Chapter

Social Support, Identity, and Meaning: A Phenomenological Analysis of Post-Concussion Syndrome

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Abstract

After a traumatic blow to the head, it is common to experience difficulty focusing, disorientation, dizziness, nausea, sensitivity to light and sound, and often loss of consciousness. These symptoms often persist for several weeks following the concussion before diminishing completely. Post-concussion syndrome (PCS) refers to the persistence of concussion symptoms beyond the normal two-week window. For some, symptoms can continue for several months to several years, even further manifesting into depression, anxiety, and substance abuse in time. Though the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) has continued to grow with each new version, PCS has not been included in its most recent iteration. An acquired brain injury rehabilitation specialist can be recommended for TBI, and a clinical psychologist or psychiatrist can be recommended for Acute Stress Disorder. The authors commend this reclassification because it recognizes that brain injuries are to be studied by neurologists and other medical specialists while transformations to one's existence are to be studied by psychologists. Nevertheless, while the present analysis aims at PCS in the latter (psychological) sense, it is worth mentioning that acquired brain injury (ABI) specialists have found it appropriate and even necessary to adopt an existential-phenomenological perspectives to more fully conceptualize this phenomenon. This study utilized the Interpretive Phenomenological Analysis (IPA) and arranged case studies with three athletes who had been forced to retire from sport due to major TBI's and prolonged PCS. Authors identified common themes across each interview and used free imaginative variation to describe the dimensions of the PCS experience. Specifically, the way participants were able to cope with the loss of identity and meaning after sport, as well as their perceived level of social support in the aftermath of TBI and PCS, played major roles in ameliorating and/or exacerbating both somatic and psychological difficulties associated with TBI and PCS.

Keywords: traumatic brain injury, post-concussion syndrome, phenomenology, identity, athletic retirement

1. Introduction

After a traumatic blow to the head, it is common to experience difficulty focusing, disorientation, dizziness, nausea, sensitivity to light and sound, and often loss

of consciousness. These symptoms often persist for several weeks following the concussion before diminishing completely. Post-concussion syndrome (PCS) refers to the persistence of concussion symptoms beyond the normal two-week window. For some, symptoms can continue for several months to several years.

Though the American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM) has continued to grow with each new version, PCS has not been included in its most recent iteration. The *DSM-5* task force explains, "[s]ymptoms previously termed *postconcussive* (e.g., headaches, dizziness, sensitivity to light or sound, irritability, concentration deficits) can occur in brain-injured and non-brain injured populations, including individuals with acute stress disorder" ([1], p. 286). The argument is that the causal linkage between traumatic brain injury (TBI) and PCS breaks down because the symptoms of PCS are either a variation of Acute Stress Disorder or TBI. An acquired brain injury rehabilitation specialist can be recommended for TBI, and a clinical psychologist or psychiatrist can be recommended for Acute Stress Disorder. The authors commend this reclassification because it recognizes that brain injuries are to be studied by neurologists and other medical specialists while transformations to one's existence are to be studied by psychologists.

While the present analysis aims at PCS in the latter (psychological) sense, it is worth mentioning that acquired brain injury (ABI) specialists have found it appropriate and even necessary to adopt an existential-phenomenological perspective as well. American rehabilitation physician and scholar Gary Goldberg [2] explains how "brain injury deeply affect[s] the subjectivity of the person injured—that is, their existence as a human person—because of the potentially significant aspects of personhood impacted [...], it can also produce significant problematic impairment of self-awareness" (p. 397). Like neuropsychiatrist Kurt Goldstein [3] argued nearly a century earlier, Goldberg and others have called for a transformation of the philosophical paradigm that has traditionally been used to understand brain injury [4–9]. To this end, the present phenomenological analysis of PCS will be of interest to sport psychologists, clinical psychologists, and rehabilitation specialists working with acquired brain injury.

1.1 Medicalization and DSM

Since the third edition was published in 1980, *Diagnostic and Statistical Manual of Mental Disorders* (DSM) has used an increasingly biomedical model for explaining psychological disorders (1980). The biomedical model has replaced the psychoanalytic drive-theory model of explanation [10, 11].

The most recent iteration, *DSM-5* [1], continues down the pathway of biomedical explanation. The task-force explains: "The science of mental disorders continues to evolve. However, the last two decades since DSM-IV was released have seen real and durable progress in such areas as cognitive neuroscience, brain imagining, epidemiology, and genetics" (p. 5). They continue, "[s]uch an approach should permit a more accurate description of patient presentations and increase the validity of diagnosis (i.e., the degree to which diagnostic criteria reflect the comprehensive manifestation of an underlying psychopathological disorder)" (p. 5). Here we see that by "psychological disorder" the *DSM-5* task force has in mind an underlying pathogen, and diagnostic validity can be improved with advances in neuroscience, brain imaging, and so forth.

Medicalization, however, has its dissidents. *DSM-5* has been repeatedly criticized for its medicalization and somatization of psychological disorders. American philosopher of medicine Kevin Aho [12] has explained that this has led to a "growing dependence on biological explanations which tend to downplay socio-historical

factors" (p. 3). Peter Kinderman, British psychologist and former president of the British Psychological Association's division for clinical psychology, recommends that a psychosocial model replace the medical model [13]. He suggests, for example, that "an effective way to reduce rates of mental health problems might be to reduce inequality in society" (p. 39). In an open letter to *DSM-5* task force, Division 32 of the American Psychological Association provides four specific examples of how the newer biomedically validated diagnostic criteria have actually lowered diagnostic thresholds, making it easier to receive a diagnosis [14]. In some cases, exclusionary criteria have been removed (such as the bereavement exclusion for depression of Major Depressive Disorder. In others, diagnostic requirements have been reduced (such as with the number of symptoms required for the diagnosis of adult attention-deficit hyperactivity disorder, ADHD).

Former director of the American National Institute of Mental Health, psychiatrist Tom Insel, has complained that the newest version of *DSM*, while *more* biomedical than previous editions, is still inadequately medicalized. On the NIMH website, he explained how "[i]n the rest of medicine, [psychological diagnoses] would be equivalent to creating diagnostic systems based on the nature of chest pain or the quality of fever" ([15]; in [16], p. 522). Indeed, the medicalization of psychological disorders is in presumed etiology only. ADHD, for example, is diagnosed based on patient symptoms which belong to the private world of the patient (e.g., "has trouble waiting his or her turn"). To this diagnosis a biomedical explanation is added. There are no biological tests for depression or ADHD, and the same can be said of a great majority of psychological disorders. It is uncertain what is gained by *explaining* them this way.

