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# A qualitative study of barriers and opportunities for concussion communication and management among parents of youth sports athletes

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#### Abstract

**Background:** Concussion, a commonly reported injury among young athletes, can lead to shortand long-term physical, cognitive, emotional, and sleep-related symptoms. Parents are in a unique position to help identify a possible concussion and to support an athlete's recovery.

**Methods:** This qualitative study used a focus group methodology to explore five research questions focused on two main topics: (1) parents' perception of concussion and (2) parent—athlete communication. Two authors independently reviewed notes from each of the focus groups and then generated a list of emerging themes related to five research questions.

**Results:** Parents in this study valued and were interested in discussing concussion with their athletes. However, parents were uncertain about their role in promoting concussion safety and often rely on coaches to communicate with athletes about concussion reporting and recovery. Participants described barriers their athletes may face in concussion reporting and suggested strategies to improve communication about both reporting and recovery.

**Conclusion:** Concussion education efforts may benefit from promoting specific actions parents can take to prevent concussion and how to communicate effectively with their child about reporting a possible concussion.

#### **Keywords**

Parent; sport; education		

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# Introduction

A concussion is a type of traumatic brain injury caused by a bump, blow, or jolt to the head that causes the head and brain to move rapidly back and forth. Concussions can occur in a wide range of daily activities, such as from a fall or motor vehicle crash or during sports and recreational-related activities. In the recent Youth Behavior Risk Factor Survey, U.S. high school students were asked about their experience with concussion. Findings from this survey indicate that approximately 2.5 million students self-reported having had a sports- or recreational activity-related concussion within the last 12 months. It is unclear how many of these concussions were not reported by the athlete to a parent, coach, or athletic trainer.

Reporting a possible concussion is a critical first step to support positive health outcomes; however, underreporting of concussion is still pervasive. Rivara et al. followed 778 football players over the course of the season and conducted telephone-based interviews to assess for possible concussions. Through this process, researchers determined that of the athletes who reported having had a possible concussion, as many as 69% did not report their injury to their coach.<sup>3</sup>

Perceived social pressures (e.g. not wanting to let their team down) and concerns about losing play time or position on the team have been identified by researchers as potential barriers for concussion reporting among athletes.<sup>4,5</sup> Other factors include an uncertainty or lack of knowledge among athletes of concussion symptoms, as many concussion symptoms are not unique to this injury and may not be noticed by an athlete.<sup>4,5</sup> Identifying strategies to improve concussion reporting is critical, as athletes who continue to play with concussion symptoms are at risk for a repeat concussion or other serious brain injury, as well as a prolonged recovery.<sup>6</sup>

Parents are in a unique position to identify subtle changes in the ways their children are behaving or feeling that may indicate concussion. Parents also play an integral role in the concussion recovery process. Current evidence-based guidelines emphasize that parental and family support, which often entails ensuring that athletes follow appropriate return to school and play protocols, can help shorten recovery time and promote positive health outcomes.<sup>7</sup>

Previous studies have shown that parents are concerned about concussion. A recent survey found that 84% of parents believed that concussion is a critical issue. Another study found that 93% of parents agreed that all concussions are serious. While studies have assessed parents' knowledge and attitudes related to concussion, research is limited about how parents communicate with their young athletes about concussion and the actions they take to protect their young athletes from concussion. Devidence suggests parents can help promote positive concussion safety behaviors. Provance et al. assessed parents' influence on their child's helmet use while skiing or snowboarding and found that parents' helmetwearing behavior was strongly associated with the child/adolescent's helmet-wearing behavior. Kroshus et al. found that parents whose child had a previous concussion were more likely to communicate with their child about reporting a possible concussion, and that parents who perceived their child to be at higher risk of getting a concussion were more

likely to communicate with their child about reporting a possible concussion. However, there is uncertainty about how to and what to educate parents about concussion. <sup>12</sup>

To help identify information gaps that can support the development of education efforts, this study assessed perceptions of concussion among parents of young athletes between the ages of 12 and 18. In addition, this study assessed parent—athlete communication about concussion prevention, reporting, and recovery. Findings from this study can help inform ongoing efforts to support awareness of concussion among parents by the Centers for Disease Control and Prevention (CDC) and other key stakeholders working to protect athletes from this potentially devastating injury.

