Patient, parent and educator perspectives on paediatric concussion

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Abstract
Background: Past research on paediatric concussion awareness, management, impact and outcome priorities has focused on health care professionals and sports organizations, yet little is known about patient, parent and educator perspectives. Methods: To address this knowledge gap, we conducted a qualitative descriptive study using semi-structured interviews with three participant groups: patient-participants including children with acute or chronic concussion; parent-participants including caregivers of children at risk for or with history of concussion; and educator-participants including teachers and athletic coaches from three Ontario secondary schools. We designed our interview guide to elicit participants’ perspectives across four domains: concussion awareness, concussion experience, support and resources, and outcome priorities. We analyzed our resultant data using a qualitative content analysis approach. Results: Nine paediatric patient-participants, 17 parent-participants, and 14 educator-participants completed the study. Participants described concussion as a serious health concern and attributed greater concussion awareness to increased media attention and concussion protocol implementation within schools/sports. While most educator-participants regarded concussion protocols positively, some feared student manipulation. Parent- and educator-participants desired consistent information and resources from reliable sources. The impact of concussion ranged from a few days to prolonged absences (from school, sports, and socializing) and necessitated accommodations in both academic and sport settings. Short-term problems (e.g., decreased peer-contact) primarily troubled patient-participants, whereas long-term problems (e.g., impaired academics, psychological stress) concerned parent and educator groups. Conclusion: Patients, parents and educators worry about the consequences of paediatric concussion. Initial concussion recovery in youth should focus on a timely return to academics and on minimizing social isolation by ensuring peer-contact during recovery.

Keywords
Concussion, paediatric, parent-perspective, educator-perspective, qualitative methods

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Introduction
Paediatric concussion has been recognized as an increasing health problem,1 with emergency department (ED) and physician office visits for paediatric concussion quadrupling over the last decade.2–4 Further, up to one-third of children with concussion experience post-concussive symptoms beyond one month.5 These prolonged symptoms negatively impact quality of life,6 reduce peer-contact and social activities,7,8 and can lead to prolonged absenteeism from school.9
Evaluations of concussion awareness, management, and outcome priorities following paediatric concussion have thus far focused largely on the perspectives of front-line physicians and other health care professionals and sports organizations. Existing studies are skewed towards youth athletes rather than the general paediatric population, focus primarily on concussion guideline implementation, or target small samples of children with acute concussion rather than prolonged concussion symptoms. In contrast, there is a paucity of research focused on patient, parent and educator perspectives on paediatric concussion, resulting in a knowledge gap in how concussion impacts patients’ activities of daily living at home and school, how activities should be prioritized during recovery, and how paediatric concussion guidelines are received by end users. As paediatric concussion guidelines and return-to-learn and return-to-play protocols differ depending on the targeted end-user, it is important to consider the perspectives of children and adolescents, their parents, and academic as well as athletic educators. As such, this qualitative study sought to describe the perspectives of children/adolescents with either acute or chronic concussion symptoms and their parents, as well as educators and coaches, relevant to paediatric concussion awareness, impact, management and outcome priorities.

Methods

We selected a qualitative approach known as qualitative description to present a comprehensive summary of the perspectives of paediatric concussion patients and those most closely involved in their daily care: parents and educators. Interviews focused on paediatric concussion awareness, the influence of concussion on daily activities and outcome priorities during recovery. The choice of domains of management and outcome priorities was two-fold: 1. to evaluate the first comprehensive paediatric concussion guidelines and inform the updated version, and 2. to provide insight into the most important patient-priority outcomes in concussion management to inform future clinical trials in paediatric concussion.

Participant groups

To capture a variety of perspectives within and across participant groups, we employed a maximum variation purposeful sampling method. Paediatric patient-participants were selected to include children and adolescents aged 8 through 18 years with an acute (<24 hours of sustaining injury) concussion diagnosis or chronic concussion (persistent symptoms beyond 4 weeks of injury) and were recruited from the Children’s Hospital of Eastern Ontario Emergency Department (CHEO ED) (Ottawa, ON) and the CanChild Centre for Childhood Disability Research at McMaster University (Hamilton, ON) respectively. To increase heterogeneity, parent-participants consisted of the parents/caregivers of eligible patient-participants, as well as parents/caregivers of children and adolescents presenting to CHEO ED for a traumatic injury other than concussion (but with a past history of concussion). Eligible educator-participants were all academic and/or athletic teaching staff employed at one of three secondary schools (grades 9–12) in the Thames Valley District School Board within Ontario, Canada. These schools were selected by a study collaborator (LW; see acknowledgements) familiar with the district to represent a variety of settings including urban, suburban, and rural communities (collectively, these schools serve approximately 2500 students).

