

School experiences following traumatic brain injury: A longitudinal qualitative study

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Abstract.

BACKGROUND: This longitudinal qualitative study tracked students with traumatic brain injury (TBI) from hospital discharge through their return to school and then for an average of four years of school.

OBJECTIVE: To better understand the experiences of students and parents in the education system following TBI.

METHODS: Participants were parents and educators of 21 students with TBI. Interviews were conducted using open-ended questions and students were observed in the classroom.

RESULTS: From these data, three themes were identified: lack of student tracking year to year, lack of educator training, and conflicting views between educators and parents about students' needs. These factors ultimately led to parent frustration and eventually conflict and deteriorating relationships between parents and educators.

CONCLUSION: The results suggest that improving educator training could positively affect the factors identified and possibly mitigate parent frustration.

Keywords: Low incidence disability, teacher quality, professional development, teacher education, qualitative

1. Introduction and background

Each year, approximately 23,075 children and adolescents are hospitalized after sustaining moderate to severe brain injuries from motor vehicle crashes, falls, sports, and physical abuse; an additional 812,000 children experience concussion or mild traumatic brain injury (TBI) and are seen in hospital emergency rooms and released (Centers for Disease Control and Prevention, 2019). Those incidence estimates of pediatric TBI are significant undercounts because many

children present to primary care physicians and specialty clinics or seek no treatment at all (Centers for Disease Control and Prevention, 2018; Thurman, 2016).

Children with TBI are at risk for a range of disabilities that impair their academic performance and transition to postsecondary education and employment (Babikian et al., 2015). Children with moderate or severe injuries are likely to have cognitive, behavioral, and social difficulties that affect their long-term quality of life (Rivara, Vavilala, et al., 2012); approximately 62% of students with moderate–severe brain injuries will experience disability (Rivara, Koepsell, et al., 2012). However, even mild injuries (i.e., concussion) to a developing brain can result in persistent

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neural alterations that significantly affect educational and social functioning (Prasad et al., 2017) and become more pronounced and debilitating with age (Keenan et al., 2018; Prasad et al., 2017).

After a TBI, many students have deficits in attention, concentration, and executive functioning (Babikian et al., 2015;) that limit their achievement and school success. Children with severe TBI are also prone to developing psychiatric disorders following their injuries (Max et al., 2022), with problems persisting or worsening over time (Narad et al., 2019). TBI in youth may be linked to risk-taking behaviors (Kennedy et al., 2017) and challenges with emotional regulation (Williams et al., 2018). After TBI, deficits in social information processing are apparent across a variety of domains, including theory of mind (Dennis et al., 2013) and other higher-level elements of social cognition (On et al., 2021). Disruption of those skills place children at risk for social isolation, difficulties with peer and family relationships, and decreased quality of life (Zamani et al., 2019).

Hospitals and emergency departments treat children and adolescents with TBI in their initial course of recovery, but it is ultimately the school system that serves as the long-term provider of services to these young people (Centers for Disease Control and Prevention, 2018). However, although existing policies and laws (e.g., Individuals with Disability Education Act (IDEA), Section 504) provide a foundation for appropriately serving students with TBI, those students continue to experience significant challenges in school (Fuentes et al., 2018; Rivara, Koepsell, et al., 2012; Rivara, Vavilala, et al., 2012) and poor post-high school outcomes (Todis et al., 2011). A significant body of research documents the health, academic, and social outcomes of childhood TBI (Babikian et al., 2015; Haarbauer-Krupa et al., 2017), but few studies have explored the school experiences of children and youth with TBI.

This study was part of a larger multi-method study that tracked students with TBI from hospital discharge through their return to school (Glang, Todis, et al., 2008). The purpose of the larger study was to examine the factors that influence educational service practices for students with TBI. The sample for the quantitative study was parents of 56 youth who were hospitalized with TBI in the Pacific Northwest. From that larger group, we followed 21 students and examined their parents' and educators' perceptions of their school experiences. That examination produced two qualitative analyses. The first analysis focused on the return to school experience (Todis et al., 2018)

and found that the link between medical and educational staff established when students first returned to school was short-term. In addition, those results showed that most communication between the two systems focused on medical rather than educational factors and did not always lead to the provision of adequate supports, perhaps because educators lacked training in appropriate accommodations and supports after TBI (Todis et al., 2018). The second analysis, presented here, investigates parent and educator perceptions of the child's school experience beyond the initial return-to-school period. Our objective in this analysis was to better understand the school experiences of students with TBI over time by analyzing parent and teacher experiences, perceptions, impressions, and interactions.

