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Stakeholder perspectives on navigating the pediatric concussion experience: Exploring the needs for improved communication across the care continuum

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Abstract

BACKGROUND: For children, the post-concussion return to school process is a critical step towards achieving positive health outcomes. The process requires integration between healthcare professionals, parents, and school personnel.

OBJECTIVE: This research team conducted focus groups with stakeholders including parents, education personnel, school nurses, external healthcare providers (nurses) and athletic trainers to identify communication patterns between healthcare providers outside of the school setting and school personnel.

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Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Declaration of interest

The authors report that there are no competing interests to declare.

METHODS: Data from focus groups were analyzed using a Thematic Analysis approach. Researchers used an inductive (bottom-up) coding process to describe semantic themes and utilized a critical realist epistemology.

RESULTS: We identified four key themes within focus group data: (1) lack of effective communication between hospital and outpatient healthcare providers to school personnel; (2) parents who were strong advocates had improved communication with healthcare professionals and garnered more accommodations for their children; (3) non-school professionals and families were often confused about who the point of contact was at a given school; and (4) differing experiences for athletes vs. non-athletes.

CONCLUSION: This study suggests gaps in communication between healthcare and school professionals when children return to school following a concussion. Improving communication between healthcare providers and school staff will require a multi-faceted approach.

Keywords

Qualitative; brain injury; school; healthcare

1. Introduction and background

Traumatic Brain Injury (TBI) is a significant public health concern, and mild TBI (mTBI) or concussion is the most common presentation (Centers for Disease Control and Prevention, 2018). Following concussion, families and children navigate two complex systems – healthcare and school (Haarbauer-Krupa et al., 2017). Concussion management can be fragmented as each system operates with its own purpose and priorities, affecting linkages between the two systems and the types of supports and services provided to a child with concussion (Haarbauer-Krupa et al., 2017). Children benefit when the professionals in both healthcare and school systems have clear pathways for communication within and across systems to provide coordinated care (Centers for Disease Control and Prevention, 2018; Patricios et al., 2018; Purcell et al., 2019). Clear communication between healthcare and school professionals and families also facilitates access to supports at school (Glang et al., 2008).

Recent reviews have identified gaps in communication between professionals in healthcare and school systems who care for children with concussion (Centers for Disease Control and Prevention, 2018; Collins et al., 2016; Haarbauer-Krupa et al., 2017; Lyons et al., 2017). For example, there is frequently poor communication between the healthcare professional who diagnoses the concussion and the school nurse (Wing et al., 2016). This can lead to delays in sharing guidance with school staff and in the provision of academic supports. In the case of school athletes, there is often little communication between those who oversee athlete health (athletic trainer) and those who oversee the athlete's academic program (e.g., school psychologist, counselor) (Kasamatsu et al., 2016). Often there is inadequate communication between the child's physician, school staff and parents (Lyons et al., 2017). Parents play a critical role in their child's return to school and activity (Gioia et al., 2015), and are often the liaison between the school and health care providers (Kasamatsu et al., 2016; Lyons et al., 2017). However, many parents are not fully aware of the consequences of brain injury in

children (Gfroerer et al., 2008) and have misconceptions about brain injuries (McKinlay & Buck, 2019) that can lead to ineffective communication with professionals.

The purpose of this study was to 1) learn how information is conveyed between healthcare and school systems after a student sustains a concussion and 2) examine the barriers and facilitators to communication between healthcare professionals, school professionals and families. It is important to better understand the lived experiences of stakeholders within school settings to determine what types of communication are most important between hospitals and schools, and what gaps exist in current practice.

2. Methods

2.1. Ethics approval and consent

This research project is part of a larger research project, Promoting Recovery in Children Who Sustain a Mild Traumatic Brain Injury: mTBI Evaluation and Management (TEaM), funded by the Centers for Disease Control and Prevention. The study was approved by Emory University's Institutional Review Board (IRB000108674). The focus groups are approved as a sub-study under the same IRB number: TBI Evaluation and Management - Stakeholder Perspectives on Real-world Techniques (TEaM SPoRT).

2.2. Participants and recruitment

We used purposeful sampling to collect data from key stakeholders and explore relevant variables of interest (Patton, 2002). Stakeholders consisted of parents whose children had sustained a concussion, athletic trainers or coaches, school healthcare personnel, external healthcare personnel and teachers/program coordinators (educators) in the schools. Stakeholders were recruited through outreach involving the Georgia Department of Public Health, Georgia Department of Education, a local children's hospital, and a local concussion program. All participants were contacted via email and provided with a brief description of the study for the purposes of recruitment.

