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Parent Management of the School Reintegration Needs of Children and Youth Following Moderate or Severe Traumatic Brain Injury

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Abstract

Purpose—School reintegration following children's traumatic brain injury (TBI) is still poorly understood from families' perspectives. We aimed to understand how both unique and common experiences during children's school reintegration were explained by parents to influence the family.

Methods—Data came from an investigation using descriptive phenomenology (2005–2007) to understand parents' experiences in the first 5 years following children's moderate to severe TBI. Parents (N = 42 from 37 families in the United States) participated in two 90-minute interviews (first M = 15 months; second M = 27 months). Two investigators independently coded parents' discussions of school reintegration using content analysis to understand the unique and common factors that parents perceived affected the family.

Results—Parents' school negotiation themes included: 1) legal versus moral basis for helping the child; 2) inappropriate state and local services that did not consider needs specific to TBI; and, 3) involvement in planning, implementing, and evaluating the child's education plan. Parents perceived that coordinated and collaboration leadership with school personnel lessened families' workload. Families who home-schooled had unique challenges.

Conclusions—School reintegration can add to family workload by changing roles and relationships, and by adding to parents' perceived stress in managing of the child's condition.

Keywords

Parents; Children; Young Adults; Traumatic Brain Injury

Children and young adults in the United States spend up to 32 hours per week immersed in the school environment [1]. Although school is often referred to as children's work, it differs from adult work in that it is also an environment where a good deal of peer socialization and identity development occurs [2]. While the overall rates of moderate to severe traumatic

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brain injury (TBI) have fallen in the United States in the last decade [3], TBI is still a leading cause of morbidity in children because a heterogeneous range of long-term physical, emotional, behavioral, and cognitive impairments are common [4, 5].

Following moderate to severe traumatic brain injury, children are typically absent from the school environment for weeks to months. Prolonged absence and functional changes can not only affect children’s academic advancement alongside their peers, but these factors may also affect their social status [2, 6, 7]. Returning to school can be a powerful motivator for children who are supported socially, but it can also be the point at which children recovering from TBI can perceive avoidance or rejection from peers [8–10]. Programs to assist families in transitioning their child back to school in the United States are not consistently available in all locales, so many parents must become the primary advocates for the child [9– 12].

Studies have begun to explore parental perceptions of family school needs following children’s TBI [10, 12–14]. Yet, details on these topics are still needed: 1) the types of school negotiations parents must be prepared to navigate post-injury; 2) the educational supports that families find helpful; and 3) the educational barriers families encounter. Parents’ appraisals of these factors are important to consider because they are in a unique position to consider whether laws, policies, or supportive programs have been successfully implemented for the child and whether the strategies are relevant to the family needs and how particular experiences affect the family’s roles, relationships, and management of the child’s TBI [15].

In a prior qualitative study conducted by the first author, parents overall experiences in the first five years following moderate to severe TBI were explored using descriptive phenomenology [11]. School reintegration was one important source of perceived difficulties and / or support reported by parents at various points in time following children’s return to the community. The specific factors parents appraised as supports or barriers, and what contextual factors made their appraisals similar or different were not able to be fully explored in the original analysis. A secondary analysis was subsequently conducted in order to address the following questions: a) what school reintegration factors that parents appraised as important to their family; and, b) what contextual factors made parents’ appraisals similar or different; and, c) how parents perceived that various educational policies and practices affected their family roles, relationships, and management of the child’s condition over time. Parents’ insights can contribute to further refinement of theories, practices, and future research questions related to family management of children’s moderate or severe TBI.

METHODS

Protection of participants

This secondary analysis was conducted in accordance with all established ethical criteria for the conduct of research on humans via Institutional Review Board approval. Written informed consent was obtained from all parent participants in the original study to explore their experiences. Parents were made aware of this secondary analysis and a copy of the manuscript was shared with all whose contact information was current. Transcript data were de-identified so that participant confidentiality was maintained throughout. Pseudonyms are used in examples to protect identities.

Design

The aim of this secondary analysis was in line with the original study aim (to understand parents overall experiences in the first five years post-injury), design (semi-structured qualitative interviews with prolonged engagement), and methodology (descriptive phenomenology) [16, 17, 18]. Conventional content analysis [19] was then used to explore and describe parents' perceptions of their child's school reintegration experiences and how they believed their particular experiences affected their family. This secondary analysis was justified because parents' interviews were thick with description and highlighted how critical they believed parent advocacy was in helping to create a positive social environment for the child at school. Many of the parents' experiences were contextually bound and not fully explained by the child's impairments alone [20–22]. Parents described how local, state, or broader socio-cultural and political factors were also perceived to shape the availability of resources in school reintegration [20].

Participants

The original investigation enrolled 42 parents from 37 families between 2005 and 2007. Recruitment in the original investigation was primarily aimed at enrolling a socially diverse group of school aged children with moderate to severe TBI for another study exploring children's experiences following moderate to severe TBI. At least one of their parents or legal guardians had to also participate to understand how parents described their family's experiences. For any parent/guardian to be included, the injured child first needed to be: (a) 6 to 18 years of age at time of TBI; (b) categorized with moderate to severe TBI by Glasgow Coma Scale Score (GCS) (GCS score ≤12); (c) able to participate in an interview, (d) at least 4 months and no greater than 36 months post TBI; (e) still dependent on parent(s)/guardian(s); (f) conversant in English; and (g) able to assent or consent to participation. Children were excluded if they had spinal cord injury or any other significant developmental impairment prior to TBI. Parents/guardians had to speak and understand English and consent to be interviewed separately from the child. Enrollment ceased when themes were repeated (data saturation) in both the children and parent groups and the children were reasonably diverse following specific attempts to recruit racial and ethnic under-represented participants [18, 23].

