Sport participation and related head injuries following craniostynostosis correction: a survey study

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OBJECTIVE Craniostynostosis (CS) affects about 1 in 2500 infants and is predominantly treated by surgical intervention in infancy. Later in childhood, many of these children wish to participate in sports. However, the safety of participation is largely anecdotal and based on surgeon experience. The objective of this survey study was to describe sport participation and sport-related head injury in CS patients.

METHODS A 16-question survey related to child/parent demographics, CS surgery history, sport history, and sport-induced head injury history was made available to patients/parents in the United States through a series of synostosis organization listservs, as well as synostosis-focused Facebook groups, between October 2019 and June 2020. Sports were categorized based on the American Academy of Pediatrics groupings. Pearson's chi-square test, Fisher's exact test, and the independent-samples t-test were used in the analysis.

RESULTS Overall, 187 CS patients were described as 63% male, 89% White, and 88% non-Hispanic, and 89% underwent surgery at 1 year or younger. The majority (74%) had participated in sports starting at an average age of 5 years (SD 2.2). Of those participating in sports, contact/collision sport participation was most common (77%), and 71% participated in multiple sports. Those that played sports were less frequently Hispanic (2.2% vs 22.9%, $p < 0.001$) and more frequently had undergone a second surgery (44% vs 25%, $p = 0.021$). Only 9 of 139 (6.5%) sport-participating CS patients suffered head injuries; 6 (67%) were concussions and the remaining 3 were nondescript but did not mention any surgical needs.

CONCLUSIONS In this nationwide survey of postsurgical CS patients and parents, sport participation was exceedingly common, with contact sports being the most common sport category. Few head injuries (mostly concussions) were reported as related to sport participation. Although this is a selective sample of CS patients, the initial data suggest that sport participation, even in contact sports, and typically beginning a few years after CS correction, is safe and commonplace.

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KEYWORDS craniostynostosis; craniofacial reconstruction; sport participation; sport-related head injury

CRANIOSYNOSTOSIS (CS) is a craniofacial abnormality resulting from premature fusion of the cranial sutures. The overall incidence of CS has been estimated at 1 in 2500 births.¹⁻³ Isolated single-suture CS is most common, representing > 80% of cases, with multisuture and syndromic CS each contributing less than 10% of cases.¹⁻³ Both for cosmesis and to avoid complications associated with the possible development of intracranial hypertension, children with CS typically undergo surgical correction in infancy.⁴⁻⁷ The optimal timing of intervention

is generally within the 1st year of life in order to mitigate developmental delay and orbital/calvarial deformities.⁷

While a small subset of patients may demonstrate subtle deficits on neuropsychological assessments, most children who undergo single-suture CS correction in early infancy demonstrate normal neurological development.⁸ Given the frequently normal postsurgical neurodevelopment, many of these children (and parents) wish to participate in sports with their peers.

There is limited evidence regarding the safety of sports

ABBREVIATIONS CS = craniostynostosis; REDCap = Research Electronic Data Capture; TBI = traumatic brain injury; UK = United Kingdom.

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in adolescents following CS surgery. Given the extent of the surgery required and high incidence of sport and recreation-related head injury,⁹ both providers and parents may be anxious regarding the prospect of enrolling a child with previously corrected CS in sports, or they may limit the range of sports in which the child is allowed to participate. These concerns, while reasonable, lack any foundational evidence. In fact, sparse evidence on the topic suggests that, in general, CS patients experience a similar rate of traumatic brain injury (TBI) to non-CS children.¹⁰ Recently a small study of postsurgical CS patients in the United Kingdom (UK) found that many CS patients surveyed had participated in sports with only a few minor head injuries reported.¹¹

Despite these initial investigations, physicians and parents continue to rely on anecdotal recommendations. The objective of the current survey study was to broadly describe the sport participation experience of children who have undergone surgical correction of CS, including whether participation led to any significant head injuries. We hypothesized that a wide spectrum of sport participation would be reported with few catastrophic head injuries.

Methods

Study Design

A survey-based cross-sectional study was designed to estimate the frequency of sport participation and any related head injuries for children following CS repair. The study received approval from the Vanderbilt University Medical Center institutional review board. Electronic consent was required from participants prior to accessing the survey questions. The survey was open from October 1, 2019, to June 30, 2020.

