# The Lived Experiences of Retired Collegiate Athletes With a History of 1 or More Concussions

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**Context:** Concussions remain misunderstood, underreported, and undiagnosed. Although most concussion symptoms resolve within 2 weeks, some patients experience persistent symptoms that adversely affect physical, emotional, social, or cognitive functioning or a combination of these. Minimal evidence delineating the effect of concussions on recently retired collegiate athletes currently exists.

**Objective:** To examine the lived experiences of retired collegiate athletes with a history of 1 or more concussions to discern individual concussion histories, knowledge and perceptions of concussions, and postconcussion quality of life.

Design: Qualitative study.

Setting: Telephone interviews.

**Patients or Other Participants:** Former National Collegiate Athletic Association Division I athletes (n = 14) with a history of 1 or more concussions and retired from 1 to 5 years.

**Data Collection and Analysis:** Fourteen semistructured telephone interviews (8 men and 6 women) were audiotaped. 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 the findings.

**Results:** Participants sustained their first concussion during adolescence and often experienced difficulties transitioning back into the postconcussion 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 postconcussion period but did not feel their concussion history decreased their current quality of life.

**Conclusions:** Adolescent exposure to concussions is of concern due to the risk imposed on the developing brain and the potential for adverse outcomes later in life. Although a 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, investigators should continue to assess how a history of concussion affects quality of life in recently retired collegiate athletes.

*Key Words:* brain injuries, quality of life, concussion education

#### **Key Points**

- A majority of participants reported a history of multiple concussions, with the first occurring during adolescence.
- Participants often remained engaged in academic activities despite continuing postconcussion symptoms.
- Judgements of injury severity were evident in participants' knowledge and perceptions of concussions.
- · Concussions created short-term quality-of-life deficits but limited long-term effects.

pproximately 300 000 sport-related concussions (SRCs) are estimated to occur in the United States on an annual basis.1 At the collegiate level, statistics compiled from the 2009-2010 to 2013-2014 National Collegiate Athletic Association (NCAA) seasons showed that SRCs constituted about 6.2% of injuries and that nearly 1 of every 11 reported concussions was recurrent.<sup>2</sup> Research has also revealed that a significant number of concussions are undiagnosed.<sup>3</sup> In a study<sup>3</sup> of former athletes' recalled and clinically diagnosed concussions, 39.6% of the respondents believed that they had sustained at least 1 undiagnosed concussion. Robbins et al<sup>4</sup> found that athletes' understanding of concussion was not consistent with medical definitions, thus contributing to the underreporting of concussions to health care providers. After being provided with a definition of concussions, 73% of the athletes increased their number of self-recalled concussions.<sup>4</sup> Although research on athletes' perceptions of SRCs is limited, high school athletes demonstrated discrepancies between knowledge and their willingness to report.<sup>5</sup> Despite a solid understanding of concussions and concussion symptoms, Anderson et al<sup>5</sup> discovered that only 54% of their participants would willingly report a symptom, and 53% of the respondents expressed that they would continue to play with 1 or more symptoms.

Most concussion symptoms resolve in 1 or 2 weeks.<sup>1</sup> However, postconcussion symptoms may continue for months and even years after the initial injury.<sup>6</sup> From 40% to 80% of concussed individuals developed persistent postconcussion symptoms, and about 10% to 15% still experienced symptoms after 1 year.<sup>6</sup> Unfortunately, persistent postconcussion symptoms have been shown to negatively influence patients' quality of life in myriad ways.<sup>6–12</sup>

Physical fatigue is one of the most common postconcussion symptoms and causes the greatest disruption in daily activities.9 Using the Rivermead Post-Concussion Symptoms Questionnaire, Ahman et al<sup>9</sup> observed that 53.4% of their participants reported fatigue related to mild traumatic brain injury (mTBI) 3 years after the initial injury. Participants also expressed feelings of identity loss, difficulty controlling emotions, and loss of connection with their body.<sup>9</sup> Fatigue from posttraumatic brain injury (TBI), along with difficulty dealing with daily frustrations, life events, and interpersonal stress, has also been reported to be positively associated with elevated levels of chronic situational stress in community-dwelling adults.<sup>13</sup> Cognitive limitations in the form of impaired memory, difficulty concentrating, and feelings of mental fogginess have also been reported by individuals who experience persistent postconcussion symptoms.<sup>8,9</sup> Other authors<sup>14,15</sup> have noted that concussed individuals experienced less satisfaction with life, friendships, and relationships with peers, along with various levels of emotional dysfunction, than nonconcussed individuals. Concussion has been reported to nearly double the experience of depressive symptoms.<sup>12,15</sup> Vargas et al<sup>12</sup> demonstrated elevated depression scores in 11% of participants at baseline and in 23% postconcussion.