First interviews were all conducted in-person between 4 and 36 months following the child's TBI (M = 15 months; SD = 10 months). Second interviews were primarily conducted by phone at 20 to 48 months post TBI (M = 27 months post-TBI; range of 12–15 months following completion of first interviews). The choice for the mode of the second interview was up to the parents. Parents had been good informants and a relationship had developed from prolonged engagement at the first meeting, so it was reasoned that either interview approach would satisfy the goals of second interviews [23]. The current analysis is based only on the data from the interviews with parents.

Data collection

Parents completed a demographic questionnaire describing family social demographics, child's medical history and injury circumstances, and the child's acute and rehabilitation history. Parents participated in two semi-structured interviews, which lasted at least 90 minutes each, and the investigator spent additional time with most families at the first meeting to develop a relationship and get to know how TBI was affecting the family. All parents were interviewed by the same investigator (first author) and interviews were audio-recorded and transcribed verbatim. Investigator field notes helped to further contextualize interview data.

First interviews covered parents' experiences from the moment they learned of the child's injury to that point in time of the interview. Second interviews gathered parents' accounts of experiences since the first interview and solicited their feedback on the investigator's summary of themes so it was assured any presentations represented their points of view accurately.

Data analysis

Transcripts were compared by the primary investigator against the digital recordings for fidelity. School experiences were independently coded by two persons with experience in qualitative research (C. R. and D. F.) by hand. Coders of this secondary analysis first read both first and second interview transcripts to get a sense of the family's overall experiences, so they could understand the school reintegration experiences in context of other experiences [16, 17]. Coders met in-person after batches of 7–10 transcripts were coded to discuss their coding and to resolve any differences in the application of the codes. Parents' narrative data and the investigator's field notes were used as the sole sources to come to a final coding consensus [18, 24]. A matrix was then created describing contextual nuances of each family and themes related to parents' descriptions of school negotiations following school reintegration. This matrix allowed a within-case (each family across time) and across-case (across families) approach in the analysis, which helped to promote critical reflection on the bi-directional factors that might be influencing individual or common family experiences related to school reintegration, which strengthened the contextual richness and relevance of our findings [25].

Rigor was maintained by using several techniques: (a) participants' descriptions were the primary source of data so that findings maintained fidelity to participants overall narratives; (b) an audit trail was maintained throughout; (c) peer debriefing with two senior research mentors assured that transparency was maintained; d) member checks in second interviews with parents confirmed the primary investigator's impressions of how school reintegration experiences were perceived and affected the family [26].

RESULTS

The final sample consisted of 42 parents from 37 families who resided in 13 of the 50 United States. The ages of referenced children ranged from 8 to 20 years (M = 15.5; SD = 3.4) at their first interview with their injury severities categorized as severe TBI (n = 29 parents from 25 families) or moderate TBI (*n* = 13 parents from 12 families). All parents participated in first interviews, but at least one parent from 33 of the original 37 families participated in the second interviews, which were conducted either in person (*n* = 4 families) or by phone (*n* = 29). Of the four families lost to follow-up, three had children categorized with moderate TBI and those parents had expressed that the child's daily life was relatively returned to baseline at first interviews. These families might not have believed their inclusion had any further relevance to the study so they did not respond to requests to set up a second interview (*n* = 2) or the contact information was not kept up to date (*n* = 1). The parent of a child with severe TBI declined to participate in the second interview in order to avoid re-visiting past emotional experiences.

The demographics reported by participants consisted of individual mothers (*n* = 29), individual fathers (*n* = 3), and both parents (*n* = 5 couples). Despite several targeted attempts to recruit a racially and ethnically diverse sample of children and therefore, diverse parents, the final sample was primarily White (*n* = 39 parents) and non-Hispanic (*n* = 38 parents). Families were, however, diverse in other areas. Parental makeup of the referenced families was described as: single parent (*n* = 11), married/or living with partner (*n* = 25), and grandparent with custody (*n* = 1). Families' social living settings were reported as: suburban (*n* = 17), rural (*n* = 13), and urban (*n* = 7). Annual family incomes were: < $20,000 (*n* = 7); $20,000 to < $40,000 (*n* = 10); $40,000 to < $60,000 (*n* = 5); $60,000 to < $ 80,000 (*n* = 5); $80,000 to < $100,000 (*n* = 5); and > $100,000 (*n* = 5). Family differences in school choices are reported within each of the relevant themes or sub-themes. Children's school situations often changed across the first five years as a part of: a) the local policies or school services offered after injury; b) the child's academic progression; or, c) a family decision to change schools in order to provide a more suitable and supportive environment for the child.

Parents' school reintegration experiences revealed the differing contextual factors that they believed affected the family's experiences. Common themes were related to how the family was consistently at risk post-injury for encountering a social environment that parents characterized as guided by misinformed attitudes and beliefs about the child post TBI. Misinformed attitudes or beliefs were perceived to not only influence others' behaviors towards the parents, but also the child's self-concept through direct support to the child or indirect influences in the school setting (influencing the services offered to the child or others' behaviors towards the child). Parents believed they had to push for an environment that would strengthen the child's self-concept and improve their academic engagement and competency.

Bronfenbrenner's bio-ecological theory [16–18] is used in Table 1 to show the divergent and nested contextual factors that parents described as playing a role in shaping their family's efforts to reintegrate the child back to school. We then present the common themes that parents perceived as vital to the family's reintegration experiences: a) the legal versus moral basis for supporting the child; b) how parents wanted to be involved in identifying, defining, and supporting the child's needs; and finally how c) parents who home-schooled their child had different experiences and needed support for their unique needs. Parents reported that school leadership and collaboration with families resulted in decreased stress within the family.

