a fear of an uncertain future. Individuals with PCS often feel anxiety for their own future, which is made more uncertain by the unknowable teleology of their course of recovery. A similar anxiety is felt on a national level by parents of athletes.

¹¹⁷ Rosemarie Scolaro Moser et al. (2011) specifically zero in on the emerging concern around youth-based concussions as a public health concern (187–207). Their article suggests practical steps that can be taken by parents to prevent and also help manage mTBI in their children and also propose a public awareness campaign: “the present author has introduced the model of *brain hygiene*, similar to the concept of dental hygiene, for public and health education purposes” (Rosemarie Scolaro Moser et al. 2011:201). These authors have highlighted the dual need of educating physicians, parents and athlete about the need to literally treat our brains with more respect.

changes.¹¹⁸ The spark that initiated the widespread trepidation currently being experienced came from the research findings out of Boston University on CTE, coupled with Canada's best hockey player¹¹⁹ struggling to recover.

I see the issue of sports-related concussions in Canada becoming a larger public health issue and as such carry at least a palpable trepidation¹²⁰ felt among the Canadian public which is most profoundly experienced by the parents of athletes. The media has played a central role in providing a platform for *moral entrepreneurs* to raise the alarm about concussions in sport. Their long-term health impacts are reinforced by reports of retired hockey players committing suicide or young people "dying from concussions" in sensational fashion across the media. Compounding the public's growing trepidation is a sense that mTBI and long-lasting PCS equally attack young people and elite professional athletes, seemingly springing up and striking without warning. Professional athletes are thought of as pinnacles of strength, fitness, and the ability to rapidly recovery from injury but useless when they can't (Howe 2004:56). However, when they struggle to recover from PCS, the public and in particular the parents of young athletes justifiably have trepidation about the future. This public trepidation resulted in proposed changes to

¹¹⁸ Here we can see the borders drawn by society to group people into understandable categories. The brain injured athlete is one such group that is speculated on within the popular media. Sharon Kirkey's (2013) article on a study of high-school students includes purported medical backing. This adds a level of social legitimacy in Cohen's model (Ilie et al. 2013).

¹¹⁹ I asked my athletes a question about any affinity they felt toward Crosby and his struggles. While they recognized that some experiences might be shared in a somatic sense, non-concussed people (i.e. friends and parents) were more likely to make the connection during intersubjective encounters.

¹²⁰ "Criticisms have been lodged at Cohen for his insistence on the term "moral panic" (Boethius 1994; Cornwell and Linders 2002; Miller and Kitzinger 1998), which argue that "moral prevents links to other kinds of issues, such as health scares. Panic imputes irrationality that those involved react emotionally to largely mythical fears" (Citcher 2008:1137). mTBI is neither a mythical fear nor is it an irrational reaction (see Appendix 1.5 for mTBI rates in Ontario), but it involves a broadspread emotional reaction. I employ Cohen's model because it shares strong resemblances to the trepidation around mTBI in the Canadian context but the emotional reaction in this case is more of worry or uncertainty than panic about riotous mobs of youth roaming the beaches of the Untied Kingdom.

Ontario's Education Act (Bill 39) which would legislate many of the preventative and monitoring techniques that my MPs advocate for (SCAT2, GRTP protocols, mandatory removal from play, etc.). Such legislation has the potential to evoke permanent societal change that would be mobilized through medical practice.

7.2 MORAL TREPIDATION: MTBI AS A PUBLIC HEALTH CONCERN

Stanley Cohen's (2002[1972]) moral panic model was developed as a means of understanding the relationship between society-wide panics which arise in response to perceived threats to important social ethics, morals, or values:

A condition, episode, person or group of persons emerges to become defined as a threat to societal values and interests; its nature is presented in a stylized and stereotypical fashion by the mass media; the moral barricades are manned by editors, bishops, politicians and other right-thinking people; socially accredited experts pronounce their diagnoses and solutions; ways of coping are evolved or (more often) resorted to; the condition then disappears, submerges or deteriorates and becomes more visible. Sometimes the object of the panic is quite novel and at other times it is something which has been in existence long enough, but suddenly appears in the limelight. Sometimes the panic passes over and is forgotten . . . at other times it has more serious and long-lasting repercussions and might produce such changes as those in legal and social policy or even the way society conceives itself. [Cohen 2002(1972):1]

The mass media plays a unique role in spreading moral panics but are not the originators of the panics themselves.¹²¹ With mTBIs in professional sports, the sporting public will tend to judge the concussive event and seek to place blame on either a concussed athlete or the person who instigated the event. This attribution of blame points toward the moral

¹²¹ "The media have long operated as agents of moral indignation in their own right: even if they are not self-consciously engaged in crusading or muck-raking, their very reporting of certain 'facts' can be sufficient to generate concern, anxiety, indignation or panic" (Cohen 2002[1972]:7). The media is the vehicle through which social values or morals are cast and debated by the viewing public.

transgressions that have occurred within the sporting culture of each individual sport (for the purposes here we will focus on ice hockey as the sporting field¹²²). The secondary role of the media is in providing a platform through which “socially accredited experts”¹²³ propose solutions¹²⁴. If moral panics persist for a long period of time or are immediately threatening in the present moment, politicians (and I would include lobbyists in today’s context) will seek to legislate change, which is also announced via channels of mass media.

I see a number of key elements in Cohen’s model that can be applied to the sociocultural context of mTBI awareness, research, prevention, and its unique cultural legacy in the Canadian context. A dominant feature of experiencing and managing mTBI and PCS is a generalized anxiety and uncertainty about the future of individual health (which I term the unknowable teleology of mTBI). A similar uncertainty is embodied by the general public through exposure to sensational accounts in the media. This trepidation is more deeply felt when individuals have a personal stake in mTBI (athletes with them, their parents, friends, team personnel, and of course medical professionals). Due to

¹²² I compare the concussions sustained by Lindros or Crosby, where blame is tenuously placed (Lindros skating through the middle of the ice and Crosby not sitting out longer after his first concussion), with the concussions sustained by the Olympian during her two crashes. Because she plays an individual sport, blame is only placed on herself or on the course (which could include layout and conditions). The Nordic skier sustained her concussion while riding her bike in the rain without a helmet. She entirely blames herself for transgressing the moral conduct set out by her parents and the example they set (the whole family would ride bikes together and always wore their helmets).

¹²³ In the context of public health, the concept of “thought leaders” was outlined in Moynihan and Cassels (2006) to refer to two different groups of people: pharmaceutical industry-sponsored physicians, selected for their achievements in medical research and practice and who are paid for speaking engagements; and public health advocates who attempt to speak out against these practices and the drugs themselves. Here I employ the term to refer to those groups who are “manning the barricade, proposing solutions, and/or making permanent societal changes.” In the final chapter we will see examples of some of these thought leaders taking advantage of the trepidation around concussion in sport and using it as a marketing ploy, financial opportunity, and promotion platform.

