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THE LIVED EXPERIENCE OF RETIRED COLLEGE ATHLETES WITH A
HISTORY OF 1 OR MORE CONCUSSIONS

BY
REBECCA COVER

A thesis submitted in partial fulfillment of the requirements for the

Master of Science

Major in Nutrition and Exercise Science

Specialization in Exercise Science

South Dakota State University

2017

THE LIVED EXPERIENCE OF RETIRED COLLEGE ATHLETES WITH A
HISTORY OF 1 OR MORE CONCUSSIONS

REBECCA M. COVER

This thesis is approved as a creditable and independent investigation by a candidate for the Master of Science degree and is acceptable for meeting the thesis requirements for this degree. Acceptance of this thesis does not imply that the conclusions reached by the candidate are necessarily the conclusions of the major department.

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ABSTRACT

THE LIVED EXPERIENCE OF RETIRED COLLEGE ATHLETES WITH A
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REBECCA COVER

2017

CONTEXT: Concussions remain misunderstood, underreported, and undiagnosed. While most concussion symptoms resolve within 2 weeks, some patients experience persistent symptoms which adversely affect physical, emotional, social, and/or cognitive functioning. Minimal evidence delineating the effect of concussions on recently retired college athletes currently exists.

OBJECTIVE: To examine the lived experience of retired collegiate athletes with a history of 1 or more concussions to discern individual concussion histories, knowledge and perceptions of concussions, and post-concussion quality of life.

DESIGN: Qualitative.

SETTING: Personal life after retirement from competitive athletics.

PATIENTS or OTHER PARTICIPANTS: Former Division I athletes (n=14) 1-5 years post-athletics retirement with a history of 1 or more concussions.

DATA COLLECTION and ANALYSIS: Fourteen semi-structured telephone interviews (8 males and 6 females) were audio-taped. Interviews were transcribed and inductively analyzed by 3 athletic trainers with 34 combined years of professional experience.

Themes were negotiated through consensual review. Participant checks were completed to ensure trustworthiness of results.

RESULTS: Participants sustained their first concussion during adolescence and often experienced difficulties transitioning back into the post-concussion academic

environment. Judgments of injury severity were clearly evident in participants' knowledge and perceptions of concussions. Participants experienced an array of emotional, physical, cognitive, and social challenges during the immediate post-concussion period, but did not feel that their concussion history decreased their current quality of life.

CONCLUSIONS: Adolescent exposure to concussions is of concern due to risk imposed on the developing brain and potential for adverse outcomes later in life. Although graduated return-to-play is heavily emphasized in concussion management, researchers need to investigate barriers inhibiting the implementation of return-to-learn protocols. Concussion education should aim to modify indifferent attitudes toward concussive injuries. Additionally, researchers should continue investigating how a history of concussions affects quality of life in recently retired college athletes.

KEY WORDS: Concussion, retired athlete, quality of life

CHAPTER 1

Introduction

Approximately 300,000 sports-related concussions (SRCs) are estimated to occur in Americans on an annual basis.¹ At the collegiate level, statistics compiled from the 2009-2010 to 2013-2014 NCAA seasons found that SRCs constituted about 6.2% of injuries and that nearly 1 out of 11 of the reported concussions was recurrent in nature.² Research has also revealed that a significant number of concussions go undiagnosed.³ In a study investigating former athletes' recalled and clinically-diagnosed concussions, 39.6% of the respondents stated that they believe they sustained at least one concussion that went undiagnosed.³ Robbins et al⁴ found that athletes' understanding of what a concussion represents is not consistent with medical definition, thus contributing to the underreporting of concussions to healthcare providers. After being provided with a definition of concussions, 73% of the athletes in the study increased their number of self-recalled concussions.⁴ While research on athlete perceptions of SRCs is limited, a study on high school athletes found discrepancies between athlete knowledge and willingness to report.⁵ Despite a solid understanding of concussions and concussion symptoms, Anderson et al⁵ discovered that only 54% of the participants would willingly report a symptom and 53% of the respondents expressed that they would continue to play with one or more symptoms.

Most concussions symptomatically resolve in one or two weeks.¹ However, studies have found that post-concussion symptoms may exist months and even years after the initial injury.⁶ Reports have shown that anywhere from 40-80% of concussed individuals develop persistent post-concussion symptoms and about 10-15% experience

symptoms after 1 year.⁶ Unfortunately, persistent post-concussion symptoms have been shown to negatively influence patients' quality of life in myriad ways.⁶⁻¹²

Physical fatigue represents one of the most common post-concussion symptoms causing the greatest disruption in daily activities.⁹ Using the Rivermead Post-Concussion Symptoms Questionnaire (RQP), Ahman et al found 53.4% of participants reported mTBI-related fatigue three years after their initial injury.⁹ Participants also expressed feelings of identity loss, difficulties controlling emotions, and loss of connection with their body.⁹ Post-TBI fatigue, along with difficulty dealing with daily hassles, life events, and interpersonal stress, has also been reported to be positively associated with elevated levels of chronic situational stress in community-dwelling adults.¹³ Cognitive limitations in the form of impaired memory, difficulty concentrating, and feelings of mental foginess have also been reported by individuals who experience persistent post-concussion symptoms.^{8,9} Other studies have found that concussed individuals experience less satisfaction with life, friendships, and relationships with peers, along with varying levels of emotional dysfunction, than individuals who have not experienced a concussion.^{14,15} The incidence of concussion has been reported to nearly double the experience of depressive symptoms.^{12,15} Vargas et al¹² found relevant depression scores in 11% of participants at baseline and in 23% post-concussion.