Participants

Any person who had previously undergone surgical correction of CS and those who were parents of such children were eligible to participate. Those who did not complete the survey were excluded. The survey was distributed via an email listserv maintained by FACES: The National Craniofacial Association.¹² The survey was also deposited on the “walls” (i.e., message boards) of several Facebook (www.facebook.com) communities, including Cranio Kids—Craniosynostosis Support, Adult Craniosynostosis Survivors, Vandy Cranio Moms, Craniosynostosis Support for Parents and Guardians, Craniosynostosis, and Craniosynostosis Endoscopic Surgery.

Survey Design

The survey was built using the Research Electronic Data Capture (REDCap) web application.¹³ Study data were collected and managed using REDCap electronic data capture tools hosted at Vanderbilt University Medical Center.¹³ REDCap is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages;

and 4) procedures for data integration and interoperability with external sources. At the time of the survey design, no prior empirical studies on the subject of sport participation following CS repair existed. Therefore, survey elements were designed to maximize participation by minimizing survey completion time. We tested the survey for clarity and time of completion prior to distribution. The survey contained the study team's contact information to allow feedback on the clarity of the survey or for questions. While a plan was made to pause enrollment if survey refinement was needed, no questions or concerns arose and no survey revisions were performed during the study. The full survey is available in the Supplemental Material.

Survey elements identified the respondent as either the patient or parent and confirmed that the respondent or their child had undergone surgical correction for CS in the past. All respondents were asked for patient demographic information (current age, sex, race, and ethnicity). Child age at their first surgery was reported in years and recorded as 0 years if surgery was performed prior to 1 year of age. Respondents also reported whether or not additional surgeries were needed for CS and the age at which the second surgery occurred (when applicable).

The primary outcome of interest was whether or not the child participated in sports after the initial surgery, which was simply recorded as yes or no. Those responding “yes” were then prompted to describe sport participation and ages at the time of participation as a free-text response. Those who reported sport participation were also asked if they “experienced a major head injury while playing sports.” If they responded “yes,” they were prompted to provide a free-text description of the head injury.

Statistical Analysis

To facilitate analysis, free-text responses were individually reviewed and coded. The age at first surgery was categorized as < 1 year or ≥ 1 year. Sport responses were provided as free text and subsequently grouped according to the American Academy of Pediatrics categories of sport: noncontact, low contact, contact/collision, and extreme (e.g., BMX, skateboarding, snowboarding, and skiing).¹⁴ If the respondent reported multiple sports, the recorded category reflected the highest contact level of participation. Additionally, each sport was extracted for completeness, as many respondents reported participation in several sports. The age (years) at sport participation was defined as the earliest age of participation in any sport. Information on type of head injury was converted from free-text responses to either concussion or other head injury, based on whether or not the word “concussion” was noted in the response.

Survey responses were stratified by sport participation status, and those who reported participation were substratified by head injury status. As a substantial proportion of patients reported second surgeries, a supplemental analysis was performed comparing sport participation reported by those who did and those who did not have second surgeries. Sample size was dictated by available responses. No data were imputed. Categorical variables are presented as frequencies and proportion, and continuous variables are presented as means with standard deviations. The thresh-

TABLE 1. Craniosynostosis patients stratified by sport participation after surgical correction

	Play Sports (n = 139)	Did/Do Not Play (n = 48)	p Value*	Overall (n = 187)
Male sex	88 (63.3)	29 (60.4)	0.72	117 (62.6)
White race	126 (90.6)	41 (85.4)	0.31	167 (89.3)
Ethnicity			<0.001	
Hispanic	3 (2.2)	11 (22.9)		14 (7.5)
Non-Hispanic	131 (94.2)	34 (70.8)		165 (88.2)
Unknown/other	5 (3.6)	3 (6.3)		8 (4.3)
Age ≤1 yr at op	126 (90.6)	41 (85.4)	0.31	167 (89.3)
2nd op	61 (43.9)	12 (25.0)	0.021	73 (39.0)
Mean age at 2nd op ± SD, yrs	4.90 ± 4.1	3.58 ± 3.18	0.23†	4.68 ± 3.9

Values represent the number of patients (%) unless stated otherwise.