# Methodology

This qualitative research study used a grounded theory methodology and was a component of a larger mixed-methods research study that explored opportunities to improve concussion prevention, recognition, and response. <sup>13</sup> The larger mixed-method study is currently under review for publication and seeks to present findings from a social network analysis survey, as well as a detailed evaluation of the CDC HEADS UP campaign (a concussion education and awareness campaign). The findings reported in this study are of parents' perceptions, information needs, and experiences with concussion. To create an environment that promoted in-depth input on the topics from every participant during the time available, we conducted small focus groups. Using focus groups versus in-depth interviews also allowed for observations of the social and peer dynamics between parents. <sup>14</sup> In total, a series of six focus groups were conducted with parents, including: two groups of parents of female athletes, ages 12–14; one group of parents of female athletes, ages 15–18; one group of parents of male athletes, ages 12–14; and two groups of parents of male athletes, ages 15–18.

Potential participants were screened using a standardized screening form prior to their inclusion in the study. Participants were selected to increase diversity in age, race/ethnicity, U.S. census region (Northeast, Midwest, South, and West), and the sports played by athletes. <sup>15</sup> Our goal was to obtain a wide range of perspectives from people of different backgrounds instead of narrowly focusing on one or a select few of these criteria. This approach enabled us to learn from people with varying experiences, which was important given that concussion is an injury risk among athletes of all backgrounds. We also wanted to include parents of athletes who play sports in which contact or collisions are common (e.g. soccer, lacrosse, football) and thus there is an increased risk of concussion. <sup>16,17</sup> We excluded parents whose athletes only played sports that did not pose a notable risk for contact with other athletes and concussion risk is low, such as swimming and golf. <sup>16</sup> Focus groups included parents of athletes who played in youth sports or school-based sports programs.

Participants were recruited for this study in two different ways. First, parents were recruited using purposeful sampling through the CDC HEADS UP campaign partner network. The CDC HEADS UP partner network has over 85 organizations that help distribute concussion information across the country. Research staff sent email announcements to CDC HEADS UP partners that invited parents to voluntarily participate in the study. Parents recruited

through the CDC HEADS UP partner network had a child with a history of concussion and were knowledgeable about this injury. Thus, a professional focus group recruitment vendor was used to supplement recruitment efforts and identify participants who filled demographic criteria gaps, were less familiar with concussion, and did not have a child with a history of concussion. The vendor recruits through a national panel it maintains, as well as through targeted outreach to regional and local organizations based on specific recruitment criteria. The professional recruitment vendor recruited the majority of parents (83%) for this study.

Despite attempts to have equal distribution of participants from four U.S. census regions, recruitment efforts were more effective in Southern states. <sup>15</sup> For this reason, a larger number of parents from Southern states were included in the study. We were unable to recruit participants from the Northeast.

Data collection occurred via an online webinar platform and a toll-free telephone conference line. The online platform offers many advantages, such as eliminating travel time and costs, allowing parents from different states to participate in the same group at the same time, and enabling parents to join from the convenience of their own home. A trained moderator facilitated the discussion among parents using a standardized moderator guide that focused on five research questions that fall into two main topics: (1) parents' perception of concussion and (2) parent-athlete communication (Appendix 1). During the focus groups, the moderator continuously offered summary statements to the participants to check that their input was captured accurately. Each participant signed a consent form before the groups took place, and, at the beginning of the call, the moderator asked participants to verbally consent to participation in the discussion. To ensure privacy, the moderator used only participants' first names during the discussion. Additional research staff joined the call to take notes. An assistant moderator helped the moderator manage administrative aspects of the focus groups (e.g. dealing with participants who did not show or arrived late, starting the recording).<sup>18</sup> The virtual focus groups were audio recorded for notetaking purposes. Each focus group was 90 min in length.

Notes-based analysis was used to analyze the focus group data. Transcripts were not developed; however, as needed, the audio recordings were referenced for clarification and to verify quotes. Further, a modified constant comparison analysis approach, as described below, was used to identify themes that emerged from the focus groups. <sup>18</sup> Two authors independently reviewed notes from all of the focus groups and then independently generated a list of themes they observed for each of the five research questions. This approach allowed each author to review and analyze data separately to ensure that the findings were consistent. Next, the authors developed a combined list of themes they derived from the data and coded the focus group notes based on both authors' input. Each author then coded the notes independently according to the agreed-upon themes, using a spreadsheet to record quotes. The two authors discussed and resolved any discrepancies in the coding of the quotes. No coding software was used in the analysis.

