

THESIS

PEDIATRIC TRAUMATIC BRAIN INJURY:
UNDERSTANDING PARENT PERCEPTIONS OF THEIR CHILD AND SCHOOL-BASED
SUPPORTS AND SERVICES

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ABSTRACT

PEDIATRIC TRAUMATIC BRAIN INJURY: UNDERSTANDING PARENT PERCEPTIONS OF THEIR CHILD AND SCHOOL-BASED SUPPORTS AND SERVICES

TBI affects hundreds of thousands of children each year, having a profound impact on multiple areas of functioning including cognition, social interaction, learning, and behavior, and thereby directly influencing their school performance. Despite its high incidence and potentially severe consequences, TBI-related disability among children often goes unrecognized for what it is by caregivers, educators, and physicians. In this study, we focused on the qualitative data obtained in the parent-report *Brain Check Survey* related to students with identified TBI employing a phenomenological approach. Data from fifty-one parent completed BCS tools were analyzed to gain an understanding of parent perceptions of their child with TBI, including the child's TBI-related behaviors and symptoms; and the parents' perceptions of the child's school-based supports and services in relation to their TBI-related learning needs. Data analysis yielded four major themes that represented the qualitative content provided by parents on the BCS, namely parent response types, knowledge, services, and emerging topics. Parent experience varied depending on perceived supports and barriers, highlighting the need to include parents as a frequent and permanent participant in the preparation for and development of their child's educational plan. A key recommendation is that schools assist parents of children with TBI in gaining skills in advocacy and knowledge of educational entitlements as early as possible once their child is identified in the school as having a TBI. Parents need to be empowered early on to find their voice as advocates, helping to ensure that their child is able to participate and perform in his/her student learner role as effectively as possible.

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Introduction

Traumatic Brain Injury (TBI), also referred to as an acquired brain injury, or head injury occurs when sudden trauma causes damage to the brain. TBI is a contributing factor to a third of all injury-related deaths in the United States, with an estimated 1.7 million individuals sustaining a TBI annually (Faul, Xu, Wald, & Coronado, 2010). External causes of TBI include, but are not limited to, falls, being struck by or against an object, motor vehicle collisions, and assault. In particular, TBI is a leading cause of acquired disability and death among children in the United States. According to the Centers for Disease Control and Prevention, for children up to 14 years of age, TBI results annually in an estimated 473, 947 emergency department visits, 35,136 hospitalizations, and 2,174 deaths (Faul et al., 2010). The external causes of TBI among young children vary with age. Inflicted neurotrauma (e.g. shaken baby syndrome) is the most common cause for children 24 months and younger, however the most common cause of TBI for preschoolers and elementary school-age children is falls, accounting for approximately half of that age group's TBI incidences (Ewing-Cobbs et al., 2006; Faul et al., 2010). Unfortunately, the extremely high number of TBIs among children does not account for children who sustained a TBI and did not seek medical attention and/or were discharged from the emergency department, hospital, or doctor's office without their family being given information about their injury, symptoms to watch out for, or possible long term consequences. Therefore, common belief is that the actual number of children with TBIs is much larger.

Traumatic brain injury results in wide variability in functioning, both between children and within the same child, over time, and significantly impacts multiple areas of functioning including cognition, social interaction, learning, behavior, and personality (Glang et al., 2008). In particular, children's cognitive deficits in association with TBI are commonly unidentified and

the subsequent learning needs unmet. Deficits in executive functioning are some of the most commonly reported impairments following TBI in children (Sesma, Slomine, Ding, & McCarthy, 2008). Executive functions is a broad category referring to a child's various capacities enabling purposeful and goal directed behavior, including skills such as planning, organizing, sequencing, and self-monitoring (Mangeot, Armstrong, Colvin, Yeates, & Taylor, 2002; Sesma et al., 2008). The development of these skills is often delayed due to the damage of frontal-striatal circuits that run through common lesion sites such as the frontal and prefrontal cortex (Levin et al., 1993). Despite the high prevalence of executive functioning impairments following TBI, the extent of impairment is moderated by a variety of factors including severity of injury; age at injury; premorbid functioning; and environmental influences, such as family functioning (Anderson & Catroppa, 2005; Chapman et al., 2010; Sesma et al., 2008). Recent research has demonstrated that children who have sustained more severe TBIs and at younger ages show more greatly impaired ability to acquire new skills, and greater long-term cognitive deficits (Ewing-Cobbs et al., 2004; Sesma et al., 2008).

Impairments in behavioral adjustment, adaptive functioning, and social interaction are also prevalent concerns for children following TBI, and have been seen to directly influence school performance. Specifically, secondary-onset attention deficit/hyperactivity disorder (SADHD) is a significant behavior problem which can be associated with TBI, resulting in varying levels of hyperactivity, impulsivity and inattention that frequently lead to externalizing behavior problems (Chapman et al., 2010; Max et al., 2005).

