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Research Article

Caregiver and student perspectives on school services for students with traumatic brain injury during the COVID-19 pandemic

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Abstract.

PURPOSE: This study aimed to identify unique challenges created by COVID-19 school closures for students with traumatic brain injury (TBI) and their families with relation to special education accommodations, therapy services, social support systems, and mental health complications.

METHODS: Forty-one caregivers and students participated in semi-structured, virtual interviews. Families had students in kindergarten through 12th grade who experienced a TBI prior to spring 2020 and were receiving support services at schools in Pennsylvania (US). Researchers used reflexive thematic analysis to identify themes across interviews.

RESULTS: Central themes encompassing the student- and caregiver-reported challenges and advantages of COVID-19 school closures were changes in [1] education delivery, special education services, and accommodations for children with TBI, and [2] social relationships for students with TBI and their caregivers.

CONCLUSION: COVID-19 and the transition to remote learning significantly impacted special education services and education received by students with TBI. Families in this study discussed both perceived obstacles to and advantages of remote learning in this population. As remote and asynchronous learning are now commonly integrated into the curriculum, research should clarify the facilitators and barriers for successful service provision for students with TBI.

Keywords: Traumatic brain injury, COVID-19, special education, return-to-school

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1. Introduction

Pediatric traumatic brain injury (TBI) has a worldwide impact on public health, affecting approximately 3 million children each year [1]. Although the majority of pediatric TBIs are classified as mild injuries, sustaining a TBI during childhood and adolescence during significant brain development can result in long-term, lasting effects [2, 3]. Symptoms can include acute and chronic deficits in cognition, emotional regulation, behavior, physical activity, and sleep [3–5]. Across all levels of severity, symptoms can affect daily functioning in the home and at school, resulting in an increased demand for rehabilitation services and recovery support [2, 3, 6, 7]. More than 14% of children with mild TBI and 61% of children with moderate-to-severe TBI require new services one year post-injury [2, 8]. Due to the wide range of negative long-term outcomes for children with TBI [7] and the increased need for post-injury supports [6], monitoring the effectiveness of service delivery for children with TBI is essential.

School is an important area of service delivery and support for children with TBI. The need for accommodations and special education services for students with TBI is common, as the consequences of TBI can complicate academic success [2, 7]. In the US, these services vary widely and include informal, short-term accommodations in classrooms; formal, federal accommodations like Section 504 plans; and/or eligibility for special education under the Individuals with Disabilities Education Act (IDEA) [2]. Longitudinal studies have noted the persistent need for academic services averaging six years post-injury and that these needs can continue to be identified and change over time [7, 9–11]. Such studies emphasize the importance of appropriate, longitudinal identification of the barriers to educational services and the challenges experienced by students with TBI upon their return to school [7, 10].

The COVID-19 pandemic was a recent unforeseen challenge to special education delivery. With many students in the US abruptly transitioning to remote or hybrid (mix of in-person and virtual/remote) learning in the spring of 2020, understanding the impact of these transitions on at-risk populations, especially children with pre-existing neurodevelopmental disorders and learning deficits, is imperative [12]. Particularly of concern is the reported decrease in the amount and/or intensity of special education services and accommodations received by children with chronic conditions [13–16]. A recent study of adolescents with attention-deficit/hyperactivity disorder (ADHD) noted that only 59% of school-based services and 39% of academic tutoring services were still being received after the transition to remote learning [14]. Other reported challenges faced by students due to the COVID-19 pandemic and school closures included negative effects on mental health, changes to routine, and changes in social support [16, 17]. Children with TBI are already at higher risk for requiring more support in these specific areas [18], making them especially vulnerable to pandemic-related schooling disruptions.

Few studies have addressed the challenges created by the COVID-19 pandemic and transition to full remote or hybrid learning for students receiving specialized educational services. Even fewer studies have been published on the impact of COVID-19 on students with TBI [19]. The present study addressed these gaps by examining caregiver and student perceptions of how COVID-19-related school changes impacted students in kindergarten through 12th grade with TBI who were involved in a formal return-to-school support program in Pennsylvania (US) prior to the beginning of the pandemic.

2. Methods

All procedures were approved by necessary institutional review boards prior to study initiation (primary site IRB#20210066, secondary site IRB#2020E027). All adult participants provided informed consent prior to participation in study activities; children assented to participate in interviews.

2.1. Participants

Data collected as part of the "School Transition After Traumatic Brain Injury" (STATBI) study is presented in this manuscript. The overall goal of this longitudinal study is to describe the academic, health, and social outcomes of students with TBI who receive formal return-to-school supports from the BrainSTEPS program compared to those who do not participate in a formal return-to-school program. BrainSTEPS is a formal support program for students with brain injury in Pennsylvania, funded by the Departments of Health and Education, as well as the Bureau of Special Education (see www.brainsteps.net for additional information). While the original study design for STATBI included prospective study enrollment and longitudinal follow-up, the COVID-19 pandemic and associated school closures in spring 2020 resulted in modifications for the first year of recruitment, resulting in the data shared in this paper.