The increased incidence of retired professional athletes reporting emotional and cognitive deficits from their years of sport participation has drawn increasing attention to the long-lasting effects of concussions.<sup>7,11,16</sup> However, limitations in current concussion-related research present several challenges. First, much of the TBI-related quality-of-life research did not clearly differentiate concussions from mild, moderate, or severe TBIs. Furthermore, although the volume of concussion-based research has grown, little evidence illuminates patients' perceptions of concussive injuries, including injury severity. This is problematic considering that, regardless of the initial postinjury symptom severity, patients' perceptions of head injury contribute to the experience of persistent postconcussion symptoms.<sup>17</sup> Finally, whereas some studies indicated that quality-of-life deficits may occur at lower levels of athletic participation,<sup>18</sup> sparse evidence describes the sustained effects of concussions among younger athletes, including recently retired collegiate athletes. This is concerning given the multifaceted nature of quality of life,<sup>19</sup> the number of participants competing in collegiate athletics, and the fact that fewer than 12% of collegiate players eventually pursue careers in professional athletics.<sup>20</sup> In many ways, retired collegiate athletes represent a forgotten population.

Given these limitations, the purpose of our investigation was to examine the lived experiences 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, knowledge and perceptions of concussive injuries, and postconcussion quality of life.

# METHODS

### **Participants**

Individuals who sustained at least 1 SRC during collegiate sport activity at a single NCAA Division I institution and were retired from collegiate athletics for at least 1 year but less than 5 years participated in the study. We chose the 1- to 5-year time frame to elicit more accurate

recall and capture participants' early transition to work and family life during a period in which they may still have experienced postconcussion quality-of-life deficits. Volunteers were excluded if they were no longer listed on an athletic roster at the host institution but were continuing to pursue their athletic career professionally or in college at a different location. Thirty-two athletes identified through the institutions' sports medicine electronic injury database met the inclusion criteria; 14 athletes (8 men, 6 women) agreed to participate in the study. The mean age of the participants was  $23.4 \pm 1.6$  years.

### Procedures

After approval from the institutional review board, potential recruits were contacted via telephone and provided with a brief overview of the study. Individuals who agreed to participate were e-mailed a consent letter and an informational 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 the follow-up, audiorecorded telephone interview was then identified.

# **Data Collection**

To gain valuable insight into the lived experiences of retired collegiate athletes with a history of concussive injury, we took a semistructured approach to the interview. Semistructured interviews are based on flexible guides, which allow for a loose structure of open-ended questions and exploration of the interviewees' attitudes and experiences. Furthermore, semistructured interviews have been  $used^{21-25}$  to study patients with TBI ranging from adolescents to military personnel and represent an accepted and accurate method of evaluating a phenomenon being studied.

The interview questions were designed to obtain responses that would illuminate participants' individual concussion histories, their knowledge and perceptions of concussive injuries, and their postconcussion quality of life. Based on these purposes, we developed an initial interview guide (Appendix). To improve clarity and ensure that questions on the guide would foster responses to support the purposes of the study, 2 pilot interviews were conducted. These interviews were conducted in similar fashion as the participant interviews and featured 1 male and 1 female former collegiate athlete. Based on information gathered during the pilot interviews, we convened and made final revisions to the interview guide.

Each audiorecorded interview was conducted by the same interviewer to ensure consistency in the questions and probes.<sup>26</sup> As the interview progressed, the interviewer asked follow-up questions to clarify the participant's responses. On completion of the interview, the interviewer provided the opportunity for the participant to elaborate on any responses or add more details of his or her experiences that were not addressed in the interview guide.

# **Data Analysis**

All interviews were audiorecorded and transcribed verbatim by the interviewer. Transcripts were coded to

#### Table. Participant Demographic Data

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

allow for anonymous responses. A research team of 3 athletic trainers (ATs) with 34 combined years of professional experience then analyzed each transcript through a consensual qualitative review process. *Consensual qualitative review* incorporates elements from multiple qualitative analysis approaches and emphasizes the researchers coming to a consensus on words that reflect the data. This approach treats participants as experts on the phenomenon being studied by allowing them to explore their experiences.<sup>27</sup>

Initially, each investigator read each transcript in its entirety to obtain a broad perspective of the participant's responses. During subsequent individual reviews, questions linked to the participant's concussion history, knowledge and perceptions of concussive injuries, and postconcussion quality of life within each transcribed interview were evaluated for key words, common themes, and patterns of meaning. Once the individual reviews were complete, we met as a team to discuss the findings and come to consensus on common themes. The themes were subsequently presented to participants during follow-up telephone calls to verify their accuracy and serve as a validity check.