Although not currently researched to the same extent as cognitive and behavioral deficits, social competency and skills also have been shown to be affected adversely following TBI. Children with what is considered to be more severe TBI often lack the ability to adapt their

behavior to changing social settings, specifically stressful situations, resulting in maladaptive or inappropriate behaviors (Hooper et al., 2004). Depending on the child's age at injury, the extent of social problems may not be readily apparent. However, as social demands and expectations increase with age, and the child is expected to demonstrate well-developed social skills, especially within a school setting, limitations in social competency become evident (Chapman et al., 2010; Yeates et al., 2005).

Although research demonstrates a wide range of deficits for school-aged children following TBI, children's long-term outcomes in these functional areas seem to be mediated by environmental factors including both home and school environments. According to the results of a study by Chapman et al. (2010), social economic status (SES), family functioning, and permissive parenting styles were seen to be significant contributors to the likelihood of developing increased behavioral, social and executive functioning limitations. Also, they found that unclear expectations, limited structure, and inconsistent discipline within a school environment are common predictors of increased TBI related symptoms over time.

Approximately 29,000 children a year are left with persistent disability following TBI, however this number does not account for children who have acquired mild brain injuries, which are believed to occur six to seven times more frequently than moderate and severe brain injuries (Schutzman & Greenes, 2001). Given the number of children who sustain a mild TBI, long-term effects in association with the injury, pose major developmental and health concerns and significantly limit a child's ability to engage in school activities (McKinlay, Grace, Horwood, Fergusson, & MacFarlane, 2010). According to Hooper et. al (2004), 10-15% of children who returned to school between one and ten months post injury experienced new learning and

performance difficulties. Results of research conducted by Ewing-Cobbs et. al (2006) showed that significant academic problems were 18 times greater for children with TBI.

Despite its high incidence, especially among young children, TBI-related disability often goes unrecognized by caregivers, educators, and physicians. The underidentification and misidentification of children who have sustained a TBI and who are struggling in school, is of grave concern, because without adequate support and services, many of these children are likely to fall further and further behind or possibly fail to graduate from secondary school altogether. Of particular concern is the discrepancy between national incidence of TBI data according to the Center for Disease Control (CDC) and data from the US Department of Education. Glang et al. (2008) estimates that there are 130,000 children with special education needs following a TBI, however, according to the US Department of Education's 30th Annual Report (2008), only one-fifth of those children are currently receiving special education services under the TBI category.

Various reasons exist for the low rates of identification of children with TBI in schools. One of the major reasons is the poor transition services in place between hospitals and schools, including poor communication, lack of referral for services, and reliance on family members to report the brain injury to the school (Cantor et al., 2004; Glang et al., 2008). Also, often times deficits secondary to a TBI do not present themselves immediately. Therefore, young injured children seem to be developing normally, however, with an increase in cognitive demands in school, over time they begin to experience significant cognitive and behavioral problems. Other factors include, but are not limited to, characteristics or symptoms overlapping with other disabling conditions or learning disabilities, families having misconceptions of special education programs and therefore resisting having their child referred for special education evaluation, and lack of awareness among both educators and physicians of the various indicators of long term

problems for children with TBI (Cantor et al., 2004; Dettmer, Daunhauer, Detmar-Hanna, & Sample, 2007).

Due to the presentation of symptoms and behaviors related to TBI overlapping with other learning disorders, many children with TBIs are inaccurately classified under a specific learning disability, rather than under TBI classification (Glang et al., 2008; Taylor et al., 2002). This inadequacy of identification is due to various reasons such as TBI being viewed as a low incidence disability, and/or educators' overall lack of knowledge of TBI- related symptoms, behaviors, and impact on school performance. According to Glang et. al (2008), an astounding 92% of educators have reported receiving no training in TBI identification. Therefore, the combination of current misclassification, underidentification of children with TBI, as well as lack of educator awareness, continue to result in TBI remaining a low incidence disability and perpetuating a dysfunctional cycle of underfunding and inappropriate educational services.

Among children with TBI, parents and families often are in the best position to evaluate their child's overall functioning, as they possess very intimate and accurate knowledge of their child's strengths and weaknesses. More often than not, however, parents and families of children with TBI are not aware of and do not receive information from medical personnel, regarding the possible short and long-term outcomes their child may face and the level of support and services he/she may need. Consequently, they often feel very confused and must become resourceful, assertive, and resilient in order to get information and subsequent supportive services for their child with TBI (Leith, Phillips, & Sample, 2004).

Currently, research related to parents and families' information about and perceptions of their children with TBIs is limited. Therefore, a major aim of the present study is to take a

qualitative research approach to understanding and describing the perceptions of parents of children with TBI who are in school. Data used for this study were collected from validity testing of the *Brain Check Survey* (BCS), a tool developed in the Occupational Therapy Department at Colorado State University for screening school-aged children for possible signs of TBI. Designated sections of the BCS, designed to collect qualitative data from parents as they completed and shared their information, experiences, and perceptions of their child with known TBI, provided the majority of the data used to answer the following research questions:

- 1) What are the perceptions of parents related to their child's behaviors, symptoms, and history of TBI?
- 2) What are the parents' perceptions of the school based services and supports provided to their child and focusing on their TBI-related learning needs?