For this modified protocol, researchers invited participation from caregivers of students with TBI who were enrolled in BrainSTEPS prior to spring 2020. For purposes of this study, caregivers refers to legal guardians who report a primary role in caring for a student with TBI. This protocol modification allowed researchers to gather data from families who had a student with a TBI who was already receiving support services from BrainSTEPS prior to the nationwide school disruptions that occurred in March 2020. As such, families described their experiences receiving TBI-related services during the pandemic compared to those they received prior to March 2020.. Families who consented completed one round of electronic surveys targeting academic, social, and health outcomes and one remote semi-structured interview with the caregiver and student (via Zoom). To meet inclusion criteria, the student with TBI had to be in kindergarten through 12th grade at the time of study enrollment, speak English as their primary language, and have experienced a TBI of any severity (for mild TBI, per BrainSTEPS requirements, the student had to be experiencing persistent symptoms 4–6 weeks post-injury). Injury severity was determined by caregiver report/credible history [20]. Though BrainSTEPS enrolls students with any type of brain injury (including those from non-traumatic mechanisms), due to the funding requirements of the study's sponsor, students were only eligible for this study if their brain injury was classified as a traumatic injury.

Families who entered the BrainSTEPS program between January 1, 2019, and December 31, 2019, were eligible. An opt-out letter introducing the study was initially sent via mail and email to a random list of 210 of 400 families, with the goal of enrolling 50 families as an appropriate size for interview-focused thematic analysis [21]. Families who did not opt out of the study could be contacted two additional times over a two-week period. Study staff were unable to contact 93 (44%) families. Sixty families (28.6%) opted out of the study for reasons including not being interested or not having time, not speaking English, and reporting that their student was connected to BrainSTEPS services but did not actually use any supports (e.g., student graduated, did not have needs). Fifty-four families (26%) consented to participate; 13 families began but did not complete study activities, leaving 41 families in the final dataset. All study procedures were completed between spring 2020 and spring 2021.

2.2. Procedures

Following completion of online surveys regarding their child's cognitive, health, and social outcomes post-TBI (data not included in this manuscript), caregivers were scheduled for an interview using Zoom. Three trained research coordinators led the interviews, which averaged 20 minutes (range: 15–45 minutes). Semi-structured interviews provided prompts for specific information but allowed for relevant follow-up questions pertinent to individual responses. Interview guides were created by the three lead primary researchers on this project based on the aims of the initial grant with the addition of COVID-19 related prompts and were piloted with research assistants and three families eligible to participate in the study. Their feedback was incorporated as enrollment continued. Questions and prompts are included as supplementary material. Interviewers sought to understand the caregiver's perspective about the student's TBI; experiences in school, home, and community; and how COVID-related school changes affected the family and provision of school services. If students provided assent to answer questions, interviewers also asked for their perspectives on these same topics. Students who participated, regardless of severity of injury, were able to answer questions verbally. To allow for qualitative analysis, interviews were recorded and transcribed by research assistants (undergraduate and graduate students at both the primary and secondary research sites). At the conclusion of the interview, all participants received gift cards for study participation in the amount of $100.

2.3. Data analysis

Interview transcripts were verified by a second research assistant who listened to the interview and read the transcript, editing as needed. Any discrepancies were corrected, and a third research assistant resolved remaining questions. Transcripts were uploaded into NVivo 12 (QSR International, 2018) for coding. Coding was initially completed by a doctoral student and speech-language pathologist (second author) working with the principal investigator (third author) and co-investigator (last author) for this study. Researchers analyzed interviews using the six phases of reflexive thematic analysis as described

Table 1
Participant Demographics (mean, percent; n = 41 unless otherwise noted)

Student Age at Time of Survey	14.76 (3.16)
Student Sex	
Female	27 (65.9%)
Male	14 (34.1%)
Student Race/Ethnicity	
American Indian or Alaskan Native	0 (0%)
Asian	0 (0%)
Black or African American	3 (7.3%)
Native Hawaiian or Other Pacific Islander	0 (0%)
Hispanic or Latino	4 (9.8%)
White	34 (82.9%)
Multiracial	0 (0%)
Caregiver Education (*n* = 39)	
Some High School	1 (2.4%)
GED or Equivalent	0 (0%)
High School	3 (7.3%)
2 Years of College	9 (22.0%)
4 Years of College	16 (39.0%)
Graduate or Professional School	8 (19.5%)
Other	2 (4.9%)
More Than One Primary Caregiver (*n* = 39)	
Yes	26 (63.4%)
No	13 (31.7%)
Two Partners Contributing to the Household (*n* = 39)	
Yes	25 (61.0%)
No	14 (34.1%)
Qualifies for Free/Reduced Lunch (*n* = 39)	
Yes	18 (43.9%)
No	21 (51.2%)

