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Adolescent Perspectives and Comfort Levels Communicating with Systems of Care Following Concussion

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ADOLESCENT PERSPECTIVES AND COMFORT LEVELS COMMUNICATING WITH SYSTEMS OF CARE FOLLOWING CONCUSSION

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ABSTRACT

Objective: To examine 1) adolescent communication comfort levels, 2) barriers to communication with systems of care (e.g., family, medical, school, athletic, friends), and 3) associations between communication comfort and demographic, injury characteristics, medical history, emotional well-being, and recovery outcomes following a concussion.

Methods: Participants were 73 adolescents (mean age = 14 years old, 61.6% male, 67.1% White) recruited from sports medicine clinics. Communication comfort level ratings with individuals in each system of care were assessed with possible responses including: *not at all*, *a little*, *somewhat*, and *very*. To evaluate barriers to communication, participants provided reasons for comfort ratings less than *very*. The reasons were coded into key themes through qualitative content analysis. Demographic, injury characteristics, medical history, emotional well-being, and recovery outcomes were collected to evaluate the association between communication comfort levels and those factors.

Results: The majority of participants reported feeling *very comfortable* communicating about their concussions with family and medical systems of care while approximately two thirds were *very comfortable* with the athletic system. Less than half were *very comfortable* with the school system of care. Seventy-eight percent were *somewhat* or *very comfortable* communicating with their friends. Common themes that emerged as communication barriers across systems of care included poor relationship quality/unfamiliarity, perception that others would not understand or take their injury seriously, a desire to maintain privacy, and

concern of being viewed or treated negatively. Only school level was significantly related to communication comfort for multiple systems of care as middle school students reported less comfort communicating with physicians and athletic trainers. When considering effect sizes, history of pre-injury academic accommodations was related to communication comfort with medical, friends, and athletic systems of care.

Conclusions: Adolescents were *very comfortable* talking about issues related to their concussion with medical and family systems of care followed by the athletic system of care. However, hesitancy in talking with friends and school personnel was apparent. There is a need to improve communication between adolescents with concussions, school personnel, and their friends as failure to disclose concussion symptoms may hinder recovery. Additionally, feeling heard and supported can positively impact psychological functioning during concussion recovery.

Keywords: Concussion, patient perspective, rehabilitation, medical communication, disease management, return-to-learn

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REVIEW OF BACKGROUND LITERATURE

Concussion as a Public Health Problem

A concussion, or mild traumatic brain injury (mTBI), is a condition following biomechanical forces that cause both the head and brain to move rapidly back and forth, disrupting normal brain functioning and producing clinical symptoms (Gilchrist, Thomas, Wald, & Langlois, 2007; McCrory et al., 2013). A complex neurometabolic cascade results from the forces to the brain in which there is excessive neurotransmitter release, ionic fluctuations within neurons, altered glucose metabolism, and reduced cerebral blood flow (Barkhoudarian, Hovda, & Giza, 2016; Giza & Hovda, 2014). As neurons go into overdrive to restore cellular homeostasis, there is a metabolic energy crisis (Giza & Hovda, 2014). The disruptions in brain functioning that can occur following a concussion, including loss of consciousness, posttraumatic amnesia, altered mental status, neurologic deficits, and myriad of other symptoms are believed to be directly linked to the pathophysiology of concussion (Barkhoudarian et al., 2016; Giza & Hovda, 2014). Only a portion (8% to 19%) of individuals who sustain concussions experience a loss of consciousness (Collins et al., 2003; Schultz et al., 2004). A loss of consciousness longer than 30 minutes indicates a moderate to severe traumatic brain injury and thus would not be considered a mTBI (Kay et al., 1993). Though TBIs occur in individuals of all ages, 70% of all sports- and recreation-related TBIs resulting in emergency department visits from 2001-2012 were among children and adolescents (Coronado et al., 2015). Coronado et al. (2015) also reported significant increases from 2001 to 2012 in the rates of individuals seeking care at emergency

departments for a sports- and recreation-related TBI regardless of gender and age. The largest increases were observed in those 10 to 19 years old (Coronado et al., 2015).

More recent estimates of sports- and recreation-related injuries indicate that 1.1 to 1.9 million concussions occur every year in those ages 18 and under (Bryan, Rowhani-Rahbar, Comstock, & Rivara, 2016). Overall incidence of concussion is likely even greater as there are numerous non-sports-related causes that account for up to 30% of all concussions in youth (Haarbauer-Krupa et al., 2018). Primary causes of injuries that are non-sports-related include falls (with the highest incidence in children under age 4), being struck by an object, and motor vehicle crashes (Haarbauer-Krupa et al., 2018; Langlois, Rultland-Brown, & Wald, 2006). Given the increase in prevalence among youth as well as conflicting findings regarding the long-term effects of concussions, identification and management of concussions represent a significant public health problem (Coronado et al., 2015; Lerner & Giza, 2017). Two of the greatest challenges in concussion management are the necessity for individualized treatment based on presenting symptoms and lack of definitive answers for each child's recovery trajectory (Gioia, 2016; Master, Gioia, Leddy, & Grady, 2012; Olympia, Ritter, Brady, & Bramley, 2016).

Concussion Symptoms and Recovery Course

Concussion symptoms are generally categorized into four domains: cognitive (e.g., difficulty concentrating, mental fogginess, slowed response times), physical or somatic (e.g., headache, dizziness, fatigue), emotional (e.g., irritability, sadness, anxiousness), and sleep-related (e.g., drowsiness, difficulty falling asleep; Broglio & Puetz, 2008; Dougan, Horswill, & Geffen, 2014). Some of these symptoms may occur immediately after an

impact, but others may have a delayed-onset and thus some concussions are not detected until hours or even days later (McCrory et al., 2017). Additionally, balance difficulties (e.g., gait unsteadiness), sensitivity to noise, and visual deficits (e.g., trouble focusing the eyes, eye tracking) are experienced by many individuals with a concussion (McCrory et al., 2017). Though these signs and symptoms can be severe and debilitating during the acute phase of injury (i.e., first 72 hours), macroscopic structural brain abnormalities and neuronal damage are rarely detected by conventional structural neuroimaging such as computed tomography and magnetic resonance imaging (Broglio et al., 2018). However, researchers have used more sensitive measures, such as Diffuse Tensor Imaging (DTI), to detect microscopic alterations in the brain's white matter tracts (i.e., diffuse axonal injuries) in some individuals following mTBI (Giza & Hovda, 2014; Shenton et al., 2012). Diffuse axonal injuries occur when forces on the head cause the long nerve fibers in the brain to stretch and tear as the brain shifts and rotates in the skull (Lerner & Giza, 2017). DTI is not yet a widely used clinical tool, but determining the associations between diffuse axonal injury, concussion symptoms, and recovery outcomes is a constantly expanding area within mTBI research.

Regarding concussion recovery, a period of 7 to 10 days for symptom resolution has historically been cited (McCrory et al., 2005; McCrory et al., 2009). However, that time frame is based on group-level research in adults, primarily adult athletes, and then generalized to children and adolescents. Realizing the numerous physiological, developmental, and behavioral differences between adults and children, publications on concussions in youth have increased exponentially over the last two decades (Halstead, Walter, & Moffatt, 2018). From this body of evidence, it is now widely accepted that 70 to 90% of

youth will recover within four weeks from injury while the other 10 to 30% experience symptoms past four weeks (Barlow, Crawford, Brooks, Turley, & Mikrogianakis, 2015; Davis et al., 2017; McClincy, Lovell, Pardini, Collins, & Spore, 2006; McCrea, Hammeke, Olsen, Leo, & Guskiewicz, 2004; McCrory et al., 2017; Zemek et al., 2016). Based on the consensus statement from the 5th International Conference on Concussion in Sport, "clinical recovery is defined functionally as a return to normal activities, including, school, work and sport, after injury. Operationally, it encompasses a resolution of postconcussion related symptoms and a return to clinically normal balance and cognitive functioning" (McCrory et al., pp. 5-6). Youth who continue to have symptoms after a month, known as *persistent postconcussion symptoms*, should be referred to a healthcare professional who is trained in the management of concussion (McCrory et al., 2017). Though the minority, the 10 to 30% of children and adolescents who experience persistent postconcussion symptoms often report greater obstacles in returning to activities, more academic difficulties, and overall lower quality of life (Valovich McLeod, Bay, Lam, & Snyder Valier, 2018; Wilmoth et al., 2019). Thus, there is a significant body of literature on preinjury, injury-related, and postinjury factors that may influence concussion recovery to better predict who is at risk for persistent postconcussion symptoms.

In their systematic review, Iverson et al. (2017) described factors potentially related to clinical recovery from sports- and recreation-related concussion. They concluded that "in general, the literature is complex, mixed and difficult to interpret definitively" due to the variable quality, methodologies, and length of follow-up of the studies reviewed (Iverson et al., 2017, pp. 945). The most pronounced and unvarying factor predicting longer recovery was greater severity of acute (first 72 hours after of injury) and subacute (72 hours

to 3 months) symptoms (Broglio et al., 2018; Iverson et al., 2017). Additionally, they determined preinjury history of mental health problems, history of multiple previous concussions, development of headaches during the subacute concussion period, and presence of depressive symptoms after injury to be risk factors for symptoms persisting beyond the first month following injury (Colvin et al., 2009; Corwin et al., 2014; Eisenberg, Andrea, Meehan, & Mannix, 2013; Iverson et al., 2017; McCrea et al., 2013; Meehan, Mannix, Stracciolini, Elbin, & Collins, 2013; Meehan, O'Brien, Geminiani, & Mannix, 2016; Zemek et al., 2016). Though an inconsistent result, many studies have found an association between age and recovery time, with teenagers being particularly vulnerable to persistent symptoms and longer recovery than younger children (Corwin et al., 2014; Davis et al., 2017; Eisenberg et al., 2013; Ledoux et al., 2019; Thomas et al., 2018; Zemek et al., 2016). Regarding gender, some research has indicated females are at greater risk for a longer recovery than males; however, many studies have found no significant gender differences (Iverson et al., 2017). In a recent, well designed, prospective multicenter cohort study, Ledoux et al. (2019), suggested adolescent females have protracted recoveries as the majority of their sample of adolescent females had not returned to baseline levels of symptoms by 12 weeks after injury. Of the studies reviewed by Iverson et al. (2017) only one study found a preinjury history of attention-deficit/ hyperactivity disorder (ADHD) to be significantly associated with prolonged recovery (Miller et al., 2016). Similarly, there was only one study that indicated a relationship between history of learning disability and persistent concussion symptoms (Zemek et al., 2016). Regardless of the presence or lack of risk factors associated with a longer period of recovery, it is imperative concussions in children and adolescents are accurately diagnosed, assessed, and managed from the start.

Concussion Management

Initial management involves removing any individual suspected of having a concussion from play or other activities that put the individual at risk for another biomechanical force to the body. Though extremely rare, an additional impact to the brain can result in life-threatening diffuse cerebral swelling and brain herniation, also known as “second impact syndrome” (Bey, 2009). Additionally, and perhaps more relevant to all youth athletes, prompt removal from sports participation has been associated with a shorter recovery time as opposed to those that continued to play (Asken et al., 2018; McCrea et al., 2009). Within the context of competitive sports, a brief sideline assessment, which serves as a rapid screening tool, may be conducted to determine the likelihood of concussion. Following the sideline assessment, the current consensus states a physician or licensed healthcare provider needs to complete a thorough diagnostic evaluation of the clinical symptoms, physical signs, cognitive functioning, and behavior to determine if they are consistent with a concussion (McCrory et al., 2017). If there is concern for a more serious injury, like intracranial hemorrhage, healthcare providers can use clinical prediction tools to determine a need for computed tomography (CT) imaging (Master & Storey, 2020). After a concussion is diagnosed, patients are advised to take a period of physical and cognitive rest followed by a gradual return to mental and physical activities (Gioia, 2016; Master et al., 2012). The duration and extent of rest necessary is controversial, but a significant reduction in both physical and cognitive activities, is currently recommended for the first 24 to 48 hours after injury (McCrory et al., 2017). This period of rest may help minimize the symptom burden during the acute phase of injury as well as foster recovery by reducing energy

demands on the brain (Master & Storey, 2020; McCrory et al., 2017). Thereafter, once symptoms have decreased, a gradual and controlled return to activities can begin. The key idea in returning to activities is that individuals with a concussion stay below a symptom threshold in which their activity level does not bring on new or severely worsen symptoms (Gioia, 2015; McCrory et al., 2017). Thus, activities should be modified as needed to reduce symptom exacerbation (Master & Storey, 2020). These modifications depend on the specific symptoms the individual is experiencing, the environments they are trying to reengage in, and the resources available. Within the pediatric population, *Return-to-Play* (RTP) and *Return-to-Learn* (RTL) are the two activity areas most discussed in the literature, public policy, and concussion education campaigns. The gradual processes recommended by consensus guidelines for children and adolescents to reach full RTP and RTL are each summarized in the following sections.

Return-to-Play

As the majority of concussions in youth are sustained during sports- and-recreation related activities, a great deal of focus in the literature has been on RTP. RTP, also referred to as Return-to-Sport, is defined as the resumption of participation in organized sport following a concussion injury; however, these terms also can apply to non-athletes as they return to physical activities, including exercise, recess, PE class, and free recreational play (Master & Storey, 2020). There is a standardized RTP protocol in which athletes progress through stages of increased physical activity to eventually reach full sports participation (McCrory et al., 2017). This RTP protocol has been developed, updated, and disseminated over the years through consensus statements by the Concussion in Sport Group (CISG)

(McCrory et al., 2017). Based on the latest consensus statement the strategy for graduated RTP is as follows:

> Stage 1. *Symptom-limited activities* (Daily activities, like work or school activities, which do not provoke symptoms.)
>
> Stage 2. *Light aerobic exercise* (Walking or stationary cycling at slow to medium pace with the goal to increase heart rate.)
>
> Stage 3. *Sport-specific exercise* (Running or skating drills with the goal to add movement. No head impact activities.)
>
> Stage 4. *Non-contact training drills* (Harder training drills and may start progressive resistance training with the goal of adding coordination and increased thinking to the movements.)
>
> Stage 5. *Full contact practice* (Following medical clearance, participation in normal training activities with the goal of restoring confidence in the athlete and letting the coaching staff assess functional skills.)
>
> Stage 6. *Return to sport* in which the athlete can resume normal game play. (McCrory et al., 2017, pp. 3)

Each stage must last at least 24 hours and if any symptoms are aggravated during the activities of any stage, the athlete should not continue and instead should go back to the previous stage for another 24 hours (McCrory et al., 2017). Regarding clearance for an athlete to reengage in full contact practice and then normal game play, each state has its own laws on which types of medical providers can provide such clearance. Current recommendations state that children and adolescents cannot start the RTP protocol beyond symptom-limited physical activity until they have fully returned to a regular school schedule and academic

workload (McCrory et al., 2017). Additionally, concussion related symptoms should be resolved before starting the RTP progression; however, there is evidence that structured symptom-limited exercise programs are safe and beneficial for children and adolescents who do not follow the typical recovery course and have persistent postconcussive symptoms (Leddy et al., 2019; Makdissi et al., 2017). For youth involved in organized interscholastic sports, this RTP process is usually managed by a qualified physician as well as the team's athletic training staff and requires the athlete to honestly communicate symptoms he or she is experiencing throughout the progression (Master & Storey, 2020). For youth who are not involved in organized athletics, a less formal stepwise approach is often taken, in which physical activity/exercise intensity and amount of time is gradually increased if symptoms are not exacerbated. Unfortunately many youth are involved in sports and other recreational activities in which there is not an athletic trainer, putting greater onus on physicians and parents to manage RTP (Master & Storey, 2020). While RTP is primarily an issue of the sports field, court, or rink, the process of returning youth with concussions to school and their previous cognitive workloads is universal.

Return-to-Learn

Attending school and learning is essential for all domains of child and adolescent development. Thus, a seamless integration back into the school environment following a concussion is ideal (Gioia, 2016). Concussion symptoms, such as headaches, fatigue, decreased concentration, and reduced processing speed, can affect a child's daily functioning and be easily exacerbated in the school setting (Halstead et al., 2013; Holmes, Chen, Yahng, Fletcher, & Kawata, 2020). For example, attending to visual stimuli and scanning

back and forth from the board to one's notes can lead to dizziness and headaches (Halstead et al., 2013). Besides the cognitive aspects, the school environment may provoke symptoms given the bright institutional lights, loud hallways, and common use of screens in the classroom (Master & Storey, 2020). Additionally, cognitive stamina is lowered given the metabolic energy crisis occurring in the brain (Giza & Hovda, 2014; Ransom et al., 2015). Thus, many students with concussions will need temporary academic accommodations as well as environmental modifications. Academic accommodations may include shortening assignments, extending time to complete tasks, medically excusing nonessential work, postponing tests and quizzes, giving copies of notes, and providing rest breaks amongst others depending on the student's needs (Gioia, 2016; Master & Storey, 2020). Allowing the student to eat lunch in a quiet place with a few friends, leave and arrive at the next class before the bell, and wear sunglasses inside are examples potential environmental modifications.