The study was approved by ICF's internal Institutional Review Board and the Office of Management and Budget #0920-0572. Parents were offered an online \$30 Amazon gift card as compensation for their participation that was emailed to them by research staff after the

focus group. Participants' contact information was stored in a secure project folder in order to communicate and follow up with participants regarding their incentive. The folder was destroyed at the completion of the study.

## Results

A total of 67 parents were screened and 16 parents were selected to participate across the six groups. Sports played by athletes included basketball, lacrosse, football, and soccer. Participants were screened out from the study if they did not individually meet the inclusion criteria for the study or if a specific criteria quota was already met, or if there were scheduling conflicts with the time of the focus group. A summary of participants' demographic information can be found in Table 1. Findings from the focus groups are presented for each of the five research questions. Research staff started to reach saturation (e.g. recurring themes) after four groups, but proceeded to schedule and conduct the remaining two groups in case the participants in the remaining groups might introduce a new idea or perspective that would offer key insights that informed understanding of the issue. Data saturation was confirmed by the sixth focus group.

## Do parents think it is possible to prevent concussion in sports?

Preventability of concussion emerged as an important topic in each of the focus groups. For many, concussion was seen as an inevitable part of sports. One parent stated, "things happen, there is no way to definitely prevent," while another said it is "not possible to prevent concussion, accidents happen." Another shared, "it doesn't seem possible to prevent concussion." In contrast, other parents offered ideas to prevent concussions. Parents with these views described opportunities for prevention through emphasizing good sportsmanship or playing techniques. One parent shared: "Parents should stress playing a nice, fair game." Several parents stated that coaches should teach young athletes how to prevent causing other players to potentially get injured with a concussion by teaching them to "hit correctly."

#### Are parents concerned about concussion reporting among athletes?

When discussing concussion reporting, some parents focused on the influence of external pressures, while others on athlete concussion knowledge. Parents in some groups expressed concern about peer and social pressures from their coach and teammates. One parent explained young athletes "would feel like they're letting their team down." Another stated that her son is "trained in his mind that he doesn't want to disappoint his coaches." Other parents felt an athlete's concussion knowledge was more likely to influence concussion reporting. One parent shared, "if they don't actually know the signs of a concussion they might not report."

## What are parents' views on concussion recovery?

If a concussion occurs, parents in the study believed it was important to remind young athletes recovering from concussion that they have to take time to heal and be healthy before they can participate in their sport again. One parent explained that young athletes should know that "it's okay that they're not playing their sports, and they're not letting the team down. Your team will be happier with you if you're healthy." Another parent concurred and

thought it was important that young athletes know "they can still be supportive to their teammates and be a valuable member of the team until they're healed. They're still a valuable member of the team even when they're not playing." Still, parents also discussed the challenges with balancing a child's recovery with an athlete's desire to return to school and sports. In addition, the need to get support from an athlete's school was also a common topic for parents whose children have had a previous concussion. One parent explained her young athlete's experience, "He couldn't do his work. He was behind in his classes. Schools districts need to have an option if the student can't complete assignments." Parents of athletes with a history of concussion also advocated for sports teams to follow certain concussion protocols to prevent athletes from going back to playing their sports too early.

# Are parents comfortable talking with their athletes about concussion safety?

Parents' efforts to communicate about concussion varied. All of the parents in the focus groups reported that they would feel comfortable discussing concussion with their young athletes, although several parents reported they rarely did so. One parent shared, "I don't have a problem talking to kids about that or anything," but concussion isn't talked about "until it's a potential problem." Other parents reported that having concussion discussions depended on their child's sport. One parent explained, "We talked about concussion during soccer. She doesn't get hit a lot now in volleyball and basketball so we don't talk about it much." Another parent similarly shared that she rarely discussed concussion because "volleyball is a noncontact sport." Among those who did report discussing concussion, many said it was discussed during parent meetings for their children's sports. As one parent noted, "we talk about incidents on the field and how we can prevent this stuff in the future."

Parents expressed a reliance on their athlete's coaches to educate their children about concussion. Parents also discussed that coaches should have the final say and not be afraid of aggressive parents and should sit an athlete out with a possible concussion. One parent explained that "if the coaches pull them out and a parent gets upset, oh well - it's your child's life and their brain. It's not the parent's choice."