by Braun and Clarke [22–24]. Coding was an iterative process, in which the second author revisited the transcript multiple times to make full sense of the ideas the participants were conveying. The third and last author re-reviewed all codes and exemplar quotes, adding and modifying the identified themes. A final reorganization occurred as the first author reviewed, and all authors discussed, collaborated, and refined their interpretations of the points expressed by caregivers. In the results to follow, frequency counts are meant to be a general descriptor related to a theme. The terms “majority” and “most” are used when over half of all participants reported a similar idea, while “some” or “several” refers to quotes from less than half of the interviewees. Exact quotations from participants are indicated with quotation marks, though often edited for comprehension, and noted with an ellipse to remove repetitions and revisions or to indicate a shortening of a quotation. Student (S) and caregiver (C) quotations are followed by a participant identification number. Caregivers’ and their students’ numbers are the same (i.e., C1 is the caregiver for S1). To further aid interpretation of the results, included in parentheses is the severity of TBI sustained by the student: mild, moderate, severe.

3. Results

3.1. Participants

Forty-one caregivers participated in semi-structured interviews. On average, students were 11.8 years old at the time of injury (standard deviation [SD] = 4.3) and 14.2 years old at the time of interviews (SD = 3.3). A mild TBI was sustained by 41.3% of students, with 26.1% reporting moderate and 28.3% reporting severe TBI. A majority of the students with TBI were female (67.4%) and White (78.2%). At the time of interviews, 45.5% of students were in fully remote instruction (also referred to in participant quotations as *virtual* or *online*), 40.9% were hybrid (mix of in-person and remote), 9.1% were fully in-person, and 4.5% reported “other” mode of instruction. Demographic information for the participants is detailed in Table 1. Injury information for the students is detailed in Table 2. Table 3 links participants’ identification number to their injury severity, age at injury, and school supports received prior to the COVID-19 pandemic. While all students received supports through BrainSTEPS, only some students received formalized services

Table 2
Injury Information (n = 41)

			Mean (SD) or n (percent)
Age at Injury			12.15 (3.79)
Time Since Injury			2.39 (1.86)
Injury Mechanism			
Fall			7 (17.1%)
Sports			12 (29.3%)
Car Accident			6 (14.6%)
Struck by or with an Object			1 (2.4%)
Assault			1 (2.4%)
Unknown			1 (2.4%)
Other			13 (31.7%)
Injury Severity			
Mild (Concussion)			19 (46.3%)
Moderate			12 (29.3%)
Severe			10 (24.4%)
Academic Grade at Injury			
Before Formal Schooling			1 (2.4%)
Preschool			0 (0%)
Kindergarten			1 (2.4%)
Elementary School (grades: 1–5)			11 (26.9%)
Middle School (grades: 6–8)			14 (34.1%)
High School (grades: 9–12)			14 (34.2%)
Academic Placement after Injury			
Regular Education			35 (85.4%)
504 Plan			2 (4.9%)
IEP			4 (9.8%)
Academic Placement at Study Entry by Injury Severity			
	Regular education	504 Plan	IEP
Mild ($n = 19$)	8	6	5
Moderate ($n = 12$)	4	6	2
Severe ($n = 10$)	0	1	9

SD: standard deviation; IEP: Individualized Education Plan.

through 504 plans or Individualized Education Plans (IEPs), as indicated in Table 3.

3.2. Interview themes

Qualitative analysis of these interviews identified two main themes focusing on how COVID-19-related school changes impacted students with TBI: changes in 1) education delivery, services, and accommodations for students with TBI and 2) social relationships for students with TBI and their caregivers.

3.2.1. Education delivery, services, and accommodations for students with TBI

Students and caregivers reported on the impact of COVID-19-related school changes to the general delivery of education in a remote/hybrid format, changes in delivery of services, and changes in use of technology. Subthemes focused on a) impact of a remote/hybrid setting on services; b) impact of a remote/hybrid setting on general education; and c) access to and use of technology.

3.2.1a Impact of a remote/hybrid setting on services

Students and caregivers reported a wide range of experiences related to services and accommodations in the remote and hybrid settings, with some students no longer being offered any services and other students having no service interruptions.