While there are many competing hypotheses about what causes depression (even among biomedical psychopathologists; [17]), depression is diagnosed based on behavioral signs and subjective symptoms. In an interview, Insel implores fellow psychiatrists to begin treating psychological disorders as brain disorders, e.g., relying exclusively on brain scans for depression diagnoses [18]. Until that day comes, depression will be diagnosed even in the absence of biomedical evidence.

Another troubling problem arises in addition to diagnostic validity. When biomedical factors are emphasized to the neglect of psychosocial, cultural, political, and historical factors, who benefits? The increasing medicalization of *DSM* has led to a suspicious partnership between the American Psychiatric Association and pharmaceutical companies [12, 19, 20].

2. Medicalization of PCS

PCS has not shared the fate of other psychological disorders. Like depression, PCS is diagnosed from behavioral and physiological signs (such as alcohol intolerance and problems shifting focus) and subjective symptoms (such as decreased music-listening pleasure). Also like depression, for PCS there is no neurological, biogenetic, or hormonal diagnostic procedure. However, depression remains in *DSM-5* and PCS does not. The *DSM-5* task force explains, "[s]ymptoms previously termed *postconcussive* (e.g., headaches, dizziness, sensitivity to light or sound, irritability, concentration deficits) can occur in brain-injured and non-brain injured populations, including individuals with acute stress disorder" ([1], p. 286). The argument is that the causal linkage between traumatic brain injury (TBI) and PCS breaks down because the symptoms of PCS can be attributed to additional causes (such as Acute Stress Disorder). As such, PCS is eliminated from *DSM-5*, and can be understood as either a variation of Acute Stress Disorder or TBI. An acquired brain injury rehabilitation specialist can be recommended for TBI; a clinical psychologist or psychiatrist can be recommended for

Acute Stress Disorder. The authors commend this reclassification because it recognizes that brain injuries are to be studied by neurologists and other medical specialists while transformations to one's existence are to be studied by psychologists.

While the present analysis aims at PCS in the latter psychological sense, it is worth mentioning that acquired brain injury (ABI) specialists have found it appropriate and even necessary to adopt an existential-phenomenological perspective as well. American rehabilitation physician and scholar Gary Goldberg [2] explains how "brain injury deeply affect[s] the subjectivity of the person injured—that is, their existence as a human person—because of the potentially significant aspects of personhood impacted…, it can also produce significant problematic impairment of self-awareness" (p. 397). Like neuropsychiatrist Kurt Goldstein [3] argued nearly a century earlier, Goldberg and others have called for a transformation of the philosophical paradigm that has traditionally been used to understand brain injury [4–9].

3. Using the phenomenological method to understand psychological disorders

The issues of diagnostic validity and medicalization emerge when the goal of scientific inquiry and treatment is law-governed explanation (*Erklären*). *DSM* reliance on neuroscience, brain imaging, and genetics is in service to explaining what constitutes a psychological disorder and, by extension, what causes each. Explaining phenomena is rooted in a Netwonian philosophy of science which views persons and things in their objectivity—that is, stripped of all qualities that cannot also be explained. Experimental procedures focus on identifying temporally and spatially proximal causes. This kind of knowledge is the goal of the natural sciences.

Erklären cannot reach human existence because existence is not divisible into objects. German philosopher Martin Heidegger [21] has argued that modern natural science has confused existence (i.e., *being*) with explanatory objects (i.e., beings). German philosopher Edmund Husserl, who inspired Heidegger, has also argued (1972) that modern natural science is incapable of understanding human experience. Husserl [22] has advocated for a humanistic science tasked with *understanding* human experience and proposed the phenomenological method for examining and describing the structure of human consciousness. This is in line with the methods of human science of 19th century German philosopher Wilhelm Dilthey (1833–1911) who emphasized *Verstehen* knowledge which focuses on meaning (*see* [23]).

Verstehen and *Erklären* are important for understanding psychological disorders because the latter are diagnosed through signs (objective behaviors) and symptoms (subjective experiences. Where *DSM-5* searches exclusively for physiological explanations for psychological disorders, it has either ignored the importance of understanding subjective experience (symptoms) or has confused symptoms with signs. To adequately address the breadth of psychological disorders, attention must be paid to understanding symptoms. This need has been identified for common psychological disorders [12] and advanced psychoses (*see* [24]). In the present article, the authors describe PCS with the goal of better understanding how it is experienced.

The descriptive phenomenological method begins, Giorgi explains, "by obtaining concrete descriptions of experiences from others who have lived through situations in which the phenomenon that the researcher is interested have taken place" [25]. These descriptions are the raw data of an empirical phenomenological analysis. This form of qualitative analysis follows three distinct steps: 1) Reading each protocol (that is, the raw data) for a sense of its whole. This means familiarizing oneself with the event as it has been described by each subject.

2) A determination of meaning units within the protocol. In this step of the analysis, the investigator tries to note any affective, experiential, or other shifts that occur within the protocol. 3) Transforming the natural attitude expressions into phenomenologically psychologically sensitive expressions. That is, the *psychological insights regarding the phenomenon* can be discussed without *reducing* the phenomenon to its psychological description.

4. Design

Authors obtained IRB approval before distributing a general call to university coaches and athletic trainers who supplied contact information for athletes interested in participating in a PCS study. Authors followed up with prospective participants and arranged interviews with three athletes. Participants 1 and 3 were males whose concussions had forced an early retirement from careers in football. Participant 2 was a female mountain climber. Interviews were recorded using a digital recording device and subsequently transcribed into text. Transcripts were analyzed using the descriptive phenomenological method [25]. Authors identified common themes across each interview and used free imaginative variation to describe the dimensions of the PCS experience.