A total of 45 participants joined the six focus groups (parents $n = 5$, athletic trainers/coaches $n = 7$, school healthcare personnel $n = 19$, external healthcare personnel [nurses] $n = 3$, and educators $n = 11$). Demographic information for participants is detailed in Table 1. Notably, the educators group consisted of elementary, middle and high school classroom teachers, special education teachers, home-school teachers (parents), paraprofessionals, administrators, student support team directors, academic coaches, special education administrators, and 504 coordinators. Educator participants represented a range of school types (private, public, charter) and with varying degrees of access to resources.

2.2. Procedures

Focus groups were conducted by a team of three people that included the research project manager with experience in focus group facilitation, a research team member with program evaluation experience, and a research team member who is a content expert with extensive experience studying the topic of children with brain injury. The full research team developed a protocol based on their knowledge of the post-concussion communication process in

schools. Focus groups began with questions about stakeholders' personal and professional experiences with concussions. Facilitators used follow-up questions and prompts to better understand stakeholders' awareness of the return to school process in their school districts. Stakeholders were also asked about their individual roles in the return to school process, and barriers and facilitators of communication with healthcare professionals outside of the school setting. Due to the semi-structured nature of the protocols, facilitators had the opportunity to allow the conversation to focus on the most salient details, which were relevant to the study.

2.3. Data analysis

Data from focus groups were analyzed using a thematic analysis approach. Consistent with Braun and Clarke (2006), the research group addressed the important "decisions" of thematic analysis and decided to provide a "rich description" using an inductive coding process in order to describe semantic themes from a critical realist ontology and epistemology. Thematic Analysis is described as a six-phase process. The first two phases of the analysis required an intensive review of transcripts as well as organization and coding of the data across stakeholder groups and settings. The third phase of the analysis was iterative and involved the identification of overarching themes derived from the relationships between the initial codes. The fourth phase of the process required the research team to then review and discuss each theme, and the fifth stage of the process was the creation of formal titles and definitions for each theme. The sixth and final phase is the writing up of the analysis results (Braun & Clarke, 2006, 2020). The first author completed phases 1–3 and for the purposes of greater reliability within the process, all of the authors each contributed to phases 4, 5, and 6.

3. Results

We identified four key themes from the analysis of focus group data. Each of the themes were related to patterns of communication. These included: (1) lack of effective communication from hospital and outpatient healthcare providers to school personnel; (2) parents who were strong advocates had improved communication with healthcare professionals and more accommodations for their children; (3) non-school professionals and families were often confused about the point of contact at a given school; and (4) there were differing experiences for athletes vs. non-athletes. Each theme is further described below.

3.1. Lack of effective communication

Each of the stakeholder focus groups described a pattern of a lack of effective communication from providers in healthcare settings to school professionals. This was true for providers across all three healthcare settings where children are seen initially: emergency department, urgent care, and primary care providers. Additionally, stakeholders mentioned that children can be seen initially by individuals at any combination of the three settings and that each of them has different forms of communication about the injury itself and/or the effects of the injury. Researchers characterized the majority of that communication as ineffective. Often there was no communication between healthcare providers and schools, as one parent explained:

Basically, we went to the doctor, they said she had a mild concussion. They talked about the things that we should and shouldn't do at home ... but once we sent her back to school that was about two days later, there was nothing for the teachers.

In other cases, there was communication, but it was in a manner that was difficult for educators to implement. One example was the school nurse who explained:

One of the primary physicians gives wonderful care, but ... we have a form, our short-term medical accommodation form, he would not fill it out. Instead, he would send six journal articles that he wanted our teachers to read.

Some parents described an inability to communicate with healthcare providers after receiving unclear directions about their child's post-concussion return to school process:

They're in and out. They diagnose and they don't give you a number so when you call back [with a question] you're circling around... nothing was clear so I wouldn't know which way to move.

There were a few examples of communication that stakeholders deemed effective, though in those cases that positive communication could be attributed to the services being received at a clinic that specialized in treating concussions. The majority of the examples provided by stakeholder groups, whether related to a complete lack of communication, unclear or difficult to implement communication, or a lack of follow-up communication, were determined to be in need of improvement and thus were characterized as ineffective communication patterns.

