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Parent perceptions of school-based support for students
with traumatic brain injuries

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Abstract

Primary objective: To determine whether parents believe schools provided necessary support to their children who sustained traumatic brain injuries.

Research design: Interview, to determine parent perceptions

Methods and procedure: Sixty-six primary caregivers of school-age children who experienced a TBI within the previous 2 years were interviewed regarding what types of special support were needed by and provided for their children during the 3 months immediately following school reentry. They then rated how difficult it was to obtain support or services from the school and how satisfied they were with the support or services.

Main outcomes and results: The majority of participants did not perceive the need for school-based services, even when the injury was severe. Almost all students whose parents perceived a need for an adjusted schedule were granted that accommodation, but few students received school-based counseling or behavioural support.

Conclusions: Results indicated that participants perceived relatively few school-based, particularly given the actual academic, behavioural, and social challenges experienced by children who have sustained a TBI. Schools and hospitals must take steps to ensure appropriate post-head injury support services.

Parent perceptions of school-based support for students
with traumatic brain injuries

In 1990, the government of the United States of America (USA) passed legislation requiring provision of special education services for students with traumatic brain injuries (TBI) that adversely affect educational performance [1]. More than one million children in the USA sustain TBI every year, 30,000 of whom experience long-term disabilities as a result of the injury [2]. With the advancements in medical technology, many children with severe TBI now survive [3]. However, these survivors often experience a myriad of physical, cognitive, and social-emotional deficits [4]. Specifically, severe TBI can contribute to physical impairments (i.e., neuromotor difficulties), lowered cognitive and academic skills relative to age expectations or preinjury estimates, and problems in school performance, behavior, socialization, and adaptive functioning [5-10]. Beyond documented global reductions in ability as measured by IQ testing, mild to severe TBI may result in specific impairments in language, memory, problem-solving, perceptual-motor skills, and attention and executive function (EF) [5-6, 11-13]. Each of these sequelae might impede subsequent development and learning [14]. Additionally, problems with attention, memory, and fatigue may be subtle and difficult to distinguish from low motivation or premorbid issues. Thus, increasing rates of trauma survival have required the development of programmes and interventions to meet long-term needs of these individuals [15].

Despite the prevalence and adverse effects of traumatic brain injuries, very few systematic studies have addressed the educational needs of students with TBI [16].

Studying children with brain injuries can be difficult because one must consider neurodevelopmental aspects of the pediatric population, including age of injury and developmental stage [15,17]. Mounting evidence suggests that children injured at an early age may experience more significant long-term deficits with emerging skills being most vulnerable to disruption [17-19]. Fletcher-Janzen and Kade [15] summarized research that indicated that although the young brain may allow short-term recovery by shifting functions to another area of the brain, later abilities might be compromised. Thus, a child may temporarily appear superficially intact and then ‘grow into a deficit’ when the developing brain structures, that normally control an activity, become more important for the execution of the behaviour [20]. For example, a child injured at the age of three might not show observable outcomes of the injury until first grade when greater sustained attention to task is expected. As a result of the delayed onset of symptoms, the school problems experienced by children who have sustained a TBI experience may be misattributed to factors such as laziness, an oppositional nature, or emotional instability, rather than to the injury that occurred several years before. The failure of the school to recognize the types and degree of support needed may, in turn, lead to further behavioural deterioration.

The transition from a hospital or rehabilitation setting to school can be quite difficult for children who have sustained a TBI [21]. Many children who have sustained a severe TBI miss school due to the acute hospitalization and inpatient and outpatient rehabilitation, while others are injured during the summer months when schools are not in session. When children who have sustained brain injuries return to school, their teachers may not be aware of the child’s injuries and subsequent educational needs, particularly if

there is a lack of communication between hospital/rehabilitation, parents, and school. Readjusting to the school environment depends largely upon the quality of the transition plan that is implemented by the student's care team. The plan must specify how the learning environment needs to be adapted in order to accommodate the child's physical and cognitive deficits. Further, many of the challenges associated with school reentry are related to behavioral rather than academic concerns, such as the child's need to develop or relearn the social skills enabling him or her to function within the school environment.

Despite the research supporting specialized service delivery for students with TBI, relatively few students with head injuries are identified under the TBI label [22]. Thus, school personnel may lack the experience to fully understand the unique needs of students with head injuries. Failure to appropriately identify students' needs may reduce the likelihood of their educational needs being met. When Glang, Tyler, Pearson, Todis, and Morvant [23] surveyed parents whose children have sustained a TBI throughout Oregon, they found that lack of school staff knowledge of TBI and its effects was the primary reason for dissatisfaction with their children's instructional services.