### RESULTS

Participants' retirement from collegiate athletics ranged from 1 to 5 years, with an average of  $1.93 \pm 0.92$  years. In addition, participants averaged  $2.68 \pm 1.69$  years since their last physician-diagnosed concussion. The Table contains participants' demographic data; pseudonyms were used to protect their identities.

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

Relative to participants' concussion histories, 2 themes emerged: (1) early onset and (2) discrepancies in postconcussion 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 sports and academics during their postconcussion symptomatic window.

# Early Onset of Concussions

Most participants experienced their first concussion during preadolescence or adolescence rather than during collegiate sports. The earliest concussion reported by a participant occurred at age 10 years; the majority occurred between ages 15 and 17 years. Laura, who was 10 at the time of her first concussion, recalled falling off her horse and being kicked in the face. She also sustained physiciandiagnosed concussions resulting from horseback riding when she was 15 and 16 years old but pointed out that she was wearing a helmet during all 3 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, stating 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 of high school. Both of these injuries resulted in Randy missing school, practices, and games for brief periods of time.

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 hospital stay of 1½ weeks, occurred when she was 16. Eventually dismissed from her collegiate 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 how her life was 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 Postconcussion Sport and Academic Engagement

Throughout the interviews, participants highlighted significant discrepancies in how they engaged with their postconcussion sport and academic requirements. Although most individuals described being removed from all sportrelated activities, 10 of 14 participants remained engaged in academic activities during 1 or more of their concussion recoveries despite continuing symptoms. Grace noted that even though she missed 1 to 11/2 weeks of sport-related activities for each of her first 2 concussions, she only recalled missing 1 day of class. 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 postconcussion symptoms:

We got a couple of different opinions. I missed like 3 days of class, and then 1 physician told me that it would probably be smart of me to drop out for the semester and just 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 3 days total of class and then just toughed it out after that.

Joseph also talked about the differences in how he engaged in his postconcussion sport and academic requirements. For both his third and fourth concussions, sustained during college approximately 1 year apart, Joseph recalled missing 1 to  $1\frac{1}{2}$  weeks 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 (fourth) concussion, he said:

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 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 from sport and academics after both of her concussions, discussed the difficulty of trying to maintain her academic responsibilities without further exacerbating her postconcussion symptoms. Once she returned 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." She cited light and sound as the most troublesome aspects of the classroom environment: "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 postconcussion symptoms, the majority of participants' concussion histories seemed to be characterized by difficulties reintegrating into the academic environment.

### Judgment of Concussion Severity

Relative to the second aim of the study, participants' knowledge and perceptions of concussions were captured within 1 emergent theme: judgment of injury severity. Further analysis 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 downplayed 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 such as, "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 explained, "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 whether she currently viewed concussions differently than she did 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. Most participants admitted that, based on their knowledge of concussion, they had experienced concussions they did not report to a health care 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 commented:

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 postconcussion recovery processes. Steven portrayed the indifference of some of his teammates after the concussion that 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 cited challenges with his coaches, pointing out in 1 instance that he was told "you're just a number to me." Some of the support-system indifference toward concussions likely stemmed from a lack of outward signs of injury. Elizabeth discussed this quandary, observing 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 that "it's tough when the people who are closest to me are like, 'Well, you look fine. Are you faking it?'" Randy conveyed similar sentiments: "it felt like you were faking a concussion... you got questioned as a person." Laura, discussing her first concussion when she was quite young, remarked 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 viewed concussions differently 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.

When asked if he had any additional information he wished to share about his concussion experience, Jonathon 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 Over Time.** Although participants' views on concussions were largely characterized by indifference, their perspectives changed over time. This change in perspective was due to several factors, including the participants' own concussion experiences. George described 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 experiences: "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 a contributing factor to changes in the participants' personal views of concussion severity. Jonathon explained his thoughts based on his playing 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 the media and a recent movie about concussions resulted in the realization that concussions are a more serious injury than previously believed. Jonathon illustrated how the increased attention on concussions prompted him to 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' changes 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 [concussion] was kind of a hoax. But then you see all the stuff going around the NFL [National Football League], right, sports, it's kind of scary 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, indicating that when she was an athlete, her perspective was "I can tough through it" and "I can just keep going." Now that she was retired from collegiate athletics and had a degree in physical education, she commented 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."