3.2. Parent advocates

The second theme related to communication was the parent advocates. These are parents who took an active role in the accommodations processes, had stronger communication linkages with professionals and as a result their children received more academic accommodations. Members of each stakeholder group discussed this phenomenon. One key example was the educator who stated:

The major piece is parents have to provide the information. They have to be forthright with coming to the school and sharing that "my child has had a concussion" or if they can't get to the teachers, then stop at the nurse's office to share this information so some accommodations can be done.

Another example was provided in the form of an anecdote, and the nurse described:

I have a student who, well it's an athlete and he was diagnosed with a concussion and his mom was so good. She brought in the concussion restrictions and things that we needed to do at the school so we made the accommodations for him putting him in a quiet place. He was out of school because he kept having issues so she was taking him back and forth and taking him back and forth. And we did everything that we could to try to accommodate him then she would bring in like the pain medication to help him and it took him quite a while.

Though these were the most prevalent types of examples expressed, there were also some examples given in which stakeholders did not advocate for their children. One example

described was the athletic trainer who explained, “We have some parents that say ‘Well I didn’t take them to the doctor, I just told them to toughen up...tough it out...it’s just in your head.’” In each stakeholder focus group it became clear that students with parents who advocated for their child to school staff and healthcare providers received more school accommodations.

3.3. Confusion about point of contact

Another theme that was discussed throughout the focus groups was that there was confusion about identification of the appropriate point of contact at school for initiating concussion management strategies. Stakeholders, such as this athletic trainer, described that not having a consistent person to contact can make the job of caring for a student more challenging:

We also asked each school system directly “who do you want to be involved in these academic accommodations” so some schools said “our athletic directors need to be the point person” and some said “our cluster nurses need to be the point person or our school nurses” and some said “our counselors need to be the point person” so each school system or each county does it differently which makes it even a little more challenging.

Additionally, others, like this nurse, mentioned that the lack of consistency regarding a designated point person can create more challenges. For example, some parents became frustrated when they were unable to determine who to contact, which can cause accommodations to be deferred:

They don’t know who our touch person is...They’ll try. They’ll maybe email the counselor sometimes they’ll contact me or sometimes they’ll let nobody know and then all of a sudden they’re like, “Well my kid’s had this concussion,” and they didn’t let us know, I haven’t seen any paperwork.

This type of confusion and difficulty knowing who to contact about a child post-concussion was a consistent theme from each of the stakeholder groups.

3.4. Differing experiences: athletes vs.Non-Athletes

Stakeholder focus group participants indicated that the concussion management experiences of athletes and non-athletes were very different. Athletes who had sustained a concussion, particularly high school students, were reported to be monitored more closely by school healthcare staff, compared to non-athletes, and received more support at school. This educator described wishing that a student who had been injured was an athlete so that they would have received more accommodations that could have informed her post-concussion services:

I was thinking of one student, a girl who was in a car wreck and had a concussion through that so not an athlete...She just wasn’t, she was confused a lot of the time like you could just tell that she was different...and I remember thinking “I wish she was an athlete” because she would have had that baseline concussion protocol test or whatever but she didn’t and so she ended up pulling it out but she kind of dug the hole deeper for her trying to come back too early.

Other examples of this pattern involved this athletic trainer who explained what can happen if a student decides to forego athletics after an injury:

Now we have had some that had a concussion and don't want to go back to play and then they just fall off the face of the earth...they don't come back to see us, we don't know what happened to them.

Another example is the athlete whose coach was also his teacher in school. This coach would create improved classroom conditions for his players such as removing fluorescent lighting or providing more unconventional accommodations:

Another thing that I would let [athlete] do is wear his hoodie up. Now that's against school policy because we can't identify the student and in this age ... Most school districts have a policy against it, but it allows them some shelter from the surrounding stimulus I believe. So that's something that I would allow.

4. Discussion

This study identified gaps in communication between healthcare and school professionals, a finding that has been widely reported elsewhere (Centers for Disease Control and Prevention, 2018; Collins et al., 2016; Haarbauer-Krupa et al., 2017; Lyons et al., 2017). In a few instances, initial communication between healthcare providers and school staff was efficient and standardized. These instances of effective communication were generally attributed to children being seen in clinics that specialized in the management of concussions (typically after the initial diagnosis in the emergency department, urgent care, or primary care setting), or when the child's school had a designated brain injury contact person. However, most often the communication from healthcare providers was noted as ineffective and required intentional advocacy on the part of parents. Additionally, there was wide variability reported related to follow-up communication.