Few studies have examined parent perceptions of students' educational needs [24-26]. These studies identified parents as important informants regarding educational issues such as eligibility assessments for students with special needs, inclusion of students with disabilities, and academic engagement of typically developing students. Given the intimate knowledge parents have of their children's strengths and weaknesses and the fact that parents are critical partners in school-based intervention assistance teams, it is important that their perceptions of their child's educational needs be carefully considered. The importance of parental perceptions is evidenced in the fact that multi-factored

evaluations of student performance typically include parent interviews and/or the completion of standardized checklists (e.g. Child Behavior Checklist; parent versions of the Behavior Assessment Scale for Children (BASC), and so forth). Following a TBI, the parents are likely to be in the best position to evaluate certain aspects of the child's functioning, such as whether full school days are too exhausting, if there have been significant behaviour changes that are impacting the child's ability to socialize and learn, or whether the child is spending inordinate amounts of time completing homework that previously would have been considered 'easy'.

The purpose of this study was to examine the needs of and services provided to children who have sustained a moderate to severe TBI. The overarching goal of this study was to inform school teams of best practices in meeting the needs of head-injured students who are transitioning from hospital or rehabilitation back to school.

Method

Participants

A list of potential participants was constructed from the Trauma Registry at Cincinnati Children's Hospital Medical Center. Identified students had a traumatic brain injury within the previous 2 years (Glasgow Coma Scale Score <12 or 13-15 with evidence of brain injury on neuroimaging; see Table 1). Children with penetrating injuries were not included because the pathophysiology and effects of penetrating versus non-penetrating injuries are quite different [27]. Out of 155 possible recruits, 135 were contacted; attempts to reach the other possible recruits were unsuccessful. Sixty-six were successfully recruited for the study, all of whom agreed to participate in an intervention that was part of a treatment study.

Participants in this study were parents of children who met the study criteria. Some of the caregivers declined to participate in the study because they did not feel their child was experiencing problems as a result of the brain injury. Thus, the sample of participants likely represents a group of students with more significant problems than if all potential participants had been successfully recruited for the study. Children with a pre-morbid history of learning or behavioral difficulties were not excluded from the study; even if children were already receiving services, it was still deemed important to reevaluate the correspondence between their services and needs.

Of the children whose parents participated in the interviews, 70% were classified as having moderate head injuries; 30% had severe injuries, as determined by the Glasgow Coma Scale (GCS 3-8 was classified as *severe*; GCS 9-12 or > 12 with evidencing of

trauma-related abnormalities on imaging were classified as *moderate*). More of the students were in middle and high school (62%) than in elementary school (38%). There were nearly three times as many injured males as females (see Table 1). Consistent with demographic composition of the region, 86% of the injured students were White, 11% were Black, and 3% were multiracial.

Insert table 1 about here

Instrument and procedure

The *Back to School* Interview [28] was part of a broader 1.5 – 2 hour assessment of child adjustment and parental and family functioning. Interviewers spent time initially with parents or caregivers establishing rapport and obtaining information about the injury. Parents of the children with head injuries were interviewed by trained research assistants. To ensure quality control, each interviewer administered five practise interviews and had ongoing supervision throughout the study. The *Back to School* Interview asked each caregiver to identify areas of concern in school. Participants were then asked what types of special support were needed. For each area in which a need for supports was identified, the participating caregiver was asked whether the supports were provided to the child during the 3 months immediately following school reentry. If the participant indicated that a support was needed, he or she was also asked to rate how difficult it was to obtain support or services from the school as well as the level of satisfaction with the support or service provided.

Because children are not likely to be strong informants regarding their educational accommodations, primary caregivers were interviewed for this study. Thus, although the children with head injuries assented to be part of the study and completed some measures, they did not respond to the school interview that was used for this part of the study.

Results

Of the caregivers interviewed, 38% indicated their children needed special education services following the TBI, 38% indicated a need for an instructional assistant, and 36% reported a need for an adjusted schedule (see Table 2). The need for class changes (e.g., to move down one level from an honors course) was reported by 25% of participants. Only 20% reported a need for counseling/behavioural support and 17% reported a need for non-academic support (e.g. speech, occupational therapy, physical therapy). Thus, most caregivers did not perceive a need for special services.

According to caregiver reports, nearly all students who needed the accommodation of having an adjusted schedule received that accommodation (see Table 2). Parents least frequently reported receiving needed services in the domain of counseling/behavioural support. Sixteen of the participants reported a need for class changes; 11 reported that this change was provided. Of the 24 participants who indicated a need for an instructional assistant (I.A.), 16 were provided the IA. The percentage of students receiving non-academic support services at school, such as speech therapy, occupational therapy, and physical therapy, was relatively high. Sixty-six percent of participants indicating that their child needed special education services did in fact receive them (see Table 2).