Of the students no longer receiving direct or support services or accommodations, the two most frequently identified factors were the inability to update an IEP/504 plan and reports of teachers being unaware of or overlooking services/accommodations. Caregivers noted difficulty coordinating with all necessary individuals to develop a 504 plan due to closures and schedule changes in the school and healthcare providers' offices. One caregiver elaborated, "The school is not open to properly re-do his IEP to even get him those [pre-COVID] services" (C33, severe). One student discussed the confusion he and his teachers experienced while tran-

Table 3
Participant identification number, age, traumatic brain injury severity, and school services after injury (regular education, 504 plan, or Individualized Education Plan [IEP])

Participant ID	Severity of injury	Age at injury (years)	School services
1	Mild	15	504 Plan
2	Moderate	11	Regular
3	Mild	17	Regular
4	Moderate	11	504 Plan
5	Moderate	16	IEP
6	Moderate	13	504 Plan
7	Mild	5	Regular
8	Mild	14	Regular
9	Mild	15	504 Plan
10	Moderate	13	Regular
11	Severe	12	IEP
12	Moderate	7	IEP
13	Severe	17	IEP
14	Severe	8	IEP
15	Severe	13	IEP
16	Moderate	11	504 Plan
17	Mild	8	IEP
18	Mild	13	Regular
19	Severe	7	IEP
20	Moderate	9	Regular
21	Mild	8	IEP
22	Severe	14	IEP
23	Mild	15	504 Plan
24	Moderate	11	Regular
25	Mild	11	Regular
26	Mild	16	IEP
27	Mild	16	IEP
28	Mild	13	Regular
29	Mild	9	IEP
30	Mild	13	504 Plan
31	Severe	1	IEP
32	Mild	16	504 Plan
33	Severe	13	IEP
34	Mild	15	Regular
35	Mild	16	504 Plan
36	Mild	15	Regular
37	Moderate	6	504
38	Moderate	15	504
39	Severe	8	IEP
40	Moderate	16	504
41	Severe	16	504

sitioning between remote and hybrid learning settings regarding accommodations specified in his 504 plan: “Some important information has just kind of gotten lost out in space. Even with the teachers not remembering things because they have so much on their shoulders . . . It’s just been helter-skelter” (S30, mild).

Some students and caregivers reported that services or accommodations continued, despite transitioning to remote or hybrid formats. Some caregivers reported that services their student received were generally the same as services received prior to pandemic-related school changes, while other caregivers discussed that the format of the services changed to meet the new methods of school delivery. For example, one caregiver discussed how an accommodation to assist reading fluency was adapted to fit remote school days: “Her visual tracking isn’t the strongest . . . and that’s why we incorporate[d] people reading the test to her [before COVID-19 remote learning] . . . [Now] doing it online, . . . if she’s struggling with a word, the computer will say it for her. She does very good with accommodating . . . to be able to get it done herself” (C39, severe).

However, many students and caregivers also indicated these services and accommodations in the remote or hybrid settings came with new challenges. Multiple students reported certain services and accommodations were unable to be implemented completely, rendering them less effective: “Since COVID, [supports are] not as effective. It’s no one’s fault” (C27, mild). One of the challenges families described was the inability to fully participate in computer-based learning due to TBI-related cognitive difficulties, including reduced concentration, difficulty interacting through a screen, and inability to follow along with lesson plans while continuously opening different links and software. One caregiver stated, “Even if you put the computer in front of my son and said, ‘raise your right arm,’ he would not be able to do that or answer them. He’s not even guaranteed to look at the computer . . . Zoom is not working at all for him” (C33, severe).

Another challenge encountered was translating services to the online format. Increased screentime was a key obstacle for students, as noted by several students and caregivers who reported an increase in migraines or visual symptoms after being active on the computer for multiple hours per day. One student explained, “Being on the computer for 8–9 hours a day, especially with the concussion symptoms, my eyes get really, really strained. I started to get these migraines” (S3, mild). Accommodations for one-on-one teacher/aide check-ins were another major area of concern as caregivers observed a decrease in the consistency and efficacy of check-in occurrences. Check-ins were described by one caregiver as, “[Teachers/aides] . . . are checking in with each student on the Zooms, like ‘hey do you have any questions?’ That’s a broad statement for the whole class. That’s not how I think [individualized check-ins] should be” (C9, mild). In addition, the inability to receive specific, classroom-based technology for special education was a major challenge for some students with TBI, affecting their ability to participate and successfully learn at home: “Ever since COVID, it’s been harder for him and his learning. His computer is so small. He doesn’t have the Visioboard here. The Visioboard is too big [to be brought home]. He can’t do much on the computer” (C31, severe).

Lastly, some caregivers reported changes in delivery of speech therapy, physical therapy, and counseling services due to remote learning and COVID-19. Caregivers noted changes in frequency of therapy and counseling services, the need to miss appointments due to school or COVID guidelines, and challenges related to the transition to online sessions: “Counseling on-and-off had to be virtual, but she has had some face-to-face . . . We did have to miss two or three because of COVID things within the family” (C12, moderate). Another caregiver reported that “we had to stop all of [the therapy their child was receiving due to school closures and COVID-19]” (C15, severe). Of the students whose therapy and counseling services were interrupted, some caregivers expressed concern with their student not progressing or falling behind without those services. One caregiver-generated solution was, “I purchased some equipment to do [the child’s therapy sessions] on our own . . . we’ve done some therapy on our own. We’ve done some virtual” (C15, severe).