Data collection

After Research Ethics Board approval was granted by participating institutions [CHEO: Protocol Number 15/43X; McMaster University], participant recruitment began in May 2015 and continued until February 2016. Patient- and parent-participants were screened for eligibility by trained research volunteers (CHEO) or trained research assistants (CanChild Centre) using the same criteria as our team’s previous concussion collaboration. Educator-participants received study information through their schools’ principal via email, which included a link to a secure Research Electronic Data Capture (REDCap) tool hosted at the CHEO Research Institute to collect participant demographics and contact information. Interested participants were contacted within 7 days by telephone or email (for a maximum of five attempts) to schedule a telephone interview date.

Consent/assent was obtained from all participants (including the parents of all patient-participants) at the start of each interview. Interviews with children/adolescents preceded the interview with parents in the situation that both child and parent participated in the interviews, to prevent children from repeating their parents’ answers or opinions.

Data collection instrument

Data was generated using semi-structured interviews conducted via telephone for participant convenience. The interview guide (Table 1) was developed by the research team using the Dillman Tailored Design Method and consisted of basic demographic questions and open-ended questions (including relevant
Table 1. Individual telephone interview guides for children, parents and educators.

An evaluation of patient, parent, and teacher perspectives on childhood concussion guidelines and outcome priorities – Individual Telephone Interview Guide for Children

Thank you for taking the time to talk to me about your feelings about your concussion. Your answers will help us understand how a concussion affects your life at home, at school, with friends and during sports. We would like to learn from you what you think are the most important things doctors can do to help kids who have had a concussion feel better.

Everything that you share today will be kept private. This means that your name and other personal information will be deleted from the recording. Before we begin, do you have any questions about the interview today? Do you agree to participate in this interview? I would like to remind you that there are no right or wrong answers. You are free to stop at any time. You do not have to answer any questions that make you feel uncomfortable.

Can I have your permission to record this interview?

You are now on speakerphone in a private room and the audio recorder is running, can you hear me alright?

Experience with childhood concussion and guideline recommendations:

1. Do you remember when you hurt your head?
Probes:
- How long ago was this?
- Can you explain how it happened (at sports, playing alone or with friends, motor vehicle accident, etc.)?
- Did your head hit the ground or another surface/person?

2. Did you stay at home to rest after you hurt your head?
Probes:
- Did you miss any time at school, at sports, playtime with friends etc.?
- Did you need to change how much you watched tv, used the computer, read a book, etc.? How did you feel about this?
- Did you need to change how much you played with friends, played sports, etc.? How did you feel about this?
- Were there specific things (at school, during sports, during playtime with friends) that you found difficult to keep up with?
- How long did it take before you felt you were ‘normal’ again (hours, days, weeks, months)?

Concussion guidelines:

1. Did your school help you with steps to get back to school and sports?
Probes:
- Did you find it hard to keep up at school/sports?
- Did you feel any pressure (from friends, class mates, teachers, parents) to go back to school/sports, even if you still had some problems?
- Did you feel like you had enough help at school/sports to do your schoolwork/take part in gym class?

2. Did you find it easy to understand the steps to get back to school/playtime with friends/sports etc.?
Probes:
- Not easy at all
- Rather easy
- Very easy
- What made it easy or hard for you?
- Which recommendations, or parts, were difficult to understand?
- Suggestions?

3. Did you find it easy to follow the steps to get back to school/playtime with friends/sports etc.?
Probes:
- Not easy at all
- Rather easy
- Very easy
- What made it easy or hard for you?
- Which recommendations, or parts, were difficult to follow?
- Suggestions?

4. Is there anything that would make it easier for you to help remember and follow the steps to get back to school/playtime with friends/sports, etc.?
Probes:
- A concussion app on your computer/tablet/smartphone, on paper, etc.
Table 1. Continued

Outcome related questions:

1. What do you think are the most important things doctors should try to help kids get better with after a concussion?

Probes:
- No more symptoms (such as headache, feeling tired, etc.), not missing school/playtime with friends/sports, playing sports/wih friends as soon as possible without making your symptoms worse, concentrating in class, etc.
- How soon would you like to achieve this?

2. Would you be willing to take a break from school/sports/playtime with friends to achieve this?

3. Was there anything that helped you best to feel better after you hurt your head?

4. Would you mind taking a pill if this would make you feel better sooner?

Conclusion:

1. Is there anything we haven’t talked about?

2. Would you want to take part in any future, similar talks about concussion?

At this time, I would like to thank you for answering my questions. Your answers have been very helpful. If you have any questions please let me know. My information is written down on your copy of the information sheet.

