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School-Based Support for Families of Students with Traumatic Brain Injuries

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Abstract

Families of children with traumatic brain injuries (TBIs) often experience emotional burden related to the sudden onset, intensity, and duration of the recovery process. Family support can improve outcomes; however, parents and siblings of students with TBI often do not receive the help they need, which can impede the injured child's recovery. This qualitative study involved focus groups with school psychologists who have worked with students with TBIs. Participants were asked about challenges experienced by families of students with TBI and how school psychologists could better support families of children with TBI. Themes included: guilt, change, lack of time and resources, and inconsistent or fragmented advice and services. Four specific areas of opportunity for developing improved school-based services are discussed. These include facilitating collaborative consultation, being a direct source of support, teaching coping and resilience strategies, and elevating awareness.

Keywords: traumatic brain injury, focus group, qualitative, school psychologist

School-Based Support for Families of Students with Traumatic Brain Injuries

Introduction

Parents of students with sudden-onset disabilities, such as physical or cognitive impairments that result from disease or injury, often experience unique issues including grappling with delayed effects. Traumatic brain injuries (TBIs) can be particularly difficult because students with TBIs often "look fine," which can lead to unrealistic expectations of the child's capabilities. After the initial recovery period, students who have sustained TBIs often receive limited medical or outpatient services. The school may be the primary location for ongoing intervention. This can leave families without adequate emotional and logistical support to deal with challenges.

Comprehensive school-based support for parents and siblings of students with TBI may help improve the injured child's skills and mental health. While the role of the school psychologist can vary greatly from one place to another, school psychologists are trained to serve as both consultants and direct service providers for students and their families (NASP, 2010); therefore, more information is needed on how they can facilitate support for families of students with TBI.

Effects of TBIs

TBI is the leading cause of death and disability in children and young adults worldwide (Thurman, 2016). A traumatic brain injury is a brain dysfunction caused by an external bump, blow, or jolt to the head. Among those from birth to age 19, an average of 62,000 children each year sustain brain injuries requiring hospitalization as a result of motor vehicle crashes, falls, sport injuries, physical abuse and other causes. Approximately 1 in 550 will experience a TBI

severe enough to result in long-term disability (Faul & Coronado, 2015). This can include cognitive, physical, emotional, social, and behavioral issues. If the injury causes significant impairments that adversely affect a student's educational performance, that student can qualify for special education services under the Individuals with Disabilities in Education Act (IDEA). In some cases, issues related to the brain injury may not be immediately evident. For example, the child may not struggle in school until more abstract thinking, more sustained attention, or more complex social interactions are required.

Parents and caregivers often report personality changes in their child after a TBI (Degeneffe, Chan, Dunlap, Man, & Sung, 2011). Their child may be more (or less) outgoing or active, short-tempered, and/or quick to become frustrated. Children who have sustained TBIs often seem impatient or intolerant of change; they may become verbally or physically aggressive. Emotional and behavioral changes, as well as changes in relationships, can be sources of stress for individuals who have sustained TBIs (Davies, Bernstein, & Daprano, 2019; Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990). These issues can also affect surrounding family members and friends (Allen, Linn, Gutierrez, & Willer, 1994; Martin, 1988).

Parents of Students with TBIs

Clinicians have long-identified TBI as something that can affect the entire family system (e.g., Brown, Whittingham, Sofronoff, & Boyd, 2013; Lezak, 1988). Parents may initially feel relief that their child survived the injury and may not fully recognize the long-term disability. They may go through a process of grieving the loss of the child they once had, but may also feel shame because they "should" just be grateful their child is alive. There may be significant emotional distress, relationship discord, and burden of care (Brown et al., 2013). These effects

on the family are often related to injury severity. For example, the higher severity of the brain injury, the higher the reported levels of distress over time (Wade et al., 2006).

In their qualitative study, Roscigno and Swanson (2011) described four themes that emerged when interviewing parents following their child's moderate to severe TBI: grateful to still have my child, grieving for the child I once knew, running on nerves, and grappling to get what my child and family needs. They described having limited access to resources, such as community services or support groups, to help them manage new life stressors. Not only did their relationship with their child change, but "the very ecology of their existence was altered, at least temporarily, by their child's TBI" (Roscigno & Swanson, 2011, p. 1421).

The parents of children with TBI in Roscigno and Swanson's (2011) study described longing for interactions with considerate and knowledgeable providers who listened to their input. Many described interactions with professionals and community members who judged their child's behavior as lazy, rude, or manipulative. While parents may have been given literature about TBI in general, they wanted one-on-one conversations about the often-complicated information and to know what was going on with their child specifically. Parents reported needing to learn a great deal of complicated information in a relatively short amount of time, with minimal expert guidance, all while experiencing anxiety about their child's uncertain health condition. According to cognitive load theory, learning improves when people can build on existing knowledge and experiences or when they are guided by someone with experience (Kirschner, Sweller, & Clark, 2006). School-based professionals should be at the forefront of providing such support and guidance to parents.