3.2.1b Impact of a remote/hybrid setting on general education

Independent of obstacles related to implementing and receiving services and accommodations for complications of TBI, caregivers and students identified additional challenges with adjusting to general education delivery after school closures. Students and caregivers both noted that teaching styles and expectations in the classroom were highly impacted by remote schooling, with a decrease in hands-on, teacher-led learning activities and an increase in self-directed learning: “He needs to be instructed with a teacher and being self-taught online is not helping” (C34, mild). One caregiver elaborated on the impact of hybrid learning, where some students were present in class and others were present via virtual platforms: “His teachers, many of them, are struggling with the hybrid school model. Either they focus on the children in front of them in the classroom, or they focus on the children who are on the tablet. They cannot seem to focus on both” (C23, mild). With the new format of teaching and learning, many respondents also commented on how difficult it became to track and turn in assignments: “The classes have been getting harder, but her grades have been slipping because of her not handing in work” (C4, moderate). Caregivers discussed the increase in responsibility for the students and caregivers to stay organized and complete tasks: “[The new school format] has put a lot more pressure and responsibility on me to make sure he gets all his asynchronous work done” (C29, mild).

Motivation, focus, and distractions also became major concerns with remote/hybrid learning. One student described their lack of motivation as, “I think my drive has been really affected. Like before I had an amazing work ethic . . . [Now] I’m like, what if we shut down [next] week, then all that hard work . . . might not be worth what it would have been if we were in-person” (S30, mild). Distractions in the home were mentioned as a pivotal factor in students’ lack of focus during the school day, as pets and/or other family members were now present: “We have pets. She has a lot of distractions. If someone knocks on the door. Just daily stuff you don’t normally have in the classroom that she sometimes gets distracted by” (C4, moderate). Boredom was also recognized to play a large role in focus: “I think what it is, is I get bored after a couple hours [of online school], and then I’ll just go and do something else” (S26, mild).

Student grades were frequently discussed during the interviews, with families reporting a range of improving, declining, and/or similar grades after the transition to remote/hybrid learning. Challenges noted by students with TBI who were receiving lower grades with remote/hybrid learning included decreased understanding of topics due to reliance on self-teaching, virtual learning not working well for them, and grades staying low after sustaining their TBI. A caregiver discussing virtual learning stated, “Well, the beginning of the [2020–2021 school] year it was all virtual [remote], and her grades went really low again, even worse than when she had her concussion” (C35, mild). Interestingly, students with the same or better grades still had concerns with both teacher grading practices and their earned grades. One student described concerns with COVID-related pass/fail grading practices: “[Why work so hard just to pass]? Why am I doing my hard level, when so-and-so can slack off, and we get the same grade?” (S25, mild).

Although many challenges were identified with general education delivery in the remote or hybrid settings, students and caregivers also recognized advantages with the new school format. The most frequently acknowledged advantage was the ability to self-pace learning and assignments: “You’re kind of going through the material at your own pace and doing what you have to do to grasp it. So, there’s really no struggles” (S1, mild). This allowed for increased flexibility in daily school schedules throughout the week: “I seem to do better if I invest full days in the beginning of the week, and then a few hours on the other days. It’s better than doing a few hours every day of the week for me” (S1, mild). One student identified this flexibility as “more freedom” (S15, severe). Flexible scheduling and self-pacing were additionally helpful for children with ongoing symptoms post-TBI and those with multiple follow-up appointments throughout the week: “It would’ve been too difficult with my appointments, and I just don’t do well in the morning. So, we opted for the virtual academy. I can do it any time of the day” (S8, mild). [“Virtual academy” indicates all-remote instruction instead of an option for either hybrid or in-person learning.] One student viewed the increased flexibility and self-pacing as an increase in independence, even though they reported receiving lower grades: “I feel like my grades look a couple points lower now, but really, they are a lot higher because I’m doing a lot more things independently” (S5, moderate). In addition, one caregiver discussed how teachers permitted multiple attempts on certain assignments. Some caregivers also noted that their students with TBI felt less pressure learning in a hybrid setting: “The pressures of being in school just two days a week [has] worked well for her. She’s getting the social interaction, but it’s not five days a week that she has to be ‘on’ and front-and-center” (C10, moderate). One caregiver discussed this reduction of student stress as alleviating social anxiety: “. . . being in the school and around other people, it gives her anxiety . . . which I feel actually affected her performance. So, being at home, she doesn’t have that anxiety” (C34, mild).

3.2.1c Access to and use of technology

With the transition to remote/hybrid learning, families discussed the requirement to acquire and operate devices with internet access to attend classes and submit assignments. School-provided devices did prove challenging for some students to use, and families cited multiple technology issues. No respondents reported being unable to acquire a device or internet services, but the device being used posed specific challenges. One caregiver explained, “We have internet and we’ve been using my cell phone to let him Facetime with his teacher, which is sometimes hard because my phone is constantly going off in the middle of their sessions. We don’t have a specific device for him” (C33, severe). Caregivers and students also reported significant challenges with understanding how to navigate new applications and platforms: “She is struggling, even finding the assignments on there . . . And her dad look[ed] at it and it’s very confusing for even him, let alone someone that’s maybe [already] struggling [with online learning]” (C28, mild).