Beliefs about the Legal versus Moral Basis for Supporting the Child

Parents believed that some school personnel did not appreciate the intentions of Federal laws requiring the creation of reasonably inclusive social environments that promote diverse learning strategies to meet the needs of all children. Over time, parents believed they gained a richer understanding of the broader socio-cultural influences contributing to their child's post-injury experiences and adjustment. Several families had also experienced other negative encounters with key persons in their community post-injury (medical, rehabilitation, or lay people) and these negative encounters gave parents insights into how others' beliefs and attitudes, the child's pre-injury social status, and the child's functional changes post-injury, all worked together to shape the child's social environment and identity. Parents' insights to the critical role of the school environment in shaping the child's post-injury identity helped to synergize them to advocate for their child's complete school needs. Yet, parents' advocacy role also added to their workload because many parents did not have any supportive resources to prepare them in tackling and changing others' misinformed beliefs.

Parents recognized that the child's stage of development not only influenced his or her academic, emotional, and social needs; but also influenced the educational design of the child's school environment. For instance, elementary children and home schooled children typically have a single teacher, classroom, and group of peers for each academic subject, while adolescents and young adults educated outside the home often encounter multiple teachers, classrooms, and peers for each academic subject. The supportive nature of children's particular school environments can have a bi-directional effect. Parents of children taught outside the home perceived that some school personnel were overwhelmed, uninformed, and/or limited in their focus of how to fully support the child's complete needs. This group of parents became intensely involved because they believed that the family needed to coach school personnel on how to address their child's special needs, and they believed their requests required additional assistance because they were complicated. Margaret illustrates the complexity of her son's reintegration when he returned to high school following a severe TBI where he was still physically dependent on a wheel chair:

> [It depended on] who the teachers were, whether or not they were interested in learning about brain injury….You've got all the different teachers; you change teachers every semester, you're changing locations every hour, which is quite different than grade school….You have to have access to the elevator that other children don't have access to. You have to have access to [the] bathrooms that are wheelchair accessible….You have to get all the equipment fixed for the [electronic] doors that don't work for the wheelchair. You have to have special parking. [My teenage son] had this fabulous idea of he did not want an older woman [aide] following him around all day; he wanted to use students as his aides. So then we had to find those students and fit them to the job; fit their schedule around [my son's] schedule, or his schedule around theirs, all the time trying to keep those few that we had earmarked that we wanted [to work with my son], that were willing to learn.

Some parents' reintegration experiences were influenced by the child's previous academic history and the family's school choices (public, private, or home-schooled). For instance, parents whose children attended a private school (*n* = 5), realized that private schools are not legally required to adapt to the child's educational needs, like public schools are. Parents reported at times having to press the staff to accommodate the child's needs by emphasizing the school's moral obligation to provide a supportive environment post-injury. Connie argued that teachers and peers in the high school environment can misinterpret a teenager's post-injury behaviors as attention seeking, instead of understanding that these behaviors can be normal responses following TBI. Connie wanted to help the school personnel of a religious school understand how their behaviors were affecting her daughter emotionally. Connie positioned the school personnel's moral obligation to care for those who are vulnerable as the impetus to change how they responded to her teenage daughter after her moderate TBI:

> I called another meeting….It was like the academic director and the principal and deans and that's, and I started the meeting with a poem that [my daughter] had written….She was writing a lot of poems…and writing a lot of stories, but they were like very dark things….They describe her social environment just totally collapsing because of how they [teachers and peers] reacted to her….She was the king or queen of her social thing and then she went from that…to like nothing….Some of them started to cry and, and I said, 'Now, you all know what [my daughter] was like before this [injury]…but this is what she's like today. She's not the same person and she's very depressed to the point where she's suicidal and that she is completely overwhelmed by, you know, the school stress [she's experiencing]…saying that [you] were going to lighten the load, but she's got the same load as every other kid in her class. So how are you helping her?'

Other times parents at private or public schools felt powerless to overcome the misunderstandings (*n* = 2). Dominique, the parent of an elementary school child at a private school explained that despite informing the teacher of her daughter's moderate TBI and her subsequent cognitive symptoms prior to her daughter's return to school, she later felt that information had been ignored and so she questioned the effectiveness of her collaboration with school personnel:

> [I called the teacher when my daughter was ready to return to school] The teacher said…'We'll be done [with standardized testing on] Friday, so maybe she can come in Friday afternoon and spend a little bit of time, you know, and that's a good way to ease back in.' Well, Monday she goes back to school, you know, the late morning…but she wasn't allowed to play at recess….They had pulled her for make-up testing of the standardized test [everyone else had taken the previous week]….I was livid…she just had flipping brain injury and she's been out of school a month….So I called and I think I left a message…saying, 'I'm a little bit surprised about this, blah, blah, blah, you know I really don't think it's appropriate for her to be taking a standardized test for xyz reasons'…. [Yet after I did that] she also did a second day of makeup testing….So, it was a done deal. I couldn't do anything about it.

The history of the child’s academic relationship with their teachers was often perceived by parents to influence whether the child was fully supported. Children with a negative academic history (*n* = 4), experienced what they believed were very negative attitudes and responses that stymied the child’s attempts to change and grow post-injury. The child’s traumatic injury was reported by parents of teenagers in three of the four cases to change the child’s attitude towards having a positive regard for their academics at school. Yet, these three parents perceived their child had difficulty shaking their pre-injury academic and behavioral history with some school personnel. Marina, the mother of a teenager in a public alternative education program at a rural high school, illustrates how previous negative attitudes towards the child can influence the teenager’s attempts to make positive behavioral changes post-injury:

> The alternative school kids are kind of like the ones that, you know, you’d look and maybe label ‘bad kids’…she had already become an alternative kid before the accident….She had passed her high school exit exams…all she had to do was get those credits. [She gets home from the hospital] it’s May, you know, [I thought] she can lie in the bed until next year when school starts and we’ll decide what to do. But she decided she wanted to go back to school and she just, you know, [said to me] ‘I’m going to do things different.’ You know just [an] instant change, like every parent wants their kid to be….Until that first day when she called the teacher…she told him about the accident…’I’m going to come to school tomorrow, and I really want to try now,’ and he’s like, ‘Well, you know, It’s all fine about your accident, but where have you been for the last three weeks before the accident?’….And she was like, ‘Well I know, and yeah that was stupid on my part, but really I’m coming to school tomorrow and I really want to try’….And his comment to her was, ‘Well it couldn’t have been that major, you didn’t have very many brains anyways.’ So, at 10:30…I get a call, [my daughter] is on the phone, she is crying hysterically….I had to call the teacher and principal and demand a meeting.