Jonathon discussed his changed 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, "OK 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 [concussion], 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' identities as athletes. They 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. Grace recalled conversations with her husband's teammate who observed, "I'm pretty sure I suffered through a concussion after every game." Benjamin, when asked if he viewed concussions differently than he did as a student-athlete, remarked:

It's a little different because there is kind of an aura with football and concussions...we are being educated a lot more about them, but we still try to make light of them. You know that we know it's a serious thing, but, yeah.

Brandon also acknowledged the seriousness of concussions but stated, "I understand how those guys would not want to say anything and just play next week's game. From an athlete's standpoint, it's pretty hard to make that call."

# Immediate but Limited Long-Term Change in Quality of Life

The final aim of this study, to assess participants' postconcussion quality of life, revealed 1 primary theme: immediate effect but limited long-term change. Most interviewees described a wide range of quality-of-life deficits that were linked to their immediate postconcussion symptoms. Brittany described inhibited physical function and an inability to get out of bed: "I spent 2 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 said, "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 examinations, noting that "I was out of school...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 injury:

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 a concern for Steven, who "was just super emotional when I normally definitely wouldn't be." Lindsay concurred: "I was mad and frustrated. I would say probably more so because I couldn't play."

Social relationships were also affected for some individuals. Although few participants reported losing friendships as a result of their concussions, a number of them admitted to engaging in "reclusive" or "isolated" activities after their injuries. When asked how her social relationships were affected when she was 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 had a similar experience, "I kind of stayed close to myself."

Interestingly, regardless of the immediate postconcussion challenges or even long-term difficulties that some participants still attributed to their concussions, the majority of participants did not perceive their current quality of life as being different from that of others around them. When asked how his life was 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 experienced memory deficits from his concussions but had 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 still notices difficulties with her short-term memory. When asked how her life was currently affected by her history of concussions, she answered, "My short-term memory, definitely. I repeat myself a lot." Laura conceded that she becomes frustrated more often because, "I feel like a lot of times people think I procrastinate a lot or am not responsible." Similar to George, she has adapted her way of living: "I have to write lists a lot and make sure I keep myself more organized than I did before."

Most participants believed they had made "a full recovery" from their concussions. Grace concurred that her "lifestyle is back to completely how it was prior, especially college." She was 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."

### 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 postconcussion symptomatic window. Judgments 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. Although their immediate postconcussion quality of life was decreased in various domains, the majority of participants did not feel that their current quality of life differed from that of others around them.

### Early Onset of Concussion

Most participants experienced their first concussion during adolescence rather than during collegiate sport participation. Specifically, 4 participants sustained their first concussion between ages 10 and 14, 9 participants experienced their first concussion between ages 15 and 19, and 1 participant experienced the first concussion between ages 20 and 24. These findings corroborate those of Zhang et al<sup>28</sup> in a study of concussion diagnosis trends among US age groups between 2007 and 2014. The most vulnerable group was aged 15 to 19, with a concussion incidence of 16.5/1000 patients. Patients aged 10 to 14 were the second most vulnerable age group, followed by those aged 20 to 24.

After concussion, adolescents are at risk for prolonged effects from physical or psychological abnormalities due to the plasticity of their developing brains.<sup>29</sup> Essau et al<sup>30</sup> concluded that compared with childhood anxiety, anxiety experienced during adolescence may be associated with adverse psychological outcomes at age 30. Adolescents have also been shown to be more sensitive to the neuropsychological consequences of concussions than children and adults.<sup>31</sup> Sporting rules and regulations are changing in an effort to reduce the incidence of concussions. Clinicians should continue to investigate appropriate safety measures during sporting events, particularly those involving adolescents, due to the potential threats that concussions can pose to long-term neurologic development.

### Discrepancies in Postconcussion Sport and Academic Participation

In agreement with concussion-management recommendations,<sup>22</sup> the majority of participants in our study noted that they engaged in a period of physical rest after their injuries. Conversely, most individuals continued to engage in their academic responsibilities despite ongoing postconcussion symptoms. This is concerning given that returning to school activities prematurely may exacerbate symptoms and that even when asymptomatic, patients may still have neurocognitive deficits.<sup>32,33</sup> Engagement in the academic environment during the symptomatic postconcussion window contradicts best-practice guidelines for concussion management. Although 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 symptoms.<sup>22</sup> According to Kasamatsu et al,<sup>34</sup> only 44% of ATs in secondary schools had an existing return-to-learn policy that involved cognitive rest, academic accommodations, and limited attendance. The lack of adoption of such policies may lead to student-athletes returning to cognitive activities too soon, thereby prolonging concussion recovery. In light of current concussion-management recommendations and our results,

further education of health care providers on student-athlete return-to-learn policies may be necessary.