2. Methods

Qualitative methodologies can be a valuable tool for providing insight into teacher knowledge, attitudes, and self-efficacy about working with students with TBI — all factors associated with teacher behavior in the classroom (Trainor & Leko, 2014). These methods can also be used for in-depth investigations of parent perceptions of the supports that their children with TBI need (Minney et al., 2019) and their experiences of support after their child sustained a TBI (Kirk et al., 2015). For example, Hartman et al. (2015) used qualitative methods to examine clinician and educator experiences of the return-to-school process, and a recent study used qualitative interviews to ascertain school professionals' understanding of TBI and their perceptions of gaps in their training for working with students with TBI (Sarmiento et al., 2019). Overall, qualitative methodologies allow for a deeper and broader understanding of the school experiences of students with TBI than quantitative approaches can show.

2.1. Participants

We recruited 23 parents representing 21 student cases of TBI from our previous quantitative research study (Glang, Todis, et al., 2008). We used selective sampling to ensure that a range of variables of interest were available to study in our small number of participants (Lincoln & Guba, 1985; Schwartz & Jacobs, 1979). In this study, critical variables included age at injury, severity of injury, family socio-economic status (SES), whether rehabilitation services were

Table 1
Students with TBI participant information

Student	Gender	Age/grade at injury	Severity of injury	Rehab	Urban/Rural	Race	Transition services	IEP	504
10001	Female	12/7th	Severe	Yes	Rural	Caucasian	1	Yes	No
10003	Female	12/7th	Severe	Yes	Rural	Caucasian	3	Yes	No
10009	Male	12/7th	Severe	Yes	Rural	Caucasian	2	No	No
10016	Male	6/1st	Severe	Yes	Rural	Caucasian	2	No	No
10029	Male	8/2nd	Mild/moderate	Yes	Urban	Caucasian	2	No	No
10045	Female	13/8th	Severe	Yes	Rural	Caucasian	3	No	No
10048	Male	12/7 th	Mild	No	Urban	Caucasian	1	Yes	No
10050	Male	14/9th	Severe	Yes	Rural	Caucasian	3	No	Yes
10061	Male	10/5th	Severe	Yes	Urban	Caucasian	2	No	Yes
10064	Male	14/9th	Severe	Yes	Urban	Caucasian	2	No	Yes
10066	Female	12/6th	Severe	Yes	Urban	Caucasian	2	No	No
10068	Male	15/10th	Severe	Yes	Rural	Caucasian	2	Yes	No
10072	Male	13/8th	Mild/Moderate	No	Urban	Caucasian	3	No	No
10075	Male	7/2 nd	Mild/Moderate	No	Urban	Caucasian	3	No	Yes
10077	Male	14/9th	Severe	Yes	Rural	Hispanic	1	Yes	No
10092	Male	4/K	Severe	Yes	Urban	Caucasian	2	No	Yes
10118	Male	4/preschool	Severe	Yes	Urban	Caucasian	2	No	No
20005	Male	8/3rd	Mild/Moderate	No	Rural	Caucasian	3	No	No
20006	Male	10/5th	Mild/Moderate	Yes	Rural	Caucasian	1	No	Yes
40012	Male	10/5 th	Severe	Yes	Rural	Caucasian	3	No	No
50002	Male	10/6 th	Severe	No	Rural	Caucasian	1	No	Yes

1 = No services. 2 = Yes services direct contact between hospital and school. 3 = Parent mediated transition service.

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provided, and whether the student attended school in an urban or rural school district.

Students with TBI Participant information is presented in Table 1 and Sample Characteristics of Students with TBI is presented in Table 2. As depicted in the tables, most students were male (81%) and white (95%). The majority had experienced a severe TBI (71%) and had received inpatient rehabilitation services (76%). Parent demographic information is unavailable. Additional details about recruitment are presented in our initial paper (Todis et al., 2018). The study was reviewed and approved by the institutional review board of Western Oregon University.

2.2. Interviews and Observations

Parents were interviewed at least annually and participated in the study for an average of 4 years (range 0 to 6). We also interviewed educators nominated by each family. Educators completed an average of 1.6 semi-structured interviews. A total of 30 school observations were conducted by the same field researchers who conducted the interviews. Participants were paid \$20 for each interview or observation. More information about the interview and observation protocols are provided in our earlier paper (Todis et al., 2018).