The increased incidence of retired professional athletes reporting emotional and cognitive deficits from their years of athletic participation has drawn increasing attention to the long-lasting effects of concussions.^{7,11,16} However, limitations in current concussion-related research continue to present several challenges. First, much of the TBI-related QOL research does not clearly differentiate concussions from mild,

moderate, or severe traumatic brain injuries. Furthermore, although the volume of concussion-based research has grown, there remains little evidence illuminating patients' perceptions of concussive injuries, including injury severity. This is problematic considering that, regardless of initial post-injury symptom severity, patients' perceptions of head injury contribute to the experience of persistent post-concussion symptoms.¹⁷ Finally, while some research indicates that quality of life deficits may occur at lower levels of athletics' participation,¹⁸ sparse evidence exists describing the sustained effects of concussions in younger athletes including recently retired college athletes. This is concerning given the multi-faceted nature of quality of life,¹⁹ the number of participants competing in collegiate athletics, and the fact that less than 12% of college athletes eventually pursue careers in professional athletics.²⁰ In many ways, retired college athletes represent a "forgotten" population.

Given these limitations, the purpose of our research was to examine the lived experience of retired collegiate athletes with a history of 1 or more concussions. We hoped that by examining their experiences we would gain a more thorough understanding of their individual concussion histories, their knowledge and perceptions of concussive injuries, and their post-concussion quality of life.

CHAPTER 2

Methodology

Participants

Individuals who sustained at least one concussion during their athletic tenure at South Dakota State University participated in the study. To be eligible for the study, participants had to have been a member of a sports team within the University's Division I athletics department and finished their collegiate playing career between 2010 and 2015. Participants were excluded if they were no longer on an institutional roster but were continuing to pursue their athletic career professionally or collegiately at a different institution. Thirty two athletes identified through the athletic department's Sports Medicine electronic injury database met the inclusion and exclusion criteria; fourteen athletes (8 men, 6 women) agreed to participate in the study. The mean age of the participants was 23.4 ± 1.6 .

Procedures

Upon approval from the Institutional Review Board, potential participants were contacted via telephone and provided a brief overview of the study. Individuals who agreed to participate were emailed a consent letter and an information letter describing the purpose, risks, and benefits of the study and were given the option to sign and return the consent letter or provide verbal consent at the beginning of the scheduled interview. A mutually-agreeable time for a follow-up, audio-recorded telephone interview was then identified.

Data Collection

In order to gain valuable insight into the lived experience of retired collegiate athletes with a history of concussive injury, a semi-structured interview approach was taken. Semi-structured interviews are based on flexible guides which allow for a loose structure of open-ended questions and the exploration of attitudes and experiences of interviewees. Further, semi-structured interviews have been used to study TBI patients ranging from adolescents to military personnel, and represent an accepted and accurate method for representing a phenomena being studied.²¹⁻²⁵

The interview questions were designed to obtain responses that would illuminate participants' individual concussion histories, their knowledge and perceptions of concussive injuries, and their post-concussion quality of life. Based on these purposes, an initial interview guide was developed by the research team. To improve clarity and ensure that the questions would foster responses that supported the purposes of the study, two pilot interviews were conducted. These interviews were conducted in similar fashion to participant interviews and featured one male and one female former collegiate athlete. Based on information gathered during the pilot interviews, the research team convened and made final revisions to the interview guide (Appendix A).

Each audio-recorded interview was conducted by the same interviewer to ensure consistency with questions and probes.²⁶ As interviews progressed, the interviewer asked follow-up questions to clarify participants' responses. Upon completion of the interviews, the interviewer provided the opportunity for participants to elaborate on any responses or add additional details of their experiences that were not addressed through the interview guide.

Data Analysis

All interviews were audio-recorded and transcribed verbatim by the interviewer. Transcripts were coded to allow for the anonymity of responses and analyzed through a consensual qualitative review process. Consensual qualitative review incorporates elements from multiple qualitative analysis approaches with an emphasis on judges coming to a consensus on words which reflect the data.²⁷ The approach places the participant as an expert on the phenomena studied by allowing them to explore their experiences.²⁷

All transcripts were individually analyzed by a research team of 3 athletic trainers with 34 combined years of professional experience. Transcripts were initially read in their entirety by each reviewer to obtain a broad perspective on participant's responses. In subsequent individual reviews, questions linked to participants' concussion history, knowledge and perceptions of concussive injuries, and post-concussion quality of life within each transcribed interview were evaluated for key words, common themes, and patterns of meaning. Once individual reviews were complete, the researchers met as a team to discuss findings and come to consensus on common themes. The themes were subsequently presented to participants during follow-up telephone calls to verify accuracy and serve as a validity check.

CHAPTER 3

Results

Participants in the study ranged from 1-5 years retired from college athletics with an average of 1.93 ± 0.92 years. In addition, participants averaged 2.68 ± 1.69 years since their last physician-diagnosed concussion. **Table 1** contains participants' demographic data. Pseudonyms are used to protect participants' identity.

Table 1: Demographic data of the participants.