Methods

Participants

Parents of school children were sampled from five school districts in the state of Colorado to include a variety of population sizes within the state. As approved by the Colorado State University Human Research Committee and each school district committee, the sampling protocol included limiting eligible student/parent selections in each school district to three distinct sub-groups of student classifications: children with identified traumatic brain injury (TBI group), children currently receiving special education services for specific learning disability (SLD group), and children who were considered typically developing and not receiving any Individualized Education Plan (IEP) services. For the purposes of this study, I examined the TBI group exclusively. Whole group convenience sampling was used to obtain students with known TBI, due to the low incidence of students with formal TBI identification in schools.

The parents/legal guardians of each student with TBI from each of the five school districts became the final targeted sample, since the *Brain Check Survey* being tested is a parent-report tool. In cases where the selected parents of students lived in separate dwellings from each other, each parent was sent a survey packet, and then if both parents returned a completed survey, the two BCS forms were counted as one, averaging scores and including both sets of qualitative comments. A total of 51 students had parents who returned surveys for the study.

Instrument

The *Brain Check Survey* (BCS), formally referred to as the *Screening Tool for Identification of Acquired Brain Injury in School-Aged Children* (STI), was developed as a screening tool to identify children who are struggling in school and who may be exhibiting signs

and symptoms of a traumatic brain injury (Dettmer et al., 2007). The BCS was developed in response to research on the under-identification of TBI in children, as well as formal consultation with experts in pediatric TBI; a process which ensured content and construct validity. The BCS is a parent- report instrument and addresses three primary topic areas: history of the injury and illness, behaviors currently observed in the child, and symptoms currently displayed by the child. The survey also contains sections for the parents to report demographic data on the student and the family, the child's current strengths and weaknesses in school, any related services the child currently receives that either are being provided by the school or privately (i.e. occupational therapy, speech therapy, physical therapy, or other), and additional comment spaces within each of the primary topic areas listed above in which the parent can elaborate as they choose.

Procedure

The above sampling process for parents of students with known TBI, was carried out by data specialists at each of the five school districts. Surveys were mailed, through the school districts to the parents of all the selected children, along with an introduction letter explaining the purpose of the study, two copies of a consent form for the TBI group, a stipend disbursement form and a self-addressed, stamped envelope for return of the survey to Colorado State University. In an attempt to increase response rate, all participants were offered a \$10 stipend for return of their completed survey. Reminder packets were mailed two weeks following the initial mailing date, and contained duplicate copies of all of the materials sent in the original packets. Phone calls were made to the parents of all of the students with known TBI by assigned TBI "specialists" within each district in order to encourage their participation in the study. In addition, Spanish versions of all materials in the survey packets were available upon request for any of the recruited parents in the 5th school district, per requirement of that district's IRB team.

In order to maintain confidentiality, consent forms were filed separately from each participant's completed survey. Further, surveys were identified with a code number specific to each participant, so that individual names were not placed on any survey.

Data Analysis

Qualitative data obtained in the parent-report *Brain Check Survey* related to the group of students with TBI were analyzed using a phenomenological approach. Content analysis from this approach consisted of initial horizontalization of data, open coding, identification of significant statements, and subsequent vertical coding of statements into meaning units or themes (Creswell, 2007; Merriam, 2009; Moustakas, 1994). Since these qualitative data consist of brief written responses to the questions within the BCS form, any opportunity for probing and clarification of parent responses was not possible. I used textural and structural descriptions to analyze what was reported and how the parents reported information. As Creswell (2007) defines, textural description is using significant statements and themes to describe what the parents experienced, whereas structural description is writing a description of how the context or setting has influenced the parents' experience of the phenomenon. Therefore, these descriptions were used to understand any events in their student/child's history that resulted in an injury to the child's head, no matter what the level of severity; to analyze any issues with school-related behaviors and symptoms; to evaluate what their student/child does best in school, and has the most trouble with; and report and briefly evaluate any special services their child may have been receiving. For example, a parent's report of her child's experience in a car accident was used to understand *what* the parent experienced (textural description), whereas the parent's report of interacting and communicating with medical personnel at the hospital post injury was used to understand *how* the event was experienced (structural description).

To increase the rigor of my work, and subsequently the trustworthiness of my findings, I used three strategies. First, I clarified and included in this paper any of my known biases as I began this study (found below in the sub-section: “Researcher Personal and Professional Perspectives”). Additionally, I kept a reflexive journal of my theme ideas, analytic challenges, and any changes in my assumptions, biases, or perspectives as I wrote the analysis, findings, and discussion portions of this paper. Finally, since member checks with the parents who sent in their completed BCS forms was not possible, I completed an on-going peer review and/or debriefing of my analysis and interpretation processes with my advisor and other research committee members, in order to provide a thorough external check of my research findings and interpretations of their meanings.