5. Results

The participants who volunteered for this study had different experiences in recovery from TBI. Each participant succeeded in rehabilitating from injury but took very different paths in doing so. Common across each was a modification of personality and routine. Participant 3 had a complete recovery and full amelioration of symptoms in a relatively timely manner. He was able to do so with the least amount of adjustment. Participant 1, in comparison, had a long and turbulent recovery that involved the extension of symptoms over time and a severe and prolonged impairment in his psychosocial well-being. His recovery required a significant change to personality. Participant 2 made immediate adjustments in the wake of her injury and relied on social support to complete the readjustment and rehabilitation process.

As mentioned in the introduction and literature review, this examination of TBI and PCS focuses on the phenomenological dimensions of PCS—that is, how PCS is lived. Such examination requires we look closely at the meaning-centered aspects of recovery from head trauma, and examine how purpose, desire, and goal-orientation are adopted anew. Important themes during this process are identity formation, solidarity with others, and meaning. For our participants, psychosocial support proved to be the most significant factor affecting the severity of PCS and its rehabilitation.

The results are broken into two major subsections. The first is devoted to psychosocial factors which exacerbate PCS; the second to psychosocial factors which ameliorate PCS.

6. Impaired well-being

German hermeneutic philosopher Hans Georg Gadamer (1996) has found health a peculiar concept because it is not a good to be bought or sold. It is only when one is suffering that one comes to notice health at all. Illness and disease are impairments to health, but what is health itself but well-being? Each of our participants

experienced an impairment to his or her well-being. Routines that marked ordinary life were upset by persistent concussion symptoms, impairing relationships and identity. Attempts to ignore or overcome the disruptions through willpower only increased the disruption.

6.1 Difficulties shifting identity

A significant problem of TBI is that the activity during which it occurs is itself one that brings a person fulfillment and pride. This was the case for our participants. Two were NCAA scholarship student-athletes, and the third was an amateur rock-climber. The injury threatened the continued enjoyment each participant could find in their chosen activity.

The participants who volunteered for this study had relatively different experiences in the recovery from a traumatic brain injury. Generally speaking, the three participants' experiences covered a wide swatch of the spectrum regarding the amelioration of symptoms, health, and life satisfaction in recovery. In terms of this spectrum of health and wellbeing, one participant (P3) had what we would describe as a full recovery and full amelioration of symptoms in a relatively timely manner. A second participant (P1) had what we would describe as a long and turbulent recovery that involved the extension of symptoms over time, as well as severe and prolonged impairment in his psychosocial wellbeing. Finally, the third participant (P2) had what we would term as a moderate recovery; one that involved significant challenges early in the process but, over time, turned to a full recovery after certain psychosocial factors came into place to support her through her PCS recovery.

Of the three participants in this study, P1 (whom the authors will call Roger) struggled the most as he faced the end of his career as a football player. Roger teared up as he described this realization: "It's like, I play football, I'm the alpha male and it's a scary feeling and it's like, 'what's going to happen?'"

Roger expresses clearly the difficulty that many athletes face when injured, deselected, or forced to retire. For Roger, the multiple concussions forced an abrupt retirement from football. Perhaps for the first time since late childhood when he realized his skill as an athlete, Roger is faced with the question of identity. Who is he if not alpha male?

During the interview, Roger vacillates between recognizing then ignoring the serious difficulty transitioning out of football. In a revealing statement, Roger admits that the loss of identity continues to be a source of anguish. "I can't just hop up and say, 'oh I'm going to be an athlete again.' That's something I worked forever to be. And that's not something that I can just wake up and be [...] again."

Like Roger, P3 (whom the authors will call Philip) was a division one NCAA football player. Philip must also face the loss of his identity as a football player, a consequence that occurred in the middle of his senior season. The depth of loss was exacerbated by a game where he would have played in front of 45,000 spectators. Philip explains;

That day was really, really tough for me emotionally. [...] Besides my family, football has been the one thing in my life that I have loved endlessly, and I'm never going to stop loving it, but you know I've been playing since elementary school and it's so tough to just immediately stop when I thought I was going to have 11 more games guaranteed. [...] And I think after this season I would have been content with stopping. At times I just felt like I was letting people down. I know I did not actually quit but it kind of felt that feeling of being like a quitter for the first time in my life.

Philip experiences a complicated blend of feelings about retiring from the sport and abandoning his team. Head injuries are less conspicuous than torn ligaments and broken bones, and this means the athletes have more responsibility in decisions

to dis/continue. With a broken femur, suiting up for a game is out of the question. But with a lingering threat of another and possibly more severe concussion, the decision to play is left to the athlete, and Philip expressed guilt about his lack of commitment. To complicate this concern, upon returning to practice Philip had to wear a special uniform during practice indicating he was not to be hit. He explains, "It's like you've got this label on you that you're the kid that's injured that's no able to do the full practice. I don't want to say I felt weak but that's kind of how I felt." As a middle linebacker, Philip had a reputation of being tough. Vulnerability replaced toughness.

So too is it with the non-football player, P2 (whom the authors will call Maryann), who experienced a shift in identity following a rock-climbing head-injury. As a young college professor, Maryann prided herself in performing brilliantly and creatively in the classroom. Her brilliance was owed to endurance and focus during preparation, traits she lost after a concussion. She described the brilliant teacher as one who could roll into a classroom prepared to answer any question with ferocity and confidence. No longer able to rely on her cognitive agility, Maryann reports having to adjust to become "an economical teacher." As an economical teacher, Maryann has to ask for help in advance of, and leaned on her students during, her courses. However, she views this as a normal progression of becoming more mature as a professor. The concussion expedited this transition, but it was one towards which she found herself heading all along:

> *I am a little sad to lose the brilliance. I am a little sad to move out of that phase of my life. [However,] I almost wonder if it's not time to move into a different phase. And, so, this concussion just helped me to, like, stop, reconsider what's going on and then move in a different direction.*

All three participants experienced a loss of confidence in their identities where vulnerability supplanted strength. While the football players worry about how their weakness will be interpreted by others, Maryann sees the identity transformation as normal, even salutary. Her ease of transitioning to a post-injury life is owed to her willingness to experience vulnerability, and her openness to adopt a new professional identity. This may be compared to Roger and Philip who shared thoughts about transitioning to coaching, but who struggled to reconcile the new position on the football team with their alpha male identities (which they were unable to abandon).

6.2 Social isolation and support

Another significant factor working against participants during their recoveries was the absence of social support from peers, family, neighbors, and/or loved ones. When Roger had little to no social support for extended periods of time during his recovery, PCS symptoms were at their worst.