Pseudonym	Age, y	Number of Physician-Diagnosed Concussions	Collegiate Sport	Years Since Sport Retirement, y	Employment Status	Relationship Status	Children
Jonathon	26	2	Football	4.5	Student	Single	No
George	23	4	Football	1.5	Employed	Single	No
Steven	22	5	Football	1	Employed	Single	No
Randy	23	3	Baseball	1	Employed	Single	No
Grace	23	3	Basketball	3	Student	Married	No
Brittany	22	2	Track & Field	2	Employed	Single	No
Henry	24	4	Basketball	1	Student	Single	No
Shannon	24	2	Softball	2	Unemployed	Single	No
Laura	20	4	Equestrian	1.5	Student	Single	No
Benjamin	24	1	Football	1.5	Student	Married	No
Elizabeth	22	4	Equestrian	2	Unemployed	Single	No
Lindsay	24	4	Soccer	1.5	Student	Single	No
Brandon	26	3	Football	2.5	Employed	Married	No
Joseph	24	4	Football	2.5	Employed	Single	No

The overall purpose of our research, which was to examine the lived experience of retired collegiate athletes with a history of 1 or more concussions, was guided by three primary aims: 1) to gain a more thorough understanding of participants' concussion histories, 2) to gain a more thorough understanding of participants' knowledge and perceptions of concussive injuries, and 3) gain a more thorough understanding of participants' post-concussion quality of life.

Relative to participants' concussion histories, (2) themes emerged: 1) early onset and 2) discrepancies in post-concussion sport and academic engagement. Early onset

refers to the age at which participants described sustaining their first concussion. The second theme refers to the differences in how participants engaged in sport and academics during their post-concussion symptomatic window.

Early Onset of Concussions

The strong majority of participants experienced their first concussion during pre-adolescence or adolescence rather than collegiate sport participation. The earliest concussion reported by a participant occurred at the age of 10 with the majority occurring between the ages of 15 and 17 years. Laura, who was 10 at the time of her first concussion, recalled falling off of her horse and getting kicked in the face. She also sustained physician-diagnosed concussions resulting from horseback riding when she was 15 and 16 years old, pointing out that she was wearing a helmet during all three of these incidents. Steven, who ultimately retired prematurely from collegiate football due to his history of multiple concussions, sustained his first concussion while on a kick-off return as a sophomore in high school. He recalled this concussion as “definitely the worst”:

I went to block a guy and it was a head on head hit. I don't remember anything for probably about 5 minutes of the first quarter. I was quarterback at the time and nobody knew I had a concussion. I have collective memories of playing, but don't remember everything. I looked like an idiot out there because it would be a run play and I'm the quarterback throwing a pass to a receiver.

Randy was also a sophomore in high school when he sustained his first of 3 physician-diagnosed concussions. He vividly recalled this concussion, pointing out that “I was playing basketball. I got an elbow to the temple area, right above my left temple.” His second concussion occurred while playing football during his junior year in high school.

Both of these resulted in Randy missing school, practices, and games for a brief period of time following the concussions.

Similar to Laura, Elizabeth also reported a history of multiple concussions, all of which occurred after falling while horseback riding. Her first concussion occurred at the age of 13, and the second, which required a week and a half hospital stay, occurred when she was 16. Eventually dismissed from her college equestrian team due to “poor academic performance,” Elizabeth attributed her struggles and dismissal to what her physician termed a “double concussion” she sustained during practice. When asked in what ways her life is currently affected by her history of concussions, Elizabeth provided a sobering viewpoint:

I still have daily headaches and see a neurologist regularly. We’re trying to figure out a combination of things that allow me to go out and do day to day activities without a headache or migraine. It’s still a work in progress.

Discrepancies in Post-Concussion Sport and Academic Engagement

Throughout the interviews, participants highlighted significant discrepancies in how they engaged with their post-concussion sport and academic requirements. While the strong majority of participants described being removed from all sport-related activities, 10 out of 14 participants remained engaged in academic activities for 1 or more of their concussions despite continuing symptomology. Grace noted that even though she missed a week to a week and a half of sport-related activities for each of her first 2 concussions, she only recalled missing 1 class day. After her third concussion, the “one that caused the end of it (sport career),” Grace missed 3 days of class before returning to the academic environment even though her symptoms were so severe that she was not

allowed to play basketball. She elaborated on her decision to continue going to class despite her post-concussion symptoms:

We got a couple of different opinions. I missed like three days of class and then one physician told me that it would probably be smart of me to drop out for the semester and just like recover. And then another physician said “you know we’ll give you medication and just do what you can do” and so I just finished out the semester. And so I missed probably three days total of class and then just toughed it out after that.

Joseph too talked about the difference in how he engaged in his post-concussion sport and academic requirements. For both his 3rd and 4th concussions, sustained during college approximately 1 year apart, Joseph recalled missing a week to a week and a half of football practices and games. Despite this, he did not miss any school-related activities. Interestingly, when asked to explain the areas of his life that were specifically affected by his worst concussion (4th), he replied:

You never feel like you’re making the right choice. Everything feels kind of new to you but familiar. You know it but you can’t remember it at the time. It was just with football plays or things with school, things I just recently learned. I guess those were the hard things to get used to.

In reference to his final and self-described “worst” concussion, Randy reported missing “probably 2 weeks of baseball” yet noted that he only missed class for “3 to 5 days.” He described his attempt to reintegrate:

I didn’t think I would get a headache just from going to class, but focusing was brutal. And the headaches, you would just get headaches and be like “chill bro.”