¹²⁴ Aside from the recommendations proposed so far to help address the “concussion issue in sports”, the concluding chapter will highlight some of the potential solutions that are emerging.

increasing rates of mTBI in Canada, it is likely that in the near future most people will encounter an individual with an mTBI (sport-acquired or otherwise), making it a public health concern that is seen in some of the interventions MPs attempt in medical academia and organization. Mounting reports of professional and increasingly amateur athletes suffering concussions, cast in a sensationalized fashion by the popular media, will continue to push this health issue into public consciousness.

There are social, historical, and cultural factors that have led to mTBI becoming a public health debate within Canada over the past five years in a way that it didn't when I was a young hockey player in the mid-1990s and Eric Lindros was getting his concussions. I will begin to offer the answers and explanations that my informants raised on emerging research from Boston on CTE as the spark that ignited public acceptance and then trepidation of the prevalence of mTBI in sport through the media's usage of Sidney Crosby as a key symbol.

7.3 THE SPARK FROM BOSTON

The research that emerged from Boston University's Center for the Study of Traumatic Encephalopathy (CSTE) in 2007 was widely heralded in the media as identifying the first "organic pathology" of concussions. Through eliciting brain donations from retired professional athletes with a history of concussions, researchers

conducted postmortem autopsies and discovered the pathology of CTE.¹²⁵ The public spokesperson for this group is Chris Nowinski, a former college football player (NCAA Division 1) and professional wrestler (WWE). I first heard about CSTE's research while watching Larry King Live with my parents and by its very nature the coverage was sensational. Graphic images of decomposing brains were depicted on the screen and I distinctly remember being concerned about my own future health and in particular the threat of developing dementia. The reason this research emerged to become such an instigating force for social change is twofold: the visual¹²⁶ aspect of CTE meant people at home in their living rooms could see what multiple concussions do; also, this was happening to prominent retired football players whom many remembered in their prime (our heroes).¹²⁷

¹²⁵ "CTE is a progressive degenerative disease of the brain found in athletes (and others) with a history of repetitive brain trauma, including symptomatic concussions as well as asymptomatic subconcussive hits to the head. . . . This trauma triggers progressive degeneration of the brain tissue, including the build-up of an abnormal protein called tau. These changes in the brain can begin months, years, or even decades after the last brain trauma or end of active athletic involvement. The brain degeneration is associated with memory loss, confusion, impaired judgment, impulse control problems, aggression, depression, and, eventually, progressive dementia" ("What is CTE?," *Center for the Study of Traumatic Encephalopathy*, accessed June 22, 2013, <http://www.bu.edu/cste/about/what-is-cte/>).

CSTE was established in 2008. According to their website, "by 2009, only 49 cases of CTE had ever been studied pathologically and published in medical literature, so the disease is still poorly understood. CSTE is committed to growing our understanding of CTE through pathology and the VA CSTE Brain Bank. At this time the VA CSTE Brain Bank has over 100 brains. The brain tissue of 18 of 19 deceased former NFL players have been positive for CTE" ("Case Studies," *Center for the Study of Traumatic Encephalopathy*, accessed June 22, 2013, <http://www.bu.edu/cste/case-studies/>).

¹²⁶ See Good 1994:71–76. The primacy of "sight" or "seeing" the patient as a dysfunctional hierarchy open for examination and repair will be evoked in the next chapter. I use it here to note the dominance of the sense of sight in medical apprehension. The identification of CTE was profound to medical science and future research because the Boston researchers were able to visually show CTE and, more importantly, were able to show the public what CTE pathologically looks like through the popular media.

¹²⁷ Sport Legacy Foundation profiles players who have donated their brains to the Boston researchers. Note the number and prominent placement of young male football players as an indicator of the youth focus of this moral trepidation ("Legacy Donors," *Sport Legacy Foundation*, accessed June 21, 2013, <http://www.sportslegacy.org/research/legacy-donors/>).

The Boston research was the spark of the moral trepidation largely due to their sensationalized findings and extensive media presence. This trepidation was sustained by the media's increased reporting on former professional athletes who died under mysterious circumstances¹²⁸, and the corollary link made by the public between these strange deaths and the new findings out of Boston on CTE. The first such athlete I could find was professional football player Andre Waters, who committed suicide in 2006 and was the first former professional athlete associated with CTE. In addition to players' history of on-field mTBI, most reporting on athlete deaths from 2010 to the present has focused on the possible connection between behavior, mental health, substance abuse, and violence (often domestic violence).¹²⁹

Players who seem to elicit the strongest reaction among the public tend to be those who were "beloved" by fans: football stars like Junior Seau; hockey fighters Darren Boogaard, Rick Rypien, and Bob Probert; boxing greats Arturo Gatti and Muhammad Ali; and even professional wrestlers like Chris Benoit. Their deaths have figured into the public's consciousness through emotionally charged shared memories we have of watching these particular athletes perform. Often the media makes the connection between deaths that are considered "before their time" with neurodegenerative diseases like CTE (early onset dementia is another frequently cited trepidation). However, most of my medical professionals are wary of the methodology in Boston's research (which is

¹²⁸ "NFL Players Linked to CTE," *Napa Valley Register*, accessed June 22, 2013, http://napavalleyregister.com/news/local/nfl-players-linked-to-cte/article_3d56c53a-bd8a-11e1-b483-0019bb2963f4.html.

¹²⁹ Former players and their families filed a class-action lawsuit against the National Football League (NFL) for systemically downplaying mTBIs suffered by players dating back to the 1960s and for withholding medical treatment including insurance and pension coverage for retired players. The case was sent to mediation on July 10, 2013 (see Breslow).

part of the debate surrounding the “proposing of solutions by socially accredited experts”):

SM2: It’s always concerning when everyone has the problem. I don’t discount what they are doing, not their fault that so much media attention has been paid to their findings, but the problem is, the message comes out that if you play sports you will die this horrible death . . . The media has picked up, well if you play football you will get CTE, but we don’t have proof of this yet, it’s unfortunate that the media has chosen to pick this up. I think the Boston group has made too wide of a claim, that they MUST be related.¹³⁰

One particularly apt story brought up by the rugby player is the death of Junior Seau, who committed suicide in 2012 by shooting himself in the chest so he could donate his brain to scientific research. The National Institute of Health examined his brain and noted the presence of CTE which was confirmed by independent researchers.¹³¹ It is interesting that Seau seemed to know he had CTE or some kind of degenerative brain disease, but medical science lacked the imaging technology to detect it while he was alive. He seemingly resorted to the extreme act of committing suicide with the intention of preserving his brain for a postmortem autopsy, which is perhaps the most primitive of medical imaging methods. Stories like Seau’s have a profound impact on individuals with a history of concussions. After the rugby player brought up the Seau example, he started

¹³⁰ CTE is also contested by the ICCS’ consensus position from Zurich 2012: “Clinicians need to be mindful of the potential for long-term problems in the management of all athletes. However, it was agreed that chronic traumatic encephalopathy (CTE) represents a distinct tauopathy with an unknown incidence in athletic populations. It was further agreed that a cause and effect relationship has not as yet been demonstrated between CTE and concussions or exposure to contact sports. At present, the interpretation of causation in the modern CTE case studies should proceed cautiously. It was also recognized that it is important to address the fears of parents/athletes from media pressure related to the possibility of CTE” (McCrory et al. 2013:5).

