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Chronic traumatic encephalopathy: what do parents of youth athletes know about it?

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Abstract

Introduction/Background: Chronic Traumatic Encephalopathy (CTE) is a neurodegenerative disease thought to be caused by repeated head impacts and associated with deficits in cognition. Despite research and media attention, there is little science-based information available for the public. Also unclear is what the public and particularly parents of youth athletes know about CTE. The U.S. Centers for Disease Control and Prevention (CDC) surveyed parents of young athletes to fill this gap.

Methods: CDC analysed 12 CTE-related questions that appeared in Porter Novelli Public Service's 2017 SummerStyles opinion survey. Analyses focused on 674 parents of children who play in a youth sports programme.

Results: Half of parents had at least one child who plays contact sports. About one-third of respondents reported being somewhat or very familiar with CTE. Most parents (81.7%) have not received educational materials on CTE from a school or sports programme. Healthcare providers were the preferred source of information about CTE (70%), followed by sports coaches (54%).

Discussion/Conclusion: This analysis identified information needs related to CTE among parents of young athletes. These findings can be used by health educators to tailor educational materials to meet information needs. Educational materials that emphasize potential prevention strategies and symptom onset may be beneficial.

Keywords

Chronic Traumatic Encephalopathy; concussions; youth athletics

Introduction

Despite being first described in the 1920s(1), there are still many unanswered questions about Chronic Traumatic Encephalopathy (CTE). The nature of the onset, presentation, and progression of CTE symptoms, the threshold level of trauma necessary to cause the disease, accurate diagnostic criteria and the true prevalence of CTE are by and large unknown (2–7). In an attempt to answer some of these questions, many research institutes have begun CTE-

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intensive research programs. For example, in 2013, the U.S. National Institutes of Health (NIH) embarked on a large-scale effort to advance the research and more fully understand CTE (8,9). As part of this effort, NIH held the first consensus workshop to define the neuropathological criteria for the diagnosis of CTE (10). NIH is currently funding a large research study to learn how to diagnose CTE while a person is still alive (9,11).

Coinciding with a growth in research and publication of high profile studies on CTE, there has also been a significant increase in media attention on CTE. Much of the media reports focus on professional athletes and also include movies and television shows depicting personal stories of individuals diagnosed with CTE post-mortem. However, a search for science-based educational materials for CTE, especially those aimed at parents of young athletes, will yield little. Thus, those interested in learning about CTE often look to media reports. As Kuhn and colleagues (p. 1) note, “the public’s perception of sport-related CTE is likely not based on the totality of empirical data, but rather on highly publicized and emotionally charged events.”(12)

In order to inform the development of science-based educational information for parents on CTE, the U.S. Centers for Disease Control and Prevention (CDC) surveyed parents of young athletes. This survey sought to better understand their current level of knowledge and opinions about CTE to help determine information needs to form the basis of such educational materials. To our knowledge, this is the first time that general awareness of CTE among parents of youth athletes has been studied.

Background

CTE is a neurodegenerative disease believed to be caused, in part, by exposure to repetitive head impacts, including concussions (and other traumatic brain injuries) and subconcussive trauma (i.e. head impacts that do not cause symptoms of concussions) (3,13). Descriptions of the clinical features of CTE are based primarily on interviews with family members of deceased individuals who were diagnosed with CTE after death (7,14,15). Based on these studies, clinical presentation of CTE is thought to be associated with changes and deficits in cognition, mood, and motor skills (16–21).

Individuals may have a higher risk of developing CTE if they engage in activities that increase their chances for having repetitive hits to the head (e.g. collisions during sports activities), are exposed to repeated acts of physical violence, or if they have been exposed to explosive blasts in the military (14,22–29). Most CTE studies to date examine individuals with a significant history of participation in contact sports or sports in which collisions are common (such as football, ice hockey and soccer). As such, high profile studies have garnered significant media attention and placed a spotlight on sports safety.