The involvement and education of parents regarding the treatment of their child with a TBI is important for the child's outcomes. For example, one study found that when parents had

lower psychological functioning, their child was more likely to exhibit externalizing behaviors after sustaining a TBI; conversely, when parents promoted communication and involvement with their child who sustained a TBI, the child was less likely to exhibit negative externalizing behaviors (Raj et al., 2013). Further, children of parents who were involved in an online course on positive and negative parenting behaviors experienced fewer negative behaviors after their TBI (Wade et al., 2017).

Parents of children with disabilities identify a range of barriers to well-being, including access to information and services, financial barriers, school and community inclusion, and family support (Resch et al., 2010). Resch et al. concluded that many of these challenges are due to a lack of necessary environmental supports. A key element of family coping in a student's recovery from a health issue is a strong family-school partnership (Power, DuPaul, Shapiro, & Kazak, 2003). Thus, the present study expands on these findings to define and describe potential school-based environmental supports that can be more family-centered, particularly for families of students with traumatic brain injuries. This includes their brothers and sisters.

Siblings of students with TBIs

Siblings of students with TBIs may feel resentment and anger over the shift in attention and resources to their injured brother or sister. One study suggests that siblings of individuals with severe TBIs may experience psychological distress for up to five years post-injury (Orsillo, McCaffery, & Fisher, 1993). Depending on the circumstances of the TBI, siblings might feel guilt or relief that they were spared injury themselves. They also may be embarrassed by their sibling's needs or behaviors. Some children who witnessed their brother or sister's injury may be fearful or have difficulty sleeping. Older siblings might have new responsibilities related to caring for themselves, others, or the household (De Caroli & Sagone, 2013; Emerson & Giallo,

2014; Incledon et al., 2015). The entire family may experience stress due to the changes in time commitments and financial resources.

Support for Families of Children with Disabilities

In recent years, there has been a growing focus on family-centered care for children with disabilities. Family-centered care emphasizes the family as partners in decision-making regarding goals and treatment for the child with a disability. Core principles include focusing on family strengths, respecting family culture and values, encouraging joint decision making and empowerment, and open and collaborative communication (Bailey, Raspa, & Fox, 2012). When implemented correctly, this approach achieves four primary goals: (a) helping families cope with the unique needs of caring for and raising a child with a disability, (b) helping families understand their child's development and needs, (c) promoting high-quality parent—child interactions, and (d) preserving and reinforcing family dignity and independent decision making (Bailey et al., 2012).

Many families of students with disabilities find support through advocacy groups, such as Autism Speaks, the largest autism advocacy organization in the United States. Parents of students with developmental disabilities typically experience a growing realization that their child had special needs and were gradually introduced to the world of disability advocacy and special education. Conversely, a TBI is an instantaneous event, resulting in a family's rapid introduction to medical and rehabilitative care. This often occurs while parents are also grieving the loss of the child they once had and thus may have difficulty taking the lead in the care process. Medical practitioners and educators who are sensitive to this are essential.

Interpersonal resources such as friends, family, and a spouse can have a moderating effect on parental adjustment after a child's TBI (Rivara et al., 1996; Wade et al., 2004).

Likewise, resources such as friends and school resources can be a moderating effect for adolescent adjustment following TBI (Lantagne et al., 2018). Less is known about how school resources and school-based support can affect parent and sibling adjustment.

Parents interviewed in Roscigno and Swanson's (2011) study reported that early interactions with community healthcare providers either positively or negatively affected their outlook on their child's injury; further, the family environment was directly impacted by the resources available to them (e.g. knowledge, insurance, income, and community supports). This suggests that professionals need to be proactive about educating and supporting families immediately following the injury and carrying on consistent support in the years to come.

School Psychologists and Support for TBI

When considering school-family partnerships after a TBI, well-trained school psychologists may be a crucial link between families and school personnel (Conoley & Sheriden, 2005). Many families are not aware that professionals are available at their schools to provide support and resources to the entire family—and many professionals do not take the initiative to serve in such roles. In fact, a recent study indicated school psychologists reported a number of barriers to meeting the needs of students with TBI, including: communication about the injury, a lack of training/knowledge among school personnel, a perceived lack of importance of TBI by school personnel, a lack of resources to support students, procedural impediments, and inadequate placement options (Canto, Chesire, Buckley, Andrews, & Roehrig, 2014). These barriers can also inform opportunities for school psychologists, such as consultation and training for educational professionals, providing direct interventions, and providing support to the child's extended support system, including parents and siblings (Havey, 2002). School psychologists

regularly interact with parents of students with TBI during the special education evaluation process and thus are in a good position to interface with and support families.