¹³¹ “Seau Suffered from Brain Disease,” *New York Times*, accessed June 22, 2013, http://www.nytimes.com/2013/01/11/sports/football/junior-seau-suffered-from-brain-disease.html?pagewanted=all&_r=0.

talking about his own thoughts on donating his brain to the Boston researchers at the suggestion of his doctor.¹³²

The fact that professional athletes are experiencing prolonged PCS and in some cases CTE is uniquely troublesome for the public as there is an understanding that these athletes have unparalleled access to advanced medical resources and are supported by well-funded organizations and teams owned by billionaires. Furthermore, these athletes are seen as being at the pinnacle of health and fitness. Trepidation therefore lies in the realization that if these athletes are unable to recover from mTBIs, what hope is there for the average athlete?

The irony that my physicians recognize in stories of professional athletes dying before their time is their benefit of increasing general awareness among the public but also how these stories can have the reverse effect of dissuading athletic participation:

SM2: At the end of the day, your risk of concussion is much lower than your risk of having heart disease . . . the benefits of sports and exercise are so massive in everything we do. The media has picked up, well if you play football you will get CTE. But we don't have proof of this yet.

7.4 WHY SIDNEY AND NOT ERIC OR BRETT?

It goes without saying that public perception and opinion change over time. As a teenager playing minor hockey, for me Eric Lindros and his younger brother Brett represented the two prototypical concussed athletes. Eric had a concussion-plagued

¹³² The reference was to the Boston researchers specifically despite the existence of a similar foundation in Toronto called the Canadian Sports Concussion Project, which is headed up by Dr. Charles Tator who is perhaps the foremost expert (and public medical specialist) on mTBI in Canada. The rugby player had only heard about the Boston research, likely due to their intense media campaigns which influenced his physician to make this suggestion.

career that lasted 15 years in which he was widely regarded as one of the premier power forwards in the NHL. His younger brother Brett, who was a first-round draft pick, only played 51 games in the NHL before having to retire due to “a history of concussions” in the 1995–96 season. In retrospect, their stories beg the question, why was this not seen as a bigger issue at the time?

There is a certain degree of likeability required for a professional athlete to become recognized as a public symbol who is infused with positive meanings. In retrospect I don't think any of my friends had an issue with Brett Lindros. His story was recognized as a tragic one: a career cut short by this mysterious illness known as post-concussion syndrome. His older brother Eric, on the other hand, was selected first overall in the 1991 draft by the Quebec Nordiques, whom he refused to play for, demanding a trade and eventually landing in Philadelphia. This move essentially alienated him from the Canadian hockey fan base in much the same way as did Brett Hull's refusal to play for Team Canada.¹³³ Besides the refusal to play for Quebec, Eric Lindros was also resented, I feel, for his unique combination of size and skill (6'4", 240 lbs and could pass,

¹³³ The Philadelphia Flyers' general manager and former NHL player Bobby Clark noted how Lindros' concealment of his injuries was a morally ambiguous move in professional sport: “I can't speak for Eric, but I'm assuming Eric, like all players, hides injuries. Players forever have felt that's the courageous and right thing to do. If Eric feels he has a headache, we didn't know he had a concussion. If he has a headache, what are we supposed to do about it?” He continued by point to another major moral transgression made by Lindros and his family: “I see Eric Desjardins get his teeth knocked out. I didn't hear from his mom and dad. John LeClair gets his face torn up with 40 stitches, and we didn't hear from his mom and dad. I'm just so tired of our organization getting beat up so badly by all the accusations the family makes. I don't dislike Eric. I pity him. I feel sorry for him. What's it like to be 27 years old and have your mom and dad running your life? Can't even go to the . . . doctor on your own without your mom and dad coming along” (Sports Illustrated 2001). Eric's parents transgressed a morally established boundary in the NHL by constantly involving themselves in their son's recovery. It is expected that young athletes like the ones in my study will have their parents involved in decisions about retirement and continuing play, but at the professional level this is a moral taboo. I have never heard of other instances of a professional athlete's parents became publicly involved in their child's injury recovery process (they used the media to directly address management's role).

score, play defense, skate smoothly, and had a physical game) which stood in stark contrast to his perceived fragility in always getting concussions (often explained as “he’s good, but can’t take a hit”). His so-called fragility was only vaguely understood to be related to his history of concussions and the increased susceptibility that an individual with a history of concussions has in sustaining subsequent concussions.¹³⁴

My informant the hockey player remembered seeing one of Lindros’ concussions and described it as a terrifying experience:

HP: I grew up watching hockey and sports and I remember Eric Lindros and people talking more about Scott Stevens’ physicality. More people thought of that than [of] Eric Lindros’ career being over. I remember reading in the paper and it was a terrifying experience.

Scott Stevens delivered a significant concussion to Lindros in the playoffs, yet in his Hall of Fame acceptance speech he speaks to the accepted risk of the professional sporting field and does not admit to acting in a morally problematic way.¹³⁵ There still persisted a feeling that mere “headaches” from a concussion was not a justifiable excuse to remove oneself from the game. We see in the passage from Bobby Clark that mTBIs were compared to injuries like getting your teeth knocked out or receiving stitches—it is a minor athletic injury that can and should be played through. What has changed since this

¹³⁴ The belief that one concussion makes you more susceptible to a second one was not mentioned by any of my medical informants. It is implied in the consensus position of removal from play if concussion is suspected, but is not brought up in the same way as it was in the past i.e. someone with one concussion is more likely to get a second, third and fourth in an exponentially increasing fashion.

¹³⁵ See Scott Stevens’ Hockey Hall of Fame acceptance speech where he calls hockey “a dangerous game” and does not apologize for the hit on Lindros (“2007 HOF Fan Forum – Scott Stevens on Lindros hit,” YouTube video, 0:50, posted by Daniel Tolensky, November 13, 2007, http://www.youtube.com/watch?v=XeFvduxp_eM). Also see replay of the hit including the play-by-play commentators’ voices (“1999-00 Round 3 game 7 Scott Stevens hits Eric Lindros,” YouTube video, 4:00, posted by IrLaiks, January 8, 2009, <http://www.youtube.com/watch?v=g55Co-EBKys>). Note the usage of the term “catching you with your head down.” Also note the excitement in the commentators’ voices at the moment of the hit and how they check their tone at the 24-second mark.

time is that mTBI and persistent PCS, in conjunction with the widespread acceptance of the long-term health repercussions, has made it so that this injury is now seen as both serious and morally justifiable to miss time because of it. For these reasons and for the timing of his concussions (seemingly before medical science was prepared to accept them), Eric Lindros did not become the moral entrepreneur that Sidney Crosby has since become.