Researcher Personal and Professional Perspectives

I, as the researcher conducting this study, would like to express some of my known biases and assumptions before reporting the findings of this study. Over the years, I have had the privilege of working with children with diverse developmental needs and at various developmental stages, as well as with their families. Therefore, I have become quite familiar with the challenges children with disabilities face, both within and outside of the educational setting. With a school-based perspective, and consistent with IDEA, I believe that every child has the right to a quality education. From my experiences, however, I have felt this is not always a priority for educators and/or administrators. Educators and administrators have indicated many reasons to explain these students’ deficient educational experiences, including, primarily, a lack of: time, funding, and educator knowledge of children’s unique developmental and learning needs.

I also am very sensitive to the challenges and struggles experienced, and the sacrifices that have been made by the parents and families of these children. It is an assumption of mine that some parents are thankful to hear their child will be receiving additional services in schools. I also am learning, though, that many parents would not be pleased or agree that their child's work or behavior "is so bad" that he/she may need to be tested and then be labeled as having a disabling condition that is causing the child to need special education services. I am curious about the parents who chose to fill out and return the *Brain Check Survey* (BCS), especially the parents of the hundreds of children considered typical. Specifically, I am curious about what kind of information the parents from all three groups of children (with TBI, with learning disabilities [SLD], and with no known learning problems [TYP]), decided to provide about their child within the primary topic sections of the BCS, including history of any injury and illness that could have resulted in a TBI, and/or behaviors and symptoms currently observed in the child that often are indicative of a possible TBI. Since these additional comments were a primary focus of this qualitative research, I was interested in the reasoning behind these parents' decisions to provide supplementary written information about their experiences with their child, whether he/she has a known TBI or not, and more specifically what type of information they were willing to elaborate on. My initial speculation, as I began this study, was that the parents who have made additional efforts to provide details about their child's history and elaborate on specific experiences with their child also would be the ones who recognize and acknowledge that their child may need and could possibly benefit from specific TBI related supports and services within the school environment. I know the parents of the students considered TYP or SLD participated in the project probably because they wanted to be cooperative and help out the BCS developers/researchers, and/or wanted to receive the \$10 offered as a thank you for their

participation. It did intrigue me, though, that maybe those parents were wondering how their child might fare on this TBI screening tool.

Results

The data analysis process included all questions on the parent-reported BCS of the children in the TBI group. Upon completing analysis of the data set, four main themes and subsequent sub-themes emerged (see Figure 1). Descriptions of the four themes and associated sub-themes are presented below. Additionally, excerpted parent comments are used to further support and illustrate the themes. (Individual quote identifiers are indicated by numbers in parentheses following quotes.)

Theme 1. Parent Response Types

Each parent participant was requested to answer questions on the BCS related to their child's injury, behaviors and symptoms, IEP categories, services being used, and information on their child's participation and performance in school. Parent responses to these aspects differed substantially, illuminating distinct parent response categories, namely: searcher parents, silent parents, and informed parents.

Searcher parents. Many parent responses highlighted “searching” tendencies either in terms of seeking and using private services and therapies outside of what was being offered at school, challenging the “professionals’” opinions about their child's abilities and disabilities, and/or attributing their child's challenges to something other than a traumatic brain injury (TBI).

For some of these parents, their comments about their child appeared to place an emphasis on the positive. After indicating her son was receiving supports for various subjects in school, one parent responded to what her son does best in school by writing, “He is great at reading, getting along with others, great at sports. He has been nominated for national junior honor society because he has such great successes in school” (1321).