An evaluation of patient, parent, and teacher perspectives on childhood concussion guidelines and outcome priorities – Individual Telephone Interview Guide for Parents and/or Caregivers

Thank you for taking the time to talk to me today. You answers will help us understand how a concussion may impact social life, school and sports, and what factors make it easy or difficult to access and use the concussion guidelines.

Your responses will be strictly confidential except as required or permitted by law. Any information that may reveal your identity will be erased from the audio-recording and transcript so that you cannot be identified. Before we begin, do you have any questions about the interview today? Do you agree to participate?

I would like to remind you that there are no correct or incorrect answers. Your participation is voluntary. You do not have to answer any questions that make you feel uncomfortable.

Can I have your permission to record this interview?

You are now on speakerphone in a private office and the audio recorder is running, can you hear me alright?

Experience with childhood concussion:

In the last few years, concussion has received a lot of attention in the media. For example, in sports such as hockey and football. Also, the recent concussion inquest in Ontario highlighted how concussion in school-aged children may be better managed in schools and sports.

3. In your opinion, how important is concussion?

Probes:
- For example, is it very common, disabling, receives a lot of media attention, etc.
- Do you feel that concussion awareness or attention has increased in the media, your social circle, school, sports etc.?
- Do you feel that this increasing concern is justified?
- What are you most worried about (short-term, long-term effects)?

4. Has your child(ren) ever experienced a concussion?

Probes:
- What age was your child when this happened? How long ago?
- Can you explain how it happened?
- How did this affect your child’s life? your life and family?
- Were you worried about the future; impact on activities, work etc.
- Did you have to take time off work, cancel any other activities, etc.?
- Can you name specific activities or situations that were particularly troublesome?
- Did you feel any pressure (from your child, school, etc.) to have your child return to school/sports, even if they were still having symptoms?
- Was there support available to help your child return to activities at school/sports?

(continued)
Table 1. Continued

- Do you feel like this support was sufficient? If not, what did you miss? How could you/your child be better supported?
- How easy/hard was it to find useful resources to help your child manage with the concussion? Online, or other resources?

Outcome related questions:

One of the things we would like to learn is what the most important outcomes are following concussion. Researchers often use one month as a target for recovery from concussion symptoms.

1. In your opinion, would this be a good time-point, or would for example 2 weeks, or 2 months be better?

2. Do you feel that it is more important to know when it would be safe for your child to return to activities, even if still having some symptoms, or being fully free from symptoms?

3. Are there certain activities that you find most important to focus on during recovery?
   Probes:
   - For example, being able to go back to school; going back to social activities; return to exercise or sports; etc.
   - How soon would you want to achieve this outcome – 1 week, 2 weeks, one month etc.?

4. It is currently recommended that children do not participate in any physical activity until they are fully symptom free. Would you feel comfortable with your child resuming light physical activities, such as walking, while still having some symptoms?

5. If interventions would be available, what would be acceptable to speed up the recovery?
   Probes:
   - Change in rest/activity, pills, IV administration of fluids or medications, etc.

6. How should we define treatment success?
   Probes:
   - Fully symptom-free, able to resume activities at tolerable symptom-levels, etc.
   - At which time point?

Concussion education and protocols

1. Are you aware of a formal policy or protocol for concussion at your child’s school?

2. How do you feel about this policy?
   Probes:
   - Do you know where, and how, to find this policy or protocol?
   - Can you describe this policy or protocol?
   - How long has this policy or protocol been introduced? Any recent changes?
   - Do you feel that most staff knows of, and adheres to this policy or protocol?
   - Does the policy make sense, or is it difficult to follow?

In the recent inquest, some recommendations for change with regard to concussion management were suggested.

First, it was suggested to make it mandatory for all youth sports (school-based and non-school-based) to have a standardized protocol for recognizing concussion, and that players, parents and coaches receive concussion education.

5. How do you feel about this recommendation?

Another suggestion was that all youth athletes should receive education about the importance of disclosing injuries sustained by themselves or teammates, to ensure that they inform coaches or parents once they get injured.

6. How do you feel about this recommendation?
Table 1. Continued

**Usability of the guidelines:**

I would now like to ask you a few questions about the guidelines, to help us understand how we can make them easier to access and use.

1. Were you familiar with these, or other, guidelines?
   Probes:
   - If yes, which one?
   - How did you find these?

2. Was the document easy to understand?
   Probes:
   - Language
   - Formatting
   - Navigating through document
   - What made it easy or hard for you?

3. Do you feel that it would be easy to follow the recommendations in the guidelines?
   Probes:
   - Not easy at all
   - Rather easy
   - Very easy
   - What specific parts may be difficult to follow at home, school, sports etc.?

4. It is recommended that children take a period of mental rest; meaning that they do not watch TV or play videogames, stay at home, and then follow a step-wise program to go back to school. Do you think that this recommendation would be easy to follow?