Sidney Crosby was also drafted first overall. He is a perennial all-star and contender for the MVP award each year since he was drafted in 2005. Nicknamed “the next one” (in reference to Wayne Gretzky’s nickname “the great one”), he is captain of the professional hockey team the Pittsburgh Penguins. He was the youngest captain to win a Stanley Cup and scored arguably the biggest goal in Canadian hockey history since Paul Henderson’s game-winning goal in Team Canada’s victory over the Soviet Union in the 1972 Summit Series.¹³⁶ As one of the top players in the league, Crosby is often seen in the media as a spokesperson for his team, the NHL, and Canadian hockey in general. He has also signed multi-million dollar high-profile promotional deals and has appeared in a number of *Tim Hortons* commercials based on his own involvement with the *Timbits* minor hockey program when he was a child. Sidney Crosby symbolizes Canadian hockey both through his media presence and in his sporting accomplishments.

“Sid the Kid” got his first concussion (that we know) of in the 2011 Winter Classic game.¹³⁷ He got his second one just four days later on January 5 and didn’t return to play until November 22, 2011. Less than two weeks after his return, he sustained his

¹³⁶ Crosby scored the game-winning goal in the gold medal match between Canada and the USA at the Vancouver 2010 Winter Olympics. It has since become known as the “golden goal”.

¹³⁷ An annual NHL outdoor hockey game traditionally played on New Year’s Day.

third concussion of the year and remained sidelined until March 15, 2012. Canada was suddenly made aware of concussions. His long recovery was closely covered by both sports media and for the first time in Canada, the international press. The wider media picked up on this story because Crosby has transcended the confines of sport to become a public figure in much the same way as Wayne Gretzky did, who Crosby is routinely compared to. It seems to me that for concussions to emerge from the relative obscurity of the sports medicine clinics and athletic therapy rooms, it needed a prominent public figure like Crosby to get the public engaged in the discussion.

Each of my informants explicitly brought up Sidney Crosby in their interviews. The athletes all mentioned that when their concussions are discussed in casual conversation, others frequently compare them to Crosby. My Nordic skier noted how people jokingly called her “Sid”, which she did not appreciate:

Nordic: Everyone brings up Sidney Crosby. People say, “How you doing Sid?” and really dumb jokes [like that]. Okay, it’s not funny . . . just making dumb jokes like hockey players getting concussed and being dumb . . . I didn’t take them seriously at all before I got one, especially the lasting effects. I just didn’t really understand them . . . I just think it needs to be more seriously taken in sports.

The Olympic athlete mentioned:

Oly: I remember seeing an interview with Sid. Bless their hearts, my parents sent [it] to me. My parents are older. They are trying to learn. Dad even came to a session with [my doctor].

Me: When I mention to people the topic of my research they invariably say, “Oh like Sidney Crosby.”

7.5 IS SID'S INJURY A GOOD OR BAD THING?

I posed this question to my informants typically near the end of each interview as I feel it is a future-looking question which tended to evoke answers about changes they see on the horizon. Moral panics, and the individuals who cause them, are often cast by the media as a negative challenge to societal norms. In much the same way, the continual stories of athletes' premature deaths and careers being cut short are meant to challenge sporting culture, in particular violent "contact sports". The challenge is directed at two "groups of people" (Cohen 1972:1): the organizing bodies responsible for overseeing professional and amateur sport¹³⁸, and players themselves for their conduct and the need to police their own actions (i.e. goons and thugs in sports). Contrasting this challenge is the assertion that the risk of violence is inherent in the sporting fields of football and hockey, and that choosing to play carries an acceptance of a certain degree of risk of injury and watching violent sports also carries a risk of seeing others get concussed, which is emotionally problematic for some of my athletes¹³⁹:

SM2: Exposure, bigger hits—this is their career. Is that any different than if I was a teacher or something? A concussion might influence a career. For them they are younger guys, their exposure is greater, due to the nature of what they do . . . they have families and want to have a future after . . . a normal life . . . they acknowledge the risks, they take it, [and] make \$5–6 million dollars to do so.

I believe the moral trepidation has the potential to reach a panic in relation to concussions in youth. Parents of young athletes who see professional athletes struggle to

¹³⁸ The NHL and NFL were both brought up by my informants in conjunction with their history of covering up or downplaying concussions. The NFL is currently being sued in federal court over this.

¹³⁹ Both Neruosci and I can no longer watch boxing or mixed martial arts. Neurosci mentioned how he feels physically ill and cringes every time he sees a boxing match. Rugby and Hockey Player actively avoid watching "big hits" on YouTube due to the emotionally problematic somatic experiences associated with watching these clips and remembering their own concussions.

return to play, despite having access to the most advanced and expensive interventions, become concerned that the same if not worse could happen to their child. The challenge in this sense is directed at parents to at least become educated about concussions and perhaps even stop their child from playing some of the more risky sports.

Education, awareness, and prevention were continuously cited by my medical professionals as the most important steps anyone (including the sporting, medical, and media communities) can and should take in avoiding concussions. The medical professionals utilized Sidney Crosby as a precautionary example within their practices, describing the same scenario that I just did in the previous paragraph. They also noted how the “worst case scenario” can be used as a much-needed education device for the larger public:

AT: The media does give the worst case scenario . . . I think it’s good to give the worst case scenario, so that we can raise the understanding that brain injuries are serious, especially “minor” ones . . . It can be overplayed, like when Crosby was injured, with the daily interviews and updates, looking for stories . . . but I feel like people are treating their heads with more respect now because of his injury.

Crosby’s inability to quickly recover has also encouraged more people with “suspected concussions” to report to their physicians:

SM1: Sidney Crosby’s concussion was the best thing to happen on concussion awareness and education. Young athletes and parents are now interested. People now come to me and say “I’m scared I might have a concussion”, which is only happening because people now know about it. As sports medicine doctors we knew it was an issue for a long time but we are so small.

AT: Because of [Crosby’s] injury, we now see an influx in reporting . . . Some of the sports medicine doctors have days with eight concussion patients. This is a significant amount. People are reporting more due to more awareness.

Concussions are not new and it is not like they were just discovered when Crosby got his (Rowbotham 1957). What made the moral trepidation possible was the historical context in which it happened. Society was ready to make changes to sporting culture after Crosby went down on New Year's Day in 2011. SM1, SM2, AT, and RCPS all seemed poised with the theoretical knowledge, practical knowledge, and—in the case of the athlete–physician—embodied lived experience that is needed to effectively manage a concussion. What continuously troubled them was how uneducated their colleagues remained. If legislated changes are to be the result of the moral trepidation sparked within Canada, then the number one priority for medical professionals should be educating their colleagues so they can properly deal with the increased number of concussion cases that they will likely see in their offices.