A subset of students, particularly those with persistent postconcussion symptoms, may require a higher level of school support for a longer duration through a Section 504 Plan or Individualized Education Program (Gioia, 2016; Master & Storey, 2020). Difficulties with RTL appear to be associated with age, as high school students reported a lower tolerance in performing academic tasks than college students (Holmes et al., 2020) and more school-related problems relative to younger grade levels (Corwin et al., 2014; Ransom et al., 2015). Additionally, higher symptom severity has been associated with greater school-related problems (Ransom et al., 2015). The negative impact of concussion in relation to school is widespread and adolescents have reported significant distress from missing academic activities (Stein, 2016). Ransom et al. (2015) found 88% of actively

symptomatic youth indicated concussion symptoms interfered with school functioning and another 77% endorsed poorer academic skills (e.g., more time needed for homework, difficulty taking notes, and trouble understanding material). Declines in grades have also been described in the literature (Arbogast et al., 2013; Corwin et al., 2014; Ransom et al., 2015). Unfortunately, the heterogeneity in concussion presentation and recovery speed make it difficult for families, medical providers, and schools to implement accommodations and RTL plans as each student requires tailored supports for different lengths of time. There is agreement that these RTL plans need to be individualized and follow a gradual progression, but there are multiple sets of guidelines recommended in the literature. The latest consensus statement on concussion in sport describes the following stages for a graduated return-to-school strategy:

> Stage 1. *Daily activities at home that do not increase symptoms* (This may include reading, texting, screen time. Start with 5-15 minutes at a time and gradually build up.)
>
> Stage 2. *School activities* (Homework, reading or other cognitive activities out of the classroom with the goal of increasing the child's tolerance of cognitive work.)
>
> Stage 3. *Return to school part-time* (Gradual introduction of schoolwork. Youth may need to start with partial school days or with increased breaks during the day with the goal of increasing academic activities.)
>
> Stage 4. *Return to school full-time* (Gradually progress school activities until a full day can be tolerated. Return to full academic activities and catch up on missed work.)
>
> (McCrory et al., 2017, pp. 4)

Gioia (2016) outlined a similar set of gradual RTL guidelines, with more detail and emphasis on the need for maximal supports and accommodations at first, that can then be reduced as longer periods of academic activity tolerated. Periodic rest breaks during the school day in which symptoms reduce or disappear are a large component of that RTL plan (Gioia, 2016). As with the RTP protocol, decisions to move to the next stage are dependent on symptoms, which must be reported from the students themselves. In a different group of guidelines, Master and Storey (2020) recommended a physical return to the school environment with heavy cognitive restrictions as soon as symptoms are at a tolerable level. They state students should "[use] the time to simply listen to and absorb what is occurring in the classroom, without having to visually engage by taking notes or cognitively engage by trying to retain information" (Master & Storey, 2020, pp. 144). For some, the idea of attending school without the expectation of participating in any academic activity has recently come into favor as extended absences from school may contribute to negative social outcomes as well as mental health problems like depression and anxiety (DiFazio, Silverberg, Kirkwood, Bernier, & Iverson, 2016; McCrea et al., 2009). Overall, RTL is a dynamic process that requires the student to communicate his or her experiences with accommodations and the gradually increasing cognitive workload as well as coordination between the systems of care to ensure the child's needs are being met.

Communication and Relationships with Systems of Care

Though experts agree systems of care need to communicate and work together to optimize care following concussion, the perspectives of youth in this matter is a gap in the literature. As the patient, children and adolescents need to feel comfortable initiating and/or

disclosing information related to their symptoms, concerns, and recovery needs since they are "the [care] team's most valuable information sources regarding progress toward recovery" (Gioia, Glang, Hooper, & Brown, 2016, pp. 4). This information is particularly important for all systems of care to be aware of to coordinate timely intervention or assistance (e.g., school accommodations, medications, adjustments in RTP or RTL protocol directions, mental health services). As stated previously, RTP and RTL decisions are dependent on the subjective experiences of youth as they gradually increase activity levels. If children and adolescents recovering from a concussion feel uncomfortable communicating and information is underreported or misrepresented, this may complicate recovery and ultimately have a negative impact on outcomes (e.g., academic performance, quality of life, relationships, symptom severity, participation in sports and extramural activities, risk for additional injuries). Thus, it is important to evaluate the perspectives and beliefs held by adolescents about communicating with individuals involved in their concussion care.

The relationships children and adolescents have with those involved in their concussion care can vary based on many factors. Gaining knowledge about these relationships in the context of a concussion will be helpful in designing interventions for all systems of care to work together more effectively. Additionally, these relationships need to be considered from a developmental framework as different age groups tend to have different types of relationships with individuals involved in their lives. Since research within this area is lacking for youth with concussions, a brief review of the existing literature on communication among other pediatric populations and systems of care is presented here.

Family System of Care

In the context of concussion, parents or legal guardians are tasked with monitoring their child's activity levels, conveying information on their child's symptoms and recovery, and making decisions with medical providers about their child's return to activities (McCrory et al., 2017; Sady, Vaughan, & Gioia, 2011; Welch Bacon, Erickson, Kay, Weber, & Valovich McLeod, 2017). Additionally, parents or legal guardians can be a source of support through which children and adolescents can process their experiences related to the concussion injury (Alisic et al., 2017). Though adolescents desire autonomy and more control of their lives (Rice, 1990), they are not always prepared to take on their own illness management and still rely on caregivers to navigate healthcare (Lerch & Thrane, 2019; McLaughlin et al., 2019). This is especially true in the case of TBI in which more caregiver supervision and oversight may be required given the cognitive difficulties experienced by adolescents with TBI (Wilson, Donders, & Nguyen, 2011).

Much of the literature regarding adolescent communication comfort with caregivers has focused on sensitive topics such as sexual health and other risk-taking behaviors (e.g., alcohol and drug use). Researchers have largely used communication comfort to predict frequency of communication and adolescent behavior instead of describing general comfort levels (Flores & Barroso, 2017). Of studies that characterized communication comfort, the vast majority of adolescents were not comfortable talking about sex or contraceptive use with their parents (Flores, Meanley, Wood, & Bauermeister, 2020; Shakibnia, Timmons, Gold, & Garbers, 2018; Somers & Vollmar, 2006; Stewart, Widman, & Kamke, 2019). Similarly, studies of adolescents with medical conditions have focused on the barriers to communication with parents and caregivers without first describing how

widespread communication issues may be. Adolescents with a diagnosis of epilepsy or cancer have reported parental overprotection and subsequent restriction of activities as well as negative reactions, and fear of worrying their parents as barriers to communication (Ameringer, Serlin, Hughes, Frierdich, & Ward, 2006; O'Toole, Lambert, Gallagher, Shahwan, & Austin, 2016). Furthermore, adolescents in those studies felt that disclosing certain information would limit their feelings of normalcy, freedom, and independence (Ameringer et al., 2006; O'Toole et al., 2016). There is also evidence adolescents make decisions about communicating symptoms based on previous reactions of parents (Ameringer et al., 2006; Kroshus, Chrisman, Milroy, & Baugh, 2020)

In addition to the physical symptoms of a concussion, a portion of youth recovering from a concussion also experience emotional concerns such as anxiousness, irritability, and sadness. It is just as important for youth to talk about these emotional symptoms and for parents/legal guardians to be aware of them so that they can serve a source of support and help their child find necessary resources (Bokhorst, Sumter, & Westenberg, 2010; Papini, Farmer, Clark, Micka, & Barnett, 1990). Adolescents who perceived openness in family communication, family unity, and satisfactory relationships with family members were more likely to discuss their emotional states (Papini et al., 1990). A review by English and Ford (2018) indicated that adolescents and parents often disagreed on their perceptions of communication with each other and it was the adolescent's perception of the communication that impacted the adolescent's behavior the most. This further emphasizes the relevance of examining adolescent perspectives about communication following concussion injury.

Only a handful of studies have investigated parent-child communication specific to concussions. Among those, it was observed that some adolescents either did not report or underreported symptoms and possible concussion events to their parents (Rivara et al., 2014). Greater pressure from parents to achieve in athletics, to return to play, and/or to hide symptoms was associated with lower intention to report possible concussion symptoms in samples of collegiate athletes (Kroshus, Garnett, Hawrilenko, Baugh, & Calzo, 2015) and youth football players (Kroshus, Hoopes, Bernstein, Chrisman, & Rivara, 2019). However, in a large sample of middle and high school youth, over 80% disclosed possible concussion symptoms to a parent, which may indicate the majority of parents are not pressuring their adolescents (Wicklund & Coatsworth, 2020). Unfortunately, over half of surveyed parents of youth football players reported they had not talked about concussion safety with their child in the past year (Kroshus et al., 2019). This is concerning as youth may be hesitant to initiate a conversation about concussion if their parents have not previously or recently broached the topic. Additionally, that study found the athletes who had parents that communicated about concussion safety were more likely to remove themselves from play and report possible concussion symptoms (Kroshus et al., 2019). Also on a positive note, parents of youth athletes indicated a high value and strong desire to discuss concussions with their youth athletes to help get their children the necessary support for recovery (Sarmiento, Donnell, Bell, Tennant, & Hoffman, 2019). Though not specific to concussion, through audio-sampling within the first few days after discharge from an injury that required hospitalization, Alisic et al. (2017) found that parents and injured youth talked for an average of 46 minutes a day about topics related to the injury. This demonstrates that families engage in naturally occurring “injury talk”, which suggests decent levels of comfort

communicating with parents. The researchers noted the amount of injury talk varied across families and future studies are needed to determine why some families communicate more than others (Alisic et al., 2017). As the literature indicates, parents and legal guardians have an important role in their child's concussion recovery and more research is needed to understand communication practices between parents and their adolescents as it relates to concussion management, especially from the perspective of the adolescent.

Medical System of Care

The medical team (sports medicine physicians, athletic trainers present in medical clinics, primary care providers, nurses, and emergency medicine physicians) diagnose the concussion, assess for other more serious injuries to the head, and provide patients with restrictions and accommodations for RTL and RTP (Gioia, 2016). Given the limited time physicians often have to spend with patients, it is important adolescents can express their concerns regarding their condition (Mauksch, 2005). Regarding communication between medical providers and adolescents within the primary care setting, research has indicated that youth disclose more about risky behaviors and mood disturbances to board-certified adolescent medicine providers than general pediatric providers, most likely because adolescent medicine physicians often provide confidential consultation (i.e. spending time with the adolescent alone) (Gilbert, Kark, Gehrman, & Bogdanova, 2015). Another study of adolescents in a primary care setting found adolescents were less likely than their parents to report feeling involved in decisions about their care and that they received understandable answers to their questions (Byczkowski, Kollar, & Britto, 2010).

Positive relationships and good communication with medical teams has been linked to better adherence of medical recommendations and improved healthcare self-efficacy in adolescents (Sawicki, Heller, Demars, & Robinson, 2015; Taylor, La Greca, Valenzuela, Hsin, & Delamater, 2016; Zolnierek & Dimatteo, 2009). Given the importance of positive relationships between adolescents and medical providers, a review of qualitative research articles by Daley, Polifroni, and Sadler (2017) distilled the five following themes regarding what adolescents desire from their medical providers: active back-and-forth communication, respect of confidentiality and privacy (including asking parents to leave the room so private issues can be discussed), acceptance shown through non-judgmental and equal treatment, professionalism, and competence. Those five aspects may help more trusting relationships form between adolescents and their physicians. In turn, adolescents would then have a greater sense of comfort communicating, and the physicians' recommendations of preventive measures could carry more weight (Coker et al., 2010; Daley et al., 2017; Klostermann, Slap, Nebrig, Tivorsak, & Britto, 2005; McKee, O'Sullivan, & Weber, 2006). Additionally, quality communication and good interpersonal skills from their physicians are also critical to adolescents reporting satisfaction with clinic visits (Byczkowski, 2010).

Only one study was identified in which the perspectives of 15 adolescents were retrospectively evaluated in the context of service needs following mTBI (Gagnon, Swaine, Champagne, & Lefebvre, 2008). The adolescents interviewed reported a desire for: more information about their expected recovery and return to activities, trusting relationships with medical professionals, being active participants in decisions about their care, and having timely access to competent to medical professionals (Gagnon et al., 2008). Since little is known about the relationship between adolescents and their medical providers within the

specific context of concussion, collecting data about communication comfort in these relationships is a meaningful step.

School System of Care

The school system of care can consist of school nurses, athletic trainers, teachers, guidance counselors, school psychologists, social workers, and administrators, depending on the infrastructure of the school and district. This system of care fills multiple roles such as safeguarding the student from further injury, preventing exacerbation of symptoms as the child begins cognitive activity by putting accommodations into place, tracking symptoms, providing social support, and communicating cognitive progress to others involved in the student's care (Sady et al., 2011). Unfortunately, not all school personnel have formalized education on the management and identification of children with TBIs and thus may not be adequately prepared to support adolescents recovering from concussions (Dettmer, Ettel, Glang, & McAvoy, 2014; Dreer, Crowley, Cash, O'Neill, & Cox, 2017; Glang et al., 2008). Given that adolescents spend a majority of their waking hours engaged in educational activities each weekday, it is important to know how adolescents with concussions feel talking to school staff related to their symptoms, concerns, and recovery issues/needs (U.S. Bureau of Labor Statistics, *American Time Use Survey,* 2018). This is also especially crucial within the context of school because students may feel obligated to work at their previous pace instead of the gradual self-pacing needed to prevent exacerbation of symptoms (Sawicki et al., 2015). School personnel may intentionally or unintentionally influence students in this matter depending on how they interact with the student recovering from a concussion. If students do not feel comfortable speaking up about how

they are handling the workload or the school environment in general, then school personnel will not be aware that they are asking too much of a student (Master et al., 2012).

Due to the uniqueness of each individual's concussion and concussion recovery, Gioia (2016) emphasized that frequent communication is necessary to assess for symptoms and how the school environment is being tolerated. This information can aid school personnel in creating individualized and flexible approaches to academic accommodations and recommendations (Gioia, 2016). The adolescent, however, has to accurately report symptoms and any school-related difficulties they are having (Gioia, Glang, Hooper, & Brown, 2016). Also, given that young people are active managers of their health, those involved in their concussion care should consult them directly about the kinds of support they need (Halstead et al., 2013).

Much of the literature on communication between youth and school personnel involves the analysis of student-teacher relationships and very little emphasis has been given to other school personnel such as guidance counselors, administrators (e.g., principals), and school nurses (Littlecott, Moore, & Murphy, 2018). There are many factors that impact student-teacher relationships and those relationships that are positive have been found to lead to greater student engagement and academic achievement (Allee-Smith, Im, Hughes, & Clemens, 2018; Furrer & Skinner, 2003; Hamre & Pianta, 2005; Wentzel, 1998). Students reported that they would likely talk to those teachers or support staff they had already built up rapport with about health and wellbeing issues (Littlecott et al., 2018). Students in one study felt comfortable going to the nurse's office for help and deemed most school staff as being approachable (Littlecott et al., 2018); however, those in another study did not report consistent positive, supportive relationships with teachers, but expressed a desire to

strengthen those relationships (McHugh, Horner, Colditz, & Wallace, 2012). Through focus groups with high school students in the United States, it was found that teachers fostered positive relationships when they exhibited "effortful engagement" by taking actions to engage or connect with their students as well as showing genuine concern about the individual student (McHugh et al., 2012). On the other hand, barriers to positive relationships were student perceived inattention or lack of investment in a student as well as stereotyping by teachers (McHugh et al., 2012). It should be noted that it is not feasible to expect educators to form strong relationships with all their students given the time demands they face.

Focus groups of teachers indicated that student-teacher relationships were improved by collaboration on common interests, teachers' recognition of the potential needs of each student and creation of a safe environment (Krane, Karlsson, Ness, & Binder, 2016). On the other hand, unresponsiveness and communicating negative expectations was reported to hurt relationships (Krane et al., 2016). Teachers also stated that student-teacher relationships have evolved over the years in that more students share personal matters with them than did before (Krane et al., 2016). Of interest to the area of concussion communication is that adults (e.g., physicians, teachers, and school nurses) perceived adolescents to be less concerned about their health and exhibit more harmful behaviors than adolescents actually reported engaging in (Levenson, Morrow, & Pfefferbaum, 1984). Perceptions like this could contribute to the notion that school staff think adolescents are "faking" concussion symptoms to get out of assignments at school.

Though there is an expanse of literature on the school experiences and outcomes of children and adolescents with chronic illness, few studies specifically address

communication about health concerns between students and school personnel. In a review of the literature Lum et al. (2017) concluded that students with chronic illness have poorer interpersonal relationships at school than their peers without chronic illness. Diminished relationships with both teachers and peers were found as areas of concern as students with chronic illness reported teasing, feeling different from peers, and experiencing unsupportive, inflexible, and dismissive attitudes from others (Hokkanen, Eriksson, Ahonen, & Salantera, 2004; Lum et al., 2017). Negative attitudes may stem from a lack of knowledge on the academic effects of chronic illness, which was indicated by surveyed school professionals who did not think students with chronic illness had academic challenges (Berger, Valenzuela, Tsikis, & Fletcher, 2018; Brook & Galili, 2001). A survey of teachers showed they were less willing to implement burdensome accommodations for students with medical conditions, but also felt uneducated and unconfident providing appropriate academic accommodations (West, Denzer, Wildman, & Anhalt, 2013). Another study revealed concerns from teachers about the extra time and extra attention students with medical conditions may need; however, they overall reported a positive perception about children with chronic conditions in the classroom (Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004). School personnel reported five key areas of concern regarding school re-entry for a child with chronic illness: how caregivers informed the school about the child's condition, the process of re-entry, the ongoing monitoring of the child's health status, the needed education for school personnel about potential health problems, and the school personnel's expectations for the child (Kliebenstein & Broome, 2000). Those findings highlight the reality students with concussion may experience when returning to school. If school personnel have not received education or have not had a previous student with a concussion, they

may perceive accommodations as burdensome and not have the resources to provide for a student's need.

Adolescents who perceive a lack of understanding from school staff may not be motivated to communicate about their concussion, given the findings previously discussed on student-teacher relationships. Students with a disability or chronic illness reported teachers within the same school reacted differently to their condition. A strong theme in the accounts of these adolescents was the value of teachers who "understood" them (Lightfoot, Wright, & Sloper, 1999). Understanding teachers were described as those who were aware of the student's health condition, recognized the impact it had on the student's schoolwork, behavior, and socialization and then made appropriate arrangements based on this knowledge (Lightfoot et al., 1999).

From a survey of school principals, approximately half cited lack of communication between the student, physician, and school as the greatest barrier to starting academic accommodations for students with concussions (Janson, Nittoli, White, & Tekulve, 2019). School personnel have reported cultures within their schools in which the legitimacy of a student's concussion is sometimes questioned (Sarmiento, Donnell, Bell, & Hoffman, 2019). However, these school personnel, which included teachers, school psychologists, school counselors, and school nurses, who completed the survey stated they generally felt comfortable discussing concussions with their students. Of note, teachers and school nurses reported the highest levels of comfort and indicated they wanted their students to speak up and report symptoms (Sarmiento, Donnell, Bell, & Hoffman, 2019). Also interesting was the description by school psychologists and counselors that some students have appeared

to be in denial and were hesitant to ask for and accept accommodations (Sarmiento, Donnell, Bell, & Hoffman, 2019).