3.2.2. Social relationships for students with TBI and their caregivers

Within this second major theme, respondents described the social impact of transitioning to remote/hybrid learning for both students with TBI and their families. Subthemes addressed both challenges and advantages of remote learning as it impacted families and peers.

3.2.2a Family impact

Caregivers reported the transition to remote learning as demanding, since students were now home most days, and depending on the age of their student(s), some needed support during online school hours: “It’s a struggle because we have a kindergartener, a first-grader, a fifth-grader, and a ninth-grader. Our struggle is finding space for them to do their work so they are not interrupting . . . or they can be heard on the other person’s microphone” (C20, moderate). Caregivers expressed an increasing burden to ensure their student was completing work: “It puts more pressure on us as parents to put our thumb on him to make sure things are getting done” (C36, mild). The pacing of remote learning was also noted as a concern: “I constantly, basically, do the work for him on the computer, . . . I interpret for him . . . [because] it takes him a bit longer to come up with the answers” (C26, mild). Caregivers additionally expressed the stress and unpredictability that came from their students’ ever-changing schedules: “There’s a lot of uncertainty about everything . . . It kinda misplaces us for a bit when we have to switch from virtual to in-person every other month or so” (C30, mild).

Although caregivers described multiple challenges, there were also advantages to the transition to remote/hybrid learning that several families acknowledged. Spending more time at home with the entire family was a predominant positive theme surrounding remote learning: “For us it has been really healing for our family . . . So, it’s just like, we’re connecting together and . . . I think it’s helped calm [our child’s] anxieties” (C17, mild).

3.2.2b Peer impact

The leading social challenge students and caregivers defined was the overall decline in social interactions and peer support after the transition to remote learning. Caregivers described noticing social isolation and social withdrawal in their students from the onset of remote/hybrid learning, both inside and outside of the classroom. One caregiver stated, “No [she does not interact with her peers during online learning]. They don’t have that opportunity” (C28, mild). In the hybrid setting, during in-person school days, one student noted, “They have the desks so far away from each other [for social distancing], so I mean, you can’t really interact that much [with] people” (S38, moderate).

In addition to fewer peer interactions during the school day, students and caregivers also discussed the added isolation related to their TBI and managing the associated complications during COVID-19 and remote learning: “Since we aren’t in school and because I’m not hanging out with anyone outside of school due to the concussion symptoms . . . I just don’t see anybody, at all, ever” (S1, mild). Another student elaborated, “I think it’s [COVID that has] grown me really distant, but that’s also from my brain injury” (S5, moderate). Students described feelings of loneliness, sadness, and anxiety as social and emotional complications of TBI, and how these feelings were reoccurring or worsening with the transition to remote learning and COVID-19: “And then after COVID, it’s the same thing [as TBI, I was socially isolated again]” (S30, mild). One caregiver compared social interactions post-TBI and those during remote learning as, “actually not much different from each other . . . With the brain injury, she had to be home, she had to be resting. And the same thing with COVID. I think it has a very similar impact, socially” (C32, mild). Another caregiver elaborated on the feelings of isolation from peers post-TBI mirroring those experienced by other students during COVID-19 and remote learning: “A lot of the times she couldn’t do all the activities that her other friends were doing [after her TBI], so she really felt [left] out. A lot of her friends tried to understand what she was going through, but they really didn’t, so she felt . . . isolated . . . just because her friends didn’t understand. Now, COVID affects everybody. It’s not just affecting her” (C35, mild). The key difference noted by one student between remote learning and post-TBI complications was: “COVID just separated everyone. You don’t get to talk to anyone . . . unless you’re doing it online and forcefully. I could have fought through the pain [of TBI because] . . . there was the option there [to not be separated from everyone]. Whereas, during COVID, there [are] no options” (S36, mild).

Although some students and caregivers described an abundance of social challenges, others recounted no changes in social support with the transition to remote/hybrid learning: “I haven’t seen any change [with peers] from prior to injury to after injury, prior to COVID to after COVID” (C2, moderate). Other students and caregivers described continued social support from virtual social interactions, like gaming, messaging, and video-chatting. One parent noted their concern with virtual peer interactions after remote learning during the day: “Which is terrible because it’s another screen, but it’s the only way he can really talk to his friends” (C37, moderate). In terms of in-person social interactions, one student stated, “[My peers and I] just communicate now through social media . . . Some wanna be safer than others” (S22, severe). Other parents stated their child and their friends “were getting together outside,” and that they “don’t think [peer interactions have changed] . . . I don’t think these kids really follow COVID stuff” (C33, severe).