Brittany, who missed significant time in sport and academics after sustaining both of her concussions, described the difficulty in trying to maintain her academic responsibilities without further exacerbating her post-concussion symptoms. Once she started going back to class, she tried to avoid her “got to think” classes unless they included something “super important,” noting that “if I spent too much time at them, it would all go downhill again.” Specifics of the classroom environment that were most troublesome were also noted. Brittany mentioned light and sound, specifically that “if all the lights were on and they’re (professors) talking, I was out. I was done. I couldn’t focus because my head hurt so bad.” Regardless of why they chose to continue attending classes while experiencing post-concussion symptoms, the majority of participants’ concussion histories seemed to be characterized by difficulties integrating back into the post-concussion academic environment.

Judgment of Severity

Relative to the second aim of the study, participants’ knowledge and perceptions of concussions were captured within (1) emergent theme, judgment of severity. Analysis further revealed that participants’ perceptions of concussion severity were deeply connected to a sense of indifference, change in perspective over time, and athletic identity.

Indifference. Several participants down-played the significance of concussions and self-graded the severity of their own concussions with a clear sense of indifference. Jonathon stated, “I remember everything about it. So in my opinion it was pretty mild.” Other interviewees echoed this sentiment with comments like, “it wasn’t a very severe one,” “it wasn’t that bad,” and “not a big deal.” Participants repeatedly mentioned how

taking hits is just a normal aspect of playing sports. George noted, “I played fullback so I guess that’s just the nature of the position, to get your head hit.” When confronted with the question of if she views concussions differently today than as a student-athlete, Brittany expressed her indifference:

No, I think they happen. It’s an unfortunate aspect of life...sometimes you just get stuck in a situation and that happens to be the outcome.

Indifference was also evident in participants’ views toward concussion reporting. A majority of participants admitted that based on their knowledge of concussions, they had experienced concussions that they did not report to a healthcare provider; this was largely because they did not believe the injuries to be that severe. Their views were supported by the fact that they had experienced multiple concussive injuries, all of which presented very different symptoms. When asked why he did not report each of his concussions, Brandon explained:

I just didn’t feel like they (concussions) were that serious at the time. Obviously they (the unreported ones) weren’t as bad as that last one where I don’t remember anything. It was just I got a hit during practice or something like that.

Interestingly, support system indifference toward concussive injuries was a point of frustration for participants who experienced more difficult post-concussion recovery processes. Steven described the indifference of some of his teammates after the final concussion which led to his retirement:

I had a couple teammates that told me I quit on them. That was kind of concerning because the same people that told me I quit on them would go move on to a different college for their own reasons.

Steven also described challenges with his coaches, pointing out in one instance that he was told “you’re just a number to me.” Some of the support system indifference toward concussions likely stems from a lack of outward signs of injury. Elizabeth discussed this quandary, pointing out that a concussion is “not a broken leg where you can see it’s broken and watch it heal.” The absence of physical signs of injury left participants seemingly frustrated that they somehow had to justify their concussion symptoms. Grace elaborated, noting that “it’s tough when the people who are closest to me are like, ‘well you look fine. Are you faking it?’ Randy expressed similar sentiments, pointing out that “it felt like you were faking a concussion...you got questioned as a person.” Laura, discussing her first concussion experience when she was quite young, pointed out that she “got in trouble a lot” and that everyone, including her teachers, did not understand because they thought she was “making it up.” These support interactions, although frustrating, seemed to elicit a strong sense of empathy and compassion among the concussed participants. Grace, when asked whether she views concussions differently now than when she was a student-athlete replied:

I do, yeah...it’s something where I think a lot more about it because anyone you come across someday, whether it be kids or adults, [a concussion] is something on the inside. And just because you can’t see it doesn’t mean they aren’t fighting it.

Jonathon, in response to whether he had any additional information he wished to share about his concussion experience, spoke similarly:

I came in (to college) with a kid...he got 2 concussions in the first weeks of fall camp and was ridiculed so hard and got so much grief from other players and older players that he never came back. It is an institutional thing...it has to be

hammered in mind that it (concussions) is a serious thing and not something to be ashamed of or taken lightly.

Change in Perspective. While participants' views on concussions were largely characterized by indifference, there was also a sense that their perspectives changed over time. This change in severity perspective was due to several factors including participants' own concussion experiences. George described his experience with his last concussion:

My last, it was during practice. It was just a normal hit. I mean I played fullback so I guess that's just the nature of the position, to get your head hit. I just knew right away, the feeling after that. So after the really bad one, I just knew it wasn't worth it anymore. I knew I needed to give it up. I had an instant headache and some dizziness and didn't know what was going on.

Henry's perspective on concussions also changed due to his own concussion experiences, noting that "I didn't think they were that big of a deal when I came to school (college) and then after a couple of them, you learn it is a serious thing and you don't mess with them."

Changes in societal views of concussions were also noted as a contributing factor to changes in participants' personal views of concussion severity. Jonathon explained his thoughts based on his player and now coaching perspective:

In my experience, I think that it's gone from something to be ashamed of...football players are supposed to be tough. But (now) you can be brave and step forward and you don't need to go back in, you can take more time.