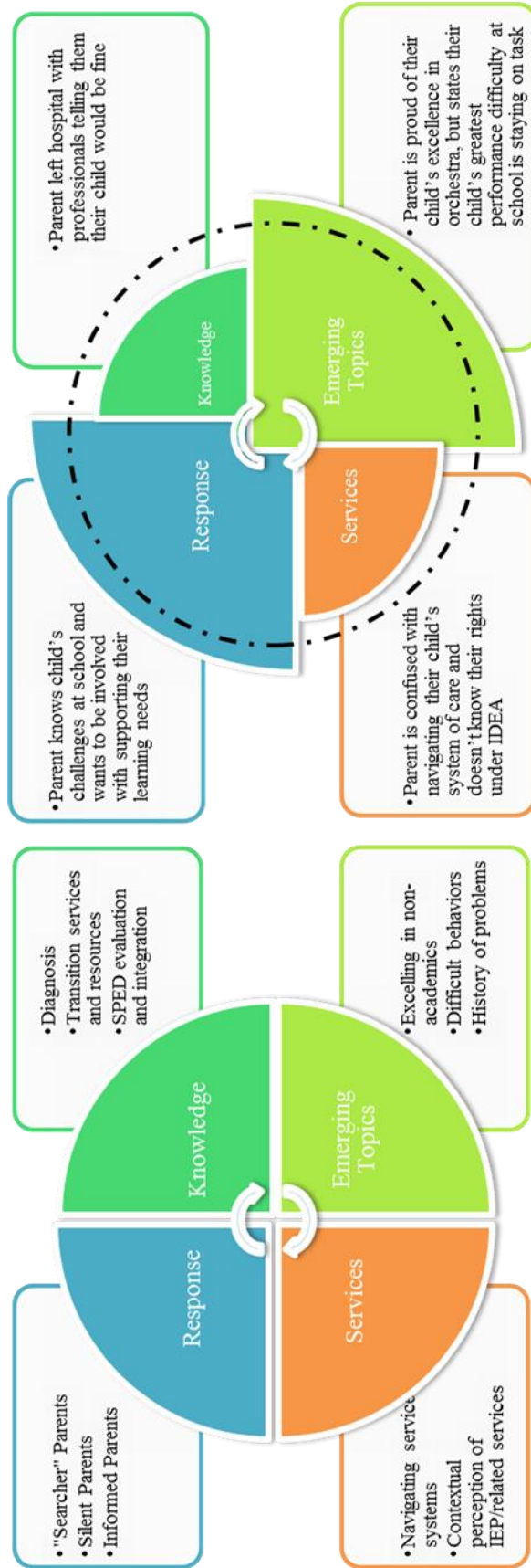


Figure 1. Parent themes and experience. Adapted from Hammel, Magasi, Heinemann, Whiteneck, Bogner, & Rodriguez (2008). This figure illustrates parent perceptions and experiences related to their child with TBI in the school system. The graphic on the left depicts the four major themes and sub-themes that emerged through analysis of the parent completed *Brain Check Surveys*. On the right, the graphic shows a specific example of a potential parent experience associated with their child's history of TBI, their child's associated behaviors and symptoms, and their school-based supports and services. These experiences may change across time and contexts as parents perceive factors to be supports and/or barriers.

Additionally, some parents tended to label non TBI- related factors for reasons why certain behaviors and/or symptoms were being displayed. One parent, in commenting on why her son was displaying high levels of moodiness, reported “[his] uncle is manic- depressive” (1223). Additionally, another parent labeled her child’s behavior difficulties in the classroom as strictly being due to his developmental age and stage: “He has random difficulty paying attention to the teacher, but she [teacher] says it’s a normal five year old problem” (5006).

Silent parents. Some parents reported not knowing specific things about their child, including details about their injury, their IEP categories, and what their child excels at and is challenged by in school. The most common theme among these parents, however, was an overall lack of response. Despite their child having a severe TBI and subsequently displaying severe behaviors and symptoms as noted by consistently high (meaning very problematic) scores on the BCS, they offered little to no explanation or supplemental information about these concerns.

While some of these parents did not respond at all, others reported overly simple and vague responses. These responses were particularly located in the answers to two qualitative questions on the BCS that ask the parent to identify what his/her child performs best at, and what the child has most difficulty with in school. Responses among these parents included admission to not knowing such as “Don’t know” (1100), “Hard to say” (1217), as well as language displaying a lack of clear knowledge and/or certainty, such as: “It *seems* to be math and P.E.” (1212).

Informed parents. For many parents, their responses demonstrated they were clearly informed about and accepting of their child’s TBI. Additionally, even through their brief answers to the survey’s qualitative questions, they seemed to possess a grounded clarity

regarding their child's strengths and weaknesses, as well as the support their child was needing to participate in school successfully. These responses also lent themselves to my further understanding the parents' overall knowledge and involvement in their child's supports and services within the school setting. One parent wrote, "[He] is on an IEP and sometimes struggles to complete assignments on time. With extra time and help he manages to keep up" (1003). In another example, a parent stated, "Needs at least some help with most academic subjects" (1208).

For these parents their responses displayed a clear knowledge of their child's participation and performance in school, and the various accommodations and modifications that are currently in place for the child. One parent said, "[He] is not working at grade curriculum, has a modified curriculum - spelling and math are hard" (1105). Another parent reported, "Barely partially proficient in grade level. Not doing much grade level work. Needs paraprofessional at ALL times during day" (1333).

Finally, parents who had a greater understanding of the services their child was receiving often chose to share their opinions on whether these services seemed to be helping or not helping their child. These informative answers may have displayed a possibly greater level of involvement, by those particular parents, in their child's education. One parent wrote, "[IEP] is incredibly helpful, we have an amazing team," (1003) while another responded with, "[IEP accommodations and modifications] yes it helps, it would be impossible otherwise" (3205).