4. Discussion

It is well documented that students with TBI are at risk for cognitive, behavioral, social, and physical difficulties that may impact their ability to manage the school curriculum [3, 4]. School-based needs have been reported by families who have children with TBI of all severity levels [2, 8]. The aim of this qualitative study was to understand the impact of COVID-19-related transitions to remote or hybrid learning for students with TBI and their families. Specifically, the students involved in this study were all part of a formal return-to-school support program pre-pandemic, giving a unique perspective on how pandemic-related school changes affected the services or supports they were receiving prior to spring 2020. Analysis identified two themes illustrating how COVID-19-related remote/hybrid learning impacted students with TBI and their families: changes in 1) education delivery, services, and accommodations for students with TBI; and 2) social relationships for students with TBI and their caregivers. In the growing body of literature examining COVID-19 and school-based special education services for children with disabilities [15, 19, 29, 30], experiences reported in the present study are comparable to those described by children with other disabilities; however, noteworthy findings specific to students with TBI were also identified. Interestingly, within this study, caregiver and student report of these main themes were found to be consistent across all TBI severity levels.

Consistent with studies in children with a wide array of disabilities [15, 31] and specifically students with TBI [19] requiring school services or accommodations during COVID-19-related school changes, students and caregivers in this study reported a decrease in the amount of, and access to, school support services and more challenges associated with delivered services or accommodations in the remote/hybrid setting. Students and caregivers perceived the nonadherence to active accommodations and decrease in new learning modifications to be due to increased demands on educators. Changing teacher roles resulted in a perceived lack of awareness of accommodations, a delay in communication for required services, and difficulty modifying accommodations to the remote/hybrid environment. Caregiver perspectives in this paper align with a recent study on educator views of special education accommodations for students with TBI during COVID-19-related remote learning. Unruh and colleagues [16] reported that educators felt accommodations were challenging to implement remotely and remote learning impacted educator-student relationships making it more difficult to recommend or recognize a need for new or changing accommodations.

Consistent with the above study [19], caregivers in this study discussed how TBI-related deficits in cognitive functioning contributed to challenges when participating in remote learning. This ranged from difficulty utilizing online platforms to the complete inability to partake in online learning due to the need for interaction through screens. Concerns voiced by caregivers included the lack of active student participation in their education, the consequent negative effect on learning outcomes, and the increased need for caregiver support to aid in learning. Although deficits in cognitive functioning were reported by caregivers of students across all levels of TBI severity, only caregivers of students with severe TBI noted cognitive or physical deficits making it substantially more difficult to interact through screens during remote learning. Considering the potential for severe injury to result in more pronounced physical or cognitive difficulties [28], this finding is not surprising. Students with severe TBI and physical limitations are uniquely at-risk for difficulties related to remote schooling access to small screens and online platforms. Additional concerns included increased screentime during remote learning. These caregiver concerns align with past research indicating that the amount of time spent on screens appears to be an influential factor in TBI recovery [29]. Caregivers also expressed worries about their student(s) with TBI losing regained skills and/or falling behind in their progress toward physical, educational, and emotional goals. These worries were compounded by therapy and counseling service interruptions due to COVID-19 [15, 33], which further increased caregiver stress and time requirements to fulfill duties no longer being provided by schools. Findings from the current study of students with TBI reflect concerns that service disruptions may result in long-term deficits and increased service needs in children following TBI (or other developmental disabilities) [15, 34, 35] or be associated with increased parental stress and time demands [15, 36, 37]. Together, service disruptions may lead to persistent negative learning outcomes. Consequently, children who need school services to support their learning may be disproportionately affected.

Several families reported instances of poorer grades for their students with TBI during remote/hybrid schooling. Some observed that it appeared linked to COVID-19-related school fluctuations and not the TBI alone, citing more substantial or notable grade changes during the pandemic than immediately post-injury.

However, it is important to consider the potential for long-term academic difficulties in students with TBI [10, 38] and the possibility of additive effects after experiencing changes to their general education delivery, gaps in their school services, and alterations to therapy or counseling services as a result of the COVID-19 pandemic. Further research is necessary to differentiate which of these factors led to this decline in grades for some students with TBI.