At public schools, even though an Individualized Education Plan (IEP) was needed, the child might not be immediately identified as eligible (*n* = 5) or parents noted that even if an IEP was created, this did not always ensure that the individualized recommendations were followed by all school personnel (*n* = 7). The resulting symptoms common after TBI (fatigue, memory problems, headaches, attention problems, or emotional/behavioral regulation problems) were perceived by parents to reinforce some teacher’s negative beliefs about the child. Parents reported they were told the child “is just not trying”; “is using their brain injury as an excuse”; or just willfully “being difficult.” Thus, parents argued that the laws alone did not ensure an inclusive environment for all children. Katrina, the mother of a teenager with moderate TBI, who developed a subsequent seizure disorder as a result of her TBI, illustrates how cultural beliefs about the child’s behaviors can play more of a role in how others actually respond to the child’s symptoms:

> I don’t think her teachers took it [her condition post-injury] seriously. And when I found out the results of her academic testing, I was angry….We told them she was having trouble! How many meetings did I have at the school? You know? We told them when she had seizures, we told them the results of the EEG, we told them

> about the [seizure] meds she was on, I told them what type of seizures he thought she was having, little absence seizures. One of the teachers in that meeting said, 'Well, she's very disruptive in class'….The teacher didn't see that as a possible head injury thing. To her, it was she's so rude, so disrespectful, so out of line, and we kept saying to them, 'I'm not trying to blame everything on her head injury, but be cognizant of, these are the small things, the little behaviors. She's not in a wheelchair, she's not crippled; that's not what you're going to see'….I wish she had a clear scar that you could see. She still has a clot in her head that runs the full length of her [head]. I mean, I just wish they could see it.

Children's cognitive and behavioral symptoms did not always become apparent until months later. Because children with moderate TBI did not have physical impairments that were evident to others, time also played an important role in shaping negative beliefs and attitudes in some others. As time passed, parents perceived that some educators believed that the moderately injured child should be 'healed' and this belief was perceived by parents to cause some school personnel or peers to resent extending continued support to the child (n = 7) as Connie explained following her daughter's moderate TBI:

> [My daughter] wanted to use like a pass [the teacher had given her earlier after injury]…to not turn her work in [one time] and [the teacher] he wouldn't let her do that and [my daughter] she said, 'Why?' you know, 'You said I could [if I needed it]'….And [the teacher] he said, 'Well haven't we helped you enough?' and then she started crying.

Recovery was slower, more complex, and diverse in children following severe TBI. Some school personnel or peers were perceived by some parents (n = 6) to believe that no improvements in the child's post-injury functioning were possible, so expending resources to their child was perceived to not be a priority for them. When negative misinformed attitudes persisted towards the child, parents believed they had to challenge others' beliefs and behaviors towards their child. Bernice, the mother of a child diagnosed with severe TBI who had significant physical and cognitive impairment post-injury explained how she had to vigilantly advocate, teach, and monitor her child's school environment to assure that he was given what he needed:

> [School personnel] They, they really don't know and understand, what exactly, a traumatic brain injury is and how to deal with the person with one. Every time I try to explain it and show them stuff and what not [to do], it's always, 'Oh, is that what it is? Oh, well why didn't you just say so?' You know, and I'm like, 'Well what do you think I've been trying to do?' I'm basically having to teach everybody at school how to deal with, you know, this kind of situation. And they [a statewide brain injury program] keep having conferences [to train educators about TBI] and every time they have a conference, I go running back over to the school. I'm like, 'Hello, um, they just had a conference. Which teachers and which counselors here at school participated in it?' [They respond] 'Oh, we didn't know anything about that.' Or, 'We didn't have teachers available for that.' I'm just like, you know, I'm running into a brick wall with these people at school….And the high school I'm dealing with now the ESE [Exceptional Student Education] specialist who knows

> [my son] and knows how his situation is, [he] has studied up on his situation, [but now he] has left the school and gone somewhere else. Now I'm having to break in a whole new person, and I don't feel I should have to do that, you know?

Parents' stories over time also revealed the dynamic and temporal nature of how changing environments (personnel, classrooms, peers, or schools) positively or negative influenced meaning for children over time. Lydia, the mother of a teenage daughter with severe TBI, described the improved social environment in her second interview after they changed junior high schools:

> [Early after return to school] Oh, she would cry for—it was terrible. I mean you or I would've committed suicide if we'd gone to work every day and felt everybody hated us, and we were just annoying and nobody was ever going to befriend us. She ate lunch alone…in group assignments nobody would ever pick [her], she'd be the one standing there that nobody wanted to be with [her]….And the teachers would do little things to try to make it better. You know, [telling a child], 'You'll be [name] partner.' You know, they wouldn't leave it open [to the peers], but [my daughter] saw right through that. She'd say, you know, [the other children] 'They didn't want to be my partner, nobody did, but the teacher made her [work with me].' So that was pretty crushing, and the last year [she moved to a new school] was in the eighth grade, which girls tend to be pretty self-centered anyway….There were more kids [at this school] that didn't really know her [before her brain injury] …they were nice. They caught on real quick, though, that [my daughter] was the 'special kid', and it wasn't really cool to hang out with her….They were just casually nice, though, because they hadn't had all this baggage with her, you know, so that seemed to at least fill her need [to be accepted] a little bit.