A number of studies have been published related to family support for students with disabilities and health issues (e.g., Bailey, Raspa, & Fox, 2012; Patel, Shafter, Bulik, & Zucker, 2014; Resch et al, 2010; Smith, Swallow, & Coyne, 2015). However, the few studies examined how to support families of children with TBIs have typically focused on caring for families from injury to discharge (e.g., Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015) or family burden during the first year after injury (e.g., Aitken et al., 2009). Relatively little is known about how such strategies can be effectively employed in the school setting, and particularly how school psychologists can lead support efforts to provide long-term family care.

The present study explored ways to provide school-based support for families (parents and siblings) of students with TBIs. The research objectives were: 1) To explore school psychologists' understanding of the needs of families of students with traumatic brain injuries (TBIs), and 2) To learn how school psychologists and other school personnel can better support parents and siblings of students with TBI.

Method

Design

This qualitative study involved focus group interviews with school psychologists to help professionals learn more about the needs of and potential services for families of students with TBI. This method was selected because it is an effective, time-efficient way to gather information on needs and interventions (Kress & Shoffner, 2007). Focus groups are widely accepted in social science and applied research; they also provide ease of access to participants (Marshall & Rossman, 2016).

Participants and Setting

Participants included a convenience sample of 11 school psychologists (one group of five, one group of six) from one state in the Midwestern United States who 1) have worked as school psychologists for at least two years and 2) have served at least three students with TBIs. The primary investigator (PI) applied a random number generator to a list of 175 school psychologists in the region. The list was created across the previous 10 years as a contact sheet for graduate students seeking professionals to shadow as part of an introductory course. The PI invited participants until reaching the desired number of 12 participants (6 per group). One confirmed participant canceled the morning of the focus group. Participants were interviewed in a private conference room at the PI's university.

The majority of participants (N=8) were female, reflecting demographics of the field of school psychology. Years of experience ranged from 2 to 32 (M=12.18, SD=10.02). Participants worked for districts (N=9) and educational service centers (N=2) serving districts of different sizes and demographics, including small, mid-size, and large student populations; urban, suburban, small town, and rural classifications; and high, average, low and very low student poverty rates. School psychologists in this region who are employed by educational service centers have professional roles in schools similar to district employees. The participants reported serving between 1 to 15 students with TBIs severe enough to require an individualized education program (IEP; M=6.27, SD=5.35), from zero to three students who were on a Section 504 plan that provided formalized accommodations for TBI (M=.91, SD=1.14), and from zero to 20 students who received temporary academic or environmental adjustments for their TBI (M=3.55, SD=5.80). Thus, participants had a range of experience with students with TBIs and their

families. Participants were told during recruitment what the study was about and consented in accordance with Institutional Review Board approval.

Instrumentation

The primary instrument used in this project was a semi-structured interview protocol designed by the primary researcher. Questions were modified from O'Shea et al.'s (2012) focus group interview guide for a study on nurse's perspectives on the needs of siblings of children with cancer. The following questions guided the focus group discussions, with follow-up prompts as needed: 1) Describe the types of interactions you have had with families of children with TBI (prompt for answers related to both parents and siblings). 2) What problems or issues have you been aware of that have been raised by families of students with TBI? 3) How have you become aware of their needs? 4) Are there formal mechanisms in place in your schools to assess the needs of families? Please describe them 5) How do you decide what information to offer families? 6) What have you noticed about the needs of siblings at different ages? 7) How have you responded to these needs? What have you found to be helpful/not helpful? 8) What outside resources have you used to meet their needs? 9) Is there anything else that you'd like to share with me?

Procedures

Prior to the focus groups, each participant reviewed and signed an informed consent form and completed a brief demographic and professional background questionnaire. Consent included permission to be audio and video recorded. The video recording was solely to aid in the transcription process (so the transcriber could determine who was speaking). The PI moderated two focus groups which took place two different days during the same week. Focus groups included 5-6 participants and took place in a conference-style room at a university during a break

week; therefore, the building was quiet and participant privacy was maintained. Each session lasted approximately one hour.

The PI created a supportive environment, facilitated the group, asked questions, followed up on key points, and ensured that all participated. A trained graduate assistant was present in the room to take field notes on interactions and observable behaviors. After the focus group, participants were provided a luncheon and a set of TBI resources to thank them for participation.

Data Analysis

Focus group recordings were transcribed verbatim with identifiers removed. Audio and video recordings were stored on the PI's password-protected computer and pseudonyms were assigned to maintain confidentiality. An inductive thematic analysis was used to interpret the transcribed interview data (Braun & Clarke, 2006). The PI and a research assistant systematically analyzed transcribed interviews to identify trends in the perceptions and opinions expressed. This analysis involved searching the transcripts for meaningful fragments, which consisted of key phrases such as "opportunity to collaborate" or "point of contact." These fragments were reviewed and used to develop a categorization scheme and matching codes. These codes were then used to sort the data so the researcher could discover patterns and themes. At that point, categorical themes were identified; as necessary, some of the themes were re-worked and recoding of the data was performed. The data were analyzed again to ensure that all themes were identified. To this end, an in-depth, holistic understanding of responses was obtained.