Understanding the views of adolescents with illness or disability can help us better predict how students with concussions may perceive communicating about their concussion with school personnel. Results of interviews with adolescents who have medical conditions and disabilities indicated they valued school and were managing the effect of their condition on school life, but still need support from others (Lightfoot et al., 1999). They reported struggling with being excluded from the curriculum and/or social activities while at school, peer isolation, their teachers' reactions, and being absent from school. These students said that they would not seek out school health staff (e.g., school nurse) for emotional support, since lack of regular contact with the school nurse prevented the development of a relationship. Instead, students reported seeking out a sympathetic teacher and noted these teachers were a valuable source of emotional support (Lightfoot et al., 1999). In fact, the majority of students reported having at least one teacher they could openly communicate with (Lightfoot et al., 1999). As the literature on adolescent perspectives communicating with school personnel about their concussion is sparse, more research is needed to better understand communication comfort levels and how they may impact recovery outcomes.

Athletic System of Care

The athletic system of care is responsible for identifying suspected concussions, protecting the athlete from a second concussive injury, monitoring for exacerbation of symptoms, guiding the athlete through the gradual RTP process, and tracking overall

recovery progress. Athletic personnel can also be involved in the RTL process and can help advise school colleagues about concussion recovery and symptom management depending on the degree to which athletic staff are integrated into the school system of care (McGrath, 2010). Much of the research on adolescent perspectives about communication surrounding concussions has been related to symptom and suspected concussion reporting behaviors within the athletic context. Using the socio-ecological framework, Kerr et al. (2014) grouped factors related to disclosure of concussion symptoms across four levels: intrapersonal (e.g., one's own concussion knowledge, gender, previous concussion history), interpersonal (e.g., external pressure, external support, other's concussion knowledge/attitudes), environmental (e.g., access to resources, sports culture, type of residential area), and policy (e.g., state legislation, mandatory concussion education). The argument was made that a multi-factor approach should be taken to understand concussion reporting behaviors in order to develop effective interventions (Kerr et al., 2014; Kroshus, Garnett, Hawrilenko, et al., 2015). In the following paragraphs these groups of factors will be further discussed, starting with the interpersonal factor of one's concussion knowledge.

Multiple studies of high school student-athletes have indicated positive associations between concussion knowledge and increased reporting or intention to report possible events resulting in concussion (Bramley, Patrick, Lehman, & Silvis, 2012; Glang et al., 2015; Register-Mihalik et al., 2013; Sullivan, Pursell, & Molcho, 2018). However, other studies have not found a relationship between knowledge and reporting behaviors and intentions (Anderson, Gittelman, Mann, Cyriac, & Pomerantz, 2016; Craig, Lininger, Wayment, & Huffman, 2019; Kroshus, Garnett, Hawrilenko, et al., 2015; Kurowski, Pomerantz, Schaiper, & Gittelman, 2014). Athletes of various levels continue to play or do

not report potential sustained concussions at rates ranging from 20% to 69% based on retrospective accounts (Anderson et al., 2016; Kaut, DePompei, Kerr, & Congeni, 2003; Kroshus, Garnett, Hawrilenko, et al., 2015; Llewellyn, Burdette, Joyner, & Buckley, 2014; McCrea et al., 2004; Register-Mihalik, Valovich McLeod, Linnan, Guskiewicz, & Marshall, 2017; Rivara et al., 2014; Sullivan & Molcho, 2018; Torres et al., 2013; Williamson & Goodman, 2006). On the other hand, in a large sample of youth ages 12 to 17, 92% surveyed stated they intended to report symptoms to their coach (Donnell, Hoffman, Sarmiento, & Hays, 2018). Even if athletes do report, there is some evidence all symptoms may not be disclosed, as Meier et al. (2015) found athletes self-reported significantly fewer symptoms to team athletic trainers than they self-reported during a standard psychiatric interview.

Given variable rates of reporting concussion symptoms, it is critical to understand what drives communication of suspected concussion symptoms. The following are some of the key reasons for not reporting concussion symptoms: athletes did not want to leave the current game or practice, they did not know their symptoms indicated a concussion, they did not want to disappoint their teammates or coaches, they did not want to be restricted from future games or practices, and they believed concussions were part of the game (Beverly et al., 2018; Chrisman, Quitiquit, & Rivara, 2013; Kerr et al., 2014; Register-Mihalik et al., 2017; Wallace, Covassin, & Beidler, 2017). Significance of the game or competition also appears to matter as 27% of high school rugby players believed a teammate with a concussion should still play in an important game (Sye, Sullivan, & McCrory, 2006) and approximately 50% of high school soccer players stated they would

never or only sometimes report concussion symptoms during a championship game (Bramley et al., 2012).

Studies have reported mixed results about the influence of prior concussions on future concussion symptom disclosure. In one study, a greater number of previous concussions was associated with worse attitudes about concussions and negative concussion disclosure behaviors (Register-Mihalik et al., 2017). Similarly, in a survey of collegiate athletes, Torres et al. (2013) found respondents were less likely to report symptoms if they had previously sustained a concussion. This was attributed to the experience the athlete had when he or she last reported a concussion, as the athlete was likely removed from play, concussion management may have been poor, and going through it could have changed the individual's beliefs about the consequences of a concussion injury (Register-Mihalik et al., 2017). However, Kroshus, Stellino, Chrisman, and Rivara (2018) found no association between history of prior concussions and intention to disclose symptoms. While the findings on prior concussion history on communication of concussion symptoms is inconsistent, pressure from others (i.e., an interpersonal factor) appears to have a clear impact on reporting behaviors.

In a sample of collegiate athletes across seven sports, 26% reported feeling pressure from coaches, teammates, fans, or parents to continue playing after a concussion or suspected concussion during the previous season. Interestingly, those that had been diagnosed with a concussion during the previous season endorsed significantly greater pressure from coaches and teammates than those that did not have a recent concussion. Additionally, participants who reported greater levels of pressure were more likely to state they would continue to play if they experienced a head impact and symptoms in future situations

(Kroshus, Garnett, Hawrilenko, et al., 2015). Of note, a little over half the sample endorsed experiencing little pressure, while 33% reported high levels of pressure from multiple sources, and 14% perceived moderate pressure from coaches and teammates only (Kroshus, Garnett, Hawrilenko, et al., 2015). These results show that contextual influences, such as direct and indirect pressure from coaches, teammates, parents, and fans, cannot be ignored when considering athlete's reporting behaviors and levels of communication comfort (Kroshus, Garnett, Hawrilenko, et al., 2015).

Though not extensively studied in regard to concussions, for other sports injuries, the relationship between the coach and athlete is a crucial factor of injury reporting as well as the athlete's adjustment and emotional wellbeing over the course of healing (Curry, 1993; Malinauskas, 2008; Nixon, 1996; Podlog, Heil, & Schulte, 2014; Roderick, Waddington, & Parker, 2000; Yang, Peek-Asa, Lowe, Heiden, & Foster, 2010). Coaches shape team norms about appropriate concussion safety by the way they communicate to their players about concussions (Baugh, Kroshus, Daneshvar, & Stern, 2014; Kroshus, Baugh, Hawrilenko, & Daneshvar, 2015). Though high school athletes acknowledged the risks of continuing to play with concussions symptoms, those with less approachable coaches who had spoken negatively about injury reporting in the past, stated they would not report concussion symptoms (Chrisman et al., 2013). Similarly, in a group of college football players, those who believed their coach was less supportive of concussion symptom reporting were more likely to hide symptoms (Baugh et al., 2014). Though it is important to understand the team's culture and beliefs towards concussions, athletes may not always perceive their team's norms accurately. Both male and female athletes significantly misperceived team concussion reporting norms, rating themselves as having safer attitudes

than their teammates (Kroshus, Garnett, Baugh, & Calzo, 2015). Misperceived team norms may persist because those who believe their preferences are deviant relative to the group norm are less likely to talk about it to avoid social disapproval (Kroshus, Garnett, Baugh, et al., 2015).

When thinking about communication practices and symptom reporting behaviors it is noteworthy to consider gender differences. A few articles have presented data suggesting female athletes have significantly higher symptom reporting intention than male athletes despite similar levels of concussion knowledge (Kroshus, Garnett, Hawrilenko, et al., 2015; Torres et al., 2013; Wallace et al., 2017). However, one study of former college athletes did not find a gender difference in the number of unreported concussions (Llewellyn et al., 2014). Work by Sullivan and Molcho (2018) demonstrated females were more likely to report concussion symptoms because they were not as concerned as males about how they would be perceived by their team. Male high school students stated the following concerns more often than females: they thought their coach would get mad, their teammates and coach might think they are weak, their parents would be upset, they would be prohibited from playing in high-stakes games or end of season games, and they would be letting their team down (Sullivan & Molcho, 2018). Interestingly, Kroshus, Baugh, et al. (2015) found male coaches of female teams reported less negative attitudes about concussions and communicated more positively with their athletes about concussion safety. While male coaches of male teams reported the most negative beliefs and attitudes about concussions, their responses to survey questions indicated stronger communication about concussion safety to their players than female coaches of female teams (Kroshus, Baugh, et al., 2015). The authors speculated this finding might be related to women taking on a more traditional

masculine identity or models in the role of coaching a team (Kroshus, Baugh, et al., 2015). Given sports- and recreation-related activities are the leading cause of concussions in youth, this study aims to examine communication comfort between athletes with a concussion and their coaches, athletic trainers, and teammates. Frequent and candid communication is critical to keeping athletes safe and on a positive recovery trajectory during their return to athletic activities.

Friend System of Care

For the purpose of this study we have conceptualized friends as a system of care given the importance of peer relationships in adolescence. Regarding adolescent communication with friends about their concussion, it is useful to consider other studies on disclosure to peers about illness or disability status. Though friends and peers can be a particularly important source of social support for individuals going through difficult experiences (Rice, 1990), some youth choose not to disclose information about their health (Ameringer et al., 2006). Studies of youth with visible (e.g., spina bifida, cystic fibrosis, muscular dystrophy, cancer) and invisible (e.g., heart, renal, rheumatological, immune) medical conditions have indicated the following reasons for nondisclosure: beliefs that it was unnecessary for peers to know, desires to maintain privacy, apprehension that peers would understand the condition, avoid the curiosity of other children, fear of rejection, concern of being stigmatized, and wanting to be viewed as normal instead of sickly or vulnerable (Ameringer et al., 2006; Kaushansky et al., 2017; Lightfoot et al., 1999; Michaud et al., 2009). These reasons are in line with the common concern of adolescents in which they are

worried about their peers' perceptions of them and their peer's reactions to their behaviors (Rice, 1990).

On the other hand, reasons for divulging were the following: wanting their peers to know what to expect, what to do in an emergency, how to interact safely with them, and a desire to foster greater understanding (Kaushansky et al., 2017; Lightfoot et al., 1999). Additionally, Kaushansky et al. (2017) found adolescents disclosed their chronic illness to a few close friends if they perceived trust and a shared experience with illness or disability. Overall, disclosure was found to be associated with the visibility of the medical condition, the anticipated response from the recipient of the information, the practical needs of disclosing, and the youth with a chronic condition determining that disclosure was justified (Kaushansky et al., 2017). Though not usually considered a chronic condition, adolescents with concussion may think of similar reasons before discussing their concussion with friends and peers. This is currently unknown as there have not been any studies examining adolescent's concussion communication with friends and peers.

Close friends have been cited as valued sources of emotional support and companionship in youth with chronic illness (La Greca, 1992; Lightfoot et al., 1999). Adolescents may share more about their personal problems and concerns to friends than caregivers, which is why evaluating how comfortable youth with a concussion feel communicating with friends is meaningful (Buhrmester & Prager, 1995; Solis, Smetana, & Comer, 2015). Like anyone with a condition that limits physical or cognitive abilities, adolescents with concussion can feel excluded from social activities and experience isolation (Lightfoot et al., 1999). At school, contact with friends may be limited by break times spent resting, time away completing make-up assignments, inability to be in the noisy lunchroom, and

absenteeism due to symptoms or medical appointments. Additionally, adolescents with chronic illness reported after-school activities were difficult due to tiredness, physical limitations, and feeling self-conscious, all of which are often also experienced by those with a concussion (Lightfoot et al., 1999).

Approximately half of the participants with chronic illness in one study felt their condition either made no difference or had a positive effect on their relationships with peers. Unfortunately, the other half reported problems with peers, including bullying, especially in the case of visible differences (e.g., needing a wheelchair, taking medicine, being treated differently by teachers) (Lightfoot et al., 1999). Juvenile Primary Fibromyalgia Syndrome (JPFS) has many similarities to those with postconcussion syndrome as both are characterized by pain, fatigue, sleep disturbances, and cognitive dysfunction. A study of the peer relationships of adolescents with JPFS indicated they are rated as more sensitive and isolated, exhibit fewer leadership behaviors, have fewer reciprocal friendships, and are less liked. Though most individuals are expected to recover from their concussions, those with prolonged symptoms may begin to be perceived by their peers like the adolescents with JPFS (Kashikar-Zuck et al., 2007). Understanding how adolescents feel communicating with friends and peers while still in the subacute phase of concussion injury can provide insight into the social norms around concussions and if peers are turned to for support.

Regarding findings of peer support specific to concussions, Bloodgood et al. (2013) asked youth how much they agreed with the statement, “I am fearful that my circle of friends would think I was dumb for caring about concussions.” About half (53%) of participants strongly disagreed and another 16% disagreed with that statement. Girls were

significantly more likely to disagree than boys. Younger respondents were more likely to disagree than older (Bloodgood et al., 2013). In a comparison of social support in collegiate athletes with concussions versus those with orthopedic injuries, both groups relied on social support from family, friends, teammates, athletic trainers, coaches, and physicians at similar rates (Covassin et al., 2014). However, the athletes with orthopedic injuries acknowledged greater satisfaction with the support they received than the athletes with concussions (Covassin et al., 2014). Previous studies have not yet evaluated youth comfort communicating with their friends and peers about concussions, which is an important piece to concussion management as youth with concussion can benefit from social support throughout recovery.

Summary & Hypotheses

As is evident from the literature presented above, there is limited empirical research on communication following a concussion from the perspective of adolescents. Previous studies have primarily focused on the views of school personnel, medical providers, sports staff, and parents/legal guardians in regard to concussion management. The only way those individuals know what an adolescent with a concussion is facing is if the adolescent openly and honestly shares his or her experiences. Progression through the gradual RTL process and RTP protocols are dependent on the adolescent's concussion symptoms and severity as well as tolerance of activities. Though there are some objective measures of physical activity tolerance, adolescents still need to report their symptoms and speak up when activities are aggravating symptoms above a tolerable level. This is especially important in the context of accommodations during RTL, as changes can only be made if the student is

vocal about symptoms and what aspects of the plan are or are not working. Hiding symptoms or "pushing through" while the brain is still recovering may prolong recovery or increase risks for reinjury, making adolescent communication all the more crucial to investigate (Gioia, 2016). Though parents/legal guardians are heavily involved in sharing their child's experience and advocating for their child's needs, they are not always available in real time during the school day or at sports practice, nor do they always know what their child is feeling. This leaves adolescents with the responsibility of making those involved in their care aware of their concerns regarding concussion issues (e.g., accommodations, symptom aggravation).

How comfortable adolescents are communicating about their concussion symptoms and subsequent needs has been understudied in the concussion literature. Thus, aim 1 of this project is to evaluate adolescent communication comfort levels among the key individuals within each system of care. Though adolescents desire autonomy, many still rely on caregivers to help them navigate the medical system. That in addition to the fact concussion is not as sensitive of a topic as sexual health or drug use, along with a recent study citing high rates of youth disclosing possible concussion symptom parents, it is hypothesized that communication comfort levels with parents/legal guardians (i.e., family system of care) will be in the *somewhat* to *very comfortable* range for most participants. Communication comfort with friends is predicted to be high given the amount of time adolescents spend with friends as well as the literature suggesting adolescents seek out emotional support from their social circles. Additionally, it is predicted that most adolescents would feel *very* to *somewhat comfortable* communicating with their physicians (i.e., the medical system of care). For the athletic system of care, we predict that a greater percentage of

participants will report higher communication comfort with athletic trainers than coaches or teammates given athletic trainers' extensive education on sports-related injuries as well as potentially less pressure or fear of negative outcomes from athletic trainers. Out of the individuals within the school system of care, we hypothesize that communication comfort will be highest with school nurses primarily due to the medical background of school nurses. Knowing which individuals within each of the systems of care adolescents feel comfortable communicating with about issues related to their concussion is critical to maximizing concussion management, as is understanding the specific reasons for reluctance in communication.

Aim 2 is to delineate reasons for barriers to communication comfort from the adolescent's perspective. Knowledge gained from this aim will help to develop efforts designed to enhance communication with various individuals from each of the systems of care. Based on the review of the literature, some reasons adolescents may not feel comfortable communicating with their parents may include anxiety that their parents will restrict them from valued activities (i.e., playing with their friends, returning to sports, using video games or computers, etc.), they may not want to worry their parents, or they may not want to draw attention on themselves. For adolescents who are not *very comfortable* communicating with their physician, we predict it might be due to reasons such as uncertainty about the concussion evaluation, unfamiliarity with the physician, the physician's communication style, and/or worry that the physician will give them activity restrictions. Themes for discomfort communicating with the school system of care may include concerns that school personnel will not understand, be too busy, think that they are trying to get out of doing schoolwork, or not take the concussion diagnosis and needed accommodations

seriously. Regarding communication with the athletic system of care, potential barriers may include reasons such as fear of disappointing the coach/athletic trainer or teammates, feeling pressure to RTP to soon, and negative attitudes from coaches/athletic trainers about concussion safety and RTP protocols. Finally, with regards to communication comfort with friends and classmates, it is predicted that those who report less comfort will give reasons related to concerns about being viewed negatively by peers.

Aim 3 of this study is to determine associations between communication comfort ratings and sociodemographic factors, injury characteristics, medical history, emotional functioning, and recovery outcomes. Given the lack of data in this understudied area, this aim is primarily exploratory. Identifying factors related to communication comfort levels may help inform individuals involved with concussion management about certain factors that may influence communication. By evaluating the perspectives of adolescents with concussions, this study builds on my thesis project to provide a broader view of the communication barriers among systems of care. Evidence from these studies can contribute to the knowledge base from which clinical rehabilitation practice recommendations are made.