Parents of young adults who subsequently transitioned to college by second interviews (n = 8) all reported that the institutional and peer responses were significantly more supportive in these settings despite the child's impairments from severe TBI. They reported post-secondary schools had coordinated systems and specialized services in order to meet the individualized academic needs, and peers seemed to be more accepting of persons with disabilities. Bob and Terry explained that their son had an easy transition to his University, "He went back to the people at the college who do that and kind of got signed up and so if he needed anything special it was there for him". Thus, parents' attitudes about the supportive nature of schools could change if the culture and support within the environment changed as illustrated by Tina's description of her daughter's transition to a University following a severe TBI (compared to Trina's subsequent narrative describing her high school experiences):

> Right before she left [for college], I mean I called housing…I called the disability center there [at her University] and went in and said, here's what's coming….They were very good….She loves college. She's living on her own in an apartment and doing great.

Such coordinated academic and social support took a large portion of responsibility for daily advocacy off the parents and shifted it to the school personnel and child, which was developmentally appropriate for the child's need to transition towards independence. Most of these families (*n* = 6 of 8) had previously experienced high school environments where parents had to invest considerable time and energy advocating for the child's needs.

One issue unique to parents whose child had transitioned to college was the academic requirements of any scholarships awarded to children (*n* = 4). This subgroup of parents reported that the child was in jeopardy of losing the merit scholarship they had been awarded prior to their TBI because they could not maintain what was considered a full credit load at their University (12 semester credit hours). Parents had to expend a great deal of effort to petition this requirement as unfair to youth following a severe TBI. Due to the child's post-injury memory and attention deficits, parents felt that children with TBI worked much harder to carry 9 semester credit hours and maintain at least a 3.0 grade point average or higher.

The significance of creating a supportive and collaborative environment for the family was illustrated by several exemplars. In parents of children with moderate TBI who were also under the age of 12 (*n* = 8), most (*n* = 6) were typically assigned a personal assistant to work with the child on their classroom assignments, but their teachers also helped involve peers in positive ways to show the child that the classroom cared about them as Sheila illustrated:

> The information from [the rehabilitation hospital], I said it was okay for them to fax it over to the school, so that [her teacher] would have a clear understanding of what's going on. They all sat down, her [school nurse], the principal, the social worker, her teacher….They all sat down and they discussed with them [rehabilitation team], what happened, what kind of effect it will have on [her learning], different cautions…that everybody would have to take when she came back to the school….They all came together as a community, and even the students, they had like a fund-raiser for her and everything, and it was nice….That school was like family.

Other families described immediate leadership and long-term support from their child's school (*n* = 4). Elizabeth and Jessie explained that due to the principal's position, they perceived he was able to instigate others to be adaptive as their son's needs from the beginning:

> The principal has been absolutely outstanding. They were—he was calling us when [my son] was in [acute care hospital], he was calling us when [my son] was in [rehabilitation], wanting to know what he could do…. And so [the principal] stepped into that really quickly, and then he continued to follow our progress through the summer….I mean, you know [he helped us] every turn…. Because when I talked to the counselors and other people, they weren't as open to make accommodations. But they needed someone to tell them 'It's okay to do this', because if they were on their own, they wouldn't have done it. Because [some counselors and teachers] they have a set criteria that they said, 'Every kid should be pushing themselves for improvement, if they're going to college; therefore, I need to do this.' So I think it was good to have that person. [Our principal] just said, he went up to the people and said, 'Here's the situation, take care of it.'

Involvement of Parents in Identifying, Defining, and Supporting the Child's Needs

Parents at times believed that state and/or school-derived policies also played a role in the child's academic or social problems. Parents whose child was placed in a special needs class (*n* = 6) upon return to school discussed their perceptions that the child's specific educational needs were often not addressed. The child was placed with other children whose special needs differed vastly and parents expressed concern for placing a child with cognitive deficits (attention, sensory information processing, or memory), with other children who had different cognitive needs and had what parents believed were profound behavioral issues. Emotional regulation can be an issue post TBI and these parents believed their child was set up for failure by placing them in an environment where the educational activities were not motivating enough for their child and the peer behaviors modeled inappropriate behaviors for their child:

> My teenage son] He got put in a Special Ed class….One kid was just, he came up and spit in my face and called me an effin' bitch….I don't want [my son] exposed to that and learning that….[My son] wasn't that hard, because [he]—it was like, to go through bolts—and weigh bolts—and you have to put bolts in the package, and look and see when it gets to one pound, and then take them off. That was too hard for [my son] at first, but he got good at it, after a month. And so he did that, but then the class, after going in there a couple times and seeing that it wasn't good for [him] to be in there, then I said, "I don't want him in here anymore." [We ended up changing schools altogether].

Some of the children from across one state were assigned to a state regulated Homebound Program (*n* = 6) early after returning to school. Two children in this program were given private tutors who came to the family's home, and this approach was reported as helpful. The four other parents reported the child was only offered classroom accessibility from their home via audio or video access. These parents argued that this policy did not consider fatigue and attention impairment symptoms common after TBI, which made this mode of learning a poor match. Vivian, the mother of a child with moderate TBI explains about her son's return to school from home:

> I don't believe Homebound is for [my son] not in his condition….Perhaps if you have, you know, a broken leg or you broke your back or, but not for brain injury….I don't think he can listen hard enough and pay attention hard enough. I don't think that's a good answer for a person to have with a brain injury. [You try to talk to the teachers about it] and then [you have] trouble with that, most of the time teachers don't show up. [The teachers] they say call them, "Call later"….He went from being a A+ student to D's and E's.