A majority of the participants emphasized how increased reporting in media, as well as a recent movie about concussions, have resulted in the idealization that concussions are a more serious injury than previously believed. Jonathon explained how the increased attention on concussions has made him reconsider the decisions he made as an athlete:

I went to that movie when it came out...and it makes you think back...you think about the helmet you wore. Maybe I should've worn a different helmet. You know, I should have done this or that and maybe I shouldn't have played football.

Participants' change in perspective regarding concussion severity also reflected an element of maturation and the ability to see the world from a broader viewpoint. Randy elaborated:

As a student-athlete at the time, it (concussions) was kind of a hoax. But then you see all the stuff going around the NFL, right, sports, it's kind of a scary thing because it jeopardizes a lot of peoples' careers. From the time that I was 18 to now, I would think I have a more positive, I don't want to sound embarrassing, but you have a smarter way of looking at concussions.

Shannon expressed similar sentiments, pointing that at the time she was an athlete, her perspective was that "I can tough through it" and "I can just keep going." Now that she is retired from college athletics and has a degree in physical education, Shannon noted that, "I see concussions in a bigger view" and that "it's like growing up and being a couple years older; I understand the issues with concussions a little bit better than I did then."

Jonathan discussed his change in severity perspective in the context of both his professional and personal life:

Once you move on from that (athletics) and can reflect and see different perspectives, maybe down the road when you have your own kids, you think, ‘okay maybe I don’t want them to play football. Or maybe I want them to wait until, you know, high school.’ I think more about the kids that I coach or if I have kids in the future; those are definitely thoughts now. If you can prevent someone else from something like that (concussions), I think you are better off for it.

Athletic Identity. A final point of emphasis that permeated the judgment of severity theme was conflict with participants’ identity as athletes. Participants discussed a “warrior mentality” and the need to “tough through” their injuries, especially in relation to maintaining their role on the team. From Steven’s standpoint,

When you’re in the middle of battling for a position, you don’t want to miss because otherwise it gives that other person all the opportunity to fill your starting roll...And also, when you’re playing, you want to play the game of football and don’t want that to hold you back.

He justified his views by noting that at the time, “there really wasn’t the research about what a concussion can do to you.”

For some participants, concussions were an accepted way of life in athletics. Benjamin mentioned how sometimes concussions are something that “football players might joke about,” while Grace recalled conversations with her husband’s teammates

who pointed out that “I’m pretty sure I suffered through a concussion after every game.”

When prompted about why she did not report all of her concussions, Elizabeth explained:

This sport is just one of those things where if you fall off and hit your head and you don’t feel the effects of any injury, you ignore it and act as if everything is okay. Then you won’t have to miss anything like school or practice or work or anything.

Immediate but Limited Long-Term Change in Quality of Life

The final aim of this study, related to participants’ post-concussion quality of life, revealed (1) primary theme: immediate impact but limited long-term change. The majority of interviewees described a wide range of quality of life decrements that were linked to immediate post-concussion symptoms. Physical function was inhibited as noted by Brittany, who described her inability to get out of bed:

I spent two full weeks at college lying in my bed with the lights off, no computer, spent the whole time pretty much sleeping.

When asked to describe her version of a concussion, Brittany replied “extreme boredom with a side of agonizing pain.” Participants also alluded to difficulties with academic demands. Grace described, “I could just not focus on anything. It was very mentally draining.” George’s symptoms were severe enough that he had to postpone his final exams, noting that “I was out of school for...I couldn’t do any of my finals. I took my finals in August. So I guess I was out for 3 months or so.” Steven, who ultimately retired due to his history of concussions, experienced significant cognitive deficits after his last concussion:

The first 8 months were tough. There was a lot of mental, a lot of me being foggy and forgetting things constantly, but you work on yourself. And for me, I just worked on my brain a lot, you know, did a lot of brain games. It's (quality of life) been 10 times better since my last concussion.

Emotional function was also an issue for Steven, who described how he “was just super emotional when I normally definitely wouldn't be,” and Lindsay who confirmed, “I was mad and frustrated. I would say probably more so because I couldn't play.”

Social relationships were also affected for some individuals. While the majority of participants reported that they did not lose any friendships over their concussions, a number of participants admitted to engaging in “reclusive” or “isolated” activities after their injuries. When asked how her social relationships were affected when she was still a student-athlete, Grace explained, “I had less than a desire to go out and hang out with friends and socialize, but it's not like I lost friends or family over it.” Shannon expressed a similar experience, “I kind of stayed close to myself.”

Interestingly, regardless of immediate post-concussion challenges or even long-term difficulties that some participants still attribute to their concussion experiences, the majority of participants did not perceive their current quality of life as being different from others around them. When asked how his life is currently affected by his history of concussions, Brandon stated, “I don't think it's affected currently. If it is, it would be something that I've already adapted to live with.” George explained that he experiences memory deficits from his concussions, however, he has adapted by writing lists:

I never was a list guy before this...my memory has I guess faded since then. I can't really remember stuff. I guess really my short-term memory. People will

tell me something and I will forget it by the end of the day. So I guess now I am more of a list guy. It's how I remember things.

Despite limitations with his memory, George still responded by saying, "my quality of life is great." Laura also stated that she still notices difficulties with her short term memory. When asked in what ways her life is currently affected by her history of concussions, she answered, "My short-term memory, definitely. I repeat myself a lot." Laura admitted that she gets frustrated more often because, "I feel like a lot of times people think I procrastinate a lot or am not responsible." She has adapted her way of living similarly to how George has, "I have to write lists a lot and make sure I keep myself more organized than I did before."