5. Was there any information missing that would have been helpful?

6. What information should teachers/coaches receive to improve their practice?

7. Do you have any suggestions how we could improve the guidelines?

**Guideline dissemination**

- Do you have any suggestions how we could best connect the public (including children themselves, parents, schools and sports organizations) with the information in the guidelines?

   Probes:
   - Through the media (television commercials, news items, articles in newspapers, online or other sources)
   - An app (smartphone)
   - Through professional concussion websites (ONF website (www.onf.org. . . . . ), pediatric concussion web portal (www.kidsconcussion.com. . . . . ), Parachute etc.)
   - Online forums
   - Information materials available at schools, sports organizations, physician offices, etc.
   - Other?

**Conclusion:**

3. Is there anything else you would like to discuss in relation to this topic that we haven’t talked about?

4. Would you be interested in participating in future projects on childhood concussion as a parent expert/community representative?
At this time, I would like to thank you for your participation. Your contribution to this study has been very insightful. If you have any further comments or questions please contact me. My contact information is included on your copy of the information sheet.

An evaluation of patient, parent, and teacher perspectives on childhood concussion guidelines and outcome priorities – Individual Telephone Interview Guide for Teachers and/or Coaches

Thank you for taking the time to talk to me today. Your answers will help us understand how a concussion may impact social life, school, and sports, and what factors make it easy or difficult to access and use the concussion guidelines.

Your responses will be strictly confidential except as required or permitted by law. Any information that may reveal your identity will be erased from the audio-recording and transcript so that you cannot be identified. Before we begin, do you have any questions about the interview today? Do you agree to participate?

I would like to remind you that there are no correct or incorrect answers. Your participation is voluntary. You do not have to answer any questions that make you feel uncomfortable.

Can I have your permission to record this interview?

You are now on speakerphone in a private office and the audio recorder is running, can you hear me alright?

Experience with childhood concussion:

In the last few years, concussion has received a lot of attention in the media. For example, in sports such as hockey and football. Also, the recent concussion inquest in Ontario highlighted how concussion in school-aged children may be better managed in schools and sports.

7. In your opinion, how important is concussion?
   Probes:
   - For example, is it very common, disabling, receives a lot of media attention, etc.
   - Do you feel that concussion awareness or attention has increased in the media, your social circle, school, sports etc.?    
   - Do you feel that this increasing concern is justified?
   - What are you most worried about (short-term, long-term effects)?

8. Have you had any children with concussion in your class or team?
   Probes:
   - How did this affect your class?
   - Did the child have trouble keeping up, concentrating, etc.?
   - Can you name specific activities or situations that were particularly troublesome?
   - Did you have to adapt your class structure, or provide any extra support?
   - Are their measures available to provide children with a concussion with a modified learning/sports program, adapted to their needs?
   - How did this work for you?
   - How easy/hard was it to find useful resources to help manage a child with concussion? Online, or other resources?

9. Do you feel any pressure to have a child return to school/sports, even if they are still having symptoms?
   - From children
   - Parents
   - School board etc.

Outcome related questions:

One of the things we would like to learn is what the most important outcomes are following concussion. Researchers often use one month as a target for recovery from concussion symptoms.

10. In your opinion, would this be a good time-point, or would for example 2 weeks, or 2 months be better?

11. Do you feel that it is more important to know when it would be safe for your child to return to activities, even if still having some symptoms, or being fully free from symptoms?

12. Are there certain activities that you find most important to focus on during recovery?
   Probes:
   - For example, being able to go back to school; going back to social activities; return to exercise or sports; etc.
   - How soon would you want to achieve this outcome – 1 week, 2 weeks, one month etc.?
Table 1. Continued

13. It is currently recommended that children do not participate in any physical activity until they are fully symptom free. Would you feel comfortable with your child resuming light physical activities, such as walking, while still having some symptoms?

14. How should we define treatment success?
Probes:
• Fully symptom-free, able to resume activities at tolerable symptom-levels, etc.
• At which time point?

Concussion education and protocols

1. Are you aware of a formal policy or protocol for concussion at your school?

2. Can you tell me more about this policy?
Probes:
• Do you know where, and how, to find this policy or protocol?
• Can you describe this policy or protocol?
• How long has this policy or protocol been introduced? Any recent changes?
• Do you feel that most staff knows of, and adheres to this policy or protocol?
• Is the policy easy/difficult to follow?
• Is there any guidance for teachers/coaches at your school as to how to gradually build a child’s schoolwork/sports following a concussion?
• Do you feel like you have sufficient support to provide children with a modified plan to help them return to school/sports?
• How could this support be any better?