Vivian discussed how the mute button was activated from the classroom side, possibly to keep noise from the child's home from disturbing the classroom, but this action also made it impossible for the injured child to interact with the class or ask questions. Vivian was a single parent, had low income, had to stay home from work with her son, and spoke English as a second language. Although Vivian tried to call the teachers and talk with them about her son's specific problems, she believed that she didn't have the personal resources to counteract what she perceived as avoidance of her attempts to intervene on her son's behalf.

Trina, the parent of a daughter with a severe TBI, explained on the other hand that her family had more social and financial resources. Both she and her husband were highly educated, were used to negotiating as a part of their professions, and they had the incomes to support paying for services out of pocket. So Trina and her husband immediately declined the home-bound option, realizing audio/video access would be inappropriate to their daughter's needs:

> The school board wanted her to have a television class or a telephone class [from home]. Well I told them, "You don't understand brain injuries, if you think that can happen, 'cause it can't"…. I finally just said, screw this, I'll hire tutors, I'll set the curriculum myself and I'll get it done that way.

Parents recognized that some peers of the child could be limited in their ability to make sense of the child's changes post TBI. Myths about the child's post-injury behaviors could create peer attitudinal barriers that had a profound negative effect on the child's social inclusion and status (*n* = 22) as Paulette explains about her son with severe TBI in her second interview:

> He was all happy and gung-ho about the whole thing [going back to school], and once he got there he was just totally depressed about it, because he couldn't do what he wanted to do. He couldn't do…what he did before and he didn't really realize it until he tried to do it….Some kids like you said can be very mean….It's like ones that would be understanding would be somebody who's been through something or maybe had a family member who's been through something. Otherwise, they can't conceive it and they just, you know, look at you like you're some strange being.

Children's particular individualized education plans (IEP) needs were not always communicated between teachers, within a school, or across school settings (n = 7) as Catrina, the mother of a child with moderate TBI explained in her second interview when her child transferred to junior high school:

> They didn't even know he had an accident or had a brain injury and that kind of ticked me off, because he has an IEP and, you know, he does have some residual things going on from that injury. And like nobody even knew it, you know. And, uh, that ticked me off. You know, it's a good school, and it's a good school district we're in, you know. That's one of the reasons we live in this town….But this is the first year he's truly, you know, going around to different classes and he has been having some problems in school and then I go and they don't even know about the IEP [he had]. It's like, 'Hello'?

When school issues persisted without relevant support, parents believed they were forced to focus their strategies on the particular needs and problems that would make the most difference in the child's life quality as Trina illustrates in her second interview, "There were battles that I was fighting with the school system and it just got to the point where it was not worth fighting. What I would have won was not worth the time it took to fight the battle." These parents expressed a mixture of feeling worn down emotionally and being empowered by their beliefs that their supportive actions were helping their child to gain an improved academic and social life.

When collaborative and supportive school services were delivered to the family, parents reported it assisted them in their attempts to normalize their daily routines; parents could concentrate on other demands in their life. Parents noted that school support also made the injured child feel like he or she and his or her future still mattered, despite new changes or differences. Drew, the single father of a child with severe TBI who attended a private high school explained the positive social culture created at his son's school during his second interview:

> I don't hear any taunting or putting down or making fun [like] "You're in the retard class," or 'You're a retard', I don't hear that at all….I think because the teachers work so hard…and it's like, [they create a culture] 'We're all the same, just different'….You're no better or worse, because you are in a gifted program, [or someone else is in] an average program, or [my son] has to be in a special program….[They say] 'We all have areas we excel in'. And that's how, that's the philosophy [there]….Putting down someone is never allowed….And the teachers email me constantly….[We have a] very strong relationship… They don't ignore a problem, but it's like, [they are] looking at the whole person.

Home-Schooled Children

Parents who home-schooled their child (*n* = 2) reported the freedom to adapt the injured child's learning environment to their new medical and rehabilitation demands and initially saw such flexibility as a positive factor. The needs to change their teaching styles, were not matched with outside academic support, so parents eventually realized they were also uniquely disadvantaged and could easily become overwhelmed. Francine, the mother of a pre-adolescent with severe TBI explained how homeschooling affected their family:

> Thank God I was home schooling them! Both of my daughters lost about a year of school, which meant the following summer they took their entire summer to catch up. So, you get to the place where you got to double-up to catch up for what you lost and the whole time you're like at double-pace, your inner self is screaming desperately to slow down, 'cause you feel yourself burning out.

Families who home-schooled also spent extensive time together, which meant they were the primary people correcting and pushing the injured child for improvements in thinking, physical functioning, and social and emotional behaviors. Nina, the mother of a young teenage girl with severe TBI and two younger school-age siblings illustrated how these conditions could result in role reversals or relationship changes. For instance, younger children might now be teaching the older child how to act and think or the parents might ask the younger children to be permissive of the inappropriate behavior in the older injured sibling. These reversed roles could lead to resentment in the injured child and/or the siblings, result in family conflict, and result in averting other family needs:

> [My daughter] has taken the center of the house….[the siblings] don't understand. Her temper and her—different things—a lot of it's due to her faulty reasoning in

> things, and so it's like, "Well, why can she do wrong, and not us?"…. I was on my own during this past year. I mean, like I said, I don't know how we survived. It'd have been nice to have a neuropsychologist around here. It would've been nice to have real support for my husband and I….I mean, it's affected our relationship.

DISCUSSION

School reintegration following moderate to severe TBI is an individualized process for each family that, unless the child is home-schooled, may involve ongoing negotiations with various school personnel and peers [10, 27]. According to these parents, the supportive nature of school has the potential to change positively or negatively with any change in personnel, peers, or physical environment where educational or social activities occur.