METHODS

Participants

This study was approved by the governing Institutional Review Board (IRB) at the University of Alabama at Birmingham (UAB). The study sample consisted of parent-child dyads recruited from three sports medicine clinics specializing in concussion treatment. *Inclusion criteria* consisted of the following: 1) ages 11 up to 18 years old for youth participants, 2) diagnosed with a concussion that occurred within the past 14 days, 3) English speaking, and 4) have consent from a parent/legal guardian who is also willing to participate in the study. *Exclusion criteria* consisted of 1) non-English speaking, 2) enrolled in college, 3) no parent/guardian permission, or 4) time between injury and research enrollment session greater than 14 days. Study staff reviewed patient referral information and clinic documents to determine eligibility for study participation. Eligible parent-child dyads were approached by a research assistant to determine interest in the study during their sports medicine clinic visit or by phone call if they were referred for potential participation by their treatment provider. All eligible youth who enrolled signed consent or assent forms depending on their age. Parent/legal guardian participants also signed consent forms.

Procedures

Enrollment Visit Data Collection

During the in clinic enrollment visit, youth participants were administered either the *Sport Concussion Assessment Tool – 3rd Edition* (SCAT3) or *Child Sport Concussion Assessment Tool – 3rd Edition* (Child-SCAT3). Youth participants were also asked questions regarding their level of comfort in communicating about their concussion with various individuals from each of the systems of care. Parent participants completed information regarding family and their child's sociodemographic and medical history.

Follow-Up Data Collection

Study personnel conducted follow-up phone calls every week after enrollment for at least four weeks (total of four follow-up calls) individually with the parent participant and the adolescent participant to obtain data on current concussion symptoms, RTL outcomes, and RTP outcomes. If the child had not reached full RTL (i.e., back in school full time with no accommodations or only with accommodations the child had in place prior to the concussion injury) by the fourth follow-up phone call, four additional phone calls were completed biweekly at 6, 8, 10, and 12-weeks post-enrollment (i.e., every other week after the fourth phone call). See Appendix A for flow chart of data collection. Both adolescent and parent participants received compensation following completion of the follow-up phone calls.

Measures

Sociodemographic and Medical History

Sociodemographic and medical information included: age, sex, race, number of prior concussions, history of neurodevelopmental disorder diagnoses, school type (public school, private school, homeschool), school level (middle or high school), preinjury special education supports/ academic accommodations, date and mechanism of concussion injury (sports- and recreation-related, non-sports-related), and participation in organized sports/recreational activities. Middle school was defined as grades 6 through 8 and high school as grades 9 through 12. Parents also reported their own sociodemographic information including age, sex, race, and family income.

Communication Comfort Ratings and Reasoning

During the enrollment visit, youth participants were asked a question developed for this study: "*How comfortable do you feel talking to the following individuals about your concussion and related symptoms?*" (See Appendix B). Participants were then asked to rate their level of comfort (1 = *not at all*, 2 = *a little*, 3 = *somewhat* , or 4 = *very*), in communicating with each of the following individuals: parents/legal guardians, physicians, teachers, school nurses, principals, guidance counselors, coaches, athletic trainers, teammates, and friends/classmates. A response option of *not applicable* was provided for youth who did not have a school nurse, athletic trainer, coach, or teammates to rate. For any response lower than *"very comfortable,"* participants were asked to describe the reason for their lower rating (See Appendix B).

As four school personnel (e.g., teacher, school nurse, principal, guidance counselor) within the school system of care were queried about, communication comfort ratings were averaged to create a mean school comfort rating. An average instead of a sum of ratings was used because some participants were in schools without nurses or guidance counselors and thus did not rate communication comfort levels with those individuals. Internal consistency for the four individuals in the school system was good (Cronbach's alpha = 0.78). Similarly, an average communication comfort rating for those in the athletic system of care (e.g., coach, athletic trainer, teammates) was calculated. Internal consistency for all three individuals in the athletic system was good (Cronbach's alpha = .78); however, only 50 of the 67 participants considered athletes had athletic trainers to report a communication comfort level for. Given this, internal consistency between ratings of coaches and teammates was calculated and found to be higher (Cronbach's alpha = .85). All analyses were conducted with the mean rating of all three, coach/teammate mean rating, and individual athletic trainer rating. There were substantive differences in the results in which it appeared that noteworthy relationships between factors of interest and mean rating across all athletic personnel were either being driven by communication comfort with athletic trainers only or by the mean rating of coaches and teammates. Due to those findings, a mean coach/teammate communication comfort rating was calculated to use in analyses while athletic trainer communication comfort ratings were evaluated independently.

Return-to-Learn

Parents were prospectively asked about their child's current stage of RTL during each follow-up phone call. For the purposes of this study, full RTL was defined as the

resumption of full cognitive workload with no accommodations or only with accommodations the child had in place prior to the concussion injury. Participants also needed to be attending school for full days to be considered in the full RTL stage. The date when the participant reached full RTL was recorded. The number of days between the date of the concussion injury and full RTL was calculated for data analyses. Some participants did not achieve full RTL status by the end of the 12-week study period. To complete quantitative analyses, days to RTL was capped as the number of days between injury and the last follow-up phone call plus one.

Return-to-Play

Parents also reported on their child's RTP status during each follow-up phone call. For this project, full RTP was defined as clearance by a medical provider to engage in normal game play or competition. The date when the adolescent participant reached full RTP was recorded and days from injury to RTP was calculated. Given that the primary outcome measure for the parent study of this project was time to RTL, some participants were not followed for long enough to determine the date of full RTP and so those data were considered missing. For those that completed a total of 8 follow-up phone calls, but had not reached full RTP, days to RTP was capped as the number of days between injury and the last follow-up phone call plus one.

Prolonged Recovery Status

To determine if a participant had a "prolonged recovery," those who experienced any persistent postconcussion symptoms 28 days after injury were coded as 1 = *yes* while those who had symptoms resolve in 28 days were coded as 0 = *no.*

Concussion Symptomatology and Severity

The *Sport Concussion Assessment Tool – 3rd Edition* (SCAT3) and *Child Sport Concussion Assessment Tool – 3rd Edition* (Child-SCAT3) are standardized tools for evaluating youth for a possible concussion (Eckner & Kutcher, 2010; McCrory et al., 2005; McCrory et al., 2013). The SCAT3 was developed for children ages 13 and older while the Child-SCAT3 was developed for children between ages 5 to 12. The SCAT3 provides a *symptom score* (number of symptoms present) and *symptom severity score* (severity of symptoms ranked). A *Total Symptom Score* is calculated by adding up the number of 22 possible symptoms endorsed (0 = *no symptoms endorsed*, 22 = *all symptoms endorsed*). A *Symptom Severity Score* is calculated by adding up the severity ratings (0 = *none*, 1 or 2 = *mild*, 3 or 4 = *moderate*, 5 or 6 = *severe*) for every symptom for a possible range of 0 to 132. The Child-SCAT3 is similar in that it provides a *symptom score* and a *symptom severity score*, but severity ratings for individual symptoms range from 0 to 3 (0 = *never*, 1 = *rarely*, 2 = *sometimes*, 3 = *often).* Additionally, there are only 20 symptoms to rate, for a *Total Symptom Severity Score* ranging from 0 to 60. Another unique aspect of the Child-SCAT3 is that there are two sections for symptom reporting – one for the child to complete and another for the parent to complete. The SCAT3 and Child-SCAT3 also include a brief assessment of cognitive functioning via the *Standardized Assessment of Concussion* (SAC

and SAC-C), respectively. Symptoms queried about are different on each measure, which did not allow for combining scores from each measure into one variable. Thus, analyses were conducted independently with SCAT3 and Child-SCAT3 symptom severity scores. The SCAT3 demonstrates excellent face validity and fair test-retest reliability (McCrory et al., 2013). For post-injury symptom severity on the SCAT3, sensitivity was 0.73 and specificity was 0.76 (Chin, Nelson, Barr, McCrory, & McCrea, 2016).

Emotional Functioning

Emotional functioning was assessed with the *Beck Youth Inventories of Emotional and Social Impairment, Second Edition* (BYI-2) during the in-clinic enrollment visit, which was within 14 days of injury (Beck, Beck, Jolly, & Steer, 2005). Only the depression and anxiety subtests of the BYI-2 were administered for the purposes of this study given the potential impact of a concussion on mental health. Both measures are self-report questionnaires with 20-items consisting of a 4-point Likert scale and are standardized for use in youth between the ages of 7 and 18 (Beck et al., 2005). For each item, youth rated if they *never, sometimes, often,* or *always* thought or felt a certain way over the past two weeks. An example item from the depression subtest is, "I think that my life is bad" and an example item from the anxiety subtest is, "I worry about the future." The sum score for each measure ranges from 0 to 60 as *never* = 0, *sometimes* = 1, *often* = 2, and *always* = 3. Higher scores indicate greater depression or anxiety severity. Sum scores were converted to standardized T-scores based on the published gender and age norms within the BYI-2 manual (Beck et al., 2005). T-scores for each measure were used for analyses rather than the raw scores. An average T score is 50, with a standard deviation of 10. For these measures, T

scores between 40 and 59 are considered in the normal range, T scores between 60 and 69 are in the moderately elevated/at risk range, and T scores 70 and above are extremely elevated and of clinical significance. The psychometric properties of these scales among pediatric populations has been deemed excellent and internal consistency on the depression scale was $\alpha = 0.93$ in one study (Beck et al., 2005; Davis & Humphrey, 2012).

Statistical Analyses

Descriptive statistics were generated for participant sociodemographic variables, injury factors, and concussion recovery variables. Frequencies were completed to summarize the percentage of adolescents who endorsed each communication comfort level for each individual within each system of care.

Given the ordinal nature and non-normal distribution of the communication comfort data, nonparametric analyses were utilized. Spearman's correlations were conducted to evaluate the relationship of communication comfort ratings and the following variables: age, family income range (entered as ordinal), concussion symptom severity, depression self-report ratings, anxiety self-report ratings, academic grades/performance (entered as ordinal), days to reach full RTL, and days to reach full RTP. For dichotomous variables, Mann-Whitney U tests were conducted to determine differences between groups on levels of communication comfort. The following dichotomous variables were evaluated: sex (male or female), race (minority or non-minority), history of at least one prior concussion (yes or no), history of ADHD (yes or no), school type (public school or private school), school level (middle school or high school), special education supports or academic accommodations prior to concussion (yes or no), involvement in organized athletics (yes or

no), mechanism of concussion injury (sports- and recreation-related or non-sports-related), and recovery status determined by presence of persistent concussion symptoms 28 days post-injury (yes or no). For the Mann-Whitney U tests, the distribution shape of the communication comfort ratings between groups were assessed by visual inspection. Since almost all variables exhibited different distribution shapes between groups, mean rank values are reported. The assumption of homogeneity of variance was not violated for any of the Mann-Whitney U tests. Because only a few participants (n = 4) reported a premorbid history of a mental health condition, analyses were not conducted with that variable. Additionally, there were only three athletes who sustained non-sports-related injuries, so comparisons regarding the mechanism injury and communication comfort with coaches, teammates, and athletic trainers were not performed. Given the overall sample size and unbalanced groups for some dichotomous variables, nonsignificant relationships with notable effect sizes are also described in the results section. Strength of correlation relationships (r_s) were evaluated using the conventions from Cohen (1988) as follows: .10 to .29 = *small*, .30 to .49 = *medium*, and ≥ .50 = *large*. Regarding the Mann-Whitney U tests, Cohen's *d* (hereafter *d*) was calculated for the effect size statistic and classified using the following conventions also from Cohen (1988) 0.20 to 0.49 = *small*, 0.50 to 0.79 = *medium*, and ≥ 0.80 = *large*. Statistical significance was set at $p < .05$. SPSS software Version 25 was used to conduct the statistical analyses.

A qualitative content analysis approach was applied to derive themes for reasons why adolescents reported lower communication comfort ratings with each system of care. To facilitate initial coding and review of the participant's comments, the qualitative data analysis software program, NVivo 13, was utilized. Two researchers independently

reviewed responses and developed themes. The researchers used an iterative process to combine the independently generated themes into final themes. The two researchers then independently coded participant responses based on the agreed upon themes. Of note, some participant responses received multiple codes depending on the length and detail of the comment. After all responses were independently coded, the two researchers came together to reach a consensus on the appropriate code(s) for each statement. For responses that were not agreed upon initially, the researchers discussed and conferred with a third investigator to assign final codes. During this stage, some themes were collapsed together or further modified. The frequency of occurrence for each theme was tabulated to determine the most frequent themes reported by the adolescent participants for each system of care.

RESULTS

Participant Characteristics

A total of N = 74 parent-child dyads were enrolled in the study. One dyad withdrew due to time constraints before completing all enrollment questionnaires, leaving a final sample of N = 73 for analyses. Descriptive characteristics can be found in Table 1. Average age of the adolescent participants was 14.4 years (*SD* = 1.8). Slightly over half of the adolescent participants were male (61.6%, *n* = 45) and 28 (38.4%) were female. Most of the concussions were sustained through sports- and recreation- activities (90.4%, *n* = 66). Though there were a variety of sports- and recreation-related activities resulting in concussion, contact or collision prone sports such as football (40.9%) and soccer (18.2%) were the most frequent causes. Of the non-sports-related causes, the most common mechanism of injury included striking the head against a stationary object (42.9%), followed by motor vehicle accidents (28.6%) and assaults/fighting (28.6%). Participants enrolled in the study approximately 8.6 days after injury (*SD* = 3.7). For annual household income, the majority of parents reported family earnings above $60,000 and 21.9% (*n* = 16) below $59,999; six parents declined to report estimated income. All follow-up phone calls were completed by 87.7% (*n* = 64) of the dyads.

Emotional Functioning

Regarding emotional functioning, overall mean T scores for the depression subtest (M = 44.6, SD = 6.2) and anxiety subtest (M = 46.8, SD = 8.8) of the BYI-2 were in the normal range. Depression T scores were positively correlated with symptom severity endorsed for sadness (r_s = .294, p = .024) and irritability (r_s = .267, p = .041) on the SCAT3. Anxiety T scores were positively correlated with the symptom severity endorsed for SCAT3 sadness (r_s = .334, p = .010), irritability (r_s = .282, p = .030), and emotionality (r_s = .343, p = .008) on the SCAT3. SCAT3 nervousness/anxiousness symptom severity was not significantly associated with anxiety T scores (r_s = .201, p = .127).

Communication Comfort Levels and Reasons for Lower Communication Comfort with Systems of Care

Family and Medical Systems of Care

Table 2 summarizes the frequency of communication comfort levels for personnel across each system of care. Overall, adolescents were *very comfortable* communicating about concussion related issues with their physicians (90%, n = 65) and parents (89.0%, n = 65). Around 8% (n = 6) reporting feeling *somewhat comfortable* and only 2.7% (n = 2) were *a little comfortable* with parents. Ratings for physicians were similar, as *somewhat* and *a little comfortable* were endorsed by only = 8.3% (n = 6) and 1.4% (n = 1), respectively. One participant did not provide a rating for his physician because he was only seen in the emergency room for his concussion and did not have follow-up with a sports medicine physician. No participants reported being *not at all comfortable* communicating with their parents or physicians. For the family system of care (i.e., parents) the mean

communication comfort rating was 3.86 (*SD* = 0.42) and the median 4.00. For the medical system of care (i.e., physicians) the mean communication comfort rating was 3.89 (*SD* = 0.36) and the median 4.00.

Those that endorsed a rating of less than *very comfortable* communicating with their parents gave reasons that fell into the following themes: worry that their parents would overreact (2 counts), discomfort in sharing thoughts (1 count), poor communication style of a parent (1 count), lack of understanding from a parent (1 count), concern of having disappointed a parent (1 count), and feeling weird about having an "invisible" injury (1 count). As only a few participants endorsed lower communication comfort levels with physicians, just four themes were derived: a lack of an established relationship with the physician (2 counts), general discomfort and hesitation in sharing thoughts (2 counts), feeling scared or nervous (2 counts), and dislike of previous medical professionals (1 count). A rank ordered list of themes and example comments for the family and medical systems of care can be found in Tables 3 and 4, respectively.

Friends and Classmates

Slightly less than half (45.2%, *n* = 33) of adolescents reported feeling *very comfortable* communicating with their friends and classmates, while 32.9% (*n* = 24) were *somewhat comfortable*, 16.4% (*n* = 12) *a little comfortable*, and 5.5% (*n* = 4) *not at all comfortable*. The mean communication comfort rating was 3.19 (*SD* = 0.91) and the median 3.00. The themes for lower communication comfort ratings with friends and classmates included: a perception their peers would not understand (10 counts), a desire to maintain some privacy (8 counts), a lack of relationship closeness (7 counts), mistrust (5 counts), concern of

being teased or bullied (5 counts), worry about being treated differently (4 counts), and miscellaneous reasons (6 counts). A rank ordered list of themes and example comments can be found in Table 5.

School System of Care

Table 2 displays reported communication comfort levels with individual personnel who are part of the school system of care. Across all participants, the average school communication comfort rating was 2.90 (*SD* = 0.75) and the median 3.00. Only 11% of participants (n = 8) rated *very comfortable* for all individuals in their school system of care. The greatest percentage of participants were *very comfortable* communicating with school nurses (50.0%, *n* = 31) followed by guidance counselors (44.3%, *n* = 27). An additional 29.0% (*n* = 18) and 21.3% (*n* = 13) of participants were *somewhat comfortable* communicating with school nurses and guidance counselors, respectively. Greater variability was observed in the ratings of communication comfort among teachers and principals. Approximately a quarter of participants reported feeling *very comfortable* communicating with teachers (23.3%, *n* = 17) while the most common rating for teachers was *somewhat comfortable* (46.6%, *n* = 34). For principals, the most common rating was *a little comfortable* (31.5%, *n* = 23) with only a fourth of participants feeling *very comfortable* (27.4%, *n* = 20). Of note, for the participants enrolled at private schools, 10 did not have a school nurse and 6 did not have a guidance counselor to rate communication comfort levels for. Additionally, 5 middle school students and 1 high school student in public schools reported not having a guidance counselor. Only 1 participant in a public school did not have a school nurse.