10. Have you received any formal concussion training or education sessions?
Probes:
• Can you describe this training or education?
• How long ago? Mandatory or voluntary?

11. Do you feel comfortable adhering to the concussion protocol or recommendations?
Probes:
• Not comfortable at all
• Rather comfortable
• Very comfortable
• For example, taking a student out of class, or providing a gradual return to activities?

In the recent inquest, some recommendations for change with regard to concussion management were suggested.

First, it was suggested to make it mandatory for all youth sports (school-based and non-school-based) to have a standardized protocol for recognizing concussion, and that players, parents and coaches receive concussion education.

12. How do you feel about this recommendation?

Another suggestion was that all youth athletes should receive education about the importance of disclosing injuries sustained by themselves or teammates, to ensure that they inform coaches or parents once they get injured.

13. How do you feel about this?

Usability of the guidelines:

I would now like to ask you a few questions about the guidelines, to help us understand how we can make them easier to access and use.

8. Were you familiar with these, or other, guidelines?
Probes:
• If yes, which one?
• How did you find these?
prompts) to elicit participants’ perspectives across four domains. The selection of these domains was informed by existing literature and team members’ subject matter expertise, and included concussion awareness, experience with concussion, support and resources, and outcome priorities. Interviews were conducted by three trained researchers (study author [AG]; a paediatric nurse with qualitative research experience; and a MSc student with paediatric research experience).

Table 1. Continued

9. Was the document easy to understand?
Probes:
- Language
- Formatting
- Navigating through document
- What made it easy or hard for you?

10. Do you feel that it would be easy to follow the recommendations in the guidelines?
Probes:
- Not easy at all
- Rather easy
- Very easy
- What specific parts may be difficult to follow at home, school, sports etc.?

11. It is recommended that children take a period of mental rest; meaning that they do not watch TV or play videogames, stay at home, and then follow a step-wise program to go back to school. Do you think that this recommendation would be easy to follow?

12. Was there any information missing that would have been helpful?

13. What information should parents receive to improve their practice?

14. Do you have any suggestions how we could improve the guidelines?

Guideline dissemination
- Do you have any suggestions how we could best connect the public (including children, parents, schools and sports organizations) with the information in the guidelines?
Probes:
- Through the media (television commercials, news items, articles in newspapers, online or other sources)
- An app (smartphone)
- Through professional concussion websites (ONF website (www.onf.org), pediatric concussion web portal (www.kidsconcussion.com), Parachute etc.)
- Online forums
- Information materials available at schools, sports organizations, physician offices, etc.
- Other?

Conclusion:
5. Is there anything else you would like to discuss in relation to this topic that we haven’t talked about?

6. Would you be interested in participating in future projects on childhood concussion as a teacher expert/community representative?

At this time
I would like to thank you for your participation. Your contribution to this study has been very insightful. If you have any further comments or questions please contact me. My contact information is included on your copy of the information sheet.
All interviews were audio-recorded and transcribed verbatim.

Data analysis

The team employed a deductive approach to qualitative content analysis\(^\text{18}\) whereby transcripts were coded using preexisting codes relevant to the study domains. Modifications to codes were made throughout the analysis to better reflect the data.\(^\text{19}\) The data analysis was informed by the team’s decision to use deductive coding based on the four a-priori defined domains. The team was open to revisiting these domains, had the data required it. Study domains and pre-existing codes originated from the literature review and were refined through ongoing research team consensus meetings. As the interview guides were tailored to each participant group, the resultant data were analyzed separately and then compared. We used NVivo 11 (QSR International), a qualitative data analysis software, to house the transcripts and facilitate the coding. One study author (AG) conducted the analysis with regular input from the team obtained through weekly peer debriefings.

Results

In total, 40 participants completed the study: 9 patients, 17 parents (13 with a concussed child and 4 with a non-concussed child), and 14 educators (Table 2). The interviews lasted approximately 30 minutes and the coded data was ultimately arranged into our four a priori defined domains. No new domains emerged from the data set during analysis.

Concussion awareness

All participants identified concussion as a priority health issue for school-aged youth. Increased media attention as well as the implementation of concussion protocols in school and youth sports were noted as important factors for a change in personal and public perception of the seriousness of concussion over the past ten years. One parent-participant [P1] commented: “I just find in general, people talk about it more or worry about it more.” According to an educator-participant [P2], concussions are handled differently now as compared to the past: “I can see that there have been concussion related injuries throughout the past that we haven’t really recognized [...] Now we realize that those injuries were actually brain related injuries.” Another educator-participant [P3] added: “I think it’s probably been underreported for a lot of years, and kids have not been as successful as they could have been because of it.”