Roger was offered the least amount of social support across the three participants. He describes his experience of social isolation and perceived lack of social support from coaches after a serious concussion while playing for his university team:

> *I just felt as though they did not care. I was just like, they do not give a fuck about me. [...] They do not call me. The only time they called me is if I did something wrong. I got a concussion, you calling me about missing something called breakfast check (where players meet with coaches)? Like, I really did not care. I was just like, I'm not going to go to anything. I'm not going to do anything and they are going to have to find me if they want me.*

As a university athlete, Roger is away from his social support structure at home, and his new support structure is made entirely of teammates and coaches—people he believes do not value him outside of his contributions on the field. The athletic relationship between players and coaches is predominantly utilitarian. It is of deep value to consider the level of perceived isolation and dehumanization that is present in his social experience after high school.

It is difficult to separate actual from perceived social support. Roger seemed incapable of recognizing support when present. For example, he felt like his mother did not care about him even though she was regularly calling. "I'm like 'mom, I don't even want to be on Earth and you're not even asking me anything.' And she's like, 'but I am, I'm calling you everyday.' And I'm like, 'but you're not, you're not here.' It was never enough." The primary shortcoming of social support may not be from Roger's social environment at all, but his willingness to recognize support when present:

> *A second form of social isolation came with treatment itself. Roger explains:*
>
> *I went to the psychiatric facility for four days and I mean all they did was we would be in groups, we could be playing cards, we could be watching TV, and they say they were evaluating you but they were just writing is he walking or is he sitting. It wasn't that much of an evaluation, there wasn't that many people to evaluate 60 people in the place. There's no way everyone can be evaluated and keyed in on. They were just doing what they were supposed to be doing, writing little notes, writing little notes. [...] It can be a weekly visit with a psychologist or a counselor. I know that's what got me through, just talking to my friends and talking to my counselor. Because I can always talk to someone that has like a point of view because you go talk to that counselor, he does not know you really, so he's going to give you the raw of what's going on.*

The psychiatric facility is Roger's final place to turn for social support. However, just as he perceives apathy from coaches, loved ones, and family members throughout this process, the overworked and understaffed nature of the psychiatric facility is unable to meet his needs. It is the desire for interpersonal connection with and empathy and support from others that Roger seeks. The absence of such support is what stands out most significantly in Roger's experience with PCS.

Maryann's situation is similar. Her dependence on others reaches its peak following her injury. "In the aftermath," she explains, "I felt so lost. It was really, really astounding. Luckily I was able to stay with a friend for weeks, so I had somebody that I knew from before the accident." But then Maryann had to move, and she rented an apartment for a few weeks in a new town which was disorienting. "Nothing smelled like me. And I thought that I was losing my mind like, I really thought that I was going crazy because I had nothing, nothing that reminded me. [My partner at the time] took off, like didn't answer calls; just disappeared."

Knowledgeable about TBI, Maryann was looking for evidence that her personality had not changed. But her new environment and social isolation provided little in the way of homogeneity. Furthermore, she describes how the social nature of her life as an academic was not conducive to her recovery process:

> *I think the hardest part about academia for me is isolation. There's no question. I played team sports my whole life, I know teams. That's how I know how to function. Nobody here knows teams. Nobody here knows teams. I know like the idea of helping each other instead of getting ahead of each other. There is no doubt that my job made the recovery more difficult because of this.*

6.3 Resistance to personality change

Though each tried, all three participants were limited or unable to continue their pre-injury commitments and routines, leading to frustration and exhaustion. The longer the commitment lasted before the injury, the greater the severity of PCS.

It wasn't until he lost blocks of time and bits of memory during a phone conversation that Roger began to suspect he had suffered his fifth concussion. This occurred during a typical phone conversation when he had trouble remembering his previous day. He was also unable to read his notes without the words dancing around on the page. The impairments to his routine were considerable.

Philip was worried he would be unable to get through a workout without passing out. Even standing up too quickly resulted in light-headedness. This was a significant change. Philip reported being the strongest member of the football team during training. He had spent years of his life repeatedly training his muscles to engage in specific exercises. The fast-twitch anaerobic muscular strength upon which he relied was no longer there for him. His body was unfamiliar.

Maryann experienced trouble looking at the computer screen for long periods of time without getting dizzy, and this impaired nearly every aspect of her occupation as professor. Inability to concentrate affected normal daily activities like driving and grocery shopping. Indeed, it was her experience of dizziness while checking items off her grocery list that prompted her to see a physical therapist.

As with all illnesses [26], PCS is experienced through disruptions to routine. In the midst of routine, the body is taken for granted and absent to experience. It is only once these routines break down that the body is noticed at all. Attempts to continue the impaired routine results in disorientation and suffering—Roger studying for an exam, Philip finishing one more workout, and Maryann reviewing a course syllabus. It is only in the midst of such routines that one feels at home, and it is upon such routines that one builds one's identity and sense of life-satisfaction. To lose these routines is distressing, but it can also interrupt one's sense of time and space. It is as Maryann describes her routines: as "anchor[s] in the day to keep me moving from one point to the next. So that even if it's disorienting in between I know where I'm supposed to be when I'm supposed to be there and that's the foundation." Without routines one is adrift.

The desire to return to their pre-injury state is understandable, but impossible. It is only once the routine is adjusted that rehabilitation may begin. For Maryann, this started with adjustments in the classroom:

> *I was just honest with the students right up front and I said "you know I have a concussion. I can't use the computer and I need the lights to be off in the room because it's making me sick having the lights on." And they were really great about it, I mean, I got a lot of athletes in my class as well so hearing "concussion" they know what that means. Yeah, and then the other thing is I usually push too hard and with a concussion you cannot.*

Maryann recognized and accepted her newfound shortcomings which she was then able to strategically address. Strategies included being more patient with her work, taking breaks, and stopping to nap when necessary. These strategies are helpful not in recovering the pre-injury personality, but in developing a new one post-injury. To that end, Maryann was able to view these personality changes as important ones—changes the injury helped her make. Even before the injury, she recognized a needed help with work/life balance. The concussion helped her back off what she described as a tendency to be a "workaholic," and pay special attention to diet, nutrition, and social networks. "So one of the things that I've noticed is that

I have to make time for my hobbies and I have to make time for other people. [...] I needed to reexamine my sense of identity and commitment to priorities. I needed to make time away from work to be with others."