### Judgment of Concussion Severity

Judgments of concussion severity were 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 consistent with the work by Register-Mihalik et al,<sup>35</sup> who noted that high school athletes only moderately agreed that a concussion was a serious injury. These attitudes could be related to a lack of knowledge of concussion causes and symptoms.<sup>35,36</sup>

Our results also revealed that indifference appeared to be a significant factor in the underreporting of concussions. Several participants said they were likely to continue playing if they did not deem a hit or fall severe enough to cause a concussion. This perspective agrees with the findings of Register-Mihalik et al,<sup>35</sup> who also discovered widespread underreporting of concussions, primarily due to the belief that the events were not significant enough to report. The work of Kurowski et al<sup>37</sup> was also supportive: despite preseason concussion education, participants were likely to continue playing with concussion symptoms or to return to play before symptoms resolved. Few authors have addressed athletes' attitudes toward concussion. Researchers should continue to investigate athletes' attitudes when studying concussion knowledge to determine their association with concussion reporting.

The indifference of persons believed to be sources of social support was also significant, as it appeared to be frustrating for several participants. Dahm and Ponsford<sup>38</sup> observed that individuals who sustained orthopaedic injuries expressed greater satisfaction with their social support than did individuals with a traumatic brain injury. Our finding of social-supporter indifference was also consistent with that of Kroshus et al,<sup>39</sup> 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 the social-supporter indifference described by our participants, who commented that concussions are "not visible injuries that you can watch heal"; they are "hidden injuries" that require trust in 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 we found was similar in part to research on the "Heads Up: Concussion in High School Sports" program developed by the Centers for Disease Control and Prevention. Sarmiento et al<sup>40</sup> discovered that 38% of coaches made efforts to change training techniques and provide safety equipment to try to reduce the incidence of concussions among their athletes. This finding is significant and reinforces the idea that perspectives on concussions change with increased awareness of the injury. However, additional research<sup>37,41</sup> has shown that despite preseason education or a solid understanding of concussion and its potential long-term effects, athletes would continue to

participate even if they were experiencing the effects of a concussive injury.

Judgments of concussion severity also appeared to be linked to athletic identity, as several participants downplayed the significance of concussions, noting that being injured is part of being an athlete. Recent investigations of athletes' attitudes and motivations about concussions and concussion reporting support this finding. When they explored the nondisclosure of sport-related concussions, Kerr et al<sup>42</sup> learned that the 2 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 that despite concussion education, conflict with athletic identity remains a barrier to concussion reporting.

Despite the implementation of concussion-education programs, results from the literature and our study revealed that athletes continued to express feelings of indifference toward concussive injuries. A new focus of education programs should be on shifting athletes' attitudes from indifference to acceptance that concussions are more than just "hidden injuries." Continued studies of the long-term consequences of concussive injuries that are 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 postconcussion symptoms, educating the general public as well as individuals within an athlete's social-support system should be paramount.

# Immediate but Limited Long-Term Change in Quality of Life

During the immediate postconcussion period, participants in our study consistently experienced a variety of impairments and functional limitations that negatively influenced 1 or more quality-of-life domains. Headaches, suggested to be the most commonly reported symptom after a concussion, were prevalent in our study.<sup>43</sup> Although immediate postconcussion headaches remain problematic, research<sup>44</sup> suggested that these headaches can persist throughout the first year postinjury. Lingering headaches may be detrimental to quality of life from a number of perspectives, including potential interference with 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 among concussed individuals.<sup>45</sup> Additionally, the challenges to social relationships we reported were similar to those in a group of retired professional hockey players with a history of concussions. Caron et al<sup>7</sup> investigated the lived experiences of retired hockey players and discovered that they expressed feelings of isolation and misunderstanding after their concussions. Most of the dissatisfaction with quality of life experienced by our respondents was likely due to their inability to fulfill both external and self-imposed expectations related to student-athlete life. They may have felt disconnected from their teammates and coaches due to their inability to participate in their sport.