Parent-participants and educator-participants expressed that concussion has received more attention within schools in recent years. According to an educator-participant [P4]: “In the past few years I’ve seen much more attention around it in the school systems and we’re attempting to do due diligence around it, but it’s a process in the making because the information was not all available or we didn’t know where to look.” Some educator-participants discussed potential drawbacks of increased concussion awareness and the implementation of protocols at school [P5]: “My only concern is that it seems that there’s been a lot of diagnosis now. So, you know, from a teacher perspective we’re seeing a lot of students missing a lot of school because of their concussions, and even parents that are trying to diagnose them without any medical expertise.” Another educator-participant [P6] adds that: “There’s so much fear about concussions now because of the media regime; it’s not necessarily a bad thing but we’re also seeing that what has happened now is that teenagers are manipulating the system [to get out of exams].”

Experience with concussion

Participants reported varying degrees of the impact of concussion on daily activities, ranging from taking a few days off to prolonged absenteeism after which schedule and classroom adaptations were necessary to facilitate a gradual return to academic and athletic activities. Parent-participants and educator-participants expressed concern about prolonged absence from school, not only because of the negative impact on the child’s academic success, but also on the potential for psychological stress and mood disturbances due to limited peer contact. Paediatric patient-participants were most concerned about social withdrawal as a result of absence from school, sports and social activities. One patient-participant [P7] mentioned: “Avoiding music class and gym class I found actually caused more anxiety and depression. [Avoiding the things that you like doing] was probably one of the things that I really struggled with, because I’m one of those people that always needs to be doing something or making progress - so when you’re not allowed to do that it’s very hard.” Several patient-participants mentioned self-perceived pressure to return to academic and sports activities too quickly. [P8] “If you’re not practicing, you’re not working hard enough...It’s basically ‘it’s on you to make this progress’. When you’re not making progress, you feel like it’s on you even though you know there’s nothing you can do about it.” Only one patient-participant perceived pressure at school to perform at a ‘normal’ level during his recovery.

Several educator-participants experienced difficulty linking the severity of the injury to the estimated impact on the child’s activities. [P6] “I’ve seen both
sides of the spectrum. I’ve seen 15 year-olds in their first year of senior high school football, and they never return. And […] it blows you away that the contact was so minimum. And then you see the other ones that you know it looks like they got hit by a freight train and they’re back in two weeks and they are okay.”

Support and resources

Approximately half of the parent- and educator-participants were familiar with existing concussion protocols or guidelines prior to participating in this study. Those parent-participants who had previously sought online resources described difficulties processing the volume and variation of concussion management recommendations available. Most parent-participants preferred receiving detailed information from health professionals. One parent-participant [P9] noted: “You can get really bombarded on the internet. I did really appreciate the handout that they gave at the hospital. I found that extremely helpful as a guideline, and it’s better when the information is provided by a health professional because then the rest of the family is more likely to take it.” Some parent-participants suggested supplementing the patient education materials supplied

Table 2. Participant demographics.

| Patients/children (n = 9) |   |
|--------------------------|---|
| Recruited                | 15|
| Withdrew                 | 6 |
| Completed                | 9 |
| Mean age                 | 13.1 years |
| Age range                | 8–17 years |
| Sex                      | Female, n = 6 Male, n = 3 |
| Condition                | Acute, n = 1 Chronic, n = 8 |
| Injury mechanism         | Sports, n = 6 Non-sport related injury, n = 2 Motor vehicle collision, n = 1 |
| Mean symptom duration    | 2.4 months (range 1 week–6 months) |
| Parents (n = 17)         |   |
| Recruited                | 34|
| Withdrew                 | 17|
| Completed                | 17|
| Sex                      | Female, n = 16 Male, n = 1 |
| Parental subgroups       | Parent of child presenting with concussion, n = 13 Parent of child with history of concussion, n = 4 |
| Educators (n = 14)       |   |
| Recruited                | 18|
| Withdrew                 | 4 |
| Completed                | 14|
| Age range                | 21–30, n = 1 31–40, n = 6 41–50, n = 7 |
| Sex                      | Female, n = 9 Male, n = 5 |
| Experience (years)       | <5 years, n = 1 5–10 years, 6 = 6 >10 years, n = 7 |
| Professional duties reporteda | Classroom, n = 9 Physical education/coaching, n = 9 Student support/special needs, n = 2 |

*aMore than one professional duty possible.*
by hospitals with links to online resources for more in-depth and up-to-date information on concussion and its management.

Patient-participants indicated that support at school ranged from no assistance to increased breaks and gradual build-up of hours using half-day increments. Only one patient-participant received structured support in the form of an individual lesson plan. Several patients-participants stressed the need for better support at gradually building academic tasks on an individual level. As for sports, patient-participants felt that they received sufficient support from their coaches to gradually build their activities according to their symptom levels.