#### What do parents think they should say to their athletes about concussion?

Parents described uncertainty about whether communication about concussion will influence their athlete's behaviors. Some parents believed that it was their responsibility to talk with athletes about concussion and help with prevention. However, others did not feel this was realistic. One parent explained, "Once the kids get to middle school, the parents aren't at practice and can't watch for potential injuries." Another parent shared, "I don't think my boys will listen to me... they'll just think I'm babying them." One parent explained that young athletes may just see it as "just mom nagging." To address this, some parents felt communication should start early, before high school.

Parents described that coaches play an important role to play in communicating about concussion reporting in particular. One parent stressed that coaches are the ones that have to make sure young athletes "don't feel embarrassed talking about concussion." Deferring to coaches may be related to concerns about how to talk with athletes about concussion, as parents in the groups expressed a need for more education on concussion for themselves.

One parent stated, "Parents need more education about concussions, such as on the value of reporting symptoms."

# **Discussion**

Parents in this study expressed a desire to play an active role in communicating about concussion with their young athletes and helping them get the support they need to recover. However, parents' uncertainty about their influence on their athlete's reporting behaviors and the preventability of concussion may serve as a barrier to parent–athlete communication. Patel and Trowbridge<sup>19</sup> also describe similar uncertainties among parents. In their study, the authors recommend using constructs of the Health Belief Model (HBM) to address parents' self-efficacy related to concussion. Created by the U.S. Public Health Service, the HBM can help public health professional better design and evaluate programs aimed at improving positive health behaviors.<sup>20</sup> Concussion education efforts may benefit from using constructs of the HBM to address perceived barriers and promote specific actions for parents, such as how to communicate effectively with their child about reporting a possible concussion.

Barriers to concussion reporting described by parents, such as concerns about disappointing their teammates, are well documented in Chrisman et al.<sup>4</sup> and Register-Mihalik et al.<sup>5</sup> However, while they were attuned to the issue, parents did not express confidence in their ability to influence their athlete's reporting behaviors. Parents' perceptions of their roles and influence with their children on this topic parallel other noted distinctions between younger and high schoolaged athletes. Specifically, research suggests that younger athletes are more concerned about concussion than older athletes.<sup>8</sup> In addition, younger athletes are not as concerned about what their teammates think of them for reporting concussion symptoms.<sup>8</sup> Combined, this indicates a need for early communication about concussion from parents when athletes may experience fewer social barriers to reporting a possible concussion. Future research should explore this topic and ways to maximize parental influence while athletes are younger and whether this can translate to behaviors in middle and high school when the influence of parents may wane.

The majority of parents in the focus groups felt there was little they could do to prevent concussions from happening to their child. Currently, the evidence-base on concussion in sports prevention is limited; however, there are emerging strategies that parents can help promote. A systematic review by Enniss et al.<sup>21</sup> provided a conditional recommendation for concussion education for athletes, coaches, and parents as a primary preventive intervention against sports-related concussion in children. In another systematic review on reducing the risk for concussion in sports, Emery et al.<sup>22</sup> highlighted sports-specific strategies (such as helmets in skiing and policies eliminating body checking in youth ice hockey). Awareness of effective strategies may help inform parents' choice of sports programs based on their concussion prevention policies and practices. In addition, as parents can help reinforce primary prevention strategies with their athletes, educational efforts customized to parents may be beneficial. Future research may also seek to explore how better awareness of concussion prevention strategies shifts parents' view on concussion preventability.

Finally, this study underscores the need for targeted educational efforts for parents. Previous studies also note the lack of evidence-based educational interventions for parents, especially those designed to be inclusive of parents with athletes under high school age, lower socio-economic status, limited education, and the inability to read in English. <sup>8,10,23-25</sup> As parents are a key driver of the culture of concussion safety, further efforts to develop and test educational efforts for parents are critical to athlete safety.

This study is subject to a number of limitations. First, this study did not include a sample that was large or diverse enough to be generalizable to the larger population of parents of young athletes. Second, as some recruitment was completed through the CDC HEADS UP campaign partner network it is reasonable to believe that these parents may be more familiar with concussion or received concussion education previously. Parents may also have been more likely to participate in the study if they have had personal experience with concussion. Given the sample size, we were unable to explore differences among parents whose child has had a concussion versus those who have not. Future research could explore this. Third, this study did not segment parents by sport, and future studies could explore variations in parents' experiences with concussion by sport. There was an indication from these initial findings that parents have different experiences and discussions about concussion based on the sports their children play, as well as the age of the athlete, and additional research could assess this in greater detail. Fourth, parents expressed a need for schools to support young athletes who are recovering from concussion, especially with navigating some of the challenges related to keeping up with school work. This study identified this need, but did not assess ways for parents to be involved in this process. Further research is needed to study how parents can successfully support their young athletes as they recover from concussion and return to school and play.