We will now turn our gaze to what's emerging on the horizon. The moral trepidation that has convalesced around symbols like Crosby is a powerful force that has resulted in politically and economically motivated actors to approach concussion treatment for the first time. My MPs, who have been engaged in mTBI management for some time resent this appearance of new “concussion experts” who promise the next “silver bullet” cure, yet tend to get mired in “trying to reinvent the wheel” (SM1, SM2, AP, RCPS). Nonetheless, the actors and their propositions described in the concluding chapter highlight a number of possible interventions that exist now in the background but have the potential to emerge to the forefront of concussion treatment and be heralded by the media as a medical breakthrough of immense social import.

CHAPTER 8

CONCLUSION

The Horizon and Political Implications of Care

8.1 INTRODUCTION

By this point the reader should be able to recognize the ambiguous nature of this injury and illness. Due to its ambiguity, concussion lends itself to a variety of possible medical and non-medical interventions in daily life that can be pursued by medical professionals and implemented by athletes. In this chapter, I will highlight some future trends and courses of action that my informants and I see as likely to have positive implications for patient care. The experience of mTBI is highly individuated—no one intervention is likely to relieve all the somatic, behavioral, and emotional ramifications of mTBI and PCS, rather a blending and adjustment process is needed. Emerging innovations in concussion management generally remain in the background due to a lack of quality clinical research to support their widespread implementation. MPs in my study did not want to promote findings backed by poor science like the findings from Boston. I will seek to provide examples of research that is at the cusp of breaking through into mainstream medical practice and supplement them with position statements derived from the Zurich 2013 ICCS meetings, which were published while this thesis was being composed. These international consensus opinions represent the voices of the leading medical researchers in the world on sports related mTBI and are supported by the major international sporting bodies. As such, their conclusions should prove to be reflective of the opinions of the medical community.

8.2 UNIVERSITY OF PITTSBURGH

There is a three-fold sedimentation of history (past, present, future) occurring at the University of Pittsburg Medical Center. Researchers who developed the ImPACT testing system in the early 1990s are currently undertaking clinical trials to test the applicability of the antiviral medication amantadine on the cognitive symptoms of PCS. In the future they could possibly combine amitriptyline and amantadine with ImPACT testing to create a potent combination of both a pharmaceutical intervention for PCS and a testing system to determine the drug's potency.

The University recently published findings from the clinical trials on the use of amantadine as a treatment for PCS and in particular its cognitive symptoms.¹⁴⁰ Two of the lead authors of this study, concussion experts Dr. Mark Lovell and Dr. Michael Collins, are two of the three co-founders of the ImPACT computerized testing system.¹⁴¹ This group did not make the same mistake as the Boston researchers by not including a control group in their findings. They conducted a double blind trial, which is considered “the gold standard of medicine” (SM2). I did, however, find a conflict of interest in the use of their own ImPACT systems as their measure. As we saw earlier, the MPs in my study tended to use a combination of SCAT2 and subjective questioning to determine

¹⁴⁰ “Results support significantly greater improvements from pre- to post-test in reported symptoms, verbal memory, and reaction time performance for the amantadine group than the matched controls. There were no significant differences for visual memory or visual motor processing speed. This study provides empirical support for amantadine as an effective pharmacologic treatment of certain concussion-related cognitive deficits and symptoms in athletes with protracted recovery of more than 3 weeks” (Reddy et al. 2013).

¹⁴¹ “ImPACT Founders,” *ImPACT Testing and Neurocognitive Tools*, accessed June 14, 2013, <http://www.impacttest.com/about/?ImPACT-Founders-6>.

progress, finding reliance on a singular measure like the ImPACT test limited and partial.¹⁴²

This is not the first research conducted on amantadine in this way (Schneider WN, et. al 1999). This is partially due to the fact that it has been used since 1969 as an intervention in neurodegeneration occurring in Parkinson’s disease (Schwab et al. 1969). The side effects of amantadine strike me as similar to the very symptoms it seeks to treat in PCS: difficulty concentrating, irritability, anxiety or agitation, trouble sleeping (nightmares), and headache.¹⁴³ Researchers are attempting to combine this drug with amitriptyline, which is generally prescribed off-label as a sleep aid. Amitriptyline is now undergoing clinical trials for treating “headaches” associated with PCS (Bell 2013: forthcoming). If findings from both trials prove medically valid, it will likely be heralded as the first singular intervention available to treat the myriad of PCS’ cognitive manifestations. According to my AP who took amantadine:

AP: I got in touch with the University of Pittsburg. Through them I am on amantadine, which is a medication for the cognitive effects, the dullness, problem with multitasking, the slowed down mental process. After a week of being on it my ability to articulate just came back, people who would say that my eyes look fuzzy said they were all of a sudden clear. It was dramatic. I would see people one week and the next it was like, oh you look so bright and clear. For me the memory, concentration, focus, ability to articulate, and the dullness that I had has really changed. My ability to tolerate stimuli

¹⁴² Through a meta-analysis researchers have scrutinized the accuracy rate of ImPACT testing systems and found “the false positive rate appears to be 30 percent to 40 percent of subjects of ImPACT . . . the false negative rate may be comparable. . . . The use of baseline neuropsychological testing . . . is not likely to diminish risk, and to the extent that there is a risk associated with ‘premature’ return-to-play . . . may even increase that risk” (“Concussion Test May Not Be Panacea,” Peter Keating, August 26, 2012, accessed June 18, 2013, http://espn.go.com/espn/otl/story/_/id/8297794/neuropsychological-testing-concussions-not-panacea).

¹⁴³ “Amantadine: Side Effects,” Mayo Clinic, accessed June 18, 2013, <http://www.mayoclinic.com/health/drug-information/DR600083/DSECTION=side-effects>.

and walk into a Starbucks has improved. I can handle background noise now.

8.3 MULTI-DEPARTMENTAL CONCUSSION REHABILITATION CENTERS

The development of multi-departmental mTBI rehabilitation centers promises to be the most wide-ranging prospect on the horizons in terms of being able to address the individual nature of PCS.¹⁴⁴ As we have seen throughout this thesis, a number of medical professionals with varying levels of education and specializations are attempting to manage the symptoms of mTBI but they are doing so in a spread out and non-communicative manner. This motivation to literally “bring everyone together under one roof” (SM2) is what spurred the development of consensus groups like the ICCS. In Ottawa, there is one such center headed by Dr. Shawn Marshall. It provides a range of services that conceivably mTBI sufferers could access, but the program seems more geared toward managing TBIs.¹⁴⁵ I believe this type of center could provide a working model for a similar center geared toward MTBI.