Theme 2. Knowledge

For the majority of parent participants, their child's injury resulted in an acquired disability, something which had not been a part of the child's life previously, and which was

greatly unexpected. This disability changed their child, his/her needs, and day-to-day parent-child interactions. Many parents wrote answers that communicated their feelings of not being equipped with the necessary knowledge to adapt effectively to their child's and family's changing circumstances, and subsequently relating to their parental involvement.

Misdiagnosis/limited transitional services from hospital. Many parents expressed leaving the hospital after their child's injury with little to no information provided from medical professionals, or occasionally with some information, which they later discovered to be inaccurate. This lack of accurate information and resources upon discharge from the hospital directly influenced parent knowledge regarding their child's injury, and additionally kept the parents ignorant of the present and future challenges their child likely would face. When describing her child's Emergency Department visit, one parent wrote,

“She was in a very bad motor vehicle accident with me when she was 5 months old. It was a very bad one where our car was run over by a cement truck. They took her for observation and after 24 hours sent her home thinking nothing was wrong. By the time she was 2 1/2 we knew there was something wrong” (1326).

Another parent, in regards to a blow to the head her child sustained at the age of 9, described it as, “resulting in no problem ‘at the time’” (1204). With transition information and resources being limited to non-existent for many of these parents, their changing circumstances were increasingly challenging.

Special Education evaluation and integration. As a result of many parents leaving the hospital thinking their child was going to be fine and/or that their child's injury was not serious, parents did not feel the need to take specific actions, such as reporting the injury to school professionals or advocating for their child to be evaluated by a special education referral team. Therefore, despite a number of these children having sustained medically-diagnosed mild-to-

severe traumatic brain injuries, the services (if they did receive any in school) were not congruent with their TBI- related needs. This mis-categorizing of the child's cause of learning problems resulted in parents not always being clear about what learning problems their child was receiving special education services to address. One parent wrote, "He has a medical plan added to his IEP." [BCS Question]...Is the IEP helping? "Yes, *kind of*. [My] child did have category of multiple disabilities, switching to TBI now, *I think*." (1325).

Theme 3. Services

Within the school system, a child who has an Individualized Education Plan (IEP) is eligible to receive special education, related services, and/or accommodations to meet their unique and individualized goals with the intent of optimizing their learning and educational potential (IDEA, 2004). These services include, but are not limited to, special education, speech therapy, occupational therapy, physical therapy, and resource room. On the BCS, parents had the opportunity to report, not only under which specific IEP category(ies) their child was receiving services, but also the opportunity to identify which specific services their child was or was not receiving, both in school and outside of school.

Understanding and navigation of services. Many parents expressed their frustration not only with not completely understanding the particular needs of their child and having accurate expectations for him/her, but also with ensuring that those needs were being met in an efficient and effective way at school. All but the *Silent Parents* reported the particular services and/or accommodations their child was receiving in school, often commenting on what was or was not working. A number of parents reported incongruence between what their child needed in order to participate effectively in school, and what actually was happening on a day-to-day basis. As an

example, in response to a BCS question about whether her child was having difficulty in school, a parent wrote, “Inconsistent staff support with testing,” (1221) seemingly suggesting that if there were more consistent support at school with testing, information regarding what could better support her child in completing his school-related tasks could be more effectively obtained.

Perception of IEP/related services. For some parents the reality of their child having an IEP that guides special education and related services is nothing new, and something they have been involved with for many years, judging by the numerical difference between the child’s age when the parent completed the BCS and the age at which they acquired an IEP. For other parents, IEPs and related services seemed unfamiliar, and navigating this new and complex system could feel overwhelming. Whether they have been a part of the system for a short time or long time, parents expressed their experiences of navigating the system as being based on a number of contextual factors, as evidenced by the following example,

“As a parent, my responses to same question can vary depending on what has been recently happening. Other factors can be my own frustrations with dealing with all the systems needed- i.e. school, doctors, therapists, etc. The question on “Is the IEP helping your child’s school performance?” needs to be reworded. As an example, my response will vary depending on where we are with the school, which school, which teacher, etc. Also having IEPs for 10 years is hard to summarize” (1221).

Theme 4. Emerging Topics

While the research questions of this study revolved around understanding the experiences of parents of children with a traumatic brain injury in the school system, there were a few specific topics that parents frequently reported on outside of this study’s original focus. These topics, nevertheless, are emergent in the sense that they were what parents often wrote about, and thus appear to be important to their everyday experiences with their child with a TBI. These

data-centered topics provide evidence that could have implications for future research, possible BCS tool revisions, and an enhanced knowledge base for practitioners working with this population.

Excelling in non-academic activities. As discussed previously, one of the questions on the BCS asked parents to report what their child does best at in school. When answering this question, 35 out of the 51 parent participants whose children were receiving services under a TBI IEP category identified nontraditional academic work or activities. Some of the most common responses included activities related to art, music, socialization, and sports. One parent expanded upon her description of her child's interest and success with orchestra by reporting, "Orchestra. He loves music and is the one area of his brain that functions on all cylinders. His music teacher was not even aware of his brain injury until I told him two weeks into school!" (1003). In instances when parents did report their child excelling in traditional academic subjects, the most common subject reported was math, occurring nine times. The parents, however, often included specific clarifiers such as "Math (*with some extra help*)" (1208) and "*When he is compliant, he does very well with math...*" (1324).