Finding meaning in injury and illness is an important part of what physician and philosopher of medicine Aaron Antonovsky has called sense of coherence (SOC). Patients that have a high SOC rehabilitate more quickly and live longer and more satisfying lives.

7. Social support and well-being

7.1 Solidarity and support

Participants credited social support for their ability to establish new forms of identity and purpose in their lives following TBI. Philip described the efforts of his teammates, family, peers, and coaches as beneficial for navigating the abrupt end of his football career. He describes a conversation with his father after Philip was sidelined with a concussion:

> *My Dad is like the hardest guy I've ever known, hardest worker. He's so supportive about football and he's played his entire life too. He loves the game and for him to be on the phone with me and to have him start crying and saying, "Alright, this is it, we got to hang it up." That's when I was like, "Alright, this is it." But, yes, I definitely felt supported by my parents throughout this process.*

Philip finds comfort in his father's empathy. He also found support from the team's linebacker coach who explained "if you were my son, I'd tell you to shut it down." Reflecting on his decision to retire from football, Philip explained that everybody around him was supportive:

> *And when it came down for me to actually say I was officially done, I sat down with my linebacker's [position-] coach and also the head coach and they were both like "this is the right decision for the long term and obviously we're going to miss you this year but your health is a lot more important".*

Support from coaches at an NCAA division I program, whose professional livelihoods are tied to young players like Philip, is difficult to overstate. With so much professional capital at stake, coaches can easily adopt a utilitarian relationship towards their players, squeezing every drop of performance from their players until there is nothing left. His position coach deliberately chooses to place himself in the position as Philip's mentor and caretaker, placing the personal well-being of his player above the productive value he might have had to the team as a starting linebacker. The whole coaching staff makes it clear that player health and well-being is more important than winning. Philip explains:

> *I have so much support from my friends, my family and no one's going to tell me that I did anything wrong in life or I was quitter or anything like that. I may have thought that but I think as I progress through my life, not doing contact sports is probably the better thing.*

Even with the family and coaching support, Philip still loses his typical in-season routines of training, practice, and competition. Though his coaches allow

him to stay with the team in a quasi-coaching role, there's a noticeable hole left by physical training and performance.

Roger was also surprised by the support he received from university football coaches following his most serious concussion. After ignoring them for weeks for fear of being rejected, he finally told them what had happened. "It was just a big change. They checked in on me. They called to see if I was okay rather than getting on me about stuff I was doing wrong. [...] And that meant the world to me."

Roger took a break from school to adjust and began working in an athletic shoes store. This gave him an opportunity to build relationships outside of football while also maintaining continuity—from athletics to athletic equipment. "That was very good for me, being in a social, interactive environment helping people getting something that they need, which is shoes." Despite the lack of glamor, there are a series of factors in Roger's new job that support well-being: strong relationships with his new coworkers, a sense of purpose and identity in his work, and unique knowledge of the field.

7.2 Accepting personality change

Beyond strong relationships, empathy, and social support from peers and loved ones, another significant factor in building a sense of well-being for participants was their ability develop a new post-injury personality. We have seen the changes accepted by Maryann in the classroom. The loss for Roger and Philip was more significant, since the injury forced them into early retirement. Something new and significant had to replace football.

As mentioned, Roger's football career ended abruptly after a series of TBI's during the preseason of his senior year in college. He describes the process of refocusing his identity and relationships:

> *(Strong relationships are) what I did not think I was going to have. It was like even though I'm social, it was like okay I work with you, cool. But no, like we actually do things outside of work. We go to movies. We go out to eat and all that stuff. To find friends so fast was great for me. I felt like I would not find friends again. I thought that was going to be harder than what it was. To find another group of friends that I could talk to outside of sports was great. Usually all of my friends were from sports, playing on teams since I was younger. Most of my friends came from like, either, the travel team I played on, the school team I played on. And like, it was cool to have friends from different walks of life. One of the girls, she's gay and in the world we are in now just to have a friend that's gay is cool because the stuff that they go through may be totally different from what you go through. Just seeing a different perspective and talking to her or helping her for how she can handle situations when people are talking bad about her and all that stuff but, to see her, how she handles things is phenomenal. A lot of stuff just rolls right off her shoulder. It's great because if she can do that just because of her sexual preference, I can do that and nothing is really going on it's all up inside my head. So, those relationships at work really helped me just like, find myself again, to know that I was okay. Get back to being the regular me. So, this is about becoming the student I want to be again and that's probably the toughest part because my brain is not where it used to be. So, it takes me a little longer to do papers. And that's what's tough right now.*

Research shows that the shift in identity for athletes, especially after abrupt retirement due to injury, can be distressing and lead to psychosocial tension (Petitpas, et al., 2000). However, this line of research also speaks to the real benefits that retired athletes can receive from engaging in a flexible sense of identity. Roger continues, describing the process of refocusing his identity and relationships:

> *I felt like I would not find friends again. I thought that was going to be harder than what it was. To find another group of friends that I could talk to outside of sports was great. Usually all of my friends were from sports, playing on teams since I was younger. Most of my friends came from like, either, the travel team I played on, the school team I played on. And like, it was cool to have friends from different walks of life.*

Finally, Philip admits that nothing in life will match the feeling you get running out onto the football field but hopes to experience it in bits and pieces throughout life. "There's going to be aspects of my life later on where it's going to be those same emotions, those same strong feelings that I'm going to get while I'm playing football." Ultimately, Philip's combination of flexible identity and social solidarity offer a clear sense of career perspective for him, and allows him to be open, adaptable, and hopeful about the inevitable shift in life he faces.

7.3 Carving a novel path forward

Beyond strong relationships, empathy, and social support from peers and loved ones, another significant factor in building a sense of well-being for participants was their ability to carve out novel behaviors, goals, and routines in the aftermath of the TBI. For both participants Roger and Philip, their respective careers in sport were definitively ended after their final TBI. Therefore, moving forward into novel endeavors was essential for a myriad of professional, motivational and emotional reasons. Though she was not forced into definitive retirement, Maryann chose to step away from rock-climbing after her serious TBI as the presence of being in the arena caused psychological and somatic symptoms that were difficult to bear. Ultimately, all participants in this study were put in a position where carving out new behaviors, goals, and routines would be essential in moving forward in their professional and recreational lives.