Regarding barriers to feeling comfortable communicating with the school system of care, 13 themes emerged. The most comments fit into the theme of not knowing well enough or not having a quality relationship with school personnel (78 counts). The majority of responses for communication comfort with principals (31 counts), guidance counselors (19 counts), and school nurses (16 counts) were coded under that theme. The next most common theme for the school system of care overall were adolescents' perceptions that school personnel lack understanding of concussions and would be dismissive (24 counts). A view that school personnel do not have a role or are not able to help with concussions was also a frequent theme (23 counts). Numerous adolescents noted the moods or personalities of certain individuals at their school were a barrier to communication as those staff members were not approachable (14 counts). Adolescents expressed concern about how school personnel would react to information about the concussion (13 counts) and that educators would perceive them as seeking secondary gains like faking symptoms to get out of work (13 counts). Some adolescents believed school personnel would not care about their concussions (11 counts), be too busy to be involved (8 counts), and disregard academic accommodations by pressuring them to finish work (9 counts). Additional themes distilled were mistrust (7 counts), nervousness or shyness (6 counts), a desire to maintain some privacy (6 counts), and miscellaneous reasons (4 counts). Table 6 includes themes and example comments for communication discomfort with the school system of care.

Athletic System of Care

Only participants who identified themselves as an athlete or being involved in an organized sports/recreational activity (n = 67) were included in analyses regarding

communication comfort with the athletic system. Of the 67 participants who were involved in athletics, 17 reported that an athletic trainer was not involved with their team or sport. Thus, all communication comfort percentages for athletic trainers are out of a subset (n = 50). Almost half of the sample (49.3%, n = 33) rated communication comfort as *very* for all personnel within their athletic system. The majority of adolescents reported feeling *very comfortable* communicating with their athletic trainers (74.0%, n = 37), coaches (64.2%, n = 43), and teammates (61.2%, n = 41). Another 26.9% (n = 18) stated they were *somewhat comfortable* communicating with their teammates while 19.4% (n = 13) and 14.0% (n = 7) were *somewhat comfortable* with coaches and athletic trainers, respectively. Only a handful of participants reported feeling *a little* or *not at all* comfortable with those in the athletic system (see Table 2).

Twelve themes were distilled for barriers to communication comfort with the athletic system of care. The most common theme was not knowing the coach, athletic trainer, or teammates well enough or lacking a quality relationship (17 counts). This was followed by the themes of lack of understanding, including a belief coaches, teammates, and athletic trainers would minimize and not take the concussion seriously (13 counts), as well as concern of being viewed negatively (7 counts). Other comments indicated concern of disclosure resulting in restrictions (5 counts) and others perceiving the athlete with concussion as seeking secondary gains through the injury (5 counts). Less common themes included: age or gender differences (5 counts), concern of disappointing (4 counts), the athletic personnel's mood or personality (3 counts), individuals being too busy (2 counts), a desire to maintain some privacy (2 counts), and miscellaneous (4 counts). Additionally, 4

participants made comments that were vague and thus coded as "no specific reason identified." A rank ordered list of themes and example comments are in Table 7.

Relationships Between Sociodemographic Characteristics and Communication Comfort

Spearman's correlations showed adolescent age and reported academic performance were not significantly related to communication comfort levels with any system of care. Mann-Whitney U tests revealed no significant differences between gender, race, and school type on communication comfort levels. Reported family income had a medium association with mean school communication comfort (r_s = .38, p = .002) such that those participants in a family with a higher income felt more comfortable communicating with school personnel.

Though nonsignificant, results of a Mann-Whitney U test indicated a small effect of gender on communication comfort with athletic trainers (U = 251.0, p = .172, d = 0.39) as well as friends/classmates (U = 742.0, p = .173, d = 0.33) . The mean ranks (shown in Table 9) suggest females are slightly less comfortable than males communicating with their athletic trainers but are more comfortable than males communicating with their friends and classmates. There was also a small, but nonsignificant, effect of race on communication comfort with friends/classmates (U = 480.5, p = .175, d = 0.34) such that those in a minority group (mean rank = 32.5) appear to be less comfortable than those in the majority group (mean rank = 39.2) talking to their friends and classmates about their concussion injury.

Statistically significant differences in the distributions of communication comfort levels between middle school students and high school students with physicians (U = 738.5, p = .010, d = 0.62) and athletic trainers (U = 329.0, p = .031, d = 0.68) were observed. High

school students (mean rank = 39.2) were more comfortable communicating with physicians than middle school students (mean rank = 32.5). Of note, all but one high school student reported being *very comfortable* communicating with their physician while six middle school students were only *somewhat* or *a little comfortable*. Regarding communication comfort with athletic trainers, the mean rank of 27.6 for high school students was greater than the mean rank of 20.0 for middle school students. Though nonsignificant, there was a small effect of school level on communication comfort with school personnel (U = 813.0, p = .058, d = 0.45). Again, high school students indicated greater communication comfort (mean rank = 40.9) than middle school students (mean rank = 31.4). Additionally, there was a nonsignificant, but small difference in which participants in private schools (mean rank = 43.8) were more comfortable communicating with school personnel than those in public schools (mean rank = 34.3; U = 478.0, p = .131, d = 0.46).

Relationships Between Injury Characteristics and Communication Comfort

No statistically significant associations were found between adolescent self-report concussion symptom severity at time of enrollment and communication comfort levels; however, there were small, nonsignificant relationships between SCAT3 symptom severity and communication comfort with parents (r_s = .22, p = .085) and athletic trainers (r_s = -.23, p = .125). Only 13 participants age 12 and younger were administered the Child-SCAT3. With this small sample size in mind, there were nonsignificant, but small to medium strength inverse relationships between Child-SCAT3 symptom severity and mean school communication comfort (r_s = -.50, p = .083), friend communication comfort (r_s = -.43, p = .140), and mean coach/teammate communication comfort (r_s = -.53, p = .076).

Though not statistically significant, the difference in communication comfort with school personnel between those reported to be involved in organized athletics or recreational activities (mean rank = 38.0) versus those who were not (mean rank = 26.3) demonstrated a medium effect size (U = 265.0, p = .196, d = 0.55). Mechanism of concussion injury dichotomized as sports- and recreation-related and non-sports-related was not significantly related to communication comfort with the family, medical, school, or friend systems of care. Comparisons between the mechanism injury and communication comfort with coaches, teammates, and athletic trainers were not conducted because there were only three athletes who sustained non-sports-related injuries.

Relationships Between Recovery Outcomes and Communication Comfort

There were no significant associations between communication comfort levels with any system of care and days to RTL or days to RTP. However, there was a nonsignificant small in effect size difference in mean school communication comfort between those who experienced persistent concussion symptoms and those who did not (U = 520.5, p = .188, d = 0.31). Participants who ended up being symptom free 4 weeks past injury reported slightly higher comfort levels (mean rank = 40.2) communicating with school personnel than those who had persistent concussion symptoms (mean rank = 33.7).

Relationships Between Health Characteristics and Communication Comfort

Results of Mann-Whitney U tests revealed no significant differences in communication comfort levels with systems of care and prior concussion history. Regarding premorbid diagnoses, there was a statistically significant difference in communication comfort

ratings with physicians between participants with ADHD and those without (U = 362.0, p = .023, d = 0.64). The mean rank was 31.1 for participants with an ADHD diagnosis while the mean rank was 38.0 for those without, demonstrating those with an ADHD diagnoses were less comfortable communicating with their physicians. There was also a medium effect of ADHD history on communication comfort with the mean coach/teammate rating (U = 244.0, p = .065, d = 0.57). Again, those with ADHD (mean rank = 25.8) rated communication comfort lower than those without an ADHD diagnosis (mean rank = 36.0).

Given that the factor of previous accommodations at school is involved directly with the school environment, analyses were conducted with the communication comfort ratings of individual school personnel to evaluate for any potential differences. Only communication comfort with teachers was trending towards significance with a medium effect (U = 144.5, p = .083, d = 0.69). The 7 participants with academic accommodations prior to concussion injury had a mean rank of 24.6 while the mean rank for those with no previous accommodations was 38.3 for teacher communication comfort. Of note, all 7 participants with academic accommodations had an ADHD diagnosis. Interestingly, there was a large effect of having previous academic accommodations with mean coach/teammate communication comfort (U = 69.5, p = .039, d = 1.03). Those with prior accommodations (mean rank = 16.9) rated their communication comfort levels significantly lower than those without accommodations (mean rank = 35.4). The Mann-Whitney U test evaluating communication comfort levels with physicians between those with (mean rank = 29.9) and without (mean rank = 37.2) academic accommodations was approaching significance (U = 181.0, p = .085, d = 0.68). Finally, though nonsignificant, there was a medium effect between those with (mean rank = 27.4) and without (mean rank = 38.0) academic accommodations

and communication comfort levels with friends and classmates (U = 164.0, p = .178, d = 0.54).

Associations were found between adolescent self-report of emotional functioning and communication comfort with some of the systems of care. For example, there were significant inverse associations between both the BYI-2 anxiety and depression subtest T scores and communication comfort levels with friends/classmates (r_s = -.28, p = .016; r_s = -.26, p = .030). Additionally, mean school communication comfort was trending towards significance with anxiety subtest T scores (r_s = -.23, p = .051). The higher the anxiety or depression ratings, the lower the comfort level in communicating with those systems of care.

In summary, factors associated with communication comfort varied widely across the systems of care. For the family system of care, the only noteworthy relationship was between greater concussion symptom severity on the SCAT-3 and higher communication comfort levels, which was trending towards significance. Communication comfort ratings with the medical system of care were significantly lower for middle school students than high school students as well as adolescents with a history of ADHD as compared to those without. No other factors emerged for communication comfort with the medical system of care. Poorer emotional functioning was significantly associated with lower communication comfort levels with friends and classmates. Additionally, there were nonsignificant, but small effect sizes indicating that those in a minority racial/ethnic group as well as those with a history of pre-injury academic accommodations were less comfortable communicating with friends and classmates. The only factor significantly associated with communication comfort with the school system of care was family income, in which adolescents

from higher income homes rated communication comfort higher with school personnel; however, there were a number of nonsignificant relationships with noteworthy effect sizes between other variables and communication comfort with the school system of care. These included being in middle school, attending a public school, experiencing persistent post-concussion symptoms, not being involved in organized athletics or recreational activities, and higher anxiety ratings, all of which showed small to medium effect sizes on lower communication comfort with the school system of care.

Regarding communication comfort with the athletic system of care, there was a significant difference in the mean communication comfort ratings for coaches and teammates between those with and without academic accommodations prior to concussion injury as well as a medium effect size for a history of ADHD as compared to those without. Those with prior academic accommodations or history of ADHD were less comfortable communicating with coaches and teammates. Additionally, higher Child-SCAT3 symptom severity was trending towards significance with lower mean coach and teammate communication comfort ratings. Finally, communication comfort with athletic trainers was significantly lower for middle school students than high school students. Nonsignificant but small effects of gender (being male) and higher SCAT3 symptom severity were also observed for lower communication comfort with athletic trainers.

DISCUSSION

The current study examined adolescent communication comfort ratings with multiple systems of care following a concussion. The majority of adolescents reported feeling *very comfortable* communicating with family and medical systems of care. These findings are reassuring as parents are critical to coordinating their child's recovery between the systems of care and physicians are tasked with developing the treatment plans, providing reassurance, and monitoring overall recovery progress. Of the themes identified for lower communication comfort, parents being overreactive or overbearing about the concussion is consistent with prior literature from chronic illness (Ameringer et al, 2006; O'Toole et al., 2016). Other themes that emerged centered around feeling weird about having an invisible injury, perceiving disappointment from a parent, and a lack of understanding from a parent. Regarding communication comfort with physicians, it should be noted many of the participants had only met with their specialty sports medicine physician once or twice before enrollment in our study given that enrollment was within 14 days of injury. Thus, it is understandable that a couple of adolescents felt the relationship was not established and others felt scared, nervous, or hesitant in communicating with the physician treating their concussion. Data were not collected on which participants knew their physicians from a prior treatment episode, but it was not the majority since 68.5% of the sample were being treated for their first concussion. Parents and physicians are the gatekeepers for an adolescent with a concussion as they ultimately provide permission for the adolescent to return

to activities. Thus, it is important communication comfort levels are high; unfortunately, this may not translate into frequent and honest communication as adolescents may be motivated to underreport symptoms and inflate overall functioning.

Though the majority of adolescents (78%) reported feeling *very* or *somewhat comfortable* communicating with their friends and classmates about their concussion, the number that responded with *very comfortable* was fewer than expected. Wicklund and Coatsworth (2020) found that around 85% of adolescents disclosed possible concussion symptoms to peers. Lower comfort ratings for could be due to the fact friends and classmates were combined into a single category for adolescents to rate in our study. These terms carry different meanings to adolescents in which "friends" are people they choose to spend time around, typically have common interests with, and have positive sentiments towards (Brown & Larson, 2009). Classmates, on the other hand, could include one's friends but may also consist of individuals with which the adolescent has indifferent feelings toward (e.g., does not know well) or perhaps has an antagonistic relationship (e.g., bullies, former friends, competitors, or just another student whom they dislike) (Abecassis, Hartup, Haselager, Scholte, & Van Lieshout, 2002; Brown & Larson, 2009). The distinction between friends and classmates became clear from the qualitative data in which numerous comments referred to lack of friendship closeness and only trusting certain individuals. Even if respondents only answered the question for individuals they considered friends, the literature suggests adolescents have varying levels of relational ties across their different friendships (Giordano, 2003; Newcomb & Bagwell, 1995). In future studies of adolescent communication in the context of concussion, peer relationships should be

evaluated in two separate categories –one indicating the close circle of friends and the other classmates.

The mean ratings across all school personnel (M = 2.90, SD = 0.75) indicated adolescents had some hesitancy in feeling comfortable communicating with the school system of care overall. However, ratings of comfort levels across school personnel were variable. Results support the hypothesis that adolescents would be the most comfortable communicating with the school nurse out of all school personnel, but only half the sample reported being *very comfortable* with the school nurse. Given the school nurse is often the sole healthcare provider within the educational setting (Halstead et al., 2013; Wing, Amanullah, Jacobs, Clark, & Merritt, 2016), it is surprising the adolescents in this study were much less comfortable with their school nurse as compared to their physicians. Additionally, over half of adolescents reported being *somewhat* to *not at all comfortable* communicating with their guidance counselors. These findings are concerning as articles have described school nurses and guidance counselors as being integral parts of concussion management teams in schools. Additionally, RTL position papers recommend either individual (i.e., school nurse or guidance counselor) be the "point person" or "case manager" within the school for RTL management (Halstead et al., 2013; Sady et al., 2011).

Many participants reported discomfort communicating with school personnel due to lack of quality relationships or just not knowing the individual well, which was the top reason for discomfort for both school nurses and guidance counselors. Of the 78 counts for that theme, 31 (39.7%) were attributed to principals with many adolescents stating they never see or talk to their principals or other school administrators. Given many participants were from suburban areas with large schools, it makes sense a notable portion reported not

knowing their principals well. Some participants also stated the lack of a quality relationship with teachers as a barrier to communication. This is not surprising as there simply is not the opportunity for all students and teachers to develop strong relationships given the structure of middle and high schools in which students have multiple teachers and teachers have numerous students and enormous time demands. A handful of participants stated they are comfortable with just a few teachers, which is consistent with the work of Littlecott et al. (2018). The next most reported barrier to communication with the school system of care was that adolescents did not view school personnel as having a role or being able to help with the concussion. This may suggest some adolescents are unaware of the impact of concussion on school functioning. Without this knowledge, and some literature suggesting cognitive issues can persist past physical symptom resolution, some students may jump back into academic activities too soon, which can cause exacerbated symptoms and stall or backtrack their recovery (Gioia, 2016). Additionally, these results may imply school concussion management teams were not working with adolescents and their families about a RTL plan at the time of enrollment in our study.

Given the degree of academic impairment students can have from their concussion while in the acute and subacute phases of injury, it is concerning that three-fourths of adolescents felt less than very comfortable discussing these issues with their teachers. In addition to not knowing their teachers well, adolescents believed teachers would not understand about the concussion, were concerned teachers would think they were seeking secondary gains and were worried about their teachers' reactions. The latter two reasons are consistent with the inverse relationship between anxiety symptoms and school communication comfort we also found within our sample. Participant responses indicated that teachers were

the least understanding of all school personnel. Additionally, participants reported feeling as if their teachers perceived them as seeking out secondary gains such as reduced work. A hallmark of the recommended approaches to RTL is flexibility based on the student's symptoms. If teachers are not understanding of the fact students with concussion need academic accommodations and make it known (whether intentionally or unintentionally) that they think the student is trying to get out of it work, it could be harmful to the student's concussion recovery, quality of life, and psychosocial functioning (Brown et al., 2014). School personnel may also find providing accommodations to students with a concussion as a hassle amidst a busy job. Inadequate education and training for school personnel has been demonstrated, which may contribute to the themes we identified (Dreer et al., 2017; Janson et al., 2019; Weber, Welch, Parsons, & Valovich McLeod, 2015). Though training alone cannot completely shift attitudes school personnel have towards concussions, providing school personnel with empirically derived information on concussions and school could help improve knowledge and possibly understanding.

Considered together, our results suggest both adolescents and school personnel have a lack of knowledge on the transient academic impact of concussions. It appears that a portion of students (30%) do not have someone within the school environment that they feel *very comfortable* going to about their concussion related concerns. Fortunately, the majority (90.4%) said they were at least *somewhat comfortable* with one or more individuals in the school system of care, but that does not guarantee students will speak up when they need to because of the plethora of reasons the participants shared. Additionally, our findings indicate, parents and medical providers should not assume adolescents are going to be willing to share about their concussion and advocate for their needs, especially when

in the school environment. This may be a critical intervention point for healthcare providers to help develop self-efficacy within concussion patients and coach them on how to appropriately advocate for themselves.

Overall, communication comfort with the athletic system of care was high. Consistent with our hypothesis, participants reported being the most comfortable communicating with athletic trainers. The number of participants who gave the response of *very comfortable* communicating with coaches and teammates was larger than expected. Additionally, around half of the adolescents surveyed rated communication comfort as *very* for all individuals within their athletic system of care. These findings are encouraging as it indicates public health awareness campaigns and mandatory concussion education efforts may be positively impacting sports cultural norms. Though this is promising, there is still room for improvement as it would be ideal for all youth to be at least somewhat comfortable communicating about concussions with coaches, athletic trainers, and teammates.