Each year, approximately 45 million children participate organized youth sports (30). To promote sports safety, some sports programmes have recently instituted contact restrictions or limits, such as reduction of tackling in football, body-checking in ice hockey, and heading in soccer, aimed at limiting concussions and head impacts overall(31). There is reason to believe that the implementation of sports-specific interventions focused on reducing head

impacts, as well as increased in media coverage about CTE, has led to strong familiarity with CTE among parents (12). However, there is currently little to no data to support this belief. Additionally, it is unclear if and how parents of young athletes seek out or receive information on CTE. This paper explores the current the level of awareness and information needs and preferences regarding CTE among a sample of parents of young athletes.

Methods

Sample

A series of CTE-related questions were included in the Porter Novelli (PN) Public Service's SummerStyles public opinion survey that was fielded in June and July of 2017. All of PN's consumer surveys utilize GfK's KnowledgePanel® (32), which is a type of multi-purpose panel (33). Panels are composed of individuals who have agreed to participate in periodic surveys about consumer, marketing, lifestyle, and health issues. These types of panels are generally thought to convey certain advantages in terms of conducting surveys, including relatively high response rates, lower attrition rates in longitudinal research, and easy access to respondent and household information (i.e. it is collected in the beginning and does not have to be collected for each survey) (34). Panel members for each specific survey are randomly recruited using probability-based sampling by home address to reach respondents regardless of their land-line phone or Internet access. If needed, households are provided with a laptop computer and access to the Internet to complete the survey. The panel is continuously replenished and maintains approximately 55,000 panelists. Porter Novelli has been conducting these surveys since 1995. The response rates for the SummerStyles panels have ranged between 66% and 74% for the last five iterations. While SummerStyles' respondents should rightly be considered a convenience sample, researchers within and outside of the CDC were able to support the reliability and validity of the panel data by comparing survey responses to a separate nationally representative dataset (35,36).

The 2017 SummerStyles survey was sent to a random sample of 5586 panelists ages 18 or older who had participated in the spring iteration of the survey as well. Email reminders were sent to non-responders on the 3rd, 15th, 21st and 23rd day of the field period. The survey contained dozens of questions covering a variety of consumer and general health topics – ranging from general health questions to questions on tobacco use and air quality. Median survey completion time was approximately 26 minutes. Respondents were not required to answer any of the questions and had the opportunity to exit the survey at any time. Respondents received 5000 cash-equivalent points for their participation (approximately \$5). Respondents who did not answer at least half of the questions were removed from the data as incomplete ($n = 14$). A total of 4107 adults qualified and completed the survey for a survey response rate of 74%. We focused our analysis on the sub-sample of respondents who had children age 5–18 who play sports in a youth or school sports programme ($n = 674$). Analyses of *SummerStyles* data are exempt from institutional review board approval because data do not include personal identifiers.

Measures

CTE knowledge and opinions

A series of 12 yes/no, Likert scale, and multiple-choice questions were included in this survey. The CTE questions were developed based on a review of the latest science outlined through the NIH CTE consensus conference (10,15) and a search for current CTE educational products available online. We identified four websites (37–40) (not inclusive of media websites or reports) for the public on CTE. We reviewed the information on each website to assess the type of content presented, understand if content on the website was consistent with the science, and whether the materials were written using plain language. After asking whether the respondent has a child 5–18 years who plays a contact sport, we asked parents a series of knowledge, opinion, information needs, and preference questions related to CTE. Topics included:

- Age respondents think children should begin to participate in contact sports
- Respondents' familiarity with and level of concern about CTE
- Whether respondents have ever received educational materials from a school or sports programme with information about CTE
- From whom respondents would like to receive educational materials on CTE
- Respondents' level of knowledge regarding causes and symptoms of CTE

The full question wording and response options are included in the tables.

Demographic variables

Respondents were asked to self-report on a series of demographic variables at the beginning of the survey. Categorical variables for parent demographic characteristics included: sex (men, women), age group (18–34, 35–49, 50–64, 65 years); race/ethnicity (white non-Hispanic, black non-Hispanic, other); education (high school graduate or less, some college, college graduate); annual household income (less than \$25,000, \$25,000–49,999, \$50,000–74,999, \$75,000–99,999, \$100,000 or more); marital status (currently married, currently cohabiting, formerly married, never married); metropolitan statistical area (MSA; non-metropolitan, metropolitan, other); and region (Northeast, Midwest, South, West)(41).