# Conclusion

Concussion education efforts may benefit from promoting specific actions parents can take to prevent concussion and how to communicate effectively with their child about reporting a possible concussion. In addition, more research is needed to study how to better support parents in having meaningful conversations with their young athletes about concussion and taking steps to improve concussion prevention, reporting, and recovery.

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# **Appendix**

#### Appendix 1.

Moderator guide questions used for the five research questions

Research question

Moderator guide questions

Perception of concussion

Research question Moderator guide questions		
1. Do parents think it is possible to prevent concussion in sports?	Do you think there are steps athletes can take to prevent concussion?	
	How can parents encourage athletes to take steps to prevent concussion?	
	<ul> <li>What is the most important thing parents need to know about concussions?</li> </ul>	
2. Are parents concerned about concussion reporting among athletes?	<ul> <li>How easy or hard is it for a young athlete to report their concussion symptoms to their parents or coach?</li> </ul>	
	<ul> <li>What makes it easier for young athletes to report their concussion symptoms?</li> </ul>	
	Why wouldn't a young athlete report their concussion symptoms?	
	<ul> <li>What needs to be said to convince athletes to tell their parents about a possible concussion?</li> </ul>	
	• Do you think a child could receive a hit to the head during a practice or game and his/her coach or a parent might not know about it?	
	<ul> <li>How would you respond to a coach pulling your child out of play?</li> </ul>	
	<ul> <li>Would you feel differently if your athlete sat out during a practice versus a regular season game?</li> </ul>	
	<ul> <li>How easy or hard is it for you, as a parent, to spot concussion symptoms? What would make it easier for you to spot concussion symptoms?</li> </ul>	
3. What are parents' views on concussion recovery?	<ul> <li>How can parents best support their child and help him/her recover after a concussion?</li> </ul>	
	<ul> <li>What can parents do to help their child return to school after a concussion?</li> </ul>	
	<ul> <li>What support does a parent need to help their child return to their sport after a concussion?</li> </ul>	
Parent-athlete communication		
4. Are parents	<ul> <li>How often do you discuss concussion with your child?</li> </ul>	
comfortable talking with their athletes about concussion safety?	How comfortable are you talking with your child about concussion?	
	<ul> <li>How comfortable do you think athletes feel talking with their parents about concussion?</li> </ul>	
	<ul> <li>Are other parents that you know talking about concussion with their children?</li> </ul>	
	<ul> <li>Have you had any difficulties or challenges talking about concussions with your child/young athlete?</li> </ul>	
	<ul> <li>What would make it easier for you to discuss concussion with your child?</li> </ul>	
	• Who should deliver this message to young athletes? Should it be their parent, coach, teammate, or someone else?	
5. What do parents think they should	What key message or information do young athletes need to hear about concussion?	
corr to thair athlets	<ul> <li>Do you think young athletes would take this concussion safety messages seriously from their parents?</li> </ul>	
say to their athletes about concussion?	seriously from their parents:	
	<ul> <li>How should parents talk to their child about sitting out of a practice or game if they have received a hit to the head?</li> </ul>	

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Table 1.

Demographics of focus group participants.

2 Black or African-American, non-Hispanic 1 White Hispanic 1 Black or African-American, non-Hispanic 1 White, non-Hispanic 1 Black or African-American, non-Hispanic 2 White, non-Hispanic 1 White, Hispanic 2 White, non-Hispanic 3 White, non-Hispanic 2 White, non-Hispanic Race/Ethnicity 1 Midwest, 1 South, 1 West 1 Midwest, 1 South Census region 2 South, 1 West 3 South 3 South 2 South Number of participants Parents of female athletes, ages 12-14 Parents of female athletes, ages 15-18 Parents of female athletes, ages 12-14 Parents of male athletes, ages 15-18 Parents of male athletes, ages 12-14 Parents of male athletes, ages 15-18 Focus group