Trustworthiness

To improve credibility of the information collected, this study utilized member checking as a way of asking participants if we "got it right" (Marshall & Rossman, 2016, p. 230). Each interview concluded with the interviewer summarizing the main points of the interview and

asking participants if the summary was accurate. Coding and analysis of the transcripts by multiple evaluators provided intercoder reliability and help confirmed the reliability of the interview data. Finally, peer debriefing involved the primary investigator meeting with a research team comprising knowledgeable colleagues to get reactions to focus group summaries, data analysis, and report drafts. The team collaboratively fine-tuned the clarity and logic of interpretations.

Results

Analysis of focus group transcripts revealed four themes related to issues faced by families of students with TBIs: guilt, change, lack of time and resources, and inconsistent or fragmented advice and services. An exploration of potential school-based services included four areas of opportunity: facilitate collaborative consultation, be a direct source of support, teach coping and resilience strategies, and elevating awareness.

Issues Faced by Families of Students with TBIs

Guilt. Participants discussed experiences with family members who felt guilty about their child's TBI. As one psychologist from an urban district recounted situation of TBIs caused by firearms and shaken baby: "Many of them feel like maybe they contributed to the problem. Like the gunshot situation, they had left firearms in their home that were unsecured, and this 12 year old got a hold of it...The shaken baby syndrome one, tons of guilt there because the perpetrator...he was the boyfriend."

Others elaborated, "[The mother] had a lot of guilt, too, because one of the falls was down the basement stairs that had a door, and one of them was the child had climbed down from the high chair...things that happen so fast" and "In the situation of the car accident, the mom was

driving the car, so there's guilt involved with that. And young children, infants, who fell off the bed while they were changing diapers, things like that, so there's guilt involved."

Change. Comments related to change included statements related to grief, chaos, "survival mode," siblings assuming a caretaker role, and a "new normal" for the whole family. An early-career school psychologist stated that prior to one student's TBI in second grade "she had been a typically functioning student, so I know that was very difficult for parents to come to terms with that."

One psychologist from a high poverty urban district explained: "The grieving process is hard for lots of families— the child I thought I was going to have, the life I thought I was going to have." She later addressed changes experienced by siblings: "And the little one is now experiencing a family where there is a lot of chaos, a lot of out of control behaviors, and is picking up a lot of those, because mom and dad don't really know how to handle the older one."

Lack of time/resources. The challenges involving lack of time and resources faced by the family include factors such as appointment frequency and financial hardship. When recounting a particular case, a psychologist explained, "It was just the amount of travel that had to be done from [city name redacted] to [a clinic four hours away] where they specialize...that seemed like that would be really overwhelming... Mom had to take off work and deal with the other sibling...and now the main priority is the student with the TBI."

Inconsistent or fragmented advice and services. Dealing with a variety of professionals and well-intentioned family and friends can be overwhelming. One participant offered some insight on this: "I think families get confused a lot because they get varying thoughts from different physicians and psychologists about the impact of [the TBI]."

The break in time between an injury and the initiation of educational services can also contribute to the fragmentation of information. As a relatively new school psychologist explained: "...you have to really dig to get information if the kid has had a concussion or if there'd been a car accident and things like that. It just doesn't jump out and parents just don't know that's important information."

The fragmentation of advice and information when communicated to teachers can also contribute to problems: "Sometimes teachers don't understand why a kid's out or why they're out for so long or, when they do come back, why the workload may be lightened."

A participant who worked in a suburban district with very low poverty summarized: "[Some parents feel] like they're getting pushed in so many directions. The doctor saying, 'Go to the school' the school saying, 'Go to the doctor' and they don't know where to go....They don't have that point of contact, so how can we create that?"

Potential School-Based Supports and Strategies

Participants shared ideas for school-based supports and strategies. These included strategies they used themselves with families of students with TBIs or other chronic conditions, as well as strategies they read or hear about others using.

Facilitate collaborative connections. Focus group participants emphasized the benefits of facilitating collaborative connections with medical professionals, communities, and sources of peer support. One participant gave a positive example of collaborating with medical professionals that ultimately benefitted the student and family: "Knowing the location of the subdural hematoma was also really important and knowing what could happen based on a specific insult in a specific part of the brain." Another agreed and offered the suggestion that "it

would be helpful if just all the medical reports I was reading [included] some of the... things to look out for in schools."

Participants also described the benefits of support for logistics. For example, "If a teacher knows that a kid in her class has a sibling who has a disability, she could help with some logistical stuff... 'Hey they're going on a field trip or they're wanting to be in a sport event, can somebody give this kid a ride?' Also, "giving parents the opportunity to collaborate with each other ... [such as] a parent support group...creating a network for them and sharing those experiences. School psychologists can partner with counselors and principals to do that."