The athlete–physician spoke about her vision to open such a center when she returns to her practice:

AP: When I go back to work, maybe I need a different setting. I want to establish a multi-departmental concussion rehab center. Under one roof, I would have a physician doing more

¹⁴⁴ “Cases of concussion in sport where clinical recovery falls outside the expected window (i.e. 10 days) should be managed in a multidisciplinary manner by healthcare providers with experience in sports-related concussion” (McCrory et al. 2013:3). Note the use of the term “manner”. They suggest, as do my physicians, that this can be done in and through a trained family physician with the help of various specialists and therapists. The multi-departmental clinical model has the added benefit of having all these services under one roof, so that the concussed patient doesn’t need to travel or remember to schedule a number of individual appointments. It also allows MPs to utilize one another’s specializations.

¹⁴⁵ “Acquired Brain Injury Program (ABI) Care Stream,” Ottawa Hospital, accessed June 18, 2013, <https://www.ottawahospital.on.ca/wps/portal/Base/TheHospital/ClinicalServices/DeptPgmrCS/Departments/RehabilitationCentre/OurProgramsAndServices/ABI>.

impactful testing and more pharmacology, a good chiropractor, overall monitoring of patients would be improved, a good physiotherapy person that can do Cranial Sacral work, having someone who can do vestibular training. I think all those pieces at any given time are part of the concussion. I am working with someone right now doing yoga, but she is also a former Olympic athlete, who has a background in Occupational Therapy and Masters in Education, someone with a blend of skills like that, it's so multi-dimensional you almost need something like this.

SM1 and SM2 also noted a multi-departmental center would be an important development they would like to see happen.

To make a model like this work in Canada, there will likely need to be changes to the way billing is structured. According to SM1, SM2, RCPS, AT, and AP, there is a need for a “concussion code” for clinical consultations to ensure physicians do not have a financial motivation to avoid mTBI cases. I imagine that a similar code or perhaps exemption could be created to allow the concussed individual to access this plethora of services without being overly financially burdened. In conclusion, PCS’ murky ambiguous nature requires changes in how medicine organizes itself in managing concussions (more multi-departmental and creative), as well as changes in how treatment is financially organized.

8.4 GENES AND BLOOD

Within the boxing and mixed martial arts communities, a number of prominent competitors have been suspended for the use of testosterone replacement therapy. The athletes argued that repetitive head trauma sustained through competition and training has caused a natural depletion of testosterone and a spike in estrogen levels. While the link between head trauma and hormone levels is a difficult correlation for medicine to make,

measuring this phenomenon through blood work is the gold standard of empiricism in terms of medical ontology.¹⁴⁶ Ordering blood work is a common practice and I imagine if this research stands up to medical methodological scrutiny, it will become a common practice in the assessment process of acute mTBI and PCS of a more chronic nature. This will happen because of the practice of symptom isolation and treatment that my MPs engage in. SM1 spoke about ordering blood work “for all my female athletes with mTBI. I typically look to make sure vitamin B12 levels are normal.” The AP had her physician colleague order blood work for her:

AP: My thyroid is off. I have never had a thyroid problem before . . . So it’s like what do you do with this kind of information. There is not a standard that we are testing for . . . what things do we replace?

We can see here that mTBI can potentially have an impact on the thyroid. In one case study (Ives et al. 2007), researchers noted hypopituitarism¹⁴⁷ in a 14-year-old boy with an mTBI. The researchers ran blood work on the boy when his parents noticed he had stopped growing. It is interesting to note that the authors propose a long-term view of clinical surveillance:

In summary, we propose this standard of care for sports concussion should include suspicion of possible hypopituitarism within the proper clinical context, and concussed athletes should be monitored for months, even long after an athlete has returned to play. [Ives et al. 2007:431]

¹⁴⁶ “There is currently insufficient evidence, to justify the routine use of biomarkers clinically” (McCrory et al. 2013:3). This quote refers to the research underway to identify hormonal, protein, and genetic indicators of chronic PCS.

¹⁴⁷ The decrease in one of the eight hormones produced by the pituitary gland, in this particular study the researchers focused on the decrease of testosterone production.

More medical research needs to be done on this subject to collect empirical evidence which may warrant the introduction of hormone replacement therapy in mTBI patients. Until such time, incidental findings like this case study may be used by athletes to justify taking human growth hormones and synthetic testosterone.

I am concerned that young people (i.e. teenage athletes) will see hormone replacement therapy as a way to gain a competitive edge that is backed by science. Monitoring hormone levels and hormone replacement therapy is a powerful intervention from a medical standpoint because of its empirical validity and because as more is learned about the endocrine system, information from tests like these will be heavily relied on for diagnostic and monitoring purposes. Capacity to handle an increased level of hormone testing requests would need to be considered, especially if bill like Ontario's Bill 39 pass. It is conceivable that future RTP decisions may be informed by blood work, which gives the medical professional (who presumably has training to interpret the results) a deeper, below the surface view of the biochemistry of PCS.

If testosterone is identified as lacking in mTBI sufferers, what will physicians do for female patients? The gendered implications of hormones from a social science perspective is expansive and beyond the scope of this thesis. Nevertheless, I want to flag this potentially controversial medical debate over hormone replacement therapy as it seems to be just on the horizon.¹⁴⁸ The controversy will also crystallize around age

¹⁴⁸ “The role of female gender as a possible modifier in the management of concussion was discussed at length by the panel. There was no unanimous agreement that the current published research evidence is conclusive enough for this to be included as a modifying factor, although it was accepted that gender may be a risk factor for injury and/or influence injury severity” (McCrory et al. 2013:4). The panel's intentionally vague and non-committal position is reflective of how contested this debate will become. Tying notions of gender to physiology is tenuous. The potential addition of differential hormonal indicators (between males and females) adds a level of medical “truth” that is lived as a compelling social fiction (within the medical encounter and in lived experience).

groups (e.g. prepubescent, adolescent, young adult) and will be complicated by differences among individual sports, various competition levels, and deeper gendered implications that have not even been considered by these scientists (e.g. transgendered athletes).

Cases like that of the Lindros brothers have the potential to be used by researchers to identify a genetic predisposition to sustaining concussions. Research has also begun to emerge that seeks to identify genetic changes that occur after sustaining a concussion (Di Pietro et al. 2013). These types of findings are still in the “academic stages” (SM1, SM2) but promise to provide, for medical ontology, a measure for future likelihoods of sustaining an mTBI as well as a retrospective measure for when a concussion was sustained (Di Pietro et al. 2013). These types of measures and any possible interventions emerging as a result are many years in the future, but I can see a time when genetic screening to detect a predisposition to mTBI will be requested before young people are permitted to enter contact sports.

In much the same way as concussed professional athletes are seen by the public as symbolic representations of the mismanagement of mTBI by sporting organizations and of the far-reaching implications of a history of mTBI, siblings like the Lindros brothers might be seen as possible test cases for the potential hereditary link in mTBI and a prolonged recovery from PCS. These types of measures (blood work and genetics) will be looked at by both athletes and MPs as a possible empirical (material) indication of the propensity that some athletes have of “being one and done”¹⁴⁹ (Rugby, Neurosci, and HP).