Insert table 2 about here

It was expected that severely injured students would be more likely to have perceived needs and would be more likely to receive school-based services. However, when comparing students' levels of injury severity, there were few differences between the needs of the groups, based on parent perceptions (see Table 3). Even in students with severe head injuries ($GCS < 9$), only 57% of caregivers indicated a perceived need for an adjusted schedule, with smaller percentages desiring other accommodations or services.

There was, however, a significant difference between severe and non-severe groups in terms of the type of non-academic support (speech, OT/PT) that was perceived as needed. More caregivers of students with severe TBI said their child needed nonacademic supports than did parents of students with moderate TBI, $\chi^2(1, N = 44) = 8.404, p = .004$. Only 7% of caregivers of students who sustained moderate TBI perceived this need compared to 43% of caregivers of children with severe TBI. In other areas, there was no significant relationship between the perceived need for services and the child's degree of injury severity. That is, parents of more severely injured students did not perceive their children as needing more services (see Table 3).

The researchers also examined whether there were differences in perceived needs or unmet needs reported by parents of elementary school students versus secondary (middle and high school) students; however, no significant differences were found (see Table 3). Although more than twice as many parents of secondary students (33%) than elementary students (14%) perceived a need for counseling/behavioral support, this

difference was not statistically significant. Elementary school and secondary students did not differ in the likelihood of having services provided. Although *no* elementary students in the sample were provided these services, compared to 33% of secondary students, these differences were not statistically significant (see Table 3).

Finally, it was hypothesized that students injured during the summer might be less likely to receive services upon their return, but that was not the case (see Table 3). There was no significant difference in perceived needs or unmet needs reported by caregivers whose children were injured during the summer versus those whose children were injured during the school year, except in the area of class changes. This, of course, would be expected, given that all students coming back to school after the summer experience a new class placement.

Insert Table 3 about here

Using a 4-point rating scale, caregivers rated how difficult it was to obtain needed services (*very easy, easy, difficult, or very difficult*). The number of respondents to these questions was very low, as many participants in the study were not receiving school-based services; therefore, reliable conclusions could not be drawn from the data. However, of note, 93% of parents indicated that it was *easy* or *very easy* to obtain needed academic supports, while only 40% of parents indicated that it was *easy* or *very easy* to obtain needed social/behavioural support.

Discussion

Although not every student who experiences a head injury requires special school-based services, the children, whose caregivers were surveyed in this study, experienced injuries that typically result in at least short-term deficits in cognition, attention, and memory that might benefit from school-based adaptations [4]. However, families of children who have sustained TBI in the current study reported fewer than expected academic and behavioural concerns during the initial 3-months following the child's return to school. The reasons for this discrepancy are unclear. This may be related to the fact that parents do not yet know about or understand the academic and behavioral issues that their child is experiencing. Parents initially may have difficulty recognizing emerging limitations and needs and may misattribute them to other factors (i.e., being spoiled as a result of the injury and hospitalization). Given what families have been through, most parents are anxious to see their child return to school and get "back to normal", and thus are focused on signs of recovery rather than impairment. Nonetheless, the child's return to school is a critical time to ease the transition and put services into place. Delaying services until the child experiences academic failure or social rejection may lead to an exacerbation of difficulties as well as a mislabeling of the condition (severe behavior handicap rather than TBI).

Parents cannot advocate for their child if they do not perceive a need. With the passage of time, parents often come to understand the long-term implications of their child's injuries; in the first three months after returning to school, they may still be coming to terms with the injury. However, if parents are told to 'just wait and see' how their child readjusts to school on his or her own, their child might miss out on a critical window for neural as well as cognitive and behavioral recovery. This is particularly true

while children are experiencing post-concussive symptoms such as fatigue and concentration difficulties that can significantly affect classroom performance. Clearly there is a need for information and education, as well as formal and informal advocacy, for families of children who have sustained a TBI [e.g. 29, 30].

We found support that the greatest unmet need was in the area of emotional and behavioural supports. These results are consistent with previous research indicating that professional educators would benefit from enhancing their knowledge about the psychosocial/behavioural aspects of TBI as well as the cognitive and academic domains [23, 31]. However, there were few differences in caregivers' perceptions of unmet needs as a function of injury severity, timing of the injury (i.e., during the school year versus during the summer) or the child's grade level in school (i.e., elementary vs. secondary)..