While laws have been in place for many years to ensure an inclusive and supportive educational environment [28, 29], such laws do not always change attitudes or misperceptions that can directly or indirectly affect school personnel or peer responses. Few school providers get specific training on TBI [12, 27, 30, 31] and misperceptions are known to persist and ultimately shape: (a) community and state policies for individualizing education delivery for conditions that are disabling; (b) the quality and likelihood of assessments for developing an IEP; (c) family input into the IEP; (d) implementation of the IEP by staff and teachers; and, (e) ongoing evaluations of the relevance of the IEP to the child's needs [6, 7, 10, 12, 14, 27, 30, 31].

At the time of this study, a Federal program from the Traumatic Brain Injury Act of 1996, was meant to promote research and the establishment of innovative programs across the United States in order to assist community reintegration for families of children with TBI. The renewed Traumatic Brain Injury Act of 2008 (P.L. 110–206) has since changed its focus to promoting development of service infrastructures and expanding service capacities to address identified community reintegration problems associated with TBI. Yet, only 21 states and territories within the United States were participating in this program as of 2012, so many families are still facing disparities based on where they live [32].

Few studies exploring reintegration experiences have included participants attending private school, college, or those who are home-schooled. The families in this study mirror the changing landscape of family education choices in the United States, which increasingly includes private schooling (10% in 2005) or home-schooling (2.9% in 2007) [33, 34]. The numbers of children and youth with various types of disabilities who are now pursuing a college education is estimated to have quadrupled (11% in 2008) in the last 25 years [35, 36]. These families have specific needs that may be quite different from families of younger children. Policies developed to meet the needs of children with other congenital disabilities may not be relevant to the needs of children or youth with TBI, as illustrated by some of these exemplars. Conflicting findings have been reported regarding whether mainstreaming students with disabilities improves their social supportive network, increases their social participation, and assists non-disabled persons to have a better understanding of the social factors that also contribute to disability [30, 37]. Yet, previous studies may have been limited by their lack of differentiation of the types of disabling conditions included, the failure to discern how invisible or stigmatizing attributes of various disabilities may influence social interactions with others, and how ‘participation’ is defined and operationalized [30].

Farmer, McAuliffe Lines, & Hamm (2011) have more recently described the importance of teachers in shaping the culture within classrooms [2] as described by the parents in this study. Farmer and colleagues explain that teachers can co-construct shared cultural values in the classroom, such as promoting the understanding that the classroom, school, and society can all benefit in learning about humanity when all children are treated with respect and included in academic and social activities at the school [2, 30, 37, 38]. Yet, as illustrated by Lydia’s narrative, the co-creation of values needs to be sincerely shared by the non-disabled children, or the child with TBI may recognize that peers are only interacting with them because they have been told to or the non-disabled children simply feel pity for child with TBI. Conversely, a teacher who has negative attitudes or beliefs regarding the child’s academic and/or social performance, may in-turn model behaviors towards the child with TBI that reinforces negative attitudes and beliefs in peers.

This group of parents pointed out various ways they believed children’s academic needs might not be met: 1) children may not be immediately identified as eligible for an IEP by school personnel; 2) the IEP may not be implemented as drafted or passed on to others; or, 3) the plan may not be evaluated for its effectiveness and revised as needed as others have reported [39, 40].

Even when parents were part of a formalized statewide program to assist them with school reintegration, it was contingent upon the child being referred into that program by medical personnel. Two children in this study had not been initially identified as eligible, so their assistance was delayed until it became apparent months later that they should have been referred [39]. Parents who were a part of this state-wide program also illustrated that school personnel had to be motivated and/or be able to attend the learning activities provided by the program in order to acquire necessary skills to address the specific needs of children with TBI. Otherwise, this subgroup of parents perceived they faced the same attitudinal barriers that other parents reported.

Parents who perceived persistent barriers at any point in time then placed the needs of the child with TBI in the foreground of their family. Parents believed that their child was socially vulnerable and would suffer long-term academic and social consequences that would cascade if they did not advocate for them [12, 13, 15, 40]. Their focus on the affected child also changed family roles, relationships, and at times interactions with their social networks [12]. Limiting the family’s social networks was perceived by some parents to protect them from any outside criticism [11], but it may have also limited other sources of support to meet the family’s increasing demands [15].

Limitations

Many individuals are involved in the school reintegration of children following TBI, and this analysis was limited to parents’ perceptions of this process. We recognize that parents’ accounts may differ from those of school and social service personnel and that many additional co-occurring social factors may also influence parents' perceptions. For example, some parents of children with moderate to severe TBI may experience traumatic encounters due to the child's accident, be traumatized by hospital experiences, or be traumatized by reactions of others within their community. Thus, some parents may be experiencing post traumatic stress [41, 42] at the time their child is reintegrating back to school, which may cause them to also be sensitized to encounters with school personnel. Parents' points of view on school reintegration, however, are important to incorporate in our theories, research, and policies because they are essential advocates for the child and can view the effects of policies and practices on the child and family. While it may seem from the compilation of these narratives that parents had generally poor views of their child's schools, we did not get that sense from parents' overall narratives. Instead, parents were merely expressing their frustrations and they were trying to convey how various behaviors negatively impacted the family because the interviewer had conveyed to them that she wanted to learn how to help families in the future.

This study presents the viewpoints of a relatively socially privileged group of parents. The families lost to follow-up or those families who we were unable to recruit may have different experiences and needs from this group of parents. Because this was a secondary analysis, school reintegration was not our primary focus. If it had been, we might have explored various sub-topics further as they were revealed in interviews. This analysis, however, gives important preliminary findings to consider, but the findings should not be generalized to all parents.

Implications

Political and cultural conditions varied across states, communities, and local school settings [39]. The results of this study make a case for broad-based prospective observations of school reintegration experiences following moderate to severe TBI. Then the bidirectional interactions could be captured and considered (i.e., administration, teachers, staff, rehabilitation personnel, families, the child, and peers). A more social diversity sample might allow researchers to discern if other social factors, such as race, ethnicity, language, or social status, might also play a role in reintegration experiences. We could not discern this due to the small and relatively homogenous sample.