* Pearson's chi-square test unless otherwise noted.

† Student 2-sample t-test.

old for statistical significance was set a priori as $p < 0.05$. Pearson's chi-square test and independent-sample t-tests were used to assess categorical and continuous variables, respectively. All statistical analyses were performed in SPSS Statistics (version 26, IBM Corp.).

Results

The survey link was opened by 221 respondents; 32 were excluded, as they or their child had not undergone surgery. Of the 189 eligible respondents, 187 (98.9%) completed the full set of questions. Of the respondents, 89.8% were parents of children who underwent CS surgery, and 10% were patients themselves. At the time of the survey, the children who had undergone surgery (herein referred to as “patients”) were a mean age of 13.2 years (SD 9.65 years, median 11 years) with a range of 53 years (2–55 years). Overall, patients were mostly White (89.3%), non-Hispanic (88.2%), and male (62.6%). Approximately 90% were younger than 1 year at the time of their first surgery. In total, 39% underwent a second surgery at a mean age of 4.4 years.

Sport Participation

Overall, 139 of 187 (74.3%) patients participated in sports following CS correction. The demographics and first surgery timing were generally similar for those who played sports compared with those who did not (Table 1). However, the distribution of ethnicity was dependent on sport participation status ($p < 0.001$), with Hispanic patients overrepresented in the nonparticipation group. Those who played sports had more frequently undergone a second surgery (43.9% vs 25%, $p = 0.021$).

Those patients who played sports started participating at a mean age of 5.1 years (SD 2.2 years), and most (76.8%) participated in at least one contact/collision sport. The top 3 sports by frequency of participation were soccer (47.8%), baseball/softball (38.8%), and basketball (32.4%). Table 2 provides a complete accounting of sports reported. CS patients who had undergone two or more surgeries reported similar participation in the most popular 5 sports, as well as in each sport category (Table 3).

Head Injuries

Of 139 patients who participated in sports, 9 (6.5%) reportedly experienced a major head injury during sports. Of these injuries, 6 (66.7%) were called “concussions” in free-text responses. There were no statistical differences in age, high contact level of sport participation, or multiple sport participation between those who had suffered head injuries and those who had not (Table 4). Three responses, reproduced in Table 5, detailed the “other” head injuries. Of those patients that reported second surgeries, 6 (9.8%) reported head injuries, compared with 3 (3.8%) of those patients reporting a single surgery ($p = 0.154$).

Discussion

Using a cross-sectional survey study, sport participation appears very common among CS patients following surgical correction and is rarely complicated by a significant head injury. CS patients participated in a wide range of sports across all contact categories, with soccer being the most common. Concussions represented 66% of head injuries, and other injuries usually were also mild or vaguely described. Sport participation and especially team sport participation can be highly beneficial for children,¹⁵ and based on this cross-sectional study, the risks of head injury for CS patients do not appear to outweigh these benefits.

Sport Participation

To date, sport participation following CS surgery has been poorly described in the literature, and surgeons rely on anecdotal experience in order to provide counseling to patients.¹¹ A small survey ($n = 59$) of postsurgical CS patients in the UK found a similarly high rate of sport participation (88%), with the majority involved in noncontact or light-contact sports.¹¹ Unfortunately, the categorization of contact levels is not completely described, and such a comparison across studies is difficult. However, soccer was included as a “light-contact” sport, and the reported 38% participation rate is generally similar to the participation rate we found for soccer alone. Similarly, participa-

TABLE 2. Sport participation

Sport category*	No. of Patients (%)
Noncontact	15 (10.9)
Low contact	14 (10.1)
Collision/contact	106 (76.8)
Extreme	3 (2.2)
Participated in multiple sports	99 (71.2)
Breakdown by sport†	
Soccer	66 (47.8)
Baseball/softball	54 (38.8)
Basketball	45 (32.4)
Football	22 (15.8)
Dance/cheer	16 (11.5)
Swim/dive	15 (10.8)
Gymnastics	12 (8.6)
Flag football (never full pads)	10 (7.2)
Volleyball	10 (7.2)
Martial arts	9 (6.5)
Cross-country/track & field	6 (4.3)
Wrestling	6 (4.3)
Other‡	6 (4.3)
Golf	5 (3.6)
Extreme§	3 (2.2)
Tennis	3 (2.2)
Lacrosse	1 (0.7)

* Sport category is the highest level of contact reported. For one response, the sport was unknown, although the patient indicated involvement in multiple sports.