Analysis

The analysis focused on the 674 respondents who indicated that they were the parent of a child age 5–18 who plays in a youth or school sports programme. We used SAS 9.3 to perform standard descriptive frequencies and bivariate associations. We performed chi square tests to compare categorical variables to determine whether there were significant differences between groups, specifically between parents who have children who play contact sports and parents who do not have children who play contact sports, and between men and women. Previous research has shown (a) concussions are more common in children who play contact sports (42) and (b) that men and women have different levels of experience, knowledge, and concern regarding concussions (43,44). For these reasons, we were interested in seeing if the level of knowledge and concern about CTE also varied by

these factors. For the purposes of this analysis for the applicable questions, “agree” comprises those who responded “agree” and “slightly agree” while “disagree” comprises those who responded “disagree” and “slightly disagree.” A statistically significant difference was noted when two-sided P values < 0.05 .

Results

Sample description

Table 1 shows that approximately half of the SummerStyles subsample (respondents who have children between the ages of 5–18 who play sports) was between the ages of 30–44 and another 42.6% was between the ages of 45–59. About 55.2% were women and 50.6% had a bachelor’s degree or higher. This was a relatively affluent sample, with 44.2% of respondents reporting a household annual income of \$100,000 or more and another 17.4% reporting an income of \$75,000–99,999 a year. Approximately 84.7% of respondents were currently married. About 86.5% lived in a metropolitan area and the sample was fairly evenly disbursed across regions of the USA.

Children, contact sports, familiarity with CTE, and concern about CTE

Of the 674 respondents who had at least one child between the ages of 5 and 18 who plays in a youth or school sports programme, about half (49.3%) play contact sports (analysis not shown). Nearly half (47.7%) of the respondents who have children between the ages of 5 and 18 who play sports believed that children should start playing contact sports between the ages of 5 and 10 and another quarter (25.4%) believed they should start between the ages of 11 and 13 (Table 2). The responses to this question varied significantly ($\chi(2)= 89.1$, $P < 0.0001$) by whether the respondent’s child currently plays a contact sport: a majority (70.2%) of parents who have children who play contact sports say that kids should start playing contact sports by age 10, compared to 36.5% of parents who do not have kids who play contact sports. This question did not show differences by gender; men and women were equally likely to report each age group as a proper starting place for contact sports.

When we asked how familiar respondents were with CTE on a 5-point Likert scale, about 38% reported being somewhat or very familiar. Parents whose children play contact sports were significantly more likely to be very or somewhat familiar with CTE (42.6%) than parents whose children do not play contact sports (34.3%) ($\chi(2)= 4.6$, $P = 0.0320$). About 1 in 4 parents (28.6%) agreed that they were concerned that their child will get CTE from playing sports. Parents whose children play contact sports were more likely to agree that they were concerned that their child will develop CTE as a result of playing sports (37.0%) than parents who do not have kids who play contact sports (21.0%) ($\chi(2)= 20.2$, $P < 0.0001$). Concern about CTE did not vary by gender.

How respondents would like to get information about CTE

Only 18.3% of respondents reported ever having received educational materials from a school or sports programme with information about CTE; another 14.7% were not sure whether they had received materials (Table 3). Doctors and nurses were the preferred source of information about CTE as 69.5% of respondents said they would like to receive

educational materials or information about CTE from them. About 54% would like to receive information from their child's coach or sports programme and 40.1% from their child's school. In terms of the vehicle for information about CTE, respondents indicated a strong preference for handouts or fact sheets (76.5%). The second most common vehicle was through a website or online content (39.0%).

Attitudes and opinions about CTE

About 47.0% of respondents agreed that their child's sports programme or school is taking the right steps to protect athletes from developing CTE (Table 4). A sizeable proportion chose the "neither" response option (as in neither agree nor disagree) for this question: 43.3%. Two-thirds of respondents knew that a person cannot get CTE exclusively from playing sports and 47.3% thought that changing the rules of play for contact sports can protect athletes from getting CTE. A little over half of the respondents (52.7%) knew that signs and symptoms of CTE do not show up right after a head or brain injury and only 10.5% believed that doctors and nurses have treatments to cure CTE. Finally, 12.0% of respondents believed that they can never protect their child from getting CTE while the vast majority believed they could protect their child at least some of the time.