The majority of participants believe that they have made "a full recovery" from their concussions. Grace concurred that her "lifestyle is back to completely how it was prior, especially college." She is able to fulfill different areas of her life, such as being "able to go out and run and not be dizzy or anything." When asked how she would explain living day to day with a history of concussions, Lindsay replied, "I would say that it's no different from my roommate or anyone else."

CHAPTER 4

Discussion

The purpose of our study was to examine the lived experiences of retired collegiate athletes with a history of 1 or more concussions. Our results suggested that participants' concussion histories were characterized by an early onset, as well as discrepancies between sport participation and academic participation during the post-concussion symptomatic window. Judgements of concussion severity permeated participants' knowledge and perceptions of concussive injuries, and largely revealed a sense of indifference that in most cases changed over time. Athletic identity was also linked to participants' views on concussion severity. While their immediate post-concussion quality of life was decreased in various domains, the majority of participants did not feel that their current quality of life was any different from others around them.

Concussion Histories

Early Onset of Concussion

Our study revealed that the majority of participants experienced their first concussion in adolescence rather than during collegiate sport participation. Specifically, 4 participants experienced their first concussion between 10 and 14 years of age, 9 participants experienced their first concussion between 15 and 19 years of age, and 1 participant experienced their first concussion between 20 and 24 years of age. These findings are corroborated by Zhang et al's²⁸ study of concussion diagnosis trends in various age groups across the United States between 2007 and 2014. The most vulnerable group from this study was 15-19 year olds with a concussion incidence of

16.5/1000 patients. Patients aged 10-14 years were the second most vulnerable age group followed by patients aged 20-24 years.

Adolescents are at risk of experiencing prolonged effects from physical or psychological abnormalities due to the plasticity of their developing brains.²⁹ Essau et al³⁰ concluded that compared to childhood anxiety, anxiety experienced in adolescence may be associated with adverse psychological outcomes at age 30. Adolescents have also been shown to be more sensitive than children and adults to neuropsychological consequences of concussions.³¹ Rules and regulations during sporting events are changing in an effort to reduce the incidence of concussions. Clinicians should continue to investigate appropriate safety measures during sporting events, particularly adolescent sporting events, due to the potential threats that concussions can pose on long-term neurological development.

Discrepancies in Post-Concussion Sport and Academic Participation

In agreement with concussion management recommendations,²² the majority of participants in our study noted that they engaged in a period of physical rest following their concussive injuries. Conversely, findings from the study illuminated how a majority of the participants continued to engage in their academic responsibilities despite ongoing post-concussion symptoms. This is concerning given that returning to school activities prematurely may exacerbate symptoms, or that even when asymptomatic, patients may still possess neurocognitive deficits.^{32,33} Engagement in the post-concussion academic environment during the symptomatic window contradicts best practice guidelines in concussion management. While research on the optimal period of cognitive rest is limited, a practical approach would be to gradually return student-athletes to school in a

manner that does not increase symptomology.²² According to Kasamatsu et al,³⁴ only 44% of athletic trainers in secondary schools have an existing return-to-learn policy that involves cognitive rest, academic accommodations, and partial attendance procedures. The lack of adoption of such policies may lead to student-athletes returning to cognitive activities too soon, thus prolonging concussion recovery. In light of current concussion management recommendations and results from our study, further education of healthcare providers on student-athletes return-to-learn policies may be deemed necessary.

Knowledge and Perceptions of Concussions

Judgement of Severity

Results from our study revealed that judgements of concussion severity were extremely prevalent and often characterized by indifference. Participants' indifference was evident when they used "minor," "stupid," "not that big of a deal," or similar adjectives to describe their concussions. This finding is congruent with work by Register-Mihalik and colleagues,³⁵ who noted that high school athletes only moderately agreed that a concussion is a serious injury. These attitudes could be related to a lack of knowledge of concussion symptoms and etiology.^{35,36}

Our results also revealed that indifference appeared to be a significant factor in underreporting of concussions. Several participants pointed out that they were still likely to continue playing if they did not deem a hit or fall severe enough to cause a concussion. This is consistent with Register-Mihalik et al³⁵ who discovered tremendous underreporting of concussions, primarily due to the belief that the events were not significant enough to report. Kurowski and colleagues³⁷ work also supports this finding

as they reported that despite preseason concussion education, participants were still likely to continue playing with concussion symptoms and return to play prior to symptoms resolving. Few studies that address athletes' attitudes toward concussion exist.

Researchers should continue to investigate athletes' attitudes as a factor of interest when studying concussion knowledge to determine its association with concussion reporting.

Indifference of persons believed to be sources of social support was also significant to our study as it appeared to be frustrating for several of the concussed participants. Dahm and Ponsford's³⁸ work, which revealed that individuals who sustained an orthopedic injury expressed greater satisfaction with their social support than individuals with a traumatic brain injury, supports this finding. Our finding of social supporter indifference is also consistent with Kroshus et al³⁹ who noted that one quarter of their participants experienced pressure from teammates, coaches, parents, or fans to continue playing after a head impact. The largely subjective nature of concussion-related impairments could be a primary reason for social supporter indifference described by participants in our study. As noted by participants, concussions are not visible injuries that you can watch heal; they are a "hidden injuries" that require trust with symptom reporting.