¹⁴⁹ Sustaining one mTBI and never regaining past functionality versus the “ability” of some to sustain multiple concussions with little discernable effect in the short term, allowing them to continue participating in sports. Brett Lindros is a perfect example of someone who would be described as being one and done.

EPILOGUE

How Can We Help?

Each of my informants believed no therapeutic avenue should be abandoned when it comes to treating mTBI and PCS. The types and duration of interventions varied among athletes and MPs tried to become as educated as possible about any conceivable type of intervention that could possibly work—they would literally try anything that had even a minimal of empirical support. This enabled them to fill up their medical tool box with a variety of interventions that could be used to address the unique nature of PCS.

The most fruitful avenue that managing medical professionals can take seems to be to basically keep doing what my MPs are doing: treat the symptom of sleep first and recommend preventative measures based on lived experience. According to the Olympian, do not be “flaky” with your patients and try to schedule as many appointments as possible and don’t cancel on them. For the specialists, many athletes with concussions look forward to but are often disappointed by their appointments with these physicians (HP, Nordic, and Rugby). As part of their hermeneutic quests, patients go to their consultations with specialists with the hope of uncovering answers. By providing a diagnosis, specialists can give an athlete who is struggling to legitimize their injuries to the non-concussed population a socially recognized “stamp of approval”. The diagnosis validates what the athlete is experiencing as both real and significant.

I believe that both athletes and non-athletes with chronic PCS could benefit from an organized support group. One of my reasons for doing this research was to finally meet people like myself who have had multiple concussions. While I could point to

professional athletes who had concussions and somewhat relate to their experience, to be able to sit down with varsity athletes who have had concussions was a privilege and also therapeutic for me. I hope to start a support group with the Olympian as we both feel a desire to help others by using our own experiences with mTBIs.

Social support is crucial for concussed athletes.¹⁵⁰ Most of this support can come from helping them accomplish tasks that to you might seem simple, but for the concussed athlete is a mini victory, a step toward normalcy. Social support can also include continuing to invite a concussed friend to come out and socialize in concussively safe ways. It is difficult to say no to social engagements but the reason we do is because we don't want to burden you with our symptoms. This concern of burdening others is also manifest in many decisions to retire from team sports as we do not want our teammates to have to play differently with us in the lineup. If we eventually move on from sports, encourage us to take up an instrument, begin painting, or some other skill that could be a positive outlet. We will approach the learning of this skill with the same voracity that we did sports. Because it is new, we lack the referential memories of past functionality, so we won't get discouraged if our symptoms prevent our engagement with the new activity:

Me: What did you do to try to alleviate the sadness (or the blues)?

Rugby: I got really into music. Looking back, music filled a void that athletics left. I have a tattoo on my arm. I have never told anyone this, but that's what it's about. I got it in between my concussions. It is very important to me,

¹⁵⁰ In recent years there has been a rapid development of online support groups through social media sites like Facebook. I recently joined one such group and I find it cathartic to share tips and strategies that I have developed over the years. More so, it feels good to finally be able to tell people and myself that suffering from an mTBI and PCS no longer needs to be such a socially isolating experience. Participating in groups like this can provide an emotionally beneficial outlet for athletes with PCS. The embodied experience of PCS is always a valuable perspective to share with others.

something that is very sentimental. People wouldn't understand if I told them. It's very dear to me. I love music and I love sports. It kind of filled the void. Now I'm taking some music courses. My parents got me a drum kit because I couldn't play anything. It was their way of making me active, and giving me an outlet.

There is now a level of awareness in Canadian society of the severity of mTBIs and PCS. The landscape has changed dramatically since I had my first concussion in 1995. Academic accommodation is available at universities for both concussed athletes and non-athletes. This is not the case at every school, university, or sports league, partly because legislation like Bill 39 continues to stall despite the vast public interest and seemingly non-partisan nature of trying to protect children and young people from brain injuries. Legislation needs to happen that mandates immediate removal from play and a monitored GRTP (and work and learn) by a medical professional who actually knows what they are doing (the education of physicians in a systematic and organized fashion on mTBI protocols would be an offshoot of legislation).

I think the onus is on us as members of the invisible brain injured community to claim this membership and make ourselves visible in public. The neurosci student plans to become a physician and when he does, he will undoubtedly lean on his own experiences recovering from mTBIs. The Nordic skier is considering public speaking engagements about the importance of bike helmets to prevent injuries like concussions. The athlete-physician is simply going to be able to treat mTBI better because of her qualitative experiences fused with her academic and practical knowledge. This fusion is underway already while she treats herself "as a guinea pig" and makes recommendations on her findings. As mentioned, she is also considering opening a multi-departmental center devoted to mTBI recovery, which is sorely needed in Canada. The rugby player is

considering donating his brain to the researchers at Boston University; I signed up to do the same several years ago. Once a year a researcher phones me to ostensibly conduct a baseline neuropsychological test, where I am asked a series of questions that are similar to those found on the SCAT2. I take these opportunities to just unload my problems and vent my concerns about my own future. I know this is not the medically relevant information they are trying to ascertain, but I figure that if I am giving them my brain, the least they could do is listen to me complain for an hour.

Like the Nordic skier, I am going to start looking for opportunities to speak publicly about my experiences. I want to publish my current and future findings in a book that would be oriented toward the general public with a specific focus on the role that parents play in the recovery of sports-related concussions. I did not consider this unique parental role when I started my interviews despite the crucial role both of my parents have and continue to play in my recoveries. Most parents feel at a loss and trapped in a difficult position where they have to convince their children to abandon the sports they love and which make up a significant part of their identities. They have seen us through countless childhood illnesses, but with PCS there is so little that can be pragmatically done that they have to stand by and watch their children struggle athletically and academically, two roles that most athletes take pride in being able to balance and succeed in. Especially with high-level varsity athletes, the ability to succeed in both the intellectual and physical realms is a source of pride that is directly effected by PCS. It seemingly snatches away pieces of our identity, leaving us wandering through life in a listless manner searching for something to anchor ourselves to.

Support and understanding will only become possible if we continue to share our experiences with others, especially the non-concussed community. I hope, through this research, to make our experiences public. Thank you to my informants for sharing yours with me.

APPENDIX 1

WORKING DEFINITIONS AND EPIDEMIOLOGY

1.1 CONCUSSION (mTBI)¹⁵¹

Concussion is a brain injury and is defined as a complex pathophysiological process affecting the brain, induced by biomechanical forces. Several common features that incorporate clinical, pathologic and biomechanical injury constructs that may be utilized in defining the nature of a concussive head injury include:

1. Concussion may be caused either by a direct blow to the head, face, neck or elsewhere on the body with an “impulsive” force transmitted to the head.
2. Concussion typically results in the rapid onset of short-lived impairment of neurological function that resolves spontaneously. However, in some cases, symptoms and signs may evolve over a number of minutes to hours.
3. Concussion may result in neuropathological changes, but the acute clinical symptoms largely reflect a functional disturbance rather than a structural injury and, as such, no abnormality is seen on standard structural neuroimaging studies.
4. Concussion results in a graded set of clinical symptoms that may or may not involve loss of consciousness. Resolution of the clinical and cognitive symptoms typically follows a sequential course. However, it is important to note that in some cases symptoms may be prolonged.