Difficulty with behaviors. Opposite to the question discussed above, parents also were asked what their child has performance difficulties with at school. Once again, instead of identifying either traditional or non-traditional academic activities, parents tended to report problem behaviors, with approximately half of the parents reporting behavior issues in regards to what their child struggled with most. The challenging behaviors cited most frequently were focusing and staying on task and the child's inability to remember things, as noted by the following parent responses: "... retaining items learned [is difficult]. Can remember sometimes then forgets what he learned" (1107), "Yes, he does not do his work by himself, needs constant

assistance staying focused” (1328), and “ He has trouble with short them memory and rarely passes a test or quiz” (1408).

History of problems. Through both horizontal and vertical coding of the data, the researcher was able to obtain a clear picture of each child based on parent written report, including demographic information such as the child’s age and gender, the nature of each child’s injury(ies), past and current services used, and the child’s overall performance and participation in school. Throughout the analysis process, the researcher discovered instances in which some of these children had a history of problems in school prior to their TBI. This was evident in many different ways as parents reported their child receiving a special education evaluation for learning or behavior problems, as well as the child receiving services under IEP categories at an age prior to their injury. For example, one parent reported that her son suffered a brain injury while in a car accident at the age of 16 and is currently on a TBI IEP, and additionally reported that her child received a SPED evaluation at the age of 9 and also was an IEP for having Significant Identifiable Emotional Disability (SIED), suggesting that this child struggled with various behaviors and symptoms impacting their school performance prior to their TBI injury.

Discussion

In conducting this research study, I as the researcher, wanted to gain an understanding of the perceptions of parents of school-aged children with traumatic brain injuries. Although research literature focused specifically on parent perceptions and experience related to having a child with a TBI is limited, there exists a much larger body of literature exploring the experiences of parenting children with disabilities that is valuable to consider. This literature base emphasizes parents' social, emotional, and cognitive well-being, assuming that these factors are directly impacting both theirs and their child's functioning. Also, it highlights the typical grieving process that parents go through in association with the disappointment and stress they experience when their child does not meet common societal developmental expectations or their own personal hopes of a healthy child (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999; Woolfson, 2004). Therefore, parents' adaptation, competence, and well-being related to their child's disability are critical in order to obtain both parent and child performance and participation outcomes.

Thus, there exists a common ground with the limited research specific to parenting a child with TBI in the school system, stressing the fact that parents are important informants and hold a unique role in understanding the child within the educational setting (Gfroerer, Wade, & Wu, 2008; Savage, DePompei, Tyler, & Lash, 2005). Parents and families provide a constant presence within a child's life, and therefore can be influential in a number of ways, including understanding the child's abilities and difficulties before and after the TBI, actively communicating with professionals inside and outside of school, as well as advocating on behalf of their child. In gaining perspective on the parents' experiences, through their qualitative responses on the *Brain Check Survey*, the results of this study have highlighted for me specific

barriers to parents' experience in fulfilling their perceived roles. Parents' conception of and reaction to their child's injury seemed to be highly dependent on the amount of knowledge, support, and resources received at the time of their child's injury and during the weeks, months, and years following. Parents emphasized the notion that beyond the initial emotional impact related to the injury, they struggled with obtaining information about the injury and in some cases did not seem to be fully aware and/or convinced that their child had sustained a TBI at all. From an inductive reasoning standpoint, this researcher argues that due to many parents' lack of knowledge about TBI-focused support and resources, including an understanding of available services their child might benefit from, many of these parents who completed the BCS for our study did not give evidence that they believed they needed to advocate for their child within the school setting, perhaps because they were unaware of the problem. This is consistent with recent research findings that parents of children with TBIs cannot and do not advocate for their child in school if they do not perceive a need to do so (Gfroerer et al., 2008).

Schools provide a unique backdrop for researchers to gain an understanding of the experiences of parents of children with TBI for a number of reasons. As discussed in the Results section above, parent participants frequently commented on their difficulty with understanding and successfully navigating their child's school system and special education services, in relation to their child's TBI. Parents with no previous exposure to special education services may have found themselves overwhelmed by the complex system of legal educational rights and entitlements available to support their child with TBI under IDEA (2004). Additionally, even parents who have been involved with special education services for many years also reported frustration with the constant and confusing coordination of multiple service systems, and suggested that it is a never-ending process as their child acquires new teachers and therapists,

transitions to new schools, and has changing needs. These findings as a major theme also are reflected in Savage et al.'s (2005) discussion of pertinent issues related to pediatric traumatic brain injury, in which parent difficulty with navigating the special needs system was one major aspect underlying family challenges.