2.3. Data analysis

To conduct the analysis, we engaged in a reflexive thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013), which allowed us to systematically code, draw connections, and explore emerging themes in the data. Transcripts and observation field notes were entered into Atlas.ti, a computer program that facilitates the analysis of qualitative data (Atlas.ti 8 Windows). Observational notes were analyzed using the same methods and contributed significantly to the triangulation of data. The first two authors read the transcripts and coded them inductively to determine some areas of interest, including hospital-school communication, parent-school communication, school performance, parent concerns, and school responses. Through weekly discussions, we created themes by analyzing relationships among the codes, and then we refined those themes. Both the coding and identification of themes were iterative processes. Then, we individually wrote brief case histories for each student to identify relevant information about the emerging themes. The case studies were compiled using interview data, observational data, and field notes from each participant. Patterns that appeared within and across cases were noted by the first author, compared with the original transcripts and field notes, and then refined by all authors.

Table 2
Sample characteristics of students with TBI

Total (n = 21)		
Sex		
Male	17	81%
Female	4	19%
Age at injury		
Mean	10.47	
Median	12	
Range	11	
SD	3.24	
Severity of Injury		
Mild/Moderate	6	29%
Severe	15	71%
Geographic		
Rural	12	57%
Urban	9	43%
Ethnicity		
White	20	95%
Hispanic	1	5%
Received rehabilitation		
Rehabilitation	16	76%
No rehabilitation	5	24%
Transition		
Did not receive transition services	5	24%
Received transition services	9	43%
Parent facilitated transition services	7	33%
IEP		
Yes	5	24%
No	16	76%
504		
Yes	7	33%
No	14	67%

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3. Results

We identified three key themes: lack of student tracking year to year, lack of educator training in both teacher preparation programs and while teaching, and conflicting views between educators and parents about the students' needs. These themes manifested primarily as specific examples of conflict between varying school personnel and parents. Some examples included arguments about accommodations, difficulties with consistency in communication, and varying beliefs about the effects of the injury on school performance that ultimately led to parent frustration. Observational notes were valuable in the triangulation of data and provided examples corroborating conflicting accounts by parents and school personnel. We provide quotes from interviews below; we do not include quotes from observational field notes.

3.1. Lack of tracking students with TBI year to year

Regardless of how knowledgeable school personnel were about a student's TBI when the student transitioned from the hospital, the teachers at the next grade level, just one year after the injury, were usually unaware that the student had experienced a TBI. This situation was compounded each year throughout the student's school career. When field researchers from our study called teachers to set up interviews, many teachers indicated that they had no idea the student had had a TBI. In some cases, they regretted that they had not had this information. (All names are pseudonyms.)

If I ever had another student with TBI who wasn't on an IEP, it would be nice if we could access information . . . , even just to check like, 'These are things that may be present in this student.' . . . I have 3 kids that are diabetic, and they need to check their blood sugar at various times, . . . and we were made aware that they might need to eat something and to allow that. I was very appreciative of that. 10050

When teachers did receive information about the TBI, it often lacked detail and did not provide helpful guidance, as this sixth-grade teacher recalls:

The first time I heard he had a head injury was at this time last year, in May, when we met with his fifth-grade teachers. And in passing, one of the teachers would describe each kid, maybe spend 30 to 60 seconds talking about their specific students that were coming to us. But the teacher said, 'Paul had a head injury a long time ago, but he's fine.' And that was all. 10029

Parents were frustrated by the lack of information-sharing from grade level to grade level, and they tended to think that educators should have taken more initiative to disseminate the information and follow through on planned accommodations. One father, whose son attended high school in a wealthy suburb, reported that two years after his son's injury, sophomore teachers were not told that he had a 504 plan. When the English teacher found out, she asked the student, "What accommodations was I supposed to be giving you?" The father concluded,

My sense is that the school district, these people are fairly busy. They're reasonably overwhelmed,

and they do anything they have to do, but they don't volunteer a lot. 10064

A mother who was a substitute teacher at her son's school noticed that there was nothing in the computer that told the teachers that he had a 504 plan. She commented,

These teachers, when they go to access information about these students, they should automatically know when they look into that computer, there should be something flagging it so they know they have a serious problem and that these kids have 504s and that they need these accommodations. That should not be my job. 10050

Although most parents initially assumed that schools would take responsibility for tracking the student's injury and accommodations, most of them eventually took on that task themselves. When they did not, they experienced negative consequences:

This is the first year that I didn't go in personally and make sure all of his records and things were sent over to the next school, and because I didn't, I think that's some of the problem. The school was not informed on Carl, and so it made it very difficult for him to not get in trouble. They were just figuring they were working with a 12-year-old boy that had a learning problem . . . The vice principal is where we had the problem because he didn't seem to understand that Carl had an injury. He just sees Carl as a brat. 10075

3.2. *Lack of educator training in TBI*

According to parents in this study, simply making school personnel aware of a student's TBI was of limited value because few teachers had received training in TBI. As one mother put it, "They have never heard of it, and they don't know what to do with it." This same mother had other children receiving special education services in the same school and felt that the school was better able to serve her other children because they were familiar with "regular developmental disabilities."