Maryann expresses sentiments of needing to, in some ways, fundamentally restructure her habits, routines, and professional approach. She expresses how she experienced relief through streamlining her professional approach at work and establishing a sense of stoic efficiency:

> *I had to change my whole approach. You really have to because there's no time. All these students are really counting on you and relying on you, your department. There's no time for you to be sitting at home and crying that you are hurt. You just have to get up and do it, so what do you need to be able to get that done? It's like alright it happened, okay. Let us do what we have to, we have to run through to the end. No tears until you get home. And what do you need, like what do you need to be able to get it done? Like, to get through this day, what do you need today? And to finally ask yourself what do you need, not how much can I take from you but what do you need to be able to get through because we need to get this done. So, it's really developed a different relationship with myself.*

As mentioned throughout, Maryann feels a tremendous sense of accountability to her students and peers. Originally, this led to her decision to not take the proper amount of recovery time after her serious TBI. However, Maryann is able to find a novel way to move forward despite the limiting circumstances due to PCS. Her ability to adjust - to shift course and construct novel tendencies and behaviors in her day to day work - opens a space for her to overcome the immediate psychological and cognitive deficiencies in the aftermath of her TBI. As is the case with all three participants in this study, we argue that it is this ability to adapt after the TBI that

supports wellbeing, psychosocial functionality, and the amelioration of symptoms for participants.

Though Philip still seems to be struggling with aspects of leaving sport - especially the emotional void that can come with leaving competition - he consistently describes how there a series of behaviors and outlets in his life that can replicate this emotional void. He expresses how he is optimistic about the possibility of his future career and its ability to fill any emotional void after football:

> *P: Being with all the guys; that's one thing that I'll definitely miss. But I think the work that you put into it just to win a football game, you realize that the entire work that you put into something made this product of a win. I know there's obviously other things in life where you put in so much time and you have a great outcome too but I think it's that one feeling when you run out onto the field and Sean Payton actually has a quote, he said, "You'll never get the same feeling when you run out onto a football field on a Friday night or a Saturday but you're going to get it in small pieces in your life" and that's like when you get married or have your first kid, you are going to get that same feeling. But it's just not going to come every single Saturday in the fall.*
>
> *I: Do you believe that? Do you believe that you will get tastes of it?*
>
> *P: Yeah, I think I definitely believe it. There's going to be aspects of my life later on where it's going to be those same emotions, those same strong feelings that I'm going to get while I'm playing football.*
>
> *I: Sure, but what about in your career? Do you think it will? Do you think in business, going into business it will replicate some of these, you said it well, strong emotions?*
>
> *P: I think so. Business is a competitive environment as well so I think the aspects that you need to be a collegiate athlete kind of transform into the business world too, so, I would say it would come here and there.*

Furthermore, he explains how deeper engagement in his academic work as a student and volunteer work outside of the classroom was deeply beneficial in the aftermath of TBI and, consequently, retirement:

> *I: What about as a student? Do you ever get it as a student?*
>
> *P: Yes. I think so.*
>
> *I: Does anything in academics or anything right now...is there anything that you do on a semi-regular basis that provides a similar kind of cathartic release to sports, or to football I should say?*
>
> *P: I do not know that's a tough one. I think I have not experienced the extent of some football emotions that you get while you are playing in the classroom but I think it's still a competitive environment obviously, you want to do better than some of the other students in the class.*
>
> *I: What about the solidarity thing? You said that you felt really connected to your teammates. Is there anything that you do outside of sports that makes you feel connected to the people around you? Even on a spectrum level? If it's not the same*

extent, is there anything that you do that falls on the spectrum of connection and solidarity?

P: I do Big Brother Big Sisters so I've had a little brother over in the [College City] project for the past four years and I developed a really good relationship with him and just seeing him grow these past couple of years I think that's been a great experience as well. That's been something that I would say is pretty close to that team connection.

Philip is fortunate enough to be at a college and in a social-professional culture that worked to promote a more holistic sense of identity beyond any exclusive notion of athletic identity. He describes how he feels like he can move between student-identity and service-identity after his athletic-identity is no longer available. These complementary forms of identity form a holistic sense of self and open space for him reconceptualize and broaden identity after sport. This allows him to experience how novel behaviors - intellectual engagement and service - can allow for a similar sense of satisfaction, solidarity, and competition after sport.

Finally, Philip expresses how he is relatively at peace with the end of his career and is anticipating the next chapter of life after football. He expresses how the combination of social support from his family, personal and team accomplishments have left him in a place where he is comfortable walking away:

I think I've definitely come to conclusions with my playing career. As I've thought about it, I'm like, okay, I got to play here at [College], I had a great experience, I had a really good career here. I played in high school. That was a great four years. I won a state championship in [State] with my best friends in high school and that was an unbelievable experience. I played my entire life with Pop Warner and as I've gone back and thought about my entire football career, I could not be more proud of myself. My parents could not be more proud of me so I think hearing that from them and I think look in the mirror at the end of the day and just actually being happy with myself and in my career I think it's made it a lot easier. I'm ready for the next chapter now.

Philip's experience of PCS in the aftermath of a series of severe TBI and his consequent transition out of sport was undoubtedly the most expedited and successful in this study. This passage almost fully encapsulates the psychosocial factors that convalesce for P3 in order to navigate this transition so smoothly. The combination of both flexible identity and social solidarity, offer a clear sense of career perspective for him. Ultimately, this provides him a space to be open, adaptable, and hopeful about the inevitable shift that his life is undergoing.

7.4 Gaining a new sense of purpose

Participants experienced a higher level of life-satisfaction by gaining a new sense of purpose. TBI forces individuals to make significant alterations to their lives, routines, habits, and careers. This came more easily for Maryann and Philip than for Roger.