Discussion

This analysis identified information needs related to CTE among parents of young athletes. These findings can be used by health educators to create and tailor educational materials to meet information needs of this audience. Educational materials that emphasize potential prevention strategies and symptom onset may be beneficial.

Fewer than 30% of respondents reported being concerned that their child will get CTE from playing sports. However, this concern was greater among parents who have children who currently play *contact* sports. This perhaps demonstrates that these parents are aware of the risks that their children face from participating in these activities. While multiple factors may contribute to an individual's risk for CTE, limiting an individual's on-going exposure to repetitive head impacts is the focus of most prevention efforts. Research on rule changes in some sports has demonstrated positive reductions in the number of head impacts. Beaudouin et al., found that after institution of the rule change in soccer aimed at stricter officiating (e.g. intentional elbow-head contact), head injuries were reduced by 29% (45). This result mirrors the results found in studies that have examined rule changes in other contact sports (46,47).

Parents whose children play contact sports were significantly more likely to be very or somewhat familiar with CTE than parents whose children do not play contact sports. Given this, educational efforts can consider taking into account the type of sport their child participates in (contact versus non-contact sports). Future studies can also explore awareness of CTE among athletes and coaches; coaches are a key influencer regarding athletes' perceptions and behaviours of sports safety.

Finally, parents will most likely look to healthcare providers for information on CTE. Our results showed that more than two-thirds of respondents in this survey would like to receive

information from a doctor or nurse about CTE. Similarly, a group of physicians and researchers recently recommended that young people, including youth athletes, be included in discussions between doctors and parents regarding the risk of concussions, repetitive head trauma, and the risk of CTE(48). In addition to healthcare providers, parents may turn to their child's sports programme: a little over half would like to see CTE information provided by their child's coach or sports programme. Receiving information from a healthcare provider or sports programmes is also supported by parents' overall preference for handouts or fact sheets.

Limitations

While all of Porter Novelli's surveys attempt to recruit a relatively representative sample, we utilized a select group of individuals who have children who play sports. Therefore, the representativeness of their responses is unclear and the sample of 674 parents should be considered a convenience sample. It is possible that these selected respondents or those who choose to participate in this survey more generally are different from the general population in ways that bias the results. Because this survey relied on self-assessment of familiarity with CTE, it is likely that there is some degree of inter-respondent variability on this measure and thus does not generalize to a wider population's familiarity with CTE. This survey was also limited in scope; the focus was only on sports-related causes of CTE. Future research is needed to determine general awareness of CTE, and information and resource gaps among Americans overall, including key audiences.

Conclusion

Despite recent increased attention to CTE in the form of media reports, movies and high-profile research studies, there is little educational information available to parents of young athletes. Results of this study show that the parents of youth athletes are still not very familiar with CTE yet are interested in learning more about this disease. This is an emerging area of research and in time parents of children who play sports may look to healthcare providers and sports programmes for additional information and recommendations. Health educators can use the findings from this study to inform the development of educational products for parents and emphasize identified information gaps. Education efforts regarding CTE should include a balance of explaining what is known with what is unknown, while also taking into account the type of sport in which a child participates.

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Disclosure Statement

The authors report no declarations of interest. The findings and conclusions in this manuscript are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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Table 1.

Demographics of SummerStyles Sample, respondents who have children who play sports.

	Frequency	Per cent
Age of respondent		
18–29	27	4.0
30–44	334	49.6
45–59	287	42.6
60+	26	3.9
Total	674	100.0
Sex		
Male	302	44.8
Female	372	55.2
Total	674	100.0
Educational Attainment		
Less than high school	18	2.7
High school	116	17.2
Some college	199	29.5
Bachelor's degree or higher	341	50.6
Total	674	100.0
Household annual income		
Less than \$25,000	42	6.2
\$25,000–49,999	106	15.7
\$50,000–74,999	111	16.5
\$75,000–99,999	117	17.4
\$100,000 or more	298	44.2
Total	674	100.0
Marital status		
Currently married	571	84.7
Formerly married	46	6.8
Never married	27	4.0
Currently cohabiting	30	4.5
Total	674	100.0
MSA designation		
Non-metropolitan	91	13.5
Metropolitan	583	86.5
Total	674	100.0
Region		
Northeast	140	20.8
Midwest	181	26.9
South	233	34.6
West	120	17.8
Total	674	100.0

Table 2.