As the second major theme identified, changes to social relationships for students with TBI and their families was a major concern during COVID-19-related remote/hybrid learning. Previous studies with both children who did and did not receive special education services have demonstrated that school closures due to COVID-19 correlate with negative effects on mental health including increased feelings of loneliness, anxiety, depression, stress, fear, and irritability [19, 30, 39, 40]. In the present study, student and caregiver descriptions of mental health were consistent with these findings, including similarities in feelings of social isolation, social withdrawal, and loneliness. Notably, students and caregivers in this study related feelings experienced during remote/hybrid learning to their experiences in the immediate post-TBI period. Since students with TBI are already at higher risk of developing mental health complications [2], it is of utmost importance to monitor mental health in this population, as additive effects of TBI complications and school closure-related mental health problems were possible. They may continue to be pervasive through the return-to-school period, especially as previous social networks and resources surrounding the student may have changed [38]. Additionally, current individual or familial isolation periods due to infection with COVID-19 may re-evoke these symptoms. Lastly, symptoms of loneliness and social withdrawal are common long-term symptoms of TBI as children enter adolescence and young adulthood [39]. These complicated factors highlight the essential need for caregivers, schools, and healthcare personnel to continue screening children with TBI for mental health complications post-TBI and evaluate for additional stressors that might amplify these symptoms, especially stressors that may lead to further social isolation.

It is important to note that a subset of caregivers and students in this study discussed specific advantages of remote/hybrid learning. Positive descriptions have also been documented for students with and without other learning disabilities [43, 44]. For some, self-pacing of assignments, flexibility in school schedules, more time for task completion, and multiple attempts at assignments helped improve student performance and reduce feelings of stress experienced in the traditional academic environment. In addition, consistent with one previous study that documented healthcare provider-reported decreases in social anxiety after school closures due to COVID-19 for students with TBI [19], some students and caregivers in this study reported similar experiences. It is also important to recognize that these advantages were described by students and caregivers across all TBI severity levels. Future research should be directed at how these advantages could be incorporated during the return-to-school process and clarify which subsets of students with TBI might benefit most from specific accommodations. For example, students with TBI missing school due to ongoing symptoms or multiple follow-up appointments may benefit from ongoing hybrid education, self-paced modules, or multiple assignment attempts. It is, however, important to consider that although some students and caregivers reported specific advantages to remote/hybrid schooling, no respondent felt that special education accommodations and services overall were more effective remotely than in-person, pre-pandemic offerings.

General delivery of education in the remote/hybrid setting came with additional challenges not necessarily unique to students with TBI or the status of their accommodations/services. As of this publication, multiple studies have documented the strains of remote/hybrid education due to COVID-19 school closures on many students [33, 45, 46]. Universal challenges included the necessity of self-directed learning, difficulties adjusting to learning platforms, alternating modes of instruction connected to levels of COVID-19 in the community, and increased demands on student executive function related to organization and task completion paired with decreased motivation and lack of focus at home.

There are several limitations that must be considered when interpreting this work and determining how these findings can be useful moving forward. First, not all individuals in the study were asked how strictly they followed social distancing guidelines outside of schooling. Conformance to these guidelines may have influenced feelings of social support and participation in extracurricular activities. Second, this study examined a unique group of students with TBI from one state in the Eastern U.S. which could have influenced experiences and perceptions. Uniquely, all students included in this study were connected with a school support program following a TBI prior to the COVID-19-related school changes. Therefore, the experiences discussed by these caregivers may not be directly generalizable to all students with TBI. Additionally, this study included a wide range of students from kindergarten through high school, resulting in different needs and types of special education services. It is likely that remote delivery of education and student support vary across this educational continuum, though it is equally important to note that reflexive analysis incorporates all perspectives to develop themes. Lastly, interruptions in supports or accommodations were discussed universally across families, regardless of TBI severity and level of school services (i.e., regular education, 504, IEP), thus the themes are presented to reflect that consistency. The themes discussed in this paper were common across caregivers and students of all TBI severity levels, unless otherwise indicated, and are believed to be reflective of common experiences shared across these families. Their perspectives may differ from other families who were not in this study, and further research is needed to explore experiences across different regions and demographic groups. Despite these limitations, this study provides insight into a special population of students who were receiving school supports due to TBI prior to the transition to remote/hybrid schooling in spring 2020.

5. Conclusions

This study was uniquely positioned to describe the experiences of families of students with TBI enrolled in a school support program, comparing the school services they received post-TBI to those received following the abrupt school closures and transition to remote/hybrid schooling between spring 2020 and spring 2021. It illustrates the pandemic-related challenges with identification and implementation of accommodations, therapy services, participation in special education and general remote education, and mental health complications for students who required supports at school following TBI. The perspectives of caregivers and students also highlight perceived advantages to remote learning, specific to obstacles students with TBI and their families may experience. While school-related closures related to the COVID-19 pandemic are finished, integrating synchronous and asynchronous learning through remote platforms may be a persistent change in educational systems [44]. Whether equivalent, effective services can be provided to students who require learning accommodations in the virtual setting remains an important question. Future work should closely follow students who may have experienced loss of services/accommodations during COVID-19-related school changes and be directed toward the perceived obstacles to and advantages of remote learning in this population. As reflected in these interviews, both long-term deficits from decreased special education services and beneficial approaches to new accommodations may be identified. The unique intersection of pre-pandemic learning challenges and pandemic-related academic and social experiences may help to identify the unique needs for these students as they continue in school and progress to vocational or higher education training.

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Supplementary material

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