The parent participants' written responses on the completed BCS varied, with some parents providing comments on the majority of questions; while other parents provided little to no response, other than to check boxes related to their child's behaviors and symptoms. This variance of response was substantial and thus gave me ample opportunities to look for insights into different parent response types. For the parent participants who did choose to respond, and in some instances elaborate, on particular questions, I found myself readily attaching certain attribute characteristics to the parents, such as their obviously high level of acceptance and concern with their child's injury, their knowledge regarding school services, their clear understanding of how their child's needs are to be addressed, and their overall openness and readiness to write about their child's school-based strengths and challenges. Conversely, parents who provided little to no information on the BCS tool, left very few clues as to their knowledge, perceptions, or beliefs. There could be several explanations for their lack of response, including their not being interested in or not understanding the purpose of the BCS testing study, their lack of knowledge of their child's participation and performance at school, their being unaware of the services/accommodations their child receives, and/or simply being unwilling to provide written answers to supplement the checked-box answers. No matter what forces were shaping this decision for these parent participants, I interpreted their not responding as a powerful response in itself. As stated in the "Researcher Personal and Professional Perspectives" section, my initial speculation was that parents who provided details about their child's history and elaborated on

specific experiences with their child would also be the ones to acknowledge that their child could benefit from specific TBI related supports and services within the school environment. While it is easy for me to make these assumptions as to why parents varied in their qualitative responses, and to confirm my initial speculations, I ethically cannot draw any conclusions from such a brief glimpse into the parent-respondents' perceptions and experiences. I have come to believe that while every parent's experiences with their child with TBI are unique, the schools, nevertheless, need to meet parents at their current level of understanding and work with the parents and their child to ensure that the child receives the most appropriate services to meet his/her identified learning needs.

Limitations

There is one major limitation to this research study that shadows any others. This researcher was involved with analyzing data that had already been collected, and therefore had no opportunity to interact with the parent participants regarding their perceptions of their child's TBI-related behaviors, symptoms and school-based experiences. I have coined the term, "frozen data" as a way to conceptualize my inability to clarify responses provided/not provided by parents, much less to probe by asking the parents follow-up questions. As Creswell (2007) describes, some essential components of rigorous data collection within qualitative research include multiple interviews with participants and prolonged engagement in the field. These basic data collection strategies are essential components of phenomenological qualitative research and thus directly influence the rigor of the data collection procedures.

A second limitation exists within the BCS tool itself. As a result of the BCS being developed and used primarily as a quantitative tool, gathering a rich and thick description of

these parents' perceptions and experiences related to their child with TBI was completely out of any researchers' control. In hindsight, perhaps the original researchers needed to require parents to add written comments throughout the tool in order to be eligible to receive the \$10 thank you stipend that was mailed to them when their completed BCS was returned. Even though this researcher had inconsistent amounts of information available from one completed BCS to another, there nevertheless were ample data to assist me in broad strokes as I sought the answers to my research questions.

Future Implications and Research

The findings of this study suggest that, while parents' experiences are unique and real to them, I did identify several common themes across parents of children with TBI in regards to their experiences and perceptions of their students' needs and school-based experiences. Following a TBI, a child's parents are most likely in the best position to provide important information on their child's functioning. The importance of this insider view which parents often provide is evidenced by the fact that evaluations of student performance and participation typically include parent interviews and/or the completion of standardized checklists. Therefore this research served to provide a brief glimpse into these parents' perceptions, and highlight emerging topic areas. Future research including follow-up in-depth parent interviews, however, could result in obtaining much more information to help researchers to gain a deeper understanding of the parents, as well as the many factors that have an impact on their daily experiences of parenting a child with TBI and their child's school-based experiences. Ongoing qualitative research is vital to acknowledge the parents' "expert" role and increase information gained to promote the development of specific strategies to enhance parents' experiences and involvement with, and advocacy for school-based services for their child with TBI.

Conclusion

In answering this study's research questions surrounding parent perceptions related to their child's history of TBI, associated behaviors and symptoms, and school-based supports and services, it was discovered that parent experiences varied depending on a variety of perceived supports and barriers. For children with TBI, their parents and/or other family members remain the constant presence among an ongoing and continually changing context of educators, professionals, and service providers. Thus, it is essential that parent expertise related to their child is valued by educators, through including them as a frequent and permanent participant in the planning and development of their child's educational services. In order for parents to effectively fulfill this role, however, they must be given the tools to do so. As on-going research continues to point out, many educators, themselves, are not aware of TBI-related symptoms and behaviors, much less which supports are appropriate for children with TBI (Glang, Dise-Lewis, & Tyler, 2006), making it increasingly important that parents be given the knowledge and skills to be a resource and advocate for their child. Parents must be empowered early on to find their voice as advocates, in order to ensure that their child is able to participate and perform in his/her student learner role as effectively and successfully as possible.

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