† Categories not mutually exclusive, and percentages will not sum to 100.

‡ Includes archery (n = 1), "netball" (n = 1), and bowling (n = 1).

§ Includes skiing (n = 2), mountain biking (n = 2), parkour (n = 1), and skateboarding (n = 1). One child participates in 4 different extreme sports.

tion in "heavy-contact" sports (e.g., rugby) was reported at approximately 10%, comparable to the 16% for American football participation found in the present study. Based on this recent study and our own results, sport participation appears generally common among CS patients.

Although Rotimi et al. previously found a correlation between increasing sport participation and decreasing contact potential,¹¹ our results do not clearly replicate this trend. Instead, our results essentially mirror the top 5 sports for both youth and high school athletes in the US.^{16,17} While parental anxiety may have a role in which sports CS patients ultimately participate,¹¹ CS patients do seem to participate in sports in a pattern similar to their peers at a national level. Unfortunately, we were not able to interview parents or delve deeply into how these decisions are reached, and to what extent surgeon counseling plays a role. This remains an open avenue for further study, both for CS patients and in general for any child who has undergone a neurosurgical operation early in life.

Interestingly, we found that patients who participated in sports had more frequently undergone a second surgery.

TABLE 3. Craniosynostosis patients' sport participation stratified by multiple versus single surgery

	≥2 Ops (n = 61)*	Single Op (n = 77)	p Value†
Sport category, n (%)			0.094
Noncontact	9 (14.8)	6 (7.8)	
Low contact	7 (11.5)	7 (9.1)	
Contact/collision	42 (68.9)	64 (83.1)	
Extreme	3 (4.9)	0 (0)	
Soccer	25 (41.7)	41 (52.6)	0.204
Football	7 (11.5)	15 (19.2)	0.214
Baseball/softball	20 (32.8)	34 (43.6)	0.195
Basketball	18 (29.5)	27 (34.6)	0.523
Dance/cheer	6 (9.8)	10 (12.8)	0.584

* For one response, the sport was unknown, although the patient indicated involvement in multiple sports.

† Pearson's chi-square test.

Given the brief nature of the electronic survey, we are unable to describe the indications of these second surgeries. One possibility is that children who expressed interest in sport participation were more likely to undergo cranioplasty prior to sport participation, as the mean age at the second surgery is just slightly younger than the age at which they first participated in sports. To our knowledge, there are no consensus guidelines on which to base the decision to pursue cranioplasty. Previously, authors have suggested that persistent defects sized 2–2.5 cm² may be considered "clinically relevant" and cranioplasty should be considered.^{6,18,19} Published rates of these relevant defects are generally around 20%–25%,^{18,20} while we found that about 44% of CS patients who have participated in sports had a second surgery. While this may suggest a more aggressive approach toward providing cranioplasty for those children wishing to participate in sport, the high rate of second surgeries may be a result of survey selection biases where parents and patients with more complicated surgical courses are more likely to belong to support groups and online communities. These findings should provide further reassurance to families and surgeons, as even CS patients who undergo multiple surgeries report sport participation without an increased injury rate.