Roger's university playing career had only just begun, and his identity as a football player (which provided a full-tuition scholarship) was tied to his identity as a student, and he withdrew from school. After building relationships at his new job, Roger is able to look back with a heavy heart at those who suffer similarly from TBI, and has a compassion that only comes from having lived through it:

> *When I was talking to my psychologist, in his report, it says that I show signs of CTE. And it's like, wow, this is something I read about and saw it in a movie and I show signs of it, that's crazy. Now I want to help people and hopefully slow things down for future players or get better helmets or something because I feel like my last concussion was because the school did not have proper equipment. But, that's besides the fact, we just need to find the right combination for guys. It is something I want to be a part of.*

TBI's have fundamentally shifted the course of Roger's life and career. They have forced him to fully retire from football and withdraw from college. However, over time Roger describes how he begins to gain a sense of perspective on his own personal trauma. This leads to a deepening desire to offer solidarity and support to peers and former athletes who may have shared a similar experience of trauma. Roger continues, expressing a sense of compassion and desire to forward his support and care to other former contact-sport athletes who may also be suffering from the effects of head trauma:

> *I remember I was talking to my cousin and he works at a strip club and there was a guy who played for the Falcons. He's retired now but he's always there. I'm pretty sure he has CTE, but he's always drunk and he's fighting people and stuff like that. Him telling me that, while I was going through this is what made me step back from the situation and have a perspective on it. I do not want to be like that because that's the guy I did look up to when I was younger. (Player's name), I mean he played for the (NFL Team) and he was pretty good and to hear how he's doing in life now, after football, I do not want to be like that. I want to be able to still have intelligent conversations and talk to people just like this. Not "ah ugh you want to have a beer man?" No, that's not me. Of course, I can loosen up and have some fun but just to be yelling at people in the club because I'm drunk and mad for no reason? That's not me. I cannot do that and I hate that for him. And I told my cousin, if you can get in contact with him, I want to talk to him. Not on being a fan, I just want to talk to him just to help because he may have some insight for myself or I may have some insight for him. You never know. I do not care that he's an NFL player and played 16 years. I want to help because I feel as though in five years, we may be saying that (NFL Player) killed himself in a car accident or with a gun. Because that's crazy for him to really be having mood swings and drinking as much as he says he drinks, it's not good. It's not good at all. They're a person. We look at them like a piece of meat like, "Oh yeah, he made these plays or this play." But that's only inside of the helmet. He has a family. His purpose in life, in the world, may be bigger than just football to his family. That's what I look at it as. [...] Football is not, it does not define us, but it does get us to different places in life. It got me to college. And at times I did not think I was going to go to college, not coming from the neighborhood I came from. [...] So, seeing people from my same background doing things that I wanted to do and now he's going through that as far as being drunk all the time and being angry and all that stuff? That's not good. That's not good at all. I want to prevent that for someone maybe in my generation or the future generations, maybe even help people that are like him right now.*

Roger feels compelled to take up a greater sense of commitment to supporting individuals who, like himself, are possibly struggling in the aftermath of excessive TBI and career transition out of sport. He is able to recognize the stark reality that many face in the aftermath of their careers and the aftermath of head trauma. Though he did not make it to the NFL, he finds a shared sense of connection and experience with former NFL players who are facing a similar dark journey in the

aftermath of TBI and their careers. He is clear here in recognizing that the difficulties of retirement are not merely limited to head trauma.

Finally, Roger mentions how symptoms of PCS are ameliorated when he is engaged in an activity that he is passionate about. He describes how his level of focus increases significantly when reading articles that are in the range of either his academic or personal interest:

> *I: And have you noticed any activities or even books or articles or movies that you do get really focused, that you can focus on?*
>
> *P: Sports. Anything with sports I can focus in good on. And it's frustrating because I was talking to my agent. She was like, normally what happens, because she's a psychology major, normally what happens is things that you get excited about, you are going to remember. I was just like, that sounds about right. But, I want to get excited about everything and remember everything. But that's just not how stuff is going to work. But it's just like, how do I get my brain to where I can retain what I used to retain? About things that are outside of sports?*
>
> *I: What about the research that you said that you did into the effects of marijuana on sleep? Were you able to focus on those things?*
>
> *P: Yeah because it was something that it was going to help me. Researching that it was more so reading what certain, what the certain strands did and the effects that it would have. And then if I was able to get my hands on it to see what it did to me, and most of the time if I got anything it was just I would get sleepy or I would get focused. And that was awesome to be able to focus in and do my work.*

Put simply, the presence of somatic and cognitive symptoms do not present universally for Roger. Instead, when he is engaged in an activity that finds personal passion and meaning in, many of the cognitive difficulties and symptoms are ameliorated. His description elucidates the role that meaning is likely to have on building focus and cognitive endurance even after a severe amount of TBI.

Maryann finds a sense of purpose in her recovery process and establishing a novel sense of purpose brings her to a greater position of well-being in the midst of her experience of PCS. She describes how getting back to the work she felt she owed her students was what drove her forward and helped her overcome the most difficult aspects of PCS:

> *I think part of the recovery was actually having something to do. You know, somewhere to be. Something to heal for because I did not want to let my students down. So that was really helpful in recovering and getting through the semester and being a bigger person for them.*

Similar to Roger, Maryann experiences a sense of cognitive endurance and the amelioration of symptoms when she is engaged in purpose-directed and meaningful activity. As mentioned throughout, she feels a sense of accountability to her peers and students and this drives her to return so quickly to work. Despite the difficulties of this early return, she gains a sense of cognitive strength through reorienting her own existential commitments through the trauma as a deep connection to her work and students.

As we have alluded to, compared to the other participants in this study (especially Roger), Philip was able to commit himself to a new sense of purpose with

relative ease in the midst of experiencing PCS after the TBI that ended his career. He describes how he was able to establish a new purpose on the team after realizing his contributions on the field were no longer possible:

> *P: I would say so because obviously I'm not contributing on the field and it's tough for me to be like a coach and not try to overstep some boundaries here and there. At times I just felt like I was letting people down and I know I did not actually quit but it kind of felt that feeling of being like a quitter for the first time in my life.*
>
> *I: Did you feel that way?*
>
> *P: I did. At first it was really hard to kind of get over that fact that I had to stop because of my health but it was like was I kind of quitting almost?*
>
> *I: Were you able to find any ways to make contributions? Or anything that you felt was a contribution to the team? During those few weeks and months as you are going through this and you are not on the field, you are not playing, you are watching from the sidelines, was there anything you could've done there or is there anything that you did do during that time that made you feel like hey I am contributing something here to the team?*
>
> *P: Yeah, definitely. I helped. I went to every practice and helped out at all of those. So, I still felt that I was a part of the team even though I wasn't playing, you know? I got to go to all of the games.*
>
> *I: And you did feel like you were able to hold up with all of this work for the team?*
>
> *P: Yeah, I was able to chart plays for the defense and contribute as much as possible but I think not actually physically contributing to a win or loss kind of made me feel a little down on myself.*