The current sample included children with premorbid behavioural and learning difficulties. Such pre-injury problems can pose difficulties in understanding the educational needs of a child who has experienced a head injury in that one's deficits post-injury may actually reflect pre-injury problems rather than being a direct result of a head injury. Premorbid conditions, such as impulsivity and hyperactivity may lead to higher head injury rates [32]. Thus, it is important to take into consideration child's status prior to the injury, as children with preinjury behavioural difficulties are at a greater risk for post-injury difficulties [33]. Further, TBI may interact with ongoing difficulties, such as pre-existing psychiatric disorders; learning disabilities; health conditions; low intellectual capacity; a previous head injury; or significantly disrupted families [33]. Because TBI can exacerbate premorbid difficulties resulting in changes in the need for academic services, it is important for both parents and teachers to be educated about these issues.

Limitations

The sample of participants likely represented a group of students with more significant problems than if all potential participants had been successfully recruited for the study. Thus, the sample may have been more likely to report problems. Conversely, because the study focuses on the first three months after the child returned to school, both parents and school professionals may have been reluctant to identify problems given everything the child had been through. Thus, it may reflect a ‘honeymoon’ or grace period in that parents are not yet aware or ready to acknowledge the long-term issues that may be involved with the child’s injury. Thus, a follow-up study to investigate whether perception of getting needs met changes over the course of the first year of school re-entry might be of interest. Further, the students being studied were potentially up to two years post-injury. This is not an ideal time frame because parents were being asked to recall services that were provided in the first three months after school re-entry.

Some of the interviews had missing data, which limited analyses that could be conducted. Further, the study relied on parent reports and it was assumed that they were knowledgeable about their child’s medical history and educational services. However, information from the schools regarding the provision of services would have been useful to corroborate parental reports. Finally, some of the questions were subjective and parents may have different ideas about what constitutes a ‘need’ (e.g. a need for special education, a need for counseling, and so forth). A future study including the teacher’s as well as the child’s perceptions of services that are needed might be a valuable complement to this study.

An additional limitation is the fact that some of the children whose parents were interviewed may have had learning or behaviour problems prior to their injury, thus making it more difficult to identify and address newly emerging problems. The sample was also heterogeneous in respect to age. School-age children from elementary school through high school were included in the study. This age range comprises a wide developmental spectrum. While the study found some differences between the needs of elementary and secondary student needs, a more detailed examination of needs of same-age students would be beneficial.

Implications

There are several steps schools and hospitals can take to ensure appropriate support following head injury. Assessments should begin prior to a student's return to the classroom and might involve early identification of skills and deficits, the teacher's management style and tolerance for inappropriate behaviour, the level of classroom structure, and the degree of classroom control. Means of assessment might include behavioural observations and interviews with the teacher and school personnel, problem-oriented evaluation scales (e.g. Glasgow Assessment Schedule), samples of student work, parent interviews, analogue methods, and functional analysis. School-based academic and psychological assessments should go beyond traditional standard practices (e.g., traditional norm-referenced tests of intelligence) and be aimed at insuring a continuum of regular education services, determining the need for special education, maintaining suitable levels of performance throughout the academic programme, and maintaining positive social relationships[14].

The degree of intervention needed depends upon the stage of recovery, specific aspects of the disability, and type of environmental support provided. Despite widespread beliefs that behaviour cannot be changed after a brain injury because of physical damage to the brain, appropriate intervention can help children who have sustained a TBI learn to respond to environmental stimuli in a more controlled, socially appropriate manner [21]. Rather than merely reducing maladaptive behaviours, interventions can also increase prosocial behaviour and help students interact more effectively with peers and adults.

In order to facilitate a smooth reintegration to the school setting, other agencies must be aware of school practises and procedures. Conflicts between hospitals or rehabilitation settings and schools might result when treatment center personnel take a militant advocacy role for children who have sustained a TBI without adequately understanding school policies (e.g. special education eligibility requirements). Suggested solutions for this potential conflict included communication and mutual respect, as well as the assignment of a case manager to coordinate data and communicate about the child to respective systems [33]. Entering into the special education system can be particularly overwhelming for parents of older students who were not previously identified with special education needs [30].

Although children with brain injuries have some similarities to students in traditional special education classifications, they often demonstrate greater discrepancies between abilities and more uneven progress patterns. Therefore, simply placing them in classrooms designed for students with other difficulties fails to recognize the need for adjusting strategies to accommodate their unique deficits [34]. The behaviour patterns for a child with TBI can be dynamic as recovery of function progresses. Thus, assessment

must be ongoing and intervention must be flexible. Intervention programmes should help a child with TBI ‘recognize, understand, and learn to compensate for his or her deficits’ [34, p. 142]. School accommodations should also be flexible and should change as the natural recovery process takes place.

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