Sport-Related Head Injuries

We found that 6.5% of CS patients who participated in sports had sustained a sport-related head injury. None of these were clearly described as requiring surgery. One respondent mentioned a TBI resulting from a line drive in baseball, which can be a severe injury regardless of prior cranial operations. Similarly, the previous UK cohort demonstrated a 5.7% rate of sport-related head injury, none of which required surgery or hospitalization.¹¹ While we do not have imaging data from these patients at the time of their head injuries, the descriptions of injuries suggest that only the one patient may have suffered a structural brain injury, let alone any form of TBI. The rarity of these events appears congruent with a prior study reporting an incidence of 0/100,000 for CS patients during a 2-year postop-

TABLE 4. Sport-participating patient characteristics stratified by head injury status

	Head Injured (n = 9)	Non-Head Injured (n = 130)*	p Value†‡
Mean age enrolled in sport ± SD, yrs	5.9 ± 2.1	5.0 ± 2.2	0.292‡
Sport category, n (%)			0.090
Noncontact	0 (0)	15 (9.5)	
Low contact	3 (33.3)	11 (8.5)	
Contact/collision	6 (66.7)	100 (77.5)	
Extreme	0 (0)	3 (2.3)	
Participated in multiple sports	5 (55.6)	94 (72.3)	0.283

* For one response, the sport was unknown, although the patient indicated involvement in multiple sports.

† Pearson's chi-square test unless noted otherwise.

‡ Student 2-sample t-test.

erative follow-up period.¹⁰ Summarily, CS patients appear to be at no increased risk of sport-related TBI.

Limitations

The limitations of this study are related to the brief survey-based design. First, selection bias in the form of response bias is introduced based on the mode of survey distribution, relying on Facebook community groups and organization listservs. Relying on these resulted in a rather homogeneous study group in terms of race and ethnicity. While CS is more common in White families in the US, the present study group is more similar to samples drawn from large tertiary care centers than a full US sample.² The disproportionate representation of Hispanic patients we report in the group not participating in sports may be related to sampling rather than true differences in participation and requires further investigation.

Relying on survey data also may have resulted in only including patients and families who have had great or very poor experiences as they may be more likely to engage in online communities and survey opportunities. However, there were very few, if any, significant injuries reported, and if these sampling biases were prominent, more extreme scenarios would have been expected. Similarly, our cohort did report a high rate of second surgeries for CS that most likely reflects sampling biases inherent in recruiting respondents through online communities and support groups, which may contain a higher proportion of complex cases.

Finally, we purposefully used a brief survey to encourage completion, and while we succeeded in this goal with a 99% completion rate, we sacrificed some details that may have helped interpret the results. For example, we do not know what proportion of CS patients underwent surgery for single-suture synostosis versus syndromic or multisuture synostosis. However, our supplemental analysis suggests that those who underwent single surgeries (i.e., presumably nearly all single-suture CS) report similar sport participation patterns as those with two or more surgeries. Similarly, we do not have detailed information

TABLE 5. Free-text responses to “other head injuries”

“Traumatic brain injury while pitching—baseball—took a line drive to the skull.”
“Gymnastics. Not sure what happened but her head swelled up and shifted.”
“Head hit by ball being kicked.”

on the nature of second surgeries to support the hypothesis that children are encouraged to undergo cranioplasty prior to participation. While the additional information is certainly of interest, these details would not dramatically change the primary study findings that CS patients can and do participate in a wide array of recreational activities without any suggestion of increased risk of TBI.

Conclusions

In this survey of postsurgical CS patients and parents, sport participation is exceedingly common, with soccer, baseball/softball, and basketball being the most frequently reported. Few head injuries (the majority being concussions) were reported as related to sport participation. Although from a selective sample of CS patients, the initial data suggest that sport participation, even in contact sports, and typically beginning a few years after CS correction, is safe and commonplace.

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Disclosures

The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

Author Contributions

Conception and design: Yengo-Kahn, Wiseman, Shannon, Golinko, Bonfield. Acquisition of data: Akinnusotu, Wiseman, Owais Abdul Ghani. Analysis and interpretation of data: Yengo-Kahn, Owais Abdul Ghani, Bonfield. Drafting the article: Yengo-Kahn, Akinnusotu, Wiseman. Critically revising the article: Yengo-Kahn, Owais Abdul Ghani, Shannon, Golinko, Bonfield. Reviewed submitted version of manuscript: all authors. Approved the final version of the manuscript on behalf of all authors: Yengo-Kahn. Statistical analysis: Yengo-Kahn. Administrative/technical/material support: Wiseman, Shannon. Study supervision: Yengo-Kahn, Shannon, Golinko, Bonfield.

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