Some parents, like this mother, tried to fill in the training gaps:

Believe it or not, a lot of teachers just don't understand it. You would think that it would be part of their training or something that they learn or do along the way, but it's amazing how little they

know about brain injury . . . I took the opportunity at the IEP meeting to teach them about it, and they really truly did not understand. I think they listened, but I don't think they get it. 10061

During interviews, field researchers asked teachers directly whether they had had training or experience with TBI. Only two teachers said that they had taught another student with TBI or had a personal experience or a family member with TBI. One school administrator, when asked whether the student's IEP listed TBI as the eligibility category, said that she was "not aware that TBI was an eligibility category under IDEA." One teacher speculated that she had not received training because no one could predict the effects of TBI or how best to deal with each case:

[The information I received on TBI during my training] was quite limited. I don't know if that's the nature of TBI, that there aren't specific things that you can teach about it and that it's case-by-case, or if I'm just completely in the dark, but it's one or the other . . . I know so little about it that I don't even know what I want to know. 10118

A school counselor recalled that they didn't know what to expect when a brain injury occurs:

The hospital said every brain injury is different, and that was surprising to me. I'm usually a cut and dry person. When something happens, I'm like, can I expect this? or this? And I think that was the scariest thing with Josh, was that I didn't know. 10064

One teacher reflected on how getting a little information about TBI gave her a new perspective on the student and left her wanting more training:

Instead of getting mad at Serena for lying, now I understand that this is part of the injury. I can just kind of say, 'Ok,' and not put blame on anybody, and now I can move past that. If she can't organize information, that's real typical [of a student with TBI], and it's like I need some class or workshop to figure out how to help with that. 10092

Another teacher realized after working with a student with TBI for some time that the kind of information she thought she needed — facts about the injury, which is what she learned from the hospital transition materials — was not the information that would be most helpful to her and her student:

Some days he is on, and some days he's not, and sometimes he'll react to this and that. So, it's more

that [we need] strategies than the specifics of what happened to him. Teachers don't really need to know that. . . . We just need to know how to help him. 10048

3.3. *Conflicting Views Between Parents and Educators of Students' Needs*

In all but two of the cases, conflict eventually arose between parents and educators over how to address problems in school. The issue that most confounded both educators and parents was whether a student's problems were attributable to the brain injury or to some other factor—personality, adolescence, or conditions such as ADHD—that pre-dated the injury. One teacher recalled that, “Before the accident she was flighty, and she didn't have an edit button. She still is.” That teacher added that pre-injury the student couldn't “organize information, can't categorize,” and that she had always had a tendency to lie, especially about whether her homework was completed and to get out of doing required tasks. “These things aren't new. They pre-date the TBI.”

One father reflected on the lack of school success for his son:

It's not because he doesn't have the ability to do it; it's because he doesn't have the motivation to do it. And I'm wondering, really, really wondering if that is from the injury. And then part of me thinks well maybe it's just that he's a pre-teen. I don't know. 10061

Although parents and educators shared this concern and confusion, they often approached it from different viewpoints: school staff became entrenched in denying that the TBI was responsible for learning issues, and parents became equally committed to getting the school to at least consider the TBI when working with their children.

Even in the few cases in which students did well academically after their TBI, parents came to have an adversarial view of school personnel, as in the case of this father, whose son was a successful student at a high school in an affluent suburb:

[My son] could use speech therapy. I think they'd pay for it if I raised a big enough stink. I would rather not have that kind of relationship with the school. I want more positive high-order things out of them, like the AP classes. I have another son coming in. I don't want him to have any more

trouble than is absolutely necessary, dealing with those scoundrels. 10064

Another area of conflict between parents and educators involved differences in expectations. Parents, based on their child's pre-injury performance, usually had higher expectations for academic achievement than did educators, who instead saw students with TBI as unfocused and unmotivated and assumed they had always been so. Teachers criticized parents for having unrealistic expectations, and parents criticized teachers for not taking the trouble to see who the child was before the injury. One mother experienced this when her child went to the brain injury rehabilitation unit:

Rehab workers thought he was doing fine, but I knew him before, and I knew how well he was doing at school. I felt like they thought I was just making things up. I mean what would the motive be for that? Are you asking me to accept him the way he is, knowing what he lost, because it's normal for a four-year-old to be this way? So, because it's normal that a four-year-old doesn't know his ABCs then it's something I'm supposed to be okay with, even though he knew them before? I need you to respect me and know that I knew my child before this. I want him back where he was, not where you think it's ok for him to be. 10118

4. Discussion

We identified three important issues in this longitudinal study: (a) students' injuries are poorly tracked over time; (b) educators lack knowledge about TBI; and (c) parents and teachers have conflicting perceptions of student needs. These issues ultimately led to parent frustration that eventually became conflict and deteriorating relationships between parents and educators. This study's results show how those factors contribute to the lack of success that many students with TBI experience in school.