A mid-career school psychologist described how a sibling of a child with a disability used her skills to help other children with disabilities: "She took on a role as a peer helper in the multiple disabilities classroom, not always necessarily helping her sister, but was kind of a helper to everyone." A psychologist who served rural schools added, "Even making that peer aware that there are others in the school...going through similar situations, who might have siblings with disabilities, just to know that they are not alone."

Be a direct source of support. Participants felt families benefitted from a school-based point of contact. Desirable qualities including being direct, listening, and the giving of one's time. "Spend one-on-one time or just plan to make it a part of your day" or "...linking with resources. I have families who appear who aren't connected with physicians or networks and don't know where to go." Another added: "Even helping them navigate through school. Do they need a 504 at some point? And what are their legal rights through that?"

An urban psychologist with more than 20 years of experience emphasized that it "always goes back to having a really good relationship with them. Because if you always have a really good relationship with a parent, they'll tell you more things, they'll share doctor's information.

They'll sign the release so you can get all that from [the hospital] and not be so closed. They have a really tough life, so if they feel like you are a part of their team that really does help them." As one participant explained: "I've gotten a lot of 'Thanks for listening to me,' because I'll be on the phone for an hour while they go on about things they are experiencing...A lot of times you're just like 'Hey, I don't necessarily know the answers to these either, but here's what we can do to help." Another concurred, saying: "Parents think they are on their own trying to search for things. It's overwhelming... We can be that point of contact."

Teaching coping and resilience strategies. Participants advocated for teaching coping skills, resilience training, and holding groups to support families of students with TBIs. One explained: "We've done some coping skills things...it was interesting the variation of their siblings' responses to that, and the role their family expected them to play. So giving them someone to talk to and kind of giving them that comradery and the coping strategies was huge." Another described that "having a lunch bunch or resilience training—some kind of positive attention but also skill teaching" could be beneficial for siblings of students with TBIs.

One participant cautioned that "We like to think that we'd do anything to accommodate for the kids, but if it's informal, (teachers) are less likely to follow through with it. If it's not an IEP or a 504 plan, you sometimes have to make it more formal."

Elevating awareness. A final category of strategies related to elevating awareness about TBIs. One participant suggested: "I think some ongoing PD for us in the neuro piece would be helpful, because obviously some of us have been out of school for a long time. Things are updated and things are new." Additional training on medications and their side effects might also be helpful. As one mid-career practitioner explained, "I don't have a lot of training in

psychopharmacology so when I get a report in that this kid is taking X, Y, and Z, I have to go to Google."

Another participant addressed elevating parents' awareness of how their child's TBI might affect siblings. She wants parents to understand, "Your child needs that one-on-one time or they need to figure out an option that allows them to do this. Normalizing that the sibling doesn't want to caretake for [their injured sibling], and they are angry that their whole life is revolving around their one sibling."

Parents also need to be educated on the importance of mentioning a head injury to educators: "A child falling and bumping their head can be a very normal experience of childhood that some parents might not know that can cause later problems...On background forms it will never be mentioned, but then it will come up in conversation and it's like, 'I knew there was something missing!'"

School psychologists also need to understand that "a person who is identified with a TBI might need more frequent evaluations because...there are more changes that happen than in other disability categories. So, stay more present and make parents aware that things might change... to check in more frequently than every three years."

Discussion

Students who sustain TBIs often experience a significant loss of cognitive, physical, and/or interpersonal skills. The sudden onset of such changes can profoundly affect the child's entire family. Once the child is discharged from hospital care, the school may be the primary source of information and support. This study examined school psychologists' experiences with families of students with TBIs and explored potential sources of school-based support. The school psychologists who participated in the focus groups described many of the same

challenges parents mentioned by Roscigno and Swanson's (2011) and Resch et al. (2010). This included guilt and change (Roscingo & Swanson described this as "grieving for the child I once knew"), lack of time/resources (Roscingo called this "running on nerves" and "grappling to get what my child or family needs"; Resch et al. included "financial barriers") and inconsistent or fragmented advice and services (Resch et al. described this as lack of "access to information and services"). The school psychologists in the present study demonstrated current understanding of what the families of students with TBIs were experiencing.

While medical professionals might assist families with the transition from inpatient to outpatient or rehabilitation services, once a child who has sustained a TBI is back at school, families are less likely to have a regular source of information and support. Thus, school psychology training programs and professional development sessions can teach practitioners to embed the following activities into their work with families of students with TBIs.

School psychologists are in a unique position to help not only students who have sustained a TBI, but also their brothers or sisters who are students in the school district. For example, some school-based professionals may offer short-term individual or small group counseling for students affected by a brother or sister's disability (Incledon et al., 2015). While limited resources may prevent these professionals from providing ongoing counseling, they might periodically check in with the sibling to monitor coping, give the student and family strategies for managing stress and change, document changes in behavior or academic performance at school, consult with teachers about signs of depression or anxiety, and/or direct families to community-based support groups. To support siblings, local community agencies may also offer programs like "Sibshops," which provide opportunities for siblings of children with special needs to gain peer support and education within a recreational context (Vatne &

Zahl, 2017). These events acknowledge that being a brother or sister can have benefits, but also may involve significant challenges. Schools might implement similar programs that involve a variety of age-appropriate information, discussion, games, and activities.