Study participants noted that, in general, "parent advocates" had stronger communication linkages with both healthcare and school professionals and were perceived to be treated differently. School staff reported that "advocate parents" often served as the linkage between healthcare and school professionals to ensure that communication was quick and efficient (Sarmiento et al., 2019; Sullivan et al., 2022).

The lack of an easily-identified point person in most schools was a challenge mentioned by all stakeholder groups. There was broad consensus among stakeholders that it would be ideal if 1) schools had a consistent concussion "point person" and 2) healthcare providers sent standard guidance to school personnel with recommendations for support in the school setting (Gioia, 2016; Vanclooster et al., 2018). Because of the range of personnel in the school setting and the variability in healthcare settings where children are seen both initially and for follow-up care, having consistent communication linkages and standardized protocols could improve communication and potentially result in more efficient and effective school supports.

Our findings suggest that students injured in non-sports activities may have markedly different experiences when they returned to school compared to injured athletes (Krug &

Turkstra, 2015; Lundine et al., 2022). Communication about athletes with healthcare and school staff, often mediated by the athletic trainer, was described as being more efficient and effective. Athletes were described as being more likely to receive immediate, targeted accommodations, and their health and academic status were perceived to be monitored more closely. Conversely, it was reported that students injured outside of athletics did not receive the same level of care coordination and did not tend to receive supports at school.

When a student's brain injury is not identified early, challenges can emerge over time that are mis-attributed to social-behavioral issues, substance use or emotional problems (Wade et al., 2019). Given the high prevalence of concussions among youth, and the fact that up to 14% of students who sustained a concussion have ongoing problems requiring academic, social and behavioral supports (Rivara et al., 2012), a lack of identification of youth who were injured outside of sports is a serious issue.

Finally, the widely-held belief among participants that many educators and healthcare professionals are unaware of the ongoing needs of youth with TBI suggests a need for training in concussion management across stakeholders (Kahn et al., 2018; Zemek et al., 2014). Without a foundation of knowledge about the effects of concussion and the risk for long-term consequences, educators and healthcare providers may have difficulty developing effective support plans and engaging in ongoing communication.

4.1. Limitations

This study represents the experiences and views of a small group of parents, teachers, school nurses and athletic trainers from a single geographical region. Although they were selected to present a range of socio-economic and cultural experiences, the experiences of the individuals who were interviewed may not be generalizable to other regions or cultural groups. Additionally, these focus groups functioned as a cross-sectional approach to this line of study; a longitudinal focus centered on stakeholders' experiences communicating with healthcare professionals after a brain injury could provide more depth and nuance in the study of this complicated phenomenon. Lastly, the global COVID-19 pandemic impacted the data collection process in that one of the focus groups needed to be conducted remotely, and in the remote focus group there were some added difficulties with transcription due to some lapses in microphone functionality for participants.

5. Conclusion

This study presents the perspectives of key stakeholders involved in caring for children with concussion. The study's findings highlight that communication from healthcare providers outside of the school system could be improved, "parent advocates" can act as an intermediary (or liaison) to reduce the impact of those communication issues, and that school systems often do not have a point person for brain injury care coordination. The study also suggests that athletes may be receiving more comprehensive care coordination than non-athletes, and showed that stakeholders understand the importance of, and have a desire for, evidence-based concussion education. The findings suggest that increased concussion education for all stakeholders paired with standardized communication protocols after a

student sustains a brain injury can address concerns about care coordination for both athletes and non-athletes.

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Table 1

Participant Demographics

Demographic Category	n (%)
Gender	
Female	35 (78)
Male	9 (20)
Prefer not to say	1 (2)
Age	
18–30	1 (2)
31–39	8 (18)
40–49	13 (29)
50–64	21 (47)
65+	2 (4)
Race	
American Indian or Alaska Native	0 (0)
Asian	1 (2)
Black or African American	13 (29)
Native Hawaiian or Other Pacific Islander	0 (0)
White	29 (65)
Prefer not to say	2 (4)
Highest Level of Education	
Less than high school	0 (0)
High school or GED	0 (0)
Some college, diploma, trade school, military	1 (2)
Associate Degree	1 (2)
Undergraduate Degree	14 (31)
Graduate School	25 (56)
Doctorate Degree	4 (9)
Role	
Parent/ Guardian of child with history of concussion	5 (11)
Athletic Trainer	6 (13)
Coach (any sport)	1 (2)
Educator (i.e., teacher, admin, counselor)	11 (25)
School Nurse or other school health professional	19 (42)
External Healthcare Personnel (Nurses)	3 (7)

Note. N= 45.