The qualitative analysis conducted in the current study allowed for further insight into factors related to communication discomfort and the potential for concussion symptom underreporting in youth athletes. There is overlap between the themes we distilled and reasons for athlete non-disclosure summarized by Kerr et al. (2014). The similar themes include concern of being viewed negatively by others, fear of disappointing the team, concern of disclosure resulting in restrictions, and worry of symptoms being minimized. Our study adds to Kerr et al. (2014) in demonstrating lack of a quality relationships with athletic personnel and believing others to have a lack of understanding about concussions factors into one's propensity to communicate about concussions. The concerns reported by our sample were heavily related to the attitudes of others (i.e., interpersonal factors) and thus

how they would be perceived rather than intrapersonal factors. This is consistent with the literature suggesting concussion knowledge is not the primary driver of reporting behaviors; however, it is reasonable to assume that adolescents with poor knowledge and attitudes towards concussion injuries may project their own beliefs onto those in their athletic system of care. As Kroshus, Garnett, Hawrilenko, et al. (2015) reported, adolescent athletes do not always perceive team norms accurately and thus some of their fears and concerns communicating about their concussion may be unfounded. Future studies should determine what behaviors and messaging from athletic personnel promote both positive and negative concussion attitudes and beliefs. Additionally, more research is needed on how to effectively establish team cultures and social norms that encourage disclosure of concussions symptoms. Only two comments about communication with coaches were coded into the lack of understanding theme, while 6 comments for teammates were coded under that theme. Of note, lack of understanding was not a theme described for athletic trainers, possibly indicating youth with concussions acknowledge athletic trainers have extensive education and experience with concussions.

Lack of a quality relationship with or not knowing athletic personnel well was a surprising reason for discomfort in communication. This reason was reported 7 times as a reason for discomfort with athletic trainers and 5 times each for coaches and teammates. Regarding athletic trainers, this may be because they are not always involved with every sport. For example, one participant indicated that she was not sure if the school's athletic trainer was even involved with her high school track team and thus rated communication comfort as not at all. Additionally, considering the size of some sports teams (e.g., football, track), it makes sense one would not be close with every teammate. As far as not knowing

coaches well, if it is an athlete's first year on a team or the team has multiple coaches, a strong relationship may not be forged with all coaches. This issue has not been reported in the literature and adds another interpersonal factor to consider when evaluating the contextual determinants of concussion reporting and communication.

A handful of significant relationships emerged between the systems of care and demographic factors, injury characteristics, medical history, emotional functioning, and recovery outcomes. School level, self-report depression and anxiety symptoms, preinjury academic accommodations, and history of ADHD were associated with communication comfort for multiple systems of care, but not all were significant. Out of all factors assessed, school level was the only one that had significant differences for more than one system of care as middle school students rated communication comfort with physicians, athletic trainers, and school personnel lower than high school students. Higher self-report depression and anxiety symptoms were significantly associated with lower communication comfort with friends and classmates while higher anxiety was trending towards significance with lower communication comfort with the school system of care. Presence of preinjury academic accommodations was significantly related to lower communication comfort with coaches and teammates while there were small to medium effect sizes between prior academic accommodations and communication comfort with physicians, friends/classmates, and school personnel. History of ADHD was significantly associated with lower communication comfort with physicians and was trending toward significance with coaches and teammates.

Regarding school level and communication with physicians, a study from Klostermann et al. (2005) found younger adolescents were more concerned and uncertain

about confidentiality than their older counterparts, but privacy issues with the physician was not a theme or comment that emerged from our data. Another possibility is the difference in concussion awareness depending on age as Register-Mihalik et al. (2018) determined those over 12 years old had better knowledge about concussions. The finding that middle school students were less comfortable communicating with athletic trainers may be explained by the fact middle school is likely the first time they have encountered athletic trainers during their sports activities so they are not as familiar with them. By the time athletes are in high school and on a school affiliated team, they are likely used to having athletic trainers and going to the athletic trainers about injuries. Of note, about half of middle school students in our sample reported access to an athletic trainer whereas almost all (88%) of high schoolers involved in sports had athletic trainers. Middle school students find themselves in larger, more impersonal environments, with multiple teachers, and more independence than they had in elementary school, but without fully developed self-confidence which may contribute to the lower communication comfort levels with the school system of care that middle school students in this sample reported.

School type had a small effect on communication comfort in that those who attended private school were more comfortable communicating with school personnel than those who attended public schools. One explanation for this is that private schools are often much smaller allowing students and staff the opportunity to get to know each other better. There was a positive correlation between family income and communication comfort with the school system of care. Families who have higher incomes may live in school districts with more resources to support a student recovering from concussion, which could account for this finding. However, these schools may also have high expectations for students and

may not be as forgiving of missed class and assignments. Lending support to this, of the 8 participants who made comments coded into the theme of feeling pressured to complete schoolwork, all but one were in families with incomes above $60,000 per year.

Though nonsignificant, the observed small effect of females being less comfortable than males communicating with their athletic trainers is opposed to literature that suggests male athletes are less likely to report concussion symptoms (Kroshus, Garnett, Hawrilenko, et al., 2015; Sullivan & Molcho, 2018; Torres et al., 2013; Wallace et al., 2017). Regarding the factor of race, there was a small, nonsignificant difference in communication comfort with friends/classmates between those of a minority racial or ethnic group and those in the majority such that minority participants felt less comfortable talking to friends and classmates. This may be a result of certain cultural norms in communicating about medical conditions, though if this factor was a significant contributor, we may have seen racial differences in communication comfort with other systems of care.

Our findings showed inverse associations between symptom severity and communication comfort levels with school personnel, friends, coaches, and teammates for participants ages 12 and younger. Of note, there were only 13 participants in this portion of the sample, so the results were not statistically significant, but had medium to large effect sizes. Given similar relationships were not observed for the 60 participants above age 12 that were administered to the SCAT3, results should be interpreted with caution. For the 60 participants above age 12, there were nonsignificant small relationships between symptom severity and communication comfort with parents and athletic trainers. Overall, symptom severity does not appear to significantly influence communication comfort levels in the acute stage of injury. It is possible symptom severity may impact communication comfort

if recovery takes longer than expected. Adolescents may come to feel like their symptoms are not taken seriously and do not want to talk about their concussion as people start to wonder why they "are not better by now," as we have anecdotally heard from working with concussion patients with persistent postconcussion symptoms. We found no noteworthy differences in communication comfort levels with any system of care and history of at least one prior concussion. This adds to the mixed literature about previous concussion impacting concussion attitudes and disclosure behaviors in which some have found no associations (Kroshus et al., 2018) and others indicated prior concussions contributed to less reporting of symptoms (Register-Mihalik et al., 2017; Torres et al., 2013).

Interestingly, adolescents with a history of ADHD were less comfortable communicating with physicians. Presumably, these adolescents have had more interactions with healthcare professionals in their lifetime and thus are familiar with medical appointments However, negative experiences at previous healthcare appointments could have impacted communication comfort with the concussion provider. One qualitative comment from a participant with a diagnosis of ADHD supports this as he said, "I have not liked my past doctors. I also did not like the physical therapists [that treated me] for my last concussion." Communication comfort with coaches and teammates was lower for those with an ADHD diagnosis as well as those that had academic accommodations in place before their concussions. Of note, every participant with prior academic accommodations also had an ADHD diagnosis. It is possible that some of the symptoms (e.g., impulsive behaviors, disruption, inattention) of ADHD have led to errors during sporting events or have been off putting to teammates and coaches during general interactions. Thus, relationships may not be as close

and so adolescents with ADHD are not as comfortable talking about their concussion with those individuals.

Though there were no notable differences between those with and without a history of an ADHD diagnosis and communication comfort with friends and classmates, there was a medium effect size between those with and without academic accommodations prior to injury. Participants who had academic accommodations may be more negatively impacted by ADHD symptoms, which can lead to peer relationship difficulties and being overlooked or rejected by peers (Gardner & Gerdes, 2015). Additionally, those with accommodations may have less confidence or self-esteem and a concussion is just another thing that makes them different from their peers. Thus, they are not comfortable discussing their concussions with friends and classmates. Notably, only one participant with previous academic accommodations reported being *very comfortable* communicating about his or her concussion with friends and classmates. Upon review of the actual responses these individuals gave about communication comfort, mistrust of others and desire to maintain privacy came up twice while concern of being treated differently came up once, in addition to two comments coded as miscellaneous. As far as the medium effect size in which those with prior academic accommodations were less comfortable communicating with teachers, it is likely those participants have various difficulties in the classroom. They may have had unpleasant interactions with teachers in the past, which contributed to the lower ratings. In fact, of the participants with academic accommodations, three said they did not like their teachers, two said their teachers would not understand, and one said he did not trust his teachers. The relationships between pre-injury academic accommodations and communication comfort are interesting and somewhat unexpected findings.

Regarding the emotional functioning of our participants in the subacute phase of concussion injury, only one participant had a depression T score one standard deviation above the mean while four participants had anxiety T scores one standard deviation above the mean. This suggests only a small portion of the study sample was at-risk for potentially clinically significant levels of depression and anxiety. Interestingly none of the participants who reported elevated levels of depression and anxiety were those with a history of a mental health condition. This may be because those individuals identified with a mental health condition were receiving treatment or had been treated in the past. We did not anticipate observing a large number of participants to have elevated symptoms on the BYI-2 because research indicates prior emotional symptoms worsen or new mood symptoms appear for the first time if concussion recovery progress is slow and we administered the measures within 14 days of injury (Eisenberg et al., 2013; Joyce, Labella, Carl, Lai, & Zelko, 2015). Overall, the rate of elevated symptoms and reported mental health conditions observed in our small sample size is comparable to national prevalence rates of mental health concerns for adolescents (Ghandour et al., 2019).

Adolescents with greater anxiety and depressive symptoms reported being less comfortable communicating with their friends and classmates. This is not surprising as adolescence is a time of determining one's identity along with the heightened awareness of the "expectations and opinions of peers" (Brown & Larson, 2009). Based on the themes distilled from the qualitative comments, such as concern of being treated differently, lack of understanding, and desire to maintain privacy, our sample appeared to care a great deal about how others perceived them and thus were possibly a little self-consciousness to talk about their concussion. A few participants described that friends who had been through a

concussion would understand the most and they would be comfortable speaking to those individuals, which is consistent with the literature in which youth are more likely to disclose about a medical condition if they perceive a shared experience with a peer (Kaushansky et al., 2017).

Limitations

Though this study adds to the gap in the concussion literature by examining adolescent perspectives about communicating with systems of care following concussion, it is not without limitations. Given the relatively small sample size, meaningful associations. between factors of interest and communication comfort ratings may not have been detected. Secondly, we only captured data from participants who disclosed concussion symptoms and were referred for additional medical evaluation at a specialty sports medicine clinic. Thus, our results are not generalizable to all adolescents, as some experience but do not report symptoms after an impact to the head. Additionally, these results may not be generalizable to families who only seek medical care from pediatricians, primary care physicians, and emergency departments. Approximately 60% of our participants continued to endorse concussion symptoms 28 days after injury, which is a much a greater percentage than expected based on the literature. Given our participants sought specialized evaluation and the prolonged recovery outcomes we observed, our sample may have been a more severely affected group of adolescents with concussion.

Another component to consider is the study design, in which participants were asked the communication comfort questions between 1 and 14 days after injury. Many of the participants who enrolled towards the end of the 14 day window already had experiences communicating with individuals in the systems of care about their concussion. Thus,

their answers were likely influenced by if those interactions were positive or negative. On the other hand, those who enrolled closer to their injury may not have been back to school or around their friends yet and thus rated communication comfort on anticipated rather than lived experiences. Given this was a cross sectional study, it is likely other biopsychosocial factors (e.g., personality traits, experiences with past medical conditions, friendship history, athletic skill, competition level) that were not evaluated in the current study may also be associated with communication comfort. Administration of a personality questionnaire measuring traits such as neuroticism, extraversion, and agreeableness would have been relevant to include in relation to communication comfort levels.

Future Studies

In the future, the strength and generalizability of the current findings could be further investigated by enrolling a larger sample size from a wider variety of medical settings (e.g., emergency department, primary care, urgent care, specialty clinics). We used communication comfort with parents as the proxy for the overall family system of care. Future studies should evaluate the family system in greater depth by inquiring about communicating comfort with siblings, grandparents, and possibly separating out ratings for mothers and fathers, as well as stepparents. Similarly, only one type of provider, the sports-medicine physician, was queried for the medical system of care communication comfort rating. Future studies could expand on this by asking about communication comfort with pediatricians, nurses, emergency department physicians and/or nursing staff, and other medical providers who may be involved in the adolescent's care later in concussion recovery. It would be interesting to conduct a follow-up with participants either after recovery or a few

months out from injury in which adolescents would be asked about their current communication comfort levels with the systems of care to make comparisons with the initial ratings. Also, with a second time point, it would be possible to prospectively assess changes in actual communication interactions across time along with factors related to potential changes. Future studies could aim to determine if reported communication comfort is predictive of the adolescent's actual behaviors. Finally, possible relationships between communication comfort and adolescent knowledge, general attitudes, and beliefs about concussion injuries should be assessed to further understand all the factors contributing to communication comfort levels.

Conclusions

Taking a mixed-methods approach to examining communication comfort levels allowed for an in-depth look at the perspectives of adolescents when speaking with others about their concussion and related needs. This project addressed a notable gap in concussion research as previous studies have only focused on youth athlete perspectives about symptom reporting intentions and behaviors. To our knowledge, this is the first study to evaluate adolescent communication comfort with school personnel and medical providers in the context of concussion. The themes such as poor relationship quality, perceived lack of understanding, concern of being viewed negatively, and a desire to maintain privacy provide insight on the real-world barriers to adolescents being active collaborators in their own concussion management. Those involved in the care of adolescents recovering from concussions cannot be expected to effectively manage symptoms if adolescents are not doing their part in communicating. Our results suggest there are portions of adolescents

who are not comfortable sharing about their concussion and related symptoms so it should not be assumed adolescents will speak up when they need to. This research can lead to improved recommendations on how all the systems of care can collaborate to best support an adolescent with a concussion because adolescent perspectives have been largely left out thus far. Effective and evidence-based concussion management strategies may reduce postinjury morbidities and expedite recovery.

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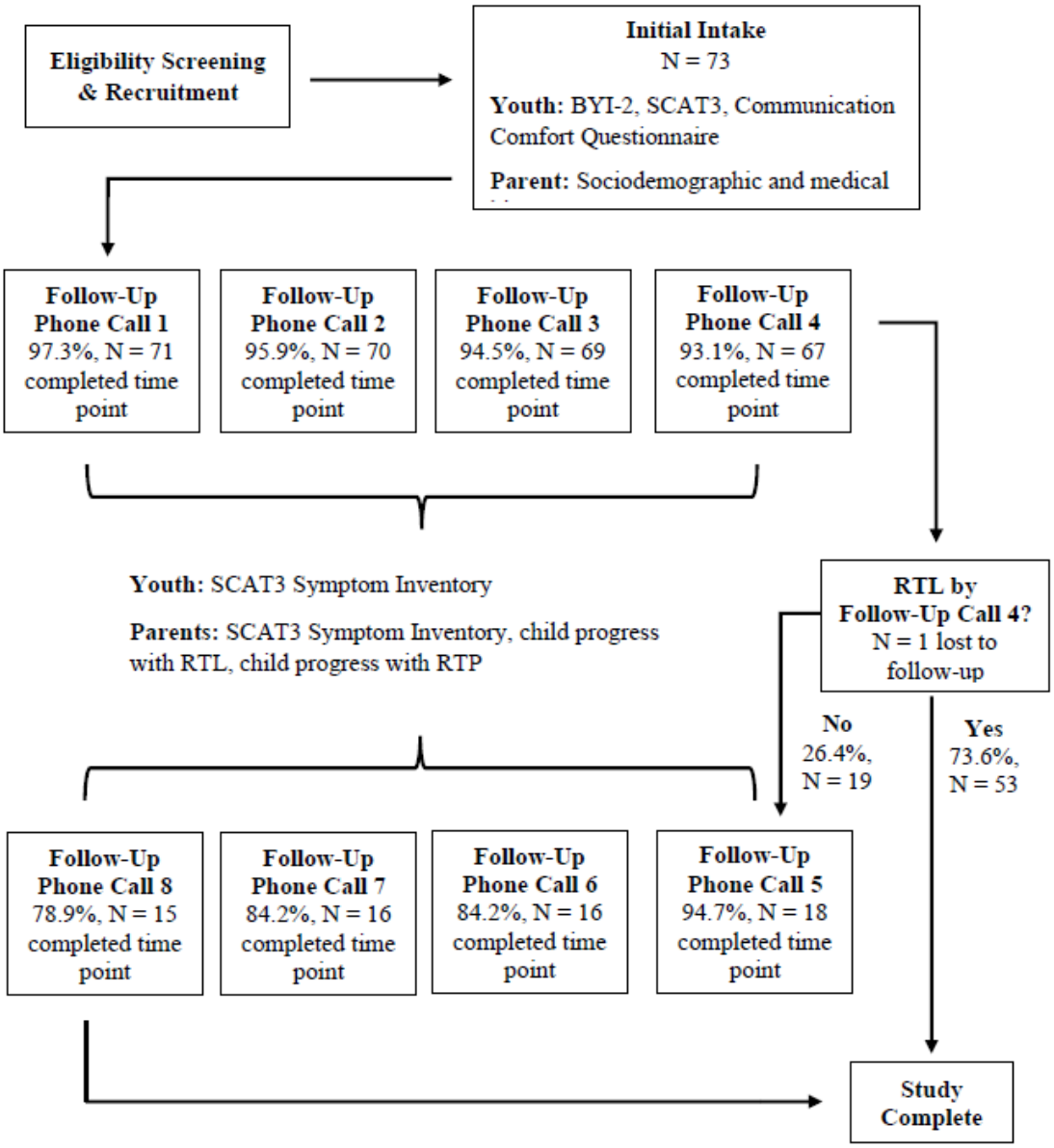
APPENDIX A