School psychologists can provide *support across settings* in a number of ways. They can ask parents to sign a release allowing them to talk directly with physicians and community care providers. This can facilitate ongoing sharing of strategies and consistency of care. School psychologists should maintain updated community contacts so they can direct parents to community support groups or counselors; they can also develop support groups in the school setting for siblings of children with chronic health issues, including TBIs.

School psychologists can also be a *direct source of support* to families, particularly at logical intervals of time, such as annual and triennial evaluations. At each of these meetings, in addition to sharing information about the child's present levels of performance, future goals, and qualification for services, school psychologists can ask supportive questions, such as "How are you coping with some of these challenges?" or "What can we do here at school to support you and the other members of your family?" They can also periodically check in with siblings, as one of the benefits of being a school psychologist is the potential to serve the entire school population (after securing signed permission in order to provide ongoing counseling).

We can also encourage adaptive coping behaviors through *directly teaching the family* coping and resilience strategies. This might include effective problem solving, monitoring and managing stress and intense emotions, strategies for seeking help and discussing the injury with others, and making meaning out of adversity (see Table 1).

Finally, school psychologists can take the lead in *elevating awareness* by conducting information sessions for other educators and community members on brain injury prevention and

response. They might lead an information session with an injured child's classmates and/or teachers if a returning student has experienced significant changes in functioning. This can alleviate some parental burden, as parents may have difficulty explaining their child's challenges to others, and particularly in developmentally appropriate terms. School psychologists can also help their districts create mechanisms for documenting brain injury history and outcomes. Finally, they can advocate for more frequent evaluations, particularly during the first few years post-TBI, when students' skills and needs can change rapidly. This not only helps ensure appropriate services for the child, but it also provides more frequent opportunities for the school team to connect with the parents.

Limitations and Future Research

Qualitative research can be subjective; further, every TBI is different and every school has different capacities for providing support and services. Therefore, the needs and strategies examined in this study may not generalize to every student who has sustained a TBI. The school psychologists who participated in the study served school districts of various sizes and demographics, however they all practiced in one Midwestern US state. Because they all practiced in the same region, it may not be possible to generalize their experiences and suggestions to different regions. Also, in this study, only school psychologists were interviewed. These professionals may have a limited interaction with families of children with TBIs and may not fully understand what would best support a family of a student with a TBI.

Future research might be conducted with more geographically diverse participants. This would allow for a wider range of perspectives and suggestions. Researchers might also interview the parents and siblings of a student with a TBI—as well as medical professionals—to gain their

perspectives on the supports they would find helpful. Finally, research that measures the effectiveness of these support strategies for families of students with TBIs is needed.

Conclusions

While TBIs are increasingly discussed in the popular media, few scholars are examining family support for injured individuals. This study contributed to the knowledge base by exploring school psychologists' understanding of the needs of and school-based support for families of students with TBIs. The school setting is of particular interest because it can be an efficient, cost-effective way of serving families.

School psychologists participating in focus groups described how families of students with TBI experienced issues related to guilt, change, lack of time and resources, and inconsistent or fragmented advice and services. Examples of potential support strategies include the school psychologists facilitating collaborative connections, being a direct source of support for families of students with TBIs, teaching coping and resilience strategies to siblings of students with TBIs, and elevating awareness regarding TBIs. In addition to directly helping the parents and siblings, providing school-based family support may indirectly help with a child with a TBI. This is because family well-being is a direct indicator of recovery and outcomes (Christian, 2016; Wade et al., 2006). Although these findings must be considered in relation to previously identified barriers to supporting students with TBI, such as those identified by Canto et al. in 2014 (e.g., communication barriers, lack of training/knowledge, lack of perceived importance, lack of resources, procedural impediments, inadequate placement options), these results can help school psychologists better understand how to include supporting families of students with TBI as a regular part of their professional practice.