Screening, identifying, tracking, and monitoring students with brain injury after they return to school is widely recommended but not commonly implemented (Dettmer et al., 2014; Lundine et al., 2020). This lack of implementation likely contributes to the low identification rate of students with TBI for special education. A recent analysis suggests that only 32% of students with TBI who should receive special education services are actually made eligible

under this category (Nagele et al., 2018). Indeed, Lundine et al. (2020) reported that 47% of students with moderate–severe TBI received no formal services when they returned to school. This issue could be at least partially remedied by a process for systematic communication between the medical and educational systems. The provision of hospital–school transition services is strongly correlated with identification for support services at school (Glang, Todis, et al., 2008; Todis et al., 2018). Education personnel, including administrators, who understand the long-term effects of TBI might actually implement tracking procedures and actively manage problems that arise over time (Dettmer et al., 2014; Gioia et al., 2015; Glang et al., 2015; Glang, Ylvisaker, et al., 2008; Ylvisaker et al., 1995).

However, even institutional or educator awareness that a student has been injured and is struggling does not automatically lead to the use of evidence-based interventions for brain injury (Todis et al., 2018). For example, if a student being tracked struggles to turn in their homework, a teacher who does not have training in TBI might default to the use of punitive consequences in the hope of correcting the problem behavior. If the problem stems from executive function deficits caused by TBI, punitive consequences are unlikely to positively affect the student's rate of turning in homework. When educators use approaches inconsistent with the injury symptomology, both parents and educators become frustrated, and conflicting opinions and perspectives emerge. Conflicting perspectives, as our data show, exacerbate minor disagreements between parents and educators and can lead to misunderstandings and hard feelings that make communication difficult.

The most promising way to begin addressing these issues might be through professional development and training for educators. Training in TBI would allow educators to better understand parents' perspectives and communicate with them knowledgeably and compassionately, bridging the gap between their views and the views held by parents (Kahn et al., 2018). If they were better trained to understand some of the unique effects of brain injury, educators might be more prepared to consistently provide correct accommodations to students and better communicate with parents (Glang et al., 2019; McCart et al., 2019). Training educators in TBI might also increase their awareness of students who have had a TBI and their unique needs, making tracking more likely to occur at both the school and individual teacher levels.

4.1. Limitations

This study represents the experiences and views of a small group of parents, teachers, and students from a single geographic area. Although participants represent a range of demographic variables, nearly all of the participants were white. Thus, the findings of this study might represent only the experiences of white families in the Pacific Northwest. Further research is needed to expand the geographic and racial demographics of the participants. Additionally, the observational component of the study focused on analyzing student interactions in the classroom, and thus the data collected through observation were not directly reported here. In the future, observations that attend specifically to the parent–educator relationship could be beneficial in the study of this dynamic.

4.2. Implications for practice

Although many areas of need remain to be addressed in service delivery for children with brain injury, educator training is the intervention area most likely to have an immediate and positive effect. Emerging evidence shows that teacher training improves educator knowledge about TBI and their applied skills and self-efficacy when working with students who have TBI (Glang et al., 2019; McCart et al., 2019). Improved educator knowledge, skills, and self-efficacy are theoretically linked to improved implementation of evidence-based practices for students with brain injury (Merle et al., 2022). Training for educators should occur within the school setting and include opportunities to practice evidence-based interventions, mentoring, feedback, and consultation with other trained educators (Glang et al., 2010). If educators are trained to use evidence-based interventions and student outcomes improve, parent satisfaction might also increase. Several comprehensive training models currently in use, such as Oregon TBI Teams (Glang et al., 2010) and BrainSteps (Brain Injury Association of Pennsylvania Inc., n.d.), incorporate features of effective professional development for educators. Both of those models focus on improving school outcomes for students with brain injury through educator professional development, consultation, and the improved use of evidence-based practices, and both programs have been evaluated using student academic, health, and social outcomes as criteria for success (Anderson et al., 2021; Ciccio, 2019).

5. Conclusion

This study's findings further support the need to design, evaluate, and implement evidence-based professional training programs to improve educator knowledge and practices for students with TBI.

Conflict of interest

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