FLOW CHART OF DATA COLLECTION


Eligibility Screening & Recruitment
Initial Intake
N = 73
Youth: BYI-2, SCAT3, Communication Comfort Questionnaire
Parent: Sociodemographic and medical
Follow-Up Phone Call 1
97.3%, N = 71 completed time point
Follow-Up Phone Call 2
95.9%, N = 70 completed time point
Follow-Up Phone Call 3
94.5%, N = 69 completed time point
Follow-Up Phone Call 4
93.1%, N = 67 completed time point
Youth: SCAT3 Symptom Inventory
Parents: SCAT3 Symptom Inventory, child progress with RTL, child progress with RTP
RTL by Follow-Up Call 4?
N = 1 lost to follow-up
No
26.4%, N = 19
Yes
73.6%, N = 53
Follow-Up Phone Call 8
78.9%, N = 15 completed time point
Follow-Up Phone Call 7
84.2%, N = 16 completed time point
Follow-Up Phone Call 6
84.2%, N = 16 completed time point
Follow-Up Phone Call 5
94.7%, N = 18 completed time point
Study Complete

APPENDIX B

COMMUNICATION COMFORT RECORD FORM

Subject: _____

Additional Patient Questions

To be <u>orally administered</u> during the initial intake session

1. **How comfortable do you feel talking to the following individuals about your concussion and related symptoms?**

	Not at all	A Little	Somewhat	Very	N/A
1. Parents or Guardians	☐	☐	☐	☐	☐
2. Teachers	☐	☐	☐	☐	☐
3. School Nurse	☐	☐	☐	☐	☐
4. Principal	☐	☐	☐	☐	☐
5. Guidance Counselor	☐	☐	☐	☐	☐
6. School Psychologist	☐	☐	☐	☐	☐
7. Coach	☐	☐	☐	☐	☐
8. Athletic Trainer	☐	☐	☐	☐	☐
9. Friends/ Classmates	☐	☐	☐	☐	☐
10. Teammates	☐	☐	☐	☐	☐
11. Physician	☐	☐	☐	☐	☐
12. Other: Please list, _____	☐	☐	☐	☐	☐

2. **For any response "not at all", "a little", or "somewhat"** (in white) **ask the adolescent to please explain why.**

APPENDIX C

IRB APPROVAL FORMS

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

470 Administration Building
701 20th Street South
Birmingham, AL 35294-0104
205.934.3789 | Fax 205.934.1301 | irb@uab.edu

APPROVAL LETTER

TO: O'Neill, Jilian A

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance # FWA00005960
IORG Registration # IRB00000196 (IRB 01)
IORG Registration # IRB00000726 (IRB 02)

DATE: 12-Dec-2017

RE: IRB-151005006
Neuropsychological Functioning and Return to Learn Among Concussed

---

The IRB reviewed and approved the Continuing Review submitted on 11-Dec-2017 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Expedited (Category 7)
Determination: Approved
Approval Date: 12-Dec-2017
Approval Period: One Year
Expiration Date: 11-Dec-2018

The following populations are approved for inclusion in this project:

- Children

The following apply to this project related to informed consent and/or assent:

- Waiver (Partial) of HIPAA

Documents Included in Review:

- assent.clean.171208
- ipr.171122
- consent.clean.171211

Project Revision/Amendment Form

Form version: June 26, 2012

In MS Word, click in the white boxes and type your text; double-click checkboxes to check/uncheck.

- Federal regulations require IRB approval before implementing proposed changes. See Section 14 of the IRB Guidebook for Investigators for additional information.
- Change means any change, in content or form, to the protocol, consent form, or any supportive materials (such as the Investigator's Brochure, questionnaires, surveys, advertisements, etc.). See Item 4 for more examples.

RECEIVED AUG 12 2016 UAB IRB

1. Today's Date	8/1/2016	26149

2. Principal Investigator (PI)

Name (with degree)	Jilian O'Neill	Blazer ID	jnieman
Department	Psychology	Division (if applicable)	Medical Clinical Psychology
Office Address	UAB Department of Psychology, CH 415, 1530 3rd Avenue South, Birmingham, AL	Office Phone	586-707-1711
E-mail	jaoneill@uab.edu	Fax Number	N/A

Contact person who should receive copies of IRB correspondence (Optional)

Name	Laura Dreer, Ph.D./Mentor	E-Mail	lauradreer@uabmc.edu
Phone	(205) 325-8681	Fax Number	205-325-8692

Office Address (if different from PI)

UAB Department of Ophthalmology
Psych. & Neuropsych. Clinical Research Services
700 South 18th Street, Office H405
Birmingham, AL 35294-0009

3. UAB IRB Protocol Identification

3.a. Protocol Number	X151005006
3.b. Protocol Title	Neuropsychological Functioning and Return to Learn Among Concussed Adolescents

3.c. Current Status of Protocol—Check ONE box at left; provide numbers and dates where applicable

- ☐ Study has not yet begun — No participants, data, or specimens have been entered.
- ☒ In progress, open to accrual — Number of participants, data, or specimens entered: 16
- ☐ Enrollment temporarily suspended by sponsor
- ☐ Closed to accrual, but procedures continue as defined in the protocol (therapy, intervention, follow-up visits, etc.)
  - Date closed:
  - Number of participants receiving interventions:
  - Number of participants in long-term follow-up only:
- ☐ Closed to accrual, and only data analysis continues
  - Date closed:
  - Total number of participants entered:

4. Types of Change

Check all types of change that apply, and describe the changes in Item 5.c. or 5.d. as applicable. To help avoid delay in IRB review, please ensure that you provide the required materials and/or information for each type of change checked.

- ☐ **Protocol revision (change in the IRB-approved protocol)**
  In Item 5.c., if applicable, provide sponsor's protocol version number, amendment number, update number, etc.
- ☒ **Protocol amendment (addition to the IRB-approved protocol)**
  In Item 5.c., if applicable, provide funding application document from sponsor, as well as sponsor's protocol version number, amendment number, update number, etc.
- ☒ **Add or remove personnel**
  In Item 5.c., include name, title/degree, department/division, institutional affiliation, and role(s) in research, and address whether new personnel have any conflict of interest. See "Change in Principal Investigator" in the IRB Guidebook if the principal investigator is being changed.

☒ **Add graduate student(s) or postdoctoral fellow(s) working toward thesis, dissertation, or publication**
In Item 5.c., (a) identify these individuals by name; (b) provide the working title of the thesis, dissertation, or publication; and (c) indicate whether or not the student's analysis differs in any way from the purpose of the research described in the IRB-approved HSP (e.g., a secondary analysis of data obtained under this HSP).

☐ **Change in source of funding; change or add funding**
In Item 5.c., describe the change or addition in detail, include the applicable OSP proposal number(s), and provide a copy of the application as funded (or as submitted to the sponsor if pending). Note that some changes in funding may require a new IRB application.

☐ **Add or remove performance sites**
In Item 5.c., identify the site and location, and describe the research-related procedures performed there. If adding site(s), attach notification of permission or IRB approval to perform research there. Also include copy of subcontract, if applicable. If this protocol includes acting as the Coordinating Center for a study, attach IRB approval from any non-UAB site added.

☐ **Add or change a genetic component or storage of samples and/or data component—this could include data submissions for Genome-Wide Association Studies (GWAS)**
To assist you in revising or preparing your submission, please see the IRB Guidebook for Investigators or call the IRB office at 934-3789.

☐ **Suspend, re-open, or permanently close protocol to accrual of individuals, data, or samples (IRB approval to remain active)**
In Item 5.c., indicate the action, provide applicable dates and reasons for action; attach supporting documentation.

☐ **Report being forwarded to IRB (e.g., DSMB, sponsor or other monitor)**
In Item 5.c., include date and source of report, summarize findings, and indicate any recommendations.

☒ **Revise or amend consent, assent form(s)**
Complete Item 5.d.

☐ **Addendum (new) consent form**
Complete Item 5.d.

☐ **Add or revise recruitment materials**
Complete Item 5.d.

☐ **Other (e.g., investigator brochure)**
Indicate the type of change in the space below, and provide details in Item 5.c. or 5.d. as applicable.
Include a copy of all affected documents, with revisions highlighted as applicable.

▶

5. Description and Rationale

In Item 5.a. and 5.b, check Yes **or** No **and see instructions for** Yes **responses.**
In Item 5.c. and 5.d, describe—and explain the reason for—the change(s) noted in Item 4.

☐Yes ☒No **5.a. Are any of the participants enrolled as normal, healthy controls?**
If yes, describe in detail in Item 5.c. how this change will affect those participants.

☐Yes ☒No **5.b. Does the change affect subject participation, such as procedures, risks, costs, location of services, etc.?**
If yes, FAP-designated units complete a FAP submission and send to fap@uab.edu. Identify the FAP-designated unit in Item 5.c.
For more details on the UAB FAP, see www.uab.edu/cto.

5.c. Protocol Changes: In the space below, briefly describe—and explain the reason for—all change(s) to the protocol.

▶ We would like to add the following individual as a Co- Principal Investigator: **Sarah C Terry** (Graduate Student/Research Assistant, B.S., Doctoral Candidate, Department of Psychology; role will be to conduct recruitment, data collection and entry, and other project tasks; no conflict of interest; previous experience with neuropsychological testing, clinical research, and knowledge of concussion literature). "*Examination of Communication Patterns Between Systems of Care Following Pediatric Concussion*" is the title of this student's thesis which aims to examine parent communication patterns between systems of care (e.g., school, medical, sport/recreation). Secondary data analysis from that of the original HSP will also be conducted to characterize the population.

▶ In order to improve data collection, we are adding 3 questions to the initial child intake interview. Added questions can be found attached and labeled "Patient Concussion Communication."

▶ In order to improve data collection, we are adding 12 questions to the "Family Information Sheet." The revised form with new questions highlighted in yellow.

▶ In order to improve data collection, we are adding 4 questions to the "Follow-Up Phone Interview." A copy of the revised form with new questions highlighted in yellow.

▶ In order to gather more detailed information regarding parent/legal guardian communication with systems of care following concussion we are expanding "Additional Questions for Parents/Legal Guardian" to include method, satisfaction, frequency, and barriers of communication. A copy of the revised form, with new questions are highlighted in yellow.

5.d. Consent and Recruitment Changes: In the space below,
(a) describe all changes to IRB-approved forms or recruitment materials and the reasons for them;
(b) describe the reasons for the addition of any materials (e.g., addendum consent, recruitment); and
(c) indicate either how and when you will reconsent enrolled participants or why reconsenting is not necessary (not applicable for recruitment materials).

Also, indicate the number of forms changed or added. For new forms, provide 1 copy. For revised documents, provide 3 copies:
- **a copy of the currently approved document (showing the IRB approval stamp, if applicable)**
- **a revised copy highlighting all proposed changes with "tracked" changes**
- **a revised copy for the IRB approval stamp.**

▶ In order to compensate our parent/legal guardians participants, we are requesting to compensate them $25 (via check) for their involvement. They will be paid at the completion of the study.

▶ Reconsent is not necessary because the previously enrolled parent participants were not involved in this for this proposed thesis study and new form.

Signature of Principal Investigator Jillian O'Neill Date 8/11/16

FOR IRB USE ONLY

☐ Received & Noted ☑ Approved Expedited* ☐ To Convened IRB

Signature (Chair, Vice-Chair, Designee) 8/22/16 Date

DOLA 12/18/15

Change to Expedited Category Y / (N) / NA

*No change to IRB's previous determination of approval criteria at 45 CFR 46.111 or 21 CFR 56.111

Table 1. ***Descriptive characteristics of adolescent participants with a concussion***

Characteristic	*n* (%) or *M* (*SD*)
Age (years)	14.4 (1.8)
Gender	
Male	45 (61.6%)
Female	28 (38.4%)
Race	
Non-Minority	49 (67.1%)
Minority	24 (32.9%)
School level	
High School	43 (58.9%)
Middle School	30 (41.1%)
School type	
Public	58 (79.5%)
Private	13 (17.8%)
Homeschool	2 (2.7%)
Academic accommodations prior to concussion	
Yes	7 (9.6%)
No	66 (90.4%)
Days from injury to study enrollment	8.6 (3.7)
Concussion mechanism	
Sports- and recreation-related	66 (90.4%)
Non-sports-related	7 (9.6%)
Sports- and recreation-related injury causes [a]	
Football	27 (40.9%)
Soccer	12 (18.2%)
Physical Education Class	4 (6.1%)
Basketball	3 (4.5%)
Cheerleading	3 (4.5%)
Softball	3 (4.5%)
Bike Riding	2 (3.0%)
Equestrian	2 (3.0%)
Gymnastics	2 (3.0%)
Lacrosse	2 (3.0%)
Other [b]	6 (9.1%)
Non-sports-related injury causes [c]	
Struck head against stationary object (pole, wall, desk)	3 (42.9%)
Motor Vehicle Accident (MVA)	2 (28.6%)
Assault/Fighting	2 (28.6%)
Involved in athletics/recreational activities	
Yes	67 (91.8%)
No	6 (8.2%)
Previous concussion	
None	50 (68.5%)
One	16 (21.9%)
Two or more	7 (9.6%)

(*Continued*)

Characteristic	*n* (%) or *M* (*SD*)
Premorbid neurodevelopmental disorder diagnosis [d]	17 (23.3%)
Attention deficit hyperactivity disorder	16 (21.9%)
Learning disorder	4 (5.5%)
Autism spectrum disorder	1 (1.4%)
Premorbid mental health diagnosis [e]	4 (5.5%)
Anxiety	4 (5.5%)
Depression	1 (1.4%)
Oppositional defiant disorder	1 (1.4%)
Emotional functioning [f]	
Beck Youth Anxiety Inventory (T score)	46.8 (8.8)
Beck Youth Depression Inventory (T score)	44.6 (6.2)
SCAT3 symptoms severity	
Child-SCAT3 Total Severity Score Child Report [g]	20.2 (11.7)
SCAT3 Total Severity Score [h]	23.8 (21.7)
Experienced prolonged symptoms [i]	
Yes	43 (58.9%)
No	30 (41.1%)
Days to RTL	33.0 (28.1)
Days to RTP [j]	44.7 (33.6)

Note. n = 73. SCAT3 = Sports Concussion Assessment Tool – 3rd Edition; RTL = Return-to-Learn; RTP = Return-to-Play

[a] Percentages are out of n = 66 that had an SRR cause of injury. [b] Other category for SRR injuries include one each for baseball, colorguard, competitive swimming, playground activity, pull up bar, and track. [c] Percentages are out of n =7 that had non-SRR injuries. [d] The categories for neurodevelopmental disorders are not mutually exclusive, some participants had multiple diagnoses. [e] The categories for mental health diagnoses are not mutually exclusive, some participants had multiple diagnoses. [f] An average T score is 50, with a standard deviation of 10. T scores between 40 and 60 are considered in the normal range. [g] Child-SCAT3 Symptom Severity Scores range from 0 to 60 and n = 13. [h] SCAT3 Total Severity Scores range from 0 to 132 and n = 60. [i] Prolonged symptoms refers to experiencing symptoms 4 weeks or more after date of injury. [j] n = 56 as exact RTP outcome (days from injury) was not obtained for every participant.

Table 2. ***Adolescent communication comfort levels with individual personnel from all systems of care***

	Not at all, n (%)	***A little, n (%)***	***Somewhat, n (%)***	***Very, n (%)***
Family (Parents)	0 (0.0%)	2 (2.7%)	6 (8.2%)	65 (89.0%)
Medical [a] (Physician)	0 (0.0%)	1 (1.4%)	6 (8.3%)	65 (90.3%)
Friends/Classmates	4 (5.5%)	12 (16.4%)	24 (32.9%)	33 (45.2 %)
Teachers	4 (5.5%)	18 (24.7%)	34 (46.6%)	17 (23.3%)
School Nurse [b]	4 (6.5%)	9 (14.5%)	18 (29.0%)	31 (50.0%)
Guidance Counselor [c]	9 (14.8%)	12 (19.7%)	13 (21.3%)	27 (44.3%)
Principal	14 (19.2%)	23 (31.5%)	16 (21.9%)	20 (27.4%)
Coach	6 (9.0%)	5 (7.5%)	13 (19.4%)	43 (64.2%)
Athletic Trainer [d]	2 (4.0%)	4 (8.0%)	7 (14.0%)	37 (74.0%)
Teammates	3 (4.5%)	5 (7.5%)	18 (26.9%)	41 (61.2%)

Note. $n = 73$. [a] Percentages out of $n = 72$. [b] Percentages out of $n = 62$ as 11 participants reported they did not have a school nurse. [c] Percentages out of $n = 61$ as 12 participants reported they did not have a guidance counselor. [d] Percentages out of $n = 50$ as 17 participants, of the $n = 67$ involved in organized sports or recreational activities, did not have athletic trainers.