References

- Aitken, M. E., McCarthy, M. L., Slomine, B. S., Ding, R., Durbin, D. R., Jaffe, K. M., Paidas, C. N.....MacKenzie, E. J. (2009). Family burden after traumatic brain injury in children, *Pediatrics*, 123, 199-206.
- Allen, K., Linn, R. T., Gutierrez, H., & Willer, B. S. (1994). Family burden following traumatic brain injury. *Rehabilitation Psychology*, *39*, 30-48.
- Bailey, D. B., Raspa, M., & Fox, L. C. (2012). What is the future of family outcomes and family-centered services? *Topics in Early Childhood Special Education*, *31*, 216-223. doi: 10.1177/0271121411427077
- Bailey, D. B., Simeonsson, R. J., Winton, P. J., Huntington G. S., Comfort, M., Isbell, P., . . .
 Helm, J. M. (1986). Family-focused intervention: A functional model for planning, implementing, and evaluating individualized family services in early intervention.
 Journal of the Division for Early Childhood, 10, 156–171.
- Brain Injury Association of America (2017). About Brain Injury. Retrieved 8 October 2018, from http://www.biausa.org/about-brain-injury.htm
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brown, F.L., Whittingham, K., Sofronoff, K., & Boyd, R.N. (2013). Parenting a child with a traumatic brain injury: Experiences of parents and health professionals. *Brain Injury*, 27(13/14), 1507-1582.
- Canto A. I., Chesire D. J., Buckley V. A., Andrews T. W., & Roehrig A. D., (2014). Barriers to meeting the needs of students with traumatic brain injury. *Educational Psychology in Practice*, 30(1), 88-103. https://doi.org/10.1080/02667363.2014.883498

- Christian, B. J. (2016). Translational research- The value of family-centered care for improving the quality of care for children and their families. *Journal of Pediatric Nursing*, *31*, 342-345. http://dx.doi.org/10.1016/j.pedn.2016.03.001
- Collins, A., (2012). What is the most effective way to teach problem solving? A commentary on productive failure as a method of teaching. *Instructional Science*, 40, 731-735. doi: 10.1007/s11251-012-9234-5
- Conoley, J. C. & Sheridan, S. M. (2005). Understanding and implementing school-family interventions after neuropsychological impairment. In R. C. D'Amato, E. Fletcher-Janzen, & C. R. Reynolds (Eds.), *Handbook of School Neuropsychology*. Hoboken, NJ: John Wiley & Sons.
- Davies, S. C., Bernstein, E. R., & Daprano, C. M. (2019). A qualitative inquiry of social and emotional support for students with persistent concussion symptoms. *Journal of Educational and Psychological Consultation*. doi:10.1080/10474412.2019.1649598
- De Caroli, M. E. & Sagone, E. (2013). Siblings and disability: A study on attitudes toward disabled brothers and sisters. *Procedia- Social and Behavioral Sciences*, 93, 1217-1223. doi:10.1016/j.sbspro.2013.10.018
- Degeneffe, C. E., Chan, F., Dunlap, L., Man, D., & Sung, C. (2011). Development and validation of the Caregiver Empowerment Scale: a resource for working with family caregivers of persons with traumatic brain injury. *Rehabilitation Psychology*, *56*(3). 243-250. doi: 10.1037/a0024465
- Delany, C., Miller, K. J., El-Ansary, D., Remedios, L., Hosseini, A., & McLeod, S. (2015).

 Replacing stressful challenges with positive coping strategies: a resilience program for

- clinical placement learning. *Advances in Health Sciences Education, 20.* 1303-1324. doi: 10.1007/s10459-015-9603-3
- Emerson, E. & Giallo, R. (2014). The wellbeing of siblings of children with disabilities.

 *Research in Developmental Disabilities, 35, 2085-2092.

 http://dx.doi.org/10.1016/j.ridd.2014.05.001
- Faul, M. & Coronado, V. G. (2015). Epidemiology of traumatic brain injury. *Handbook of Clinical Neurology*, 127, 3-13.
- Fletcher, J. M., Ewing-Cobbs, L., Miner, M.E., Levin, H. S., & Eisenberg, H. M. (1990).

 Behavioral changes after closed head injury in children. *Journal of Consulting and Clinical Psychology and Psychiatry*, 25, 459-476.
- Havey, M. J. (2002). Best practices in working with students with traumatic brain injury. In A. Thomas, & J. Grimes (Eds.), *Best practices in school psychology IV* (pp. 1433-1445). Bethesda, MD: National Association of School Psychologists.
- Incledon, E., Williams, L., Hazell, T., Heard, T. R., Flowers, A., & Hiscock, H. (2015). A review of factors associated with mental health in siblings of children with chronic illness.

 Journal of Child Health Care, 19, 182-194. doi: 10.1177/1367493513503584

 Individuals with Disabilities Education Act, 20 U.S.C. § 300 (2004).
- Kirk, S., Fallon, D., Fraser, C., Robinson, G., & Vassallo, G. (2015). Supporting parents following childhood traumatic brain injury: a qualitative study to examine information and emotional support needs across key care transitions. *Child Care Health Dev.*, 41(2), 303-13. doi: 10.1111/cch.12173.
- Kirschner, P. A., Sweller, J., & Clark, R. E. (2006). Why minimal guidance during instruction does not work: An analysis of the failure of constructivist, discovery, problem-based,

- experiential, and inquiry-based teaching. *Educational Psychologist*, 41, 75-86. doi:10.1207/s15326985ep4102_1
- Kress, V. E., & Shoffner, M. F. (2007). Focus groups: A practical and applied research approach for counselors. *Journal of Counseling & Development*, 85, 189-197.
- Lantagne, A., Peterson, R. L., Kirkwood, M. W., Taylor, H. G., Stancin, T., Yeates, K. O., & Wade, S. L. (2018). Interpersonal stressors and resources as predictors of adolescent adjustment following traumatic brain injury, *Journal of Pediatric Psychology*, 43(7), 703-712.
- Lezak, M. D. (1988). Brain damage is a family affair. *Journal of Clinical and Experimental*Neuropsychology, 10, 111–123. doi:10.1080/016886 38808405098
- Marshall, C., & Rossman, G. B. (2016). *Designing Qualitative Research (sixth edition)*.