Despite his inability to contribute to his team's success on the field, P3 is offered the opportunity to take up a pseudo-coaching and staff-support role for the team. Through this, he is able to bring some of his on the ground knowledge to his coaching staff while also offering an extra set of eyes and hands to the day-to-day work of practice and game day operations. Yet, he still expresses initial lament about not being able to physically contribute on the field to his team's efforts. P3 continues, explaining how he was able to establish a new sense of purpose and meaning through support from his coaches:

> *P: Yeah, I definitely felt supported. Even after the second concussion, I would always just talk to (Head Coach) on a Sunday. We'd talk about the game. He'd always ask me about my perspective. He would always ask me too, kind of like how the team was feeling. So, I was almost like the inside scoop for the coaching staff. Kind of the emotions of the team throughout the season.*
>
> *I: Are you grateful for that, looking back? That you were kind of able to act like this liaison between the players and coaches?*
>
> *P: Yeah I would say so. For him to trust my opinion and he asked me, "Alright, what do you think we need to do differently?" I think that was good too just to have him be supportive of my voice on the team.*

I: Did you still feel like you had some value and worth to the team by doing things like this?

P: Yeah I would say so. Definitely towards the end of the season, it got easier and easier that I wasn't playing and contributing, I think that obviously helped too just having my small role on the team.

I: I know it's hypothetical but if you did not have that what do you think it would be like? What do you think the season would have been like?

P: I think it would have been a lot harder. To be officially away from everything, that would have made it a lot lot tougher. And my parents said oh maybe you should just take some time off and not go to all of the practices and not go to the games ***but I felt it helped for me to actually still be a part of the team****. Because all of the guys in my senior class are my best friends for life. I know that's a relationship that I'm going to continue. Not being there with them in this final season of ours and how much we have gone through as a team and how many different coaches we have had, we are the first senior class of Coach Chesney obviously we have been through a lot, and if I wasn't able to be there with them, it obviously would have been a lot harder for me.*

P3 expresses, without equivocation, that the support of his coaching staff and the opportunity to reorient his identity and role on the team in the aftermath of a career ending TBI created a space for him to feel a novel sense of purpose for his life after football. His ability to take a role on the team and embrace these new behaviors, mindsets, and opportunities made him feel connected to his teammates and improved his sense of psychosocial wellbeing. This role allows him to feel that he is making a contribution to the team despite his inability to play. Ultimately, he does not stay stuck in a rigid sense of identity in the aftermath of the TBI. These new routines and behaviors are well within his acumen and ability after the TBI and build a sense of confidence and a novel concept of identity in his relationship to football. His embrace of this novel role is a new existential commitment that opens space for a reexamined life after football. This effort is aligned with both the amelioration of his symptoms and the increase in his psychosocial sense of wellbeing after the trauma.

8. Conclusion

The intention of this study was to demonstrate the need to deeply examine the psychosocial and existential realm present in individuals who are recovering from TBI. As mentioned throughout, each participant had a deeply singular experience of recovery from their major head injury. Participants who were able to conjure perspective, context, and a sustained sense of meaning around ending of their athletic career were able to recover a high level of psychosocial functioning, existential purpose, and, coincidentally or not, their symptoms were ameliorated.

Maryann and Philip were able to offer some unique perspective around the end of their career and the experience of no longer having the ability to participate in endeavors that caused their original TBI. Despite the myriad of trauma associated with her experience, Maryann continually described how she is grateful for rock climbing and how she can contextualize this experience with the longevity of her career. However, despite a traumatic ending and an injury that almost cost her health and life, she is able to put her career into perspective and expresses a sense of gratitude for her ability to engage in rock climbing. She knows that she cannot return to this arena

of competition, however, she is cognizant of the sense of strength and confidence the sport offered her. The sport built her body and offered a consistent emotional release for her throughout the physical and somatic ailments she carried through her life. Even without the ability to return to this arena for the physical, emotional, and psychological strength it provides, she conceptualizes her career in sport as having deep and lasting meaning and is grateful for this experience despite any trauma incurred.

Similar to Maryann, Philip expresses a sense of gratitude and context around his full playing career despite experiencing a bevy of head injuries and abrupt ending to his career during his senior year. Though Philip acknowledges that sacrifices were made and injuries were incurred throughout his commitment to the sport, similar to Maryann, there is a sense of sustained meaning from and gratitude for his career and experiences in football. There is a similar sense of cognizance around what the sport offered despite what was taken from him through the trauma of his career ending injuries. The connection to his teammates, the emotional catharsis of competing and engaging in a contact sport, and the lessons learned and mindsets formed through discipline and commitment form a sense of sustained meaning for Philip. Ultimately, he is not blinding his awareness from the sacrifices made and asked. Instead, he is grateful for the game along with the trauma and struggles that were incurred in his career. Like Maryann, this sense of gratitude correlates with a sense of psychosocial wellbeing after the TBI and after his career has ended.

The aftermath of Roger's injury was undoubtedly the most physically, somatically, and psychosocially traumatizing. At least initially, he was offered little social support and struggled deeply to conjure a new identity without football. As he described, for some time, he felt like he was having a dissociative break from his identity, purpose, and experience of reality. However, in time, a novel sense of purpose and identity are conjured and the cognitive, somatic, and psychological symptoms of his TBI begin to subside.

Moving forward, more phenomenological research should be devoted to unearthing the lived experience of human beings who are recovering from traumatic brain injuries. Our argument is not that these psychosocial and existential factors have a causal effect on ameliorating somatic symptoms of TBI, however, it is possible that they play some significant role in aiding the holistic recovery of the traumatized person. The less we medicalize these injuries, the more we can build a holistic conceptualization of the traumatized human being. Ultimately, further phenomenological analysis of these lived experiences might be able to unravel the nuanced and complicated relationships between these systems.

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