At what age should children begin playing contact sports, familiarity with CTE and concern about CTE, by contact sport participation and respondent gender.

	Does your child play contact sports?				Respondent Sex				Comparison Statistics	Frequency	Percentage	Comparison Statistics	Frequency	Percentage	Comparison Statistics		
	Overall		Yes		No		Male									Female	
	Percentage	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage	Frequency								Percentage	Frequency
At what age should children begin participating in contact sports?																	
$\chi^{(2)}(4) = 89.1, p = < 0.0001$																	
Under 5 years	5.9	40	10.0	32	1.6	5					6.0	18	5.9	22			
5-10 years	47.7	321	60.2	192	34.9	110					47.0	142	48.3	179			
11-13 years	25.4	171	19.4	62	32.4	102					26.5	80	24.5	91			
14 or over	17.2	116	10.0	32	23.8	75					16.6	50	17.8	66			
Never	3.7	25	0.3	1	7.3	23					4.0	12	3.5	13			
$\chi^{(2)}(1) = 4.6, p = 0.0320$																	
How familiar are you with CTE?																	
Very or somewhat	38.3	245	42.6	135	34.3	108					44.8	129	33.1	116			
Not very or not at all	61.7	394	57.4	182	65.7	207					55.2	159	67.0	235			
$\chi^{(2)}(1) = 9.2, p = 0.0024$																	
Do you agree or disagree that you are concerned that your child will get CTE playing sports?*																	
$\chi^{(2)}(2) = 20.2, p = < 0.0001$																	
Agree	28.6	191	37.0	117	21.0	66					26.8	80	30.0	111			
Neither agree nor disagree	35.0	234	31.0	98	36.0	113					24.8	104	35.1	130			
Disagree	36.5	244	32.0	101	43.0	135					38.5	115	34.9	129			

*“Agree” comprises those that responded “agree” and “slightly agree” while “Disagree” comprises those that responded “disagree” and “slightly disagree”

Table 3.

How respondents prefer to receive information about CTE.

	Frequency	Percentage
<i>Have you or your child ever received educational materials from a school or sports programme with information about CTE?</i>		
Yes	123	18.3
No	451	67.0
Don't know	99	14.7
Total	673	100.0
<i>From whom would you like to receive educational materials or information about CTE? (frequency and % yes)*</i>		
A doctor or nurse	464	69.5
My child's coach or sports programme	363	54.3
My child's school	268	40.1
Health department or government agency, such as the CDC	236	35.3
Media or spokesperson Professional athletes	150	22.5
<i>How would you like to receive educational materials or information about CTE? (frequency and % yes)*</i>		
Handout or fact sheet	463	76.5
Website or online content (such as videos)	236	39.0
Training or presentation	193	31.9
Other	150	24.8

* Responses are not mutually exclusive, therefore no total is given

Table 4.

Attitudes and opinions about CTE.

<i>My child's sports programme or school is taking the right steps to protect athletes from getting CTE</i>		
Agree/slightly agree	314	47.0
Neither	289	43.3
Disagree/slightly disagree	65	9.7
Total	668	100.0
<i>Do you think a person can only get CTE from playing sports?</i>		
Yes	86	12.9
No	442	66.3
Don't know	139	20.8
Total	667	100.0
<i>Do you think changing the rules of play for contact sports can protect athletes from getting CTE?</i>		
Yes	317	47.3
No	137	20.5
Don't know	216	32.2
Total	670	100.0
<i>Do you think signs and symptoms of CTE show up right after a head or brain injury?</i>		
Yes	71	10.6
No	352	52.7
Don't know	245	36.7
Total	668	100.0
<i>Do you think doctors and nurses have treatments to cure CTE?</i>		
Yes	70	10.5
No	324	48.4
Don't know	275	41.1
Total	669	100.0
<i>How often do you feel like you can protect your child from getting CTE?</i>		
All the time/most of the time	261	39.2
Some of the time	325	48.8
None of the time	80	12.0
Total	666	100.0