Participants' perceptions of concussion severity also appeared to evolve over time in response to several factors, including personal experience with concussions, media coverage, societal views, and maturity. The change in perspective found in our study is supported in part by research investigating the success of the "Heads Up: Concussion in High School Sports" program developed by the Centers for Disease Control and Prevention. Sarmiento and colleagues⁴⁰ discovered that 38% of coaches made efforts in

changing training techniques and providing safety equipment in an attempt to reduce concussions amongst their athletes. This finding is significant and supports the idea that perspective on concussions is changing with increased awareness of the issue. However, additional research has shown that despite pre-season education or a solid understanding of what a concussion is and its potential long-term effects, athletes would continue to participate even if they were experiencing the effects of a concussive injury.^{37,41}

Judgements of concussion severity also appeared linked to athletic identity as several participants down-played the significance of concussions, noting that getting injured is part of being an athlete. Recent literature supports this finding through investigations of athletes' attitudes and motivations about concussions and concussion reporting. In a study exploring non-disclosure of sport-related concussions, Kerr et al⁴² discovered the two most common motivations were that the athletes "did not want to leave the game/practice" and "did not want to let the team down." This finding is significant as it demonstrates how despite concussion education, conflict with athletic identity remains a barrier to concussion reporting.

Despite the integration of concussion education programs, findings from literature and our study reveal that athletes continue to express feelings of indifference toward concussive injuries. A new focus of education programs should be on shifting the attitude of athletes from that of indifference to acceptance that concussions are more than just "hidden injuries." Continued studies investigating the long-term consequences of concussive injuries with results that are made readily available to relevant stakeholders including parents, coaches, and sport participants may help in attaining this goal. Finally, in an effort to alleviate pressure on athletes to continue competing despite post-

concussion symptoms, education of the general public as well as individuals within an athlete's social support system should become paramount.

Post-Concussion Quality of Life

Immediate but Limited Long-Term Change in Quality of Life

During the immediate post-concussion period, participants in our study consistently experienced a variety of impairments and functional limitations that negatively influenced 1 or more QoL domains. Headaches, suggested to be the most commonly reported symptom following a concussion, were prevalent in our study.⁴³

While immediate post-concussion headaches remain problematic, research suggests these headaches can persist throughout the first year post-injury.⁴⁴ Lingering headaches may be detrimental to one's quality of life from a number of perspectives including potential interference in cognitive function and engagement in social relationships.

Participants in our study reported cognitive and emotional symptoms such as difficulty focusing and feeling more emotional than usual; these too are common findings in concussed individuals.⁴⁵ Additionally, challenges with social relationships reported in our study were similar to those found in a group of retired professional hockey players with a history of concussions. Caron et al⁷ investigated the lived experiences of retired hockey players and discovered that these former athletes expressed feelings of isolation and misunderstanding following their concussions. Most of the dissatisfaction with QOL found in our study was likely due to the participants' inability to fulfill external and self-imposed expectations related to student-athlete life. Participants may have felt disconnected from their teammates and coaches due to the inability to participate in their sport.

Even though they experienced immediate post-concussion QOL deficits, participants in our study overwhelmingly noted very limited long-term decreases in their QOL. This finding is contradictory to the large base of research which indicates long-term effects of traumatic brain injuries (TBI) on quality of life. This could be explained by the fact that a significant portion of literature revealing post-TBI QOL deficits has focused on moderate to severe TBIs rather than mild TBIs. Compared to a normative population, adults with moderate-to-severe TBI have been found to score significantly lower on subscales of the SF-36 QOL assessment years after injury.⁴⁶ Findings suggest that individuals suffering from more severe forms of TBI experience deficits in HRQOL as a result of psychological distress which persists in the post-acute stage.²⁴ Interestingly, mTBI patients have also been shown to suffer decreased QOL. Siponkoski et al¹⁹ found that patients experiencing mTBIs were actually found to experience a lower HRQOL than patients experiencing severe TBIs. Siponkoski and colleagues' work differed from ours in that they employed a quantitative approach as well as a longer term follow-up period of 15 years. Additionally, both Stalnacke⁴⁷ and King and Kirkwilliam¹⁰ reported significantly decreased work-related quality of life in patients who had suffered a mTBI. King and Kirkwilliam¹⁰ specifically found that 92% of participants in their study were employed prior to mTBI yet only 50% were employed following injury, with few passing into retirement. While two individuals in our study were unemployed at the time of their interview, this was likely due to the fact that they were recent graduates who were still seeking first-time employment.

Participants in our study may have perceived their lives to be no different from others who do not have a history of concussions for a number of reasons. Our

participants were still able to maintain jobs or complete their academic requirements without substantial issue. Participants further noted how they are still able to exercise and perform daily tasks similarly to how they could prior to their concussions. Although the majority of participants expressed satisfaction with their QOL, some participants discussed difficulties performing certain tasks that are consistent with the literature. De Beaumont's⁴⁸ study of adults with a history of concussions and those without revealed that participants who sustained their last concussion nearly 30 years prior demonstrated cognitive and motor alterations which contributed to memory deficits and slower motor execution. These deficits occurred despite the former athletes' high education status and maintenance of an active lifestyle. The authors suggested that the individuals managed these deficits by using compensatory neural mechanisms that require the allocation of more resources to perform tasks. They reasoned that compensatory efficiency diminishes with age; this led to decreased memory and adverse motor outcomes after suffering the concussion decades earlier.⁴⁸ Participants in our study who expressed prolonged symptoms from their concussion explained how they have adapted their way of performing tasks to fit the demands of their life. The formation of lists was the most profound adaptation that our participants utilized to fit the needs of their work and personal lives. While participants expressed that they do not currently see their QOL of life as being different from others, engaging in these compensatory mechanisms may be detrimental to their QOL in years to come.