¹⁵¹ McCrory et al. 2013:1–2.

1.2 POST-CONCUSSION SYNDROME (PCS)¹⁵²

“Postconcussion or postconcussive syndrome, first described by Strauss and Savitsky in 1934, is characterized by impairments in memory, attention, and concentration (cognition); emotional state (affect); and behavior following a closed head injury. In a closed head injury, there is no penetration of the skull, but trauma results in the brain knocking against the hard inner surface of the skull. The closed head injury itself may be accompanied by loss of consciousness, loss of memory of the trauma and events immediately following (post-traumatic amnesia), and possibly post-traumatic seizure disorder. Postconcussive syndrome usually follows mild head injury, in which loss or alteration in consciousness lasts less than 20 minutes. Cognitive symptoms include poor concentration, attention deficits, and impaired memory. Affective symptoms may include irritability, anxiety, depression, or fluctuation in mood (emotional lability). Physical symptoms can include fatigue, headaches, vertigo, or an intolerance of noise (phonophobia) and bright lights (photophobia). Occasionally, there will be visual or hearing impairments or a loss of the sense of smell (anosmia), which may affect appetite. Its definition as a syndrome reflects a lack of consensus as to the defining factors and validity of the entity as a discrete entity. Rather, it represents a pattern of signs and symptoms that have been given the name . . . Women are more likely than men to develop postconcussive syndrome. The individual will have trouble paying attention, concentrating, changing focus from one activity to another, performing more than one mental activity at the same time, remembering information, and learning new information. Three or more of the following symptoms occur after the trauma and last at

¹⁵² DSM-IV: ICD-9-CM 310, 310.2, 310.8

least 3 months: fatigue; insomnia; headache; vertigo or dizziness; anger that occurs without a good reason; anxiety, depression, or mood swings; and personality changes such as inappropriate behavior, apathy, or lack of spontaneity. The impairment represents a significant decline from pre-trauma functioning and causes significant difficulty with school or workplace performance . . . In most cases of mild to moderate head injury, the symptoms clear up in 6 to 12 months. However, some individuals may experience symptoms for several years and may never return to normal. Residual impairment and changes in mood (excitement or depression) are common. Depending on the severity of the injury, there may be residual cognitive impairment or seizures.”

1.3 POSTCONCUSSIONAL DISORDER (PCD)¹⁵³

Criteria for postconcussional disorder are as follows:

- A. A history of head trauma that has caused significant cerebral concussion.
- B. Evidence from neuropsychological testing or quantified cognitive assessment of difficulty in attention (concentrating, shifting focus of attention, performing simultaneous cognitive tasks), or memory (learning or recalling information).
- C. Three (or more) of the following occur shortly after the trauma and last at least 3 months:
 - Becoming fatigued easily
 - Disordered sleep
 - Headache
 - Vertigo or dizziness

¹⁵³ DSM-IV ICD-9-CM 310.9

- Irritability or aggression with little or no provocation
 - Anxiety, depression, or affective lability
 - Changes in personality (eg, social or sexual inappropriateness)
 - Apathy or lack of spontaneity
- D. The symptoms in criteria B and C have their onset following head trauma or else represent a substantial worsening of preexisting symptoms.
- E. The disturbance causes significant impairment in social or occupational functioning and represents a significant decline from a previous level of functioning. In school-aged children, the impairment may be manifested by a significant worsening in school or academic performance dating from the trauma.
- F. The symptoms do not meet criteria for dementia due to head trauma and are not better accounted for by another mental disorder (eg, amnesic disorder due to head trauma, personality change due to head trauma).

1.4 **APHASIA**¹⁵⁴

A type of speech disorder consisting of a defect or loss of the power of expression by speech, writing, or signs, or of comprehension of spoken or written language, due to disease or injury of the brain centers . . . Aphasia is a complex phenomenon manifested in numerous ways. The recovery period is often very long, even months or years. Because communication is such a vital part of everyday living, loss of the ability to communicate with words, whether in speaking or writing, can profoundly affect the personality and

¹⁵⁴ “Definition of Aphasia with Specific Manifestations,” Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health. 17th ed., s.v. “aphasia”.

behavior of a patient. Although aphasic persons usually require extensive treatment by specially trained speech pathologists or therapists, all persons concerned with the care of the patient should practice techniques that will help minimize frustration and improve communication with such patients.

Some Possible specific manifestations of aphasia:

- anomic aphasia: inability to name objects, qualities, or conditions. Called also amnesic or nominal aphasia
- motor aphasia: aphasia in which there is impairment of the ability to speak and write, owing to a lesion in the insula and surrounding operculum including Broca's motor speech area. The patient understands written and spoken words but has difficulty uttering the words. Called also logaphasia and Broca's, expressive, or nonfluent aphasia.
- fluent aphasia: that in which speech is well articulated (usually 200 or more words per minute) and grammatically correct but is lacking in content and meaning
- mixed aphasia: combined expressive and receptive aphasia

1.5 INCIDENT RATES OF mTBI IN ONTARIO¹⁵⁵

“876 potential mTBI cases were identified, 25 from family practice records. Key indicators of mTBI were missing on many records (e.g., 308/876 records had Glasgow Coma Scale (GCS) scores). The expert reviewer disagreed with the documented diagnosis in 380/876 cases (kappa = 0.19). The expert reviewer was more likely to give a

¹⁵⁵ Ryu et al. 2009:429.

diagnosis if the GCS was 13–14, if there was documented loss of consciousness and/or post-traumatic amnesia, and/or if there was pathology found on an acute brain scan. Calculated incidence rates of hospital-treated mTBI were 426 or 535/100,000 (expert review—hospital diagnosis). Including family physician cases increased the rate to 493 or 653/100,000.

Health record documentation of key indicators for mTBI is often lacking. Notwithstanding, some patients with mTBI appear to be missed or misdiagnosed by primary care physicians. A more comprehensive case definition resulted in estimated incidence rates higher than previous reports.”

APPENDIX 2
LIST OF INFORMANTS

ATHLETES

AP	Athlete–Physician
HP	Hockey Player
Neurosci	Neuroscience Student
Nordic	Nordic Skier
Oly	Olympian
Rugby	Rugby Player

PHYSICIANS

AP	Athlete–Physician
AT	Athletic Therapist
RCPS	Royal College of Physicians and Surgeons
SM1	Sports Medicine 1
SM2	Sports Medicine 2

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