Even though they experienced immediate postconcussion quality-of-life deficits, participants in our study overwhelmingly noted very limited long-term decreases in their quality of

life. This finding is contradictory to the large base of research, which indicated long-term effects of TBI on quality of life. This could be explained by the fact that a significant portion of the literature revealing post-TBI quality-of-life deficits has focused on moderate to severe TBIs rather than mTBIs. Compared with a normative population, adults with moderate to severe TBI scored lower on subscales of the 36-item Short Form Survey (SF-36) quality-of-life assessment years after injury.<sup>46</sup> Individuals suffering from more severe forms of TBI experienced deficits in health-related quality of life as a result of psychological distress, which persisted in the postacute stage.<sup>24</sup> Interestingly, patients with mTBI also suffered decreased quality of life. Siponkoski et al<sup>19</sup> found that patients with mTBIs actually had a lower health-related quality of life than patients with severe TBIs. The work of Siponkoski and colleagues<sup>19</sup> differed from ours in that they used a quantitative approach and a longer-term follow-up period of 15 years. Additionally, both Stalnacke<sup>47</sup> and King and Kirwilliam<sup>10</sup> reported decreased work-related quality of life in patients who had sustained mTBIs. King and Kirwilliam<sup>10</sup> showed that 92% of participants in their study were employed before their mTBI, yet only 50% were employed after the injury; few retired during this time. Although 2 individuals in our study were unemployed at the time of their interviews, this was likely because 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 those of people without a history of concussions for a number of reasons. Our participants were able to maintain jobs or complete their academic requirements without substantial difficulty. They further noted that they were still able to exercise and perform daily tasks much as they did before their concussions. Although the majority of participants expressed satisfaction with their quality of life, some discussed challenges performing certain tasks that are consistent with the literature. The De Beaumont et al<sup>48</sup> 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 that 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 required the allocation of more resources to perform tasks. They reasoned that compensatory efficiency diminished with age, leading to decreased memory and adverse motor outcomes after the concussion decades earlier.48 Participants in our study who described prolonged symptoms from their concussion explained how they had adapted their way of performing tasks to fit the demands of their lives. Drafting lists was the most common adaptation that our participants used to address the needs of their work and personal lives. Although they did not currently see their quality of life as being different from that of others, engaging in these compensatory mechanisms may be detrimental to their quality of life in years to come.

### **Limitations and Future Directions**

The aim of our study was to examine the lived experiences of retired collegiate athletes with a history of

1 or more concussions. Of the 32 individuals identified by the university's injury-tracking database, 14 agreed to the study. The database relied on multiple ATs to document injuries. Failure of an AT to record all of his or her team's concussions in the database could have led to a smaller pool of eligible participants for our study. Furthermore, the findings of our study are limited to the experiences of former student-athletes of a single NCAA Division I university and may not be applicable to the general population. Future researchers should seek larger samples from multiple geographic locations. Larger and more diverse samples would allow inferences to be made about whether the shared perspectives are unique or represent 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, whereas most of our participants adhered to what appeared to be appropriate periods of postconcussion physical rest, the transition back into the academic environment seemed problematic. Guidelines for cognitive rest and the transition back into the academic environment remain obscure; therefore, further investigation should be conducted to make these recommendations more uniform. More importantly, although graded return-to-learn protocols are available,<sup>49,50</sup> 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 health care providers and teachers and administrators. Additionally, in light of the indifference toward concussions that was evident in our study, education should focus on reforming attitudes and beliefs about concussions. Finally, our results suggested that participants experienced immediate postconcussion quality-of-life deficits but limited long-term effects. Future studies using a mixed-methods approach should be performed on 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 quality of life.

### CONCLUSIONS

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 their concussion histories, knowledge and perceptions of concussions, and postconcussion quality of life. Several important findings emerged. Although concussive injuries can occur at any age, adolescents remain a particularly vulnerable population. Furthermore, concussion-management guidelines have improved, yet the concept of cognitive rest remains somewhat ambiguous. Perceptions of and attitudes toward concussion, both from affected and unaffected individuals, seem to be improving but in many cases are still characterized by indifference. Concussions can negatively influence multiple quality-of-life domains; however, this influence is largely restricted to the immediate postconcussion period. Long-term deficits in postconcussion quality of life were not evident in this study, although several

participants did allude to adaptations to accommodate what they believed to be limitations that resulted from their concussions.

### Appendix. Interview Guide.<sup>a</sup>

#### **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 children?

#### **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?
- 3. Have you ever sustained a concussion that you did not report to a health care 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?
  - f. (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?

<sup>a</sup> The guide is reproduced in its original form.

- 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)?

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