Limitations and Future Directions

The aim of our study was to examine the unique experiences of a particular population which resulted in a sample of 32 individuals, 14 of whom agreed to partake in

the study. Our participant pool was selected from a report generated by the university's injury tracking database, which relied on multiple certified athletic trainers documenting injuries. Failure of a certified athletic trainer to record all of their team's concussions in the database could have led to a smaller pool of eligible participants in our study.

Further, the findings of our study are limited to the experiences of former student-athletes of one NCAA Division I university and may not be applicable to the general population. Future research should seek to obtain a larger sample size from multiple geographical locations. A larger and more diverse sample would allow for inferences to be made if the shared perspectives are unique or representative of a broader population.

Future generations would benefit from longitudinal studies designed to examine changes in perceived health-related quality of life over time. In addition, while the majority of participants in our study adhered to what appeared to be appropriate periods of post-concussion physical rest, the transition back into the academic environment seemed problematic. Parameters for cognitive rest and the transition back into the academic environment remain obscure; therefore, further research should be conducted to make these parameters more uniform. More importantly, while graded return-to-learn protocols are available,^{49,50} it appears that these protocols may not reach individuals such as teachers and administrators who are intimately involved in the return-to-learn process. Therefore, a better method of communication should be established to ensure that the return-to-learn protocol has appropriate carryover between healthcare providers and teachers and administrators. Additionally, in light of the indifference toward concussions that was evident in our study, concussion education should focus on reforming attitudes and beliefs about concussions. Finally, our results suggested that participants

experienced immediate post-concussion quality of life deficits, but limited long-term effects. Future studies employing a mixed-methods approach should be performed in recently retired collegiate athletes to determine the accuracy of this finding. A mixed methods approach would produce quantitative and qualitative data and thus a more well-rounded view of how concussive injuries influence participants QOL.

Conclusion

The purpose of this qualitative study of retired collegiate athletes with a history of 1 or more concussions was to gain a better understanding of participants' concussion histories, their knowledge and perceptions of concussions, and their post-concussion quality of life. Several important findings emerged. As our study found, concussive injuries can occur at any age, however, adolescents remain a particularly vulnerable population. Furthermore, while concussion management guidelines have improved, it appears that the concept of cognitive rest remains somewhat ambiguous. Perceptions of and attitudes toward concussions, both from affected and unaffected individuals, seem to be improving but in many cases are still characterized by indifference. Although concussions can negatively influence multiple QoL domains, it seems as though the influence is largely constrained to the immediate post-concussion period. Long-term deficits in post-concussion QoL were not evident in this study, although several participants did allude to ways in which they have adapted their lives to accommodate what they believe to be limitations that resulted from their history of concussions.

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Appendix A
(Interview Guide)

**The Lived Experience of Retired College Athletes with a History of 1 or More
Concussions**

Demographics:

1. How old are you?
2. When did you finish your collegiate playing career?
 - What was the reason for your career retirement?
3. What is your current employment status?
4. What is your current relationship status? If married, do you have any kids?

General Interview:

1. In your own words, how would you define a concussion?
2. How many doctor-diagnosed concussions have you sustained in your life?
 - a. How old were you when you sustained your first concussion?
 - b. Tell me about this concussion.
 - c. Did this concussion cause you to miss any practices, competitions, school or school-related activities?
 - d. (repeat a-d for each doctor-diagnosed concussion)
3. Have you ever sustained a concussion that you did not report to a healthcare provider?
 - a. If no, have you ever sustained a traumatic force to your head or neck that resulted in the onset of a headache, feeling of being in a fog, loss of consciousness, loss of memory, or other similar condition?

- b. If yes, can you estimate how many? Tell me about why you did not report.
4. In your own words, how would you define quality of life?
5. Focus on the WORST (if multiple) concussion you sustained as a collegiate student-athlete. Explain the areas of your life that were affected by this concussion.
 - a. How did your concussions affect your moods or feelings?
 - b. How did your concussions affect you physically?
 - c. How were your social relationships affected?
 - d. How was your ability to engage in conscious mental activities affected?
 - e. How would you characterize the support you received from others while you were experiencing your concussion symptoms?
 - i. (If multiple concussions) What areas of your life were affected by your other concussions?
6. In what ways, if any, is your life currently affected by your history of concussions?
 - a. How are your moods and feelings affected?
 - b. How are you affected physically?
 - c. How are your social relationships affected?
 - d. How is your ability to engage in conscious mental activities affected?
 - e. How would you characterize the support you now receive from others relative to your concussion history?
7. Currently, how would you explain living day to day with a history of concussions?

8. Do you view concussions differently today than you did as a student athlete?
 - a. If yes, how? Why do you feel this way?
 - b. If no, why do you feel this way?
9. In light of our conversation, is there anything else you feel is important to share about your concussion experience(s)?