 Thousand Oaks, CA: SAGE Publications, Inc.
- Martin, D. (1988). Children and adolescents with traumatic brain injury: impact on the family.

 *Journal of Learning Disabilities, 21, 464-70.
- National Association of School Psychologists. (2010). *Model for comprehensive and integrated* school psychological services. Bethesda, MD: Author
- Orsillo, S. M., McCaffery, R. J., & Fisher, J. M. (1993). Siblings of head-injured individuals: A population at risk. *Journal of Head Trauma Rehabilitation*, 8, 102-115.
- O'Shea, E., Shea, J., Robert, T., & Cavanaugh, C. (2012). The needs of siblings of children with cancer: A nursing perspective. *Journal of Pediatric Oncology Nursing*, 29, 221-231. doi: 10.1177/1043454212451365
- Patel, S., Shafer, A., Bulik, C., & Zucker, N. (2014). Parents of children with eating disorders: developing theory-based health communication messages to promote caregiver well-

- being. *Journal of Health Communication: International Perspectives, 19*(5), 593-608. doi: 10.1080/10810730.2013.821559
- Power, T. J., DuPaul, G. J., Shapiro, E. S., & Kazak, A. E. (2003). *Promoting children's health: Integrating school, family, and community*. New York: Guilford Press.
- Raj, S. P., Wade, S. L., Cassedy, A., Taylor, H. G., Stancin, T., Brown, T. M., Kirkwood, M. W. (2013). Parent psychological functioning and communication predict externalizing behavior problems after pediatric traumatic brain injury. *Journal of Pediatric Psychology*, 39(1), 84-95. doi: 10.1093/jpepsy/jsto75
- Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., Zhang, D. (2010). Giving parents a voice: A qualitative study on the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, *55*, 139-150. doi: 10.1037/a0019473
- Rivara, J., Jaffe, K., Polisar, N., Fay, G., Lioa, S. & Martin, K. (1996). Predictors of family functioning and changes three years after traumatic brain injury in children. *Archives of Physical Medicine and Rehabilitation*, 77, 754-764.
- Roscigno, C. I. & Swanson, K. M. (2011). Parents' experiences following children's moderate to severe traumatic brain injury: A clash of cultures. *Qualitative Health Research*, *21*, 1413-1426. doi: 10.1177/1049732311410988
- Smith, J., Swallow, V., & Coyne, I. (2015). Involving parents in managing their child's long-term condition- A concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing*, 30, 143-159.
- Steinhardt, M., & Dolbier, C. (2008). Evaluation of a resilience intervention to enhance coping strategies and protective factors and decrease symptomatology. *Journal of American College Health*, 56(4), 445-453.

- Thurman, D. J. (2016). The epidemiology of traumatic brain injury in children and youths; a review of research since 1990. *Journal of Child Neurology*, 31(1), 20-27. doi: 10.1177/0883073814544363
- Vatne, T. M. & Zahl, E. (2017). Emotional communication in support groups for siblings of children with disabilities. *Patient Education and Counseling*, *100*, 2106-2108. http://dx.doi.org/10.1016/j.pec.2017.05.021
- Wade, S. L., Stancin, T., Taylor, H. G., Drotar, D., Yeates, K. O., & Minich, N. M. (2004).
 Interpersonal stressors and resources as predictors of parental adaptation following pediatric traumatic brain injury. *Journal of Consulting and Clinical Psychology*, 725, 776-784. doi: 10.1037/0022-006X.72.5.776
- Wade, S. L., Taylor, G., Yeates, K. O., Drotar, D., Stancin, T., Minich, N. M., & Schluchter, M. (2006). Long-term parental and family adaptation following pediatric brain injury.

 **Journal of Pediatric Psychology, 31, 1072-1085. doi:10.1093/jpepsy/jsj077
- Wade, S. L., Cassedy, A. E., Shultz, E. L., Zang, H., Zang, N., Kirkwood, M. W., ... Taylor, H.
 G. (2017). Randomized clinical trial of online parent training for behavior problems after early brain injury. *Journal of the Academy of Child & Adolescent Psychiatry*, 56(11), 930-939.e2. doi: 10.1016/J.JAAC.2017.09.413
- Walcott, C. M., & Music, A. (2012). Promoting adolescent help-seeking for mental health problems: Strategies for school-based professionals. *Communiqué*, 41(1), 4-7.