Most of the children with moderate TBI were < 12 years of age when enrolled in this study. Many of their parents believed that their child's school performance was returned to baseline by first or second interviews, but because some of them were lost to follow-up we could not discern if that changed or stayed the same in all participants. Other studies have pointed out that as young children's brains develop, new cognitive problems may present later in development. Thus, it would be important to evaluate whether later problems are recognized and responded to appropriately by parents and school personnel [6, 43].

Parents in this study wanted to take an active role in promoting a positive academic and social environment for their child at school, but all parents may not be able to play such an active role. When parents recognized needs, they believed they attempted to create bridges with school personnel so that they could prepare them for the child's changed needs upon return. The long-term implications of delaying TBI assistive services for children and youth has previously been discussed [13].

How school personnel discuss the child's academic and social performance with the child's parent(s) can also shape family-teacher collaborative relationship. Parents in this study reacted more negatively to appraisals of the child when school personnel were perceived to frame their linguistic feedback about the child's new behaviors at school in abstract terms ('Timmy is disruptive') versus concrete terms ('Timmy is having trouble staying in his seat and paying attention'). Abstract feedback is aimed at the character of the person instead of a specific behavior. According to the linguistic category model [44, 45] subtle variations in teacher's linguistic feedback can be powerful in shaping the responses of parents in this case.

Community reentry programs have successfully been implemented in other countries or as a part of specialized rehabilitation programs within specific locales in the United States. These groups offer specific insights into implementing effective school reintegration programs [46–48], which are in line with the problems that were raised by this group of parents and others [39]. Yet, some families may need additional and unique help in homeschooling or in educating others within their social networks how to continue being supportive without judging the family's advocacy for the child's community reintegration needs. Until formalized and tailored support across the United States is provided to all families, some families may bear the chronic burden of trying to overcome contextual barriers in their children's educational environment and this may negatively impact family dynamics.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Research Implications

- Moderate to severe traumatic brain injury is assumed to be the primary cause of children's morbidities post-injury.
- Despite laws in the United States meant to facilitate children's school reintegration needs, parents often perceived that policies and practices differed from the intentions of laws and added to the family workload and stress.
- The school environment of the child (physical, cultural, or psychological setting) plays an important long-term role in shaping family roles, relationships, and management of the child's condition.

Table 1

An overview of 42 parents' perceptions of ecological contextual factors explaining differing school reintegration experiences in 37 families across United States.

Summary of Families' Ecology of School Reintegration Following Moderate to Severe Traumatic Brain Injury (TBI)

Systems of Ecological Interaction According to Bronfenbrenner	Parent Descriptions of Issues They Perceived Differentiated Their School Reintegration Experiences By Context
Individual Child: Child's age, gender, development, and health.	Child's injury severity influenced how some peers responded to them post-TBI and their post-injury academic abilities. Child's social status before and after TBI influenced their adjustment towards changes in social status at school. Child's support and adaption influenced their willingness to be seen as needing help/aids. Classroom/school environments differed by child's development or impairments/ abilities post-TBI. Younger children more readily received emotional support (all moderate TBI as well).
Microsystem: Immediate daily influences in the child's life.	Family insurance and its coverage of rehabilitation needs influenced child and family support for necessary therapies. Rehabilitation services available to child in their community to assist with impairments affecting academics/ socialization. Rehabilitation and medical care could also become disruptive to the child's academic and social life and stressful for family routines. Timing/availability of neuropsychological testing differed by insurance, family capital, and state resources. Family social capital influenced family's ability to supplement child assistive needs not covered by other resources. Parent perceived internal and social resources to advocate for the child differed (three parents were teachers). Differing beliefs and attitudes of school staff to child's academic and social support needs affected their willingness to learn and help family. Peer academic and social support reactions differed by development, personal experience, community, and school setting. Classroom/school choices changed child's schooling needs. Classroom/school environments differed by what services were available in the child's school, and the staff's understandings of child's needs.
Mesosystem: Interactions between the child's microsystems.	Whether rehabilitation staff prepared parents for school reintegration, assisted them, or simply warned them of impending difficulties. Whether rehabilitation staff actively interacted with parents and school staff to address needs and correct myths. Whether neuropsychological testing was explained to parents and school staff to help address the child's needs. Parents own perceived educational skills and social resources to help supplement and advocate for the child's needs.
Exosystem: Social factors that the child does not directly interact with, but indirectly affect the child by affecting their microsystems.	Class/school environments upon immediate school reintegration differed by state policies (e.g., Homebound). Differing community responses to the family to help with increased demands, social capital needs, or emotional support. Classroom/school environments differed by community resources, policies, development, and school type. Parents' family support policies affected parents' ability to advocate for child needs and feel secure in their job.
Macrosystem: The culture and subcultures related to education and school reintegration present where the adolescent lives.	A broader culture of persons with impairments not being understood, seen positively, or included in society. A broader culture of TBI needs and recovery not being understood or accepted versus a caring culture where the child's needs mattered. A broader culture of parents seen as "too involved" if they tried to help their child's complete needs at school post-TBI. Personal or professional experiences of any school staff with TBI or other stigmatizing neurologic conditions.
Chronosystem: Historical circumstances, environmental events, and transitions over time.	History of the child's academic status and their relations with school staff prior to injury. Whether the accident took place on school property or within school sanctioned events led to fear of litigation. Information often was not passed on as the child moved on, or staff believed the TBI was no longer relevant over time. Severe TBI was seen as a chronic condition while moderate TBI was often thought to be temporary. Changes in classroom, teacher(s), or school had the potential to bring new changes for experiences and meaning.