For teacher-participants, resource needs and availability varied across schools and by educator roles. While protocols for the recognition and management of concussion were implemented in all participating schools as a result of changes in Ontario legislation, it appears that only physical education staff (not all teaching staff) received formal concussion training. Similarly, our data suggests that physical education staff had better knowledge of protocol recommendations than strictly classroom-based teachers. In addition, temporary or substitute teachers were often unaware of the existence or specifics of concussion protocols, as information and training were offered only at the beginning of the academic year or during staff meetings. Resources for classroom adaptations or alternative learning environments were only available in one school.

All participants alike strongly supported the implementation of a standardized protocol for recognizing and managing concussion in all youth sports (school-based and non-school-based). All but one parent-participant felt that it is important to not only educate players, but also parents and coaches on concussion safety. Participants uniformly felt that it is important to educate children/adolescents about the importance of disclosing injuries sustained by themselves or teammates, to ensure that coaches and parents are informed once an injury occurs.

With regard to concussion protocol recommendations, most participants found return-to-learn protocols generally easy to follow. Most patient-participants noted that while it was ‘boring’, initial mental rest was perceived as an important step to recovery. Overall, patient-participants experienced most difficulties refraining from television and multimedia devices, as this increased their feelings of isolation from their peers and furthermore because many academic exercises are nowadays using online materials. Some patient-participants experienced difficulties with the return-to-learn schedule [P7]: “Actually the one [guideline] I have in front of me says to avoid music class altogether. When I tried that, it was very frustrating and it actually created anxiety and depression on top of the rest of my symptoms.” Another noted [P10]: “I felt like it was very hard to differentiate where you were because it felt like in some areas I felt like I was still in stage two, or I was in stage three, but in other parts I was kind of in stage 4. It was very hard to pinpoint what I actually should be doing to get better.” [P7] “It was really hard to find what I was supposed to do in the guidelines, because I couldn’t avoid music class and sound didn’t bother me at all, it was more light that bothered me.” For return-to-play protocols, participants groups uniformly preferred an early resumption of light aerobic activity to currently recommended complete physical rest following concussion until symptom-free.

**Outcome priorities**

Paediatric patient-participants were most worried about the short-term problems associated with concussion, including absenteeism from school, sports and social encounters. One patient-participant also noted the importance of preventing re-injury. Parent- and educator-participants shared this concern but added that long-term complications were of a growing concern. According to one educator-participant [P11]: “The long term is what we’re seeing in the news, but the short term - a lot of people don’t see that [a concussion] does impact their day-to-day living, especially school: they can’t concentrate, they’re not going to do the learning progression that they normally would do […] and I see it firsthand because I coach football, basketball, soccer, hockey, and I’m also a high school teacher.” Another educator-participant [P12] added: “So I think as adults and as coaches and educators it’s important that we remind them that this isn’t about today and next week and next month, it’s about forever […] and I think we just can’t be too careful when it comes to your brain.”

Both parent- and educator-participants perceived a timely return to school as a primary focus during concussion recovery, followed by resumption of physical activity (including sports) and social activities.

**Discussion**

Our study found that paediatric concussion is a serious health concern to patients, parents and educators. Social withdrawal, removal from sports and falling behind on academic achievements were of biggest concern to patient-participants. The majority of parent- and educator participants expressed that their primary concern had shifted from short-term to potential long-term complications following paediatric concussion,
including psychological stress, cognitive problems and potential for decreased academic achievement. Timely return to school was therefore described as the fundamental goal during concussion recovery. Increased media attention and greater awareness of concussion protocols were mentioned as important contributors to the evolving personal and public opinion on the perceived importance of paediatric concussion. Some educator-participants however felt that children and adolescents might not be as aware of these potential long-term complications, which might account for the difference in outcome priorities between children and their support network. Our study was focused on an exploratory examination of participant perspectives on pediatric concussion awareness, experience, support/resources, and outcome priorities; future research should consider explanatory analyses as to better understand the why and how of stakeholders’ perspectives in pediatric concussion.

Emerging evidence on potential short-term and long-term complications, recent concussion guideline recommendations advocating stricter follow-up and medical clearance of concussed athletes, and changes in Ontario legislation might have led to increased identification and reporting of concussion in school-aged youth.

A recent, large prospective cohort study across 9 Canadian paediatric EDs demonstrated that up to 30% of concussed youth suffer from prolonged post-concussive symptoms one-month following an acute concussion. All efforts should be made to improve paediatric concussion recognition and management to optimize concussion recovery, not only by health care providers but by everyone involved in the care for concussed youth, including parents and educators. Efforts should be made to incorporate a single standardized protocol for the diagnosis and management of concussion in school-aged youth for general use in schools and sports facilities. In addition, there is room for improvement in how this information is disseminated. Ideally, this information would be shared by schools and sports organizations at the beginning of the year or season, as well as by health professionals involved in the care of a children presenting with a head injury.