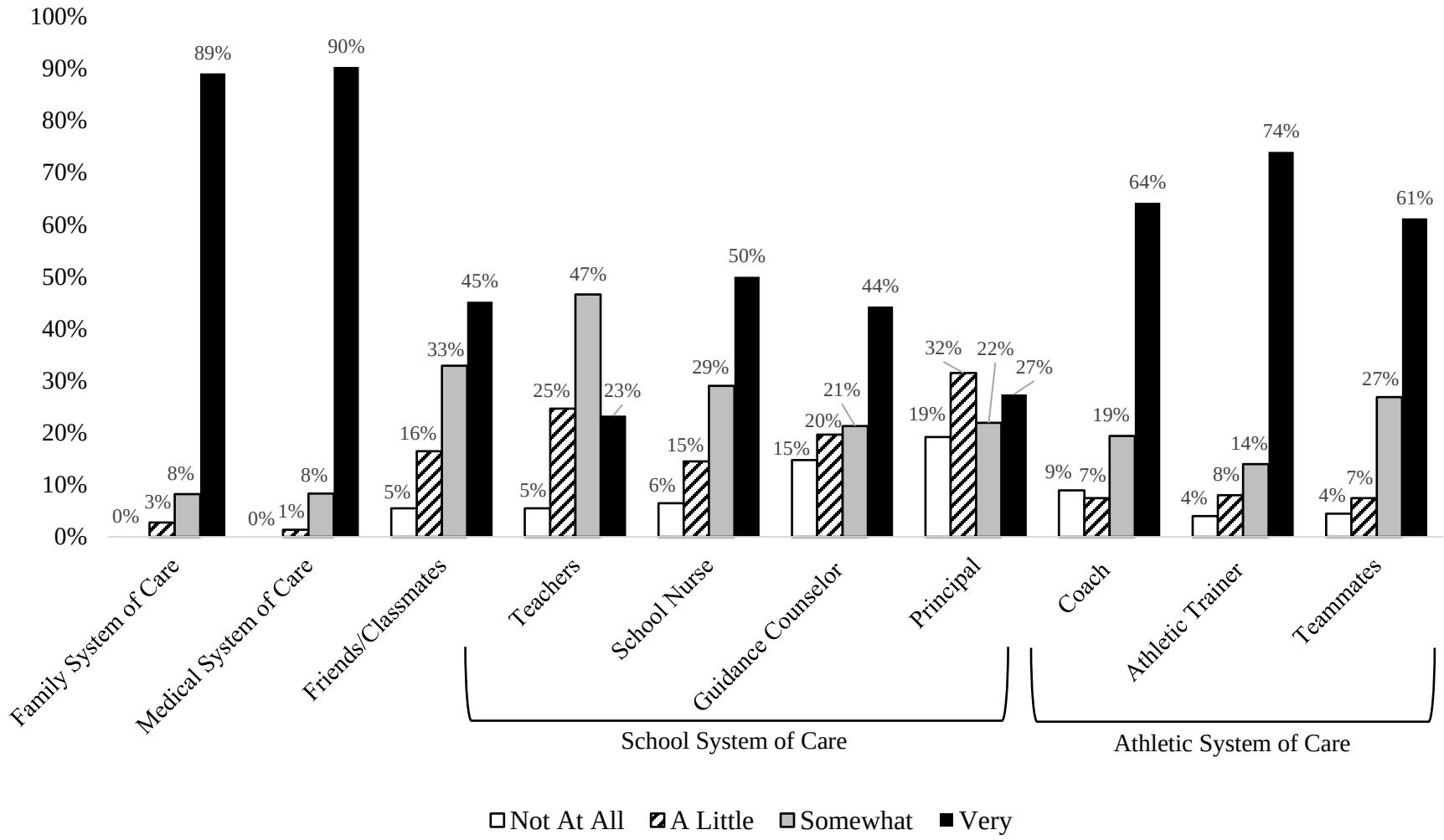


Figure 1. ***Adolescent communication comfort levels with individual personnel from all systems of care***

Table 3. ***Themes, examples, and frequency counts for lower communication comfort levels with the family system of care***

Theme	Examples	Theme Counts
1. Overreacting or overbearing parents	*"I feel like they would get upset that I was not feeling well. They would make me go to the doctor when nothing is wrong."* *"Sometimes they kind of do a little too much."*	2
2. Discomfort in sharing thoughts	*"I don't like talking about stuff that happens to me. I don't like talking about anything with others."*	1
3. Poor communication styles	*"Sometimes... It is just my mom. She gets ahead of herself. We don't communicate as well. We argue a lot. She finishes my sentences and it frustrates me."*	1
4. Lack of understanding	*"Human nature is to think you are faking it. [My] dad thinks I should get up and do things. He was not happy about me sitting around all day with my last concussion."*	1
5. Have disappointed	*"My biological dad has been a big encourager in me playing sports and helped me get where I am athletically. Now I am injured and cannot play after all that."*	1
6. Invisible injury	*"Something weird to have an injury like this. I am not wearing a cast or anything."*	1

Table 4. ***Themes, examples, and frequency counts for lower communication comfort levels with the medical system of care***

Theme	Examples	Theme Counts
1. Lack of established relationship	*"I am not that close with the physician."* *"I don't know them well enough."*	2
2. Discomfort in sharing thoughts	*"I am a little hesitant to share everything."* *"I don't know. I just don't like to talk to people."*	2
3. Feeling scared or nervous	*"The doctor makes me a little nervous."* *"I get scared. I think there might be something wrong and I don't know."*	2
4. Dislike of previous medical providers	*"I have not liked my past doctors. I also did not like the physical therapists [that treated me] for my last concussion."*	1

Table 5. ***Themes, examples, and frequency counts for lower communication comfort levels with friends and classmates***

Theme	Examples	Theme Counts
1. Lack of understanding	*"I don't feel like they would understand."* *"I think my friends that have not had a concussion might not fully understand."* *"No one would believe me. Missing a bunch of school is tricky. They expect you to be back at school unless you have something like a broken limb."*	10
2. Desire to maintain privacy	*"I don't want to say everything with them. I will tell them I have a concussion but I'm not going into the details."* *"I don't really want everyone knowing my business."* *"I don't want to share personal stuff."*	8
3. Lack of relationship closeness	*"I am only close to certain people."* *"I would tell my close friends but not all friends."* *"I am not as close with them as I am with my teammates."*	7
4. Mistrust	*"People have big mouths. I don't want them talking about confidential stuff."* *"I do not trust some of them as much as I trust others."* *"I can only trust some people."*	5
5. Concern of being teased or bullied	*"One of the guys was bullying me."* *"I don't want them to get too comfortable that they might do something that could hurt me if they were playing around."* *"I am worried that they will make fun of me because the guy who hit me was small."*	5
6. Concern of being treated differently	*"Because some of them might baby me. They keep asking me what is wrong and what happened, which is irritating."* *"They feel bad for me and I don't like it. They can be overprotective, and I just want them to treat me normally."* *"I don't want them to worry about me."*	4

(Continued)

7. Miscellaneous	*"They were cheering for me and now I can't play."* *"They can't do anything about it."* *"A lot of drama going on with some of them."* *"It is annoying that I have to repeat myself all the time."* *"I don't like telling everyone all my symptoms. I don't want to sound like I'm complaining."* *"They think I'm faking."*	6

Note. With the exception of the miscellaneous theme, three examples were selected per theme to illustrate the types of comments made by participants.

Table 6. ***Themes, examples, and frequency counts for lower communication comfort levels with the school system of care***

Theme	Teacher Examples	School Nurse Examples	Guidance Counselor Examples	Principal Examples	Theme Counts
1. Do not know well/Lack of quality relationship	*"Because I don't really know them that well to go up and talk to them about something not related to school."*	*"I don't have a connection with her. I don't go see her often."*	*"I don't know her that well. I met her maybe once."*	*"I don't really talk to him. Not a person I'd go to or want to go to."*	78
2. Minimization, dismissiveness, or lack of understanding	*"I feel they will downplay my situation."*	*"She was going to make me go back to class even when I was confused at school the other day."*	*"I feel like they don't understand."*	*"If I would talk to them about this, I don't think they would understand."*	24
3. Do not view school personnel as having a role or helping with concussion	*"I don't think they are responsible to know about my concussion."*	*"There would not be much she could do about it. She would just say to call my mom."*	*"The guidance counselors are there for guidance but not for things like concussions. They wouldn't know what to do about it."*	*"Because I just don't think it should matter. I do not feel like I will need to talk to them. I don't see their role in it."*	23
4. School personnel's mood or personality	*"A lot of them have a military personality and are stand-offish."*	*"She gives off an attitude that she does not want to get to know you or make a connection with you."*	*"She is mean."*	*"She scares me and is intimidating."*	14

(Continued)

5. Concern school personnel will perceive them as seeking secondary gains	*"It is awkward saying that I can't do a test or schoolwork because it seems like I'm saying that I have a concussion just to get out of doing the work."*	*"She might think I am faking it."*	*"I was scared they would think I was trying to get of something."*	—	13
6. Worried about the reaction of school personnel	*"I don't know what they are going to do with the info. Don't know if they will be angry or think that I can do more than I should be doing."*	—	*"I don't want to go to her and sound like I'm complaining."*	*"They could hold me out of sports if my symptoms are bad."*	13
7. Perception that school personnel do not care	*"Most of the teachers are boys so they probably don't care. Ladies would care and be more understanding."*	*"I feel like they don't care."*	*"They don't keep in touch with students' well-being."*	*"She does not care at all."*	11
8. Pressure to finish work or disregard for academic accommodations	*"They might tell me to do the work now and that I will get behind if I don't."*	—	*"I was expecting something different from her. I was complaining of not feeling well and being confused but she instead went right into a plan to get me back in class instead of addressing my complaints."*	*"With my past concussion … she did not let me exempt certain tests and assignments. She recommended I take the whole year over just because I missed two weeks of school."*	9

(Continued)

9. Perception that the individual is too busy	—	*"Each time I go, she is on the phone and I feel like I am disturbing her."*	*"They have more to worry about than my concussion so I would feel weird if they just came up to me and asked me about it."*	*"She seems to have a lot on her plate."*	8
10. Mistrust	*"Most teachers I'm somewhat comfortable with while others I'm very comfortable with. I trust some more than others."*	*"I don't trust her."*	*"I don't trust them. I don't know what they would do or who they would tell."*	*"I don't trust principals anymore because of a bad one [principal] I had."*	7
11. Nervous or shy with school personnel	*"I get nervous when talking to teachers."*	*"Because I'm shy when it comes to speaking to authority figures."* [a]	*"I am nervous to talk to them. They scare me."*	*"Because I'm shy when it comes to speaking to authority figures."* [a]	6
12. Desire to maintain some privacy	*"I don't want them to know all my business."*	*"I don't feel like they need to know all of the details."*	—	*"She already knows what happened, but I'm not very comfortable sharing everything with her."*	6
13. Miscellaneous	*"There are too many teachers."* *"They were cheering for me and now I can't play."* *"I would wait for teachers to approach me first. I would wait to give the details because the time does not need to be spent."*	—	—	*"Because he is a big authority. I don't think he should know."*	4

Note. With the exception of the miscellaneous theme, one example was chosen for each personnel type per theme to illustrate the types of comments made by adolescents. [a] One participant gave the same response for his school nurse and principal.

Table 7. ***Themes, examples, and frequency counts for lower communication comfort levels with the athletic system of care***

Theme	Coach Examples	Athletic Trainer Examples	Teammates Examples	Theme Counts
1. Do not know well/Lack of quality relationship	*"I am not really connected or close to any of them."*	*"She is nice, but I don't talk to her a lot. I don't know her very well."*	*"Some are my friends, but I don't know all of them well."*	17
2. Minimization, dismissiveness, or lack of understanding	*"Coaches are difficult. Last time I had a concussion, coach saw me running and thought I should be able to do weights and conditioning even though I was not cleared for that yet."*	—	*"Those that have had concussions I'd be comfortable with, but not those that have not had concussions."*	13
3. Concern of being viewed negatively by others	*"I don't want to sound like I'm complaining and like I can't do what I need to be doing."*	*"Because I don't want people to think I'm weak."*	*"I don't want them thinking that I am being dramatic because others have had worse."*	7
4. Concern of being perceived as seeking secondary gains	*"I was scared they would think I was trying to get out of something."*	—	*"They think I am faking."*	5
5. Concern of disclosure resulting in restrictions	*"If they know about it, I don't get to play. I'm not one of the kids who doesn't want to play. I do want to play."*	*"She can take me out of play."*	*"I just don't like telling everyone because then they might think I can't do stuff, like hang out."*	5
6. Age or gender differences	*"Since he is a guy… it is harder to talk to males about personal issues."*	*"She is young."*	*"I'm one of the oldest and tallest of kids on the team. They don't think that I can get hurt like that. I'm a leader on the team and I have to show them that I am worthy of being a team leader."*	5

(Continued)

7. Perception of disappointing them	*"He is disappointed that I can't play."*	—	*"I feel like I kind of let them down."*	4
8. Rather not share, no specific reason identified	*"I don't know. He is a good coach. No particular reason, just not as comfortable with him."*	*"I don't know."*	*"I don't really care to talk about it that much."*	4
9. Dislike of the individual or the individual's personality	*"She doesn't want to listen sometimes and jumps to conclusions."*	*"She is pretty mean. She yells and makes bad calls."*	—	3
10. Desire to maintain some privacy	—	—	*"I don't want them knowing details and extra facts about why it happened."*	2
11. Perception that the individual is too busy	*"I think he will be too worried about the team and football more. He is understanding about concussions, but I just don't want to bother or worry him."*	—	*"They need to focus on other things."*	2
12. Miscellaneous	*"He should know because you play for him."*	*"My athletic trainer should know because he treated it."*	*"Because all of them should already know."* *"I don't want them to get too comfortable that they might do something that could hurt me if they were playing around."*	4

Note. With the exception of the miscellaneous theme, one example was chosen for each personnel type per theme to illustrate the types of comments made by adolescents.

Table 8. ***Spearman correlations for adolescent communication comfort levels and sociodemographic, emotional, and injury characteristics***

System of Care	Age	Family Income	Sx Severity SCAT3	Sx Severity C-SCAT3	Depression BYI-2 T Score	Anxiety BYI-2 T Score	Academic Grades	Days to RTL	Days to RTP
Family	.18	.01	.22	-.07	-.16 [a]	-.17 [a]	-.15	.10	.16
Medical	.16	.08	.11	-.07	.02	-.02	-.07	-.12	-.16
Friends/Classmates	.01	.20	-.19	-.43	-.26*	-.28*	-.19	-.05	-.09
School	.08	.38**	.02	-.50	-.15	-.23	-.16	-.03	.00
Average Coach/Teammates	.11	.13	-.16	-.53	-.14	-.19	-.09	-.15	-.22
Athletic Trainer	.16	.10	-.23	-.16	-.12	-.06	-.01	-.24	-.17

Note. All tests were via nonparametric Spearman correlations (r_s) with pairwise deletions.

[a] One outlier was removed from each of these analyses.

Sx = Symptom; BYI-2 = Beck Youth Inventories of Emotional and Social Impairment, Second Edition; SCAT3 = Sports Concussion Assessment Tool – 3rd Edition; C-SCAT3 = Child Sports Concussion Assessment Tool – 3rd Edition; RTL = Return-to-Learn; RTP = Return-to-Play.

* $p < .05$ and ** $p < .01$.

Table 9. ***Mann-Whitney U tests for communication comfort levels across systems of care and sociodemographic, health history, and injury characteristics***

System of Care	Gender		*U*	*p*	*Cohen's d*
	Male (mean rank)	**Female** (mean rank)			
Family	36.2	38.3	667.0	.438	0.19
Medical	36.8	36.1	604.0	.787	0.07
Friends/Classmates	34.5	41.0	742.0	.173	0.33 [a]
School	36.2	38.2	596.0	.698	0.09
Average Coach/Teammates	33.7	34.4	551.0	.879	0.04
Athletic Trainer	27.3	23.0	251.0	.172	0.39 [a]
System of Care	**Race/Ethnicity**		***U***	***p***	***Cohen's d***
	Non-Minority (mean rank)	**Minority** (mean rank)			
Family	36.6	37.9	609.0	.649	0.11
Medical	35.5	38.5	624.5	.259	0.28 [a]
Friends/Classmates	39.2	32.5	480.5	.175	0.34 [a]
School	39.1	32.8	487.5	.235	0.30 [a]
Average Coach/Teammates	33.1	35.8	546.5	.561	0.15
Athletic Trainer	26.2	24.3	272.0	.559	0.17
System of Care	**School Type**		***U***	***p***	***Cohen's d***
	Public (mean rank)	**Private** (mean rank)			
Family	36.4	34.2	353.3	.499	0.21 [a]
Medical	35.5	35.6	372.0	.963	0.01
Friends/Classmates	36.8	32.6	332.5	.478	0.22 [a]
School	34.3	43.8	478.0	.131	0.46 [a]
Average Coach/Teammate	31.9	37.5	397.0	.293	0.33 [a]
Athletic Trainer	24.6	26.7	195.5	.694[†]	0.19

(Continued)

System of Care	School Level		*U*	*p*	*Cohen's d*
	Middle School (mean rank)	**High School** (mean rank)			
Family	35.0	38.4	706.5	.203	0.30 [a]
Medical	32.5	39.2	738.5	.010*	0.62 [b]
Friends/Classmates	39.8	35.0	560.0	.306	0.24 [a]
School	31.4	40.9	813.0	.058	0.45 [a]
Average Coach/Teammate	33.5	34.3	545.5	.861	0.04
Athletic Trainer	20.0	27.6	329.0	.031*	0.68 [b]
System of Care	**Experienced Persistent Postconcussion Symptoms**		***U***	***p***	***Cohen's d***
	Yes (mean rank)	**No** (mean rank)			
Family	36.5	36.5	635.5	1.00	0.00
Medical	35.2	37.1	583.5	.478	0.17
Friends/Classmates	35.2	38.2	584.0	.529	0.15
School	33.7	40.2	520.5	.188	0.31 [a]
Average Coach/Teammate	31.3	36.0	465.5	.281	0.27 [a]
Athletic Trainer	23.3	27.3	246.5	.202	0.37 [a]
System of Care	**Athlete Status**		***U***	***p***	***Cohen's d***
	Athlete (mean rank)	**Non-Athlete** (mean rank)			
Family	36.6	41.0	177.0	.374	0.38 [a]
Medical	36.7	34.1	212.5	.773[†]	0.24 [a]
Friends/Classmates	36.9	38.4	192.5	.855	0.08
School	38.0	26.3	265.0	.196	0.55 [b]
Average Coach/Teammate [d]	—	—	—	—	—
Athletic Trainer [d]	—	—	—	—	—

(Continued)

System of Care	History of ADHD		*U*	*p*	*Cohen's d*
	Yes (mean rank)	**No** (mean rank)			
Family	34.1	37.8	409.5	.252	0.32 [a]
Medical	31.1	38.0	362.0	.023*	0.64 [b]
Friends/Classmates	34.0	37.8	408.5	.497	0.19
School	35.2	37.5	427.5	.702	0.11
Average Coach/Teammate	25.8	36.0	244.0	.065	0.57 [b]
Athletic Trainer	24.7	25.7	206.0	.796	0.09
System of Care	**Presence of Academic Accommodations Prior to Injury**		***U***	***p***	***Cohen's d***
	Yes (mean rank)	**No** (mean rank)			
Family	35.9	37.1	223.5	.795	0.32 [a]
Medical	29.9	37.2	181.0	.085	0.68 [b]
Friends/Classmates	27.4	38.0	164.0	.178	0.54 [b]
School	28.6	37.9	172.5	.270	0.44 [a]
Average Coach/Teammate	16.9	35.4	69.5	.039*[†]	1.03 [c]
Athletic Trainer	25.1	25.5	90.5	.959[†]	0.04

Note. * $p < .05$. [†]exact sig. 2-sided.

[a] Small effect size $d = 0.20$ to 0.49. [b] Medium effect size $d = 0.50$ to 0.79. [c] Large effect size $d \geq 0.80$. [d] No comparisons were made given non-athletes do not have coaches, teammates, or athletic trainers to rate communication comfort with.