In addition to the use of concussion protocol guidelines, concussion legislation is another avenue to standardize the approach to paediatric concussion management. Following recent advances to better protect young athletes and educate coaches about the potential dangers of head injuries, Rowan’s Law (Bill 193) was passed in Ontario in 2018 as Canada’s first concussion safety legislation. The law establishes removal-from-sport and return-to-physical activity protocols for players suspected of having a concussion. As concussion legislation has been demonstrated to have a positive effect on health care utilization, this is an important step in optimizing concussion awareness and management in youth. In our study, educator-participants mentioned a wide variation in concussion education and knowledge not only between institutions, but also within organizations between athletic and academic staff. For any legislation to succeed, standardized protocols and training opportunities are necessary to ensure that teachers and coaches have the skills to accurately recognize and manage concussive symptoms. Including youth and their families in concussion education was positively received by patient-parent-participants in our study. Although beyond the scope of our study, educating patients and their families on paediatric concussion diagnosis and management might further optimize paediatric concussion recovery through improved adherence to protocol recommendations.

While parents mentioned utilizing online resources to better recognize and manage symptoms during concussion recovery, many struggled with the volume and variation in recommendations available. Further, parents uniformly preferred health care professionals to online resources as the primary source of concussion information. These findings are largely in line with those described in another study exploring caregivers of youth athletes in the United States.30 That study, as well as our own, suggests that more uniform and detailed patient education material (e.g., hand-outs) provided at the time of health care visits is the preferred channel for patients and their families to receive information to recognize and manage concussion and post-concussive symptoms. According to our parent-participants, handouts should include more detailed examples of cognitive and physical activities that are safe as well as those that should be avoided during recovery.

Rest has long been considered the “cornerstone of concussion management”. An initial period of full mental and physical rest until symptom resolution, as recommended by paediatric concussion guidelines at the time of study data collection, was for many patient-participants and their families challenging to achieve. All three participant groups described difficulties adhering to strict rest recommendations following concussion, particularly physical rest. Participants were uniformly in favor of a more active approach to return-to-physical activity, as long as deemed safe by medical professionals. A recent large comparative effectiveness study demonstrated that persistent post-concussive symptoms at one-month were significantly less prevalent in children who engaged in early physical activity compared to those who reported complete physical rest at one-week, and irrespective of symptoms, approximately 70% of youth participate in physical activities
within one-week following an acute concussion.\textsuperscript{32} Similarly, recent recommendations from an international consensus statement on concussion in sport suggest that after a brief period of rest (48 hours) patients can be encouraged to gradually become more active (while staying below cognitive and physical symptom-exacerbation thresholds).\textsuperscript{1} While our findings suggest that this recommendation would be acceptable to youth as the desire to participate in physical activity was expressed by our patient-participants, the optimal timing, type, intensity and duration of this activity requires further research.\textsuperscript{33}

**Limitations**

There are limitations to consider when interpreting the findings of this study. First, our team members are clinical and published experts in the field of paediatric concussion. It is possible that team members’ preconceptions of concussion and its effects on patients and families may have influenced our choice of study design, data collection and analysis. Second, as deductive coding was used to analyze four a-priori selected domains, it is possible that a different coding scheme or inductive coding might have revealed different, although likely not incompatible, results. Third, data was collected for an a-priori set time period. Post-analysis, the team concluded that additional interviews would likely not enhance our understanding of the findings. Fourth, we did not stratify enrolment based on sex or gender. Since female gender is an important predictor of prolonged post-concussive symptoms,\textsuperscript{5} this likely explains the 2:1 female to male ratio in our patient-participant sample. However, a more balanced sample would likely not have led to different results. As a qualitative study based in one Canadian province, our findings are not necessarily representative of other regions. We attempted to increase transferability of our findings by recruiting various participant groups from multiple sites within Ontario; future studies using larger sample sizes drawn from geographically dispersed sites would also provide greater representation of the paediatric concussion population and the transferability of those study’s findings.

**Conclusion**

Patients, parents and educators identify concussion as a serious health concern with reduced peer-contact, potential for decreased academic achievement, and psychological stress as principal concerns. Differences exist in the perceived outcome priorities post-concussion; short-term problems were of biggest concern to patient-participants, whereas the primary concerns for parents and educators are potential long-term complications. Timely return to school was identified as the priority during concussion recovery, in order to enable peer contact and resume academic activities. Educational materials should be tailored to ensure instructions resonate with all intended end-users and optimize concussion recovery at home, school and sports.

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