

## Paediatric traumatic brain injury: A review of pertinent issues

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### Abstract

Children with traumatic brain injury (TBI), regardless of the severity of the injury, often face challenges when living in home, school and community. Their needs are often overlooked and recognition of the long-term consequences is not always central to the management of the child in the school or community. This article provides references to pertinent literature and suggestions for intervention from the clinical experiences of four individuals with extensive experience of the family stresses, educational, cognitive-communicative and behavioural challenges that occur after TBI in children. It provides information regarding these issues, particularly educational situations, and suggests methods that may be useful for service providers and family members.

**Keywords:** *Children with traumatic brain injury, cognitive-communicative challenges, educational challenges, behavioural issues, family concerns.*

### Introduction

Traumatic brain injury (TBI) in children presents challenges at local, national and international levels. Participants from around the world who met at the Task Force for Children and Adolescents during the International Brain Injury Association's 2003 conference in Stockholm, Sweden agreed that issues for children after TBI continue to be problematic in hospital, home, school and community. Participants suggested that the impact of TBI remains under-recognized by many countries and is often misunderstood by professionals and family members. Additionally, as the child develops and grows, the long-term consequences of TBI are often largely ignored or misinterpreted. Thus, the children suffer, rehabilitation and education professionals are often perplexed and families are left caring for children without the supports they need.

This article is provided as a review of several pertinent issues facing youths after TBI when the primary service providers are located in the home, school and community. It is presented from different viewpoints of four professionals who have been involved with children and their families after TBI and who possess expertise in school reintegration. These individuals have a total of 97 years

of experience as researchers, professors and service providers. Their perspectives represent the scholarship of discovery, integration, application and teaching [1]. While children with TBI can experience challenges with physical, emotional, behavioural, communicative, cognitive, educational, community and family supports, this article emphasizes four major areas: family, educational, cognitive-communicative and behavioural issues. Challenges in each of these important areas, especially where school is concerned, and possible strategies to help are outlined.

### Issue one: Family challenges

Families remain the constant presence amidst a continually changing spectrum of providers and professionals as the child's treatment and recovery progress. Families share unique roles as: (1) observers throughout all stages of the their child's care, (2) experts with a dual perspective of pre- and post-knowledge of their child's abilities and difficulties, (3) communicators and liaisons with professional caregivers and (4) advocates for their child. Because families continue as the one constant, the authors chose to begin the review with their issues; thus

emphasizing the importance of including families in all aspects of the child's care.

The immediate emotional impact of a physical trauma is widely recognized as families experience common reactions of panic and fear, shock and denial, anger, guilt, isolation and hope [2]. Acute care and rehabilitation staff use many strategies to assist families in these early stages including provision of written information about TBI, family meetings, involvement in bedside care, family training by therapists and support groups [3]. Recognition of the needs of siblings for information and support can reduce feelings of isolation and even rejection as parents concentrate their resources and attention on the injured child [4]. Less attention has focused on family stresses over time and minimal research has been completed among families regarding long-term resiliency and effective coping strategies. Helping families over time as the child matures requires consideration of the following issues.

#### *(1) Ongoing need for information*

The ability of all professionals to provide clear and understandable information and the capacity of families to understand and retain information is a primary consideration for all over time. In the early days, weeks and even months post-injury the educational process between professional and family should be considered as essential to smooth transitioning and community reintegration. Families continually cite the need for information about TBI, even after the child has been discharged from the hospital or rehabilitation programme. A follow-up post-discharge study involving three trauma centres in North Carolina reported that additional information was a need cited by 72% of families whose children were admitted with brain injuries and by 49% of families with children treated in emergency departments for mild brain injury [5].

Because families are under considerable emotional stress during all stages of care, education about TBI must be an ongoing process that engages every service provider involved in the child's care. Repetition of information and supports to aid the family many years after the injury continue to be needed.

#### *(2) Struggle with feelings of guilt*

The mechanisms of TBI identified by the National Paediatric Trauma Registry illustrate the non-intentional nature of the vast majority of injuries [6]. They also illustrate that a TBI is a failure of every parent's most fundamental purpose—to protect the child from harm. Whether it is failure to use a protective car safety seat, failure to purchase a bicycle

safety helmet or exposure to an abusive partner or babysitter, parental guilt is among the most agonizing reactions experienced by these families.

Parents of children with other developmental disabilities frequently have some anticipatory anxiety as they observe deviations in development with peers or siblings. This leads to the formal testing and consultations that ultimately provide the diagnosis. However, these parents often can be assured that nothing they did during the pregnancy or early childrearing caused the child's condition, whether it is cerebral palsy, autism or some other condition.

Such is not the case with many parents of a child with a TBI. Reactions of self-blame, guilt and regret are very common and complicated and can prolong the mourning process for these families. When a family member, sibling, friend or stranger is also injured or killed in the incident—a common occurrence with motor vehicle crashes—the grieving process is even more complex. Feelings of guilt and remorse may resurface or be exacerbated by anniversary reactions of the injury, particularly when a parent was the driver or responsible caregiver.

This guilt and remorse can affect a family over time. While initial reactions of despair and depression are common and well recognized by clinicians in hospital and rehabilitation settings, there are fewer mental health resources in the community knowledgeable about TBI to assist families after the child returns home. Consequently, many families struggle to resolve these issues in isolation.

While data on separation and divorce is scarce, there is no question that significant marital stress can occur. A couple's decision whether to have more children may be affected in those families who remain together. Parenting styles can become sources of conflict as families try to find that balance that allows the risk taking that every child needs to explore the environment and develop skills vs the wish to protect the child from any possible exposure to further injury.

#### *(3) Difficulty anticipating the future*

The very nature of a TBI makes providing prognostic information very difficult, if not impossible. The ongoing developmental process of brain maturation, along with the changing cognitive challenges during the child's education, complicate prognostic challenges even further [7].

This uncertainty regarding the child's cognitive recovery creates special stresses for their families. First, there is no defined time period comparable to the 5 year mark often cited for cancer survivors of being 'free' of the disease. Rather, 5 years marks major developmental milestones for children and

youth who may just be 'growing into' the latent effects of the TBI.

Secondly, the pattern of more rapid physical recovery among children and youth can mask or obscure the cognitive issues. Parents repeatedly observe that the better the child looks, the harder it is for others to recognize that the brain has been injured. As behavioural challenges and cognitive needs become more evident in school and at home, parents face the challenge of identifying if and how they may be related to the TBI.

#### *(4) Difficulty dealing with educational*

In the US, educational programmes are well designed for children who are diagnosed with disabilities in early childhood. These children enter the 'special needs' system via early intervention programmes, periodic screening and development programmes, Head Start, pre-school programmes and special education under the Individuals with Disabilities Education Act (IDEA). These infants and toddlers literally grow up within a system designed to track, monitor and evaluate their needs and progress over many years. Many of these parents become skilled advocates, negotiators and service co-ordinators.

The scenario is very different for parents of youths with TBI. Unless the child has a pre-existing condition, entry to the 'special needs system' can occur at any age or educational grade post-injury as a direct consequence of the TBI. Inexperienced parents are often perplexed and overwhelmed by the array of assessments, meetings, formal planning and documentation involved. The ability of health care professionals to guide families through this transition to either regular education with special services or special education is increasingly limited by pressures to shorten lengths of stay and cost containing measures enacted under managed care.

While children transferred to inpatient rehabilitation programmes may benefit from comprehensive hospital to school transition planning, many more children are sent home directly from trauma centres with no referrals for any special services from schools [6]. Thus, parents who are already under emotional duress, who have little prognostic information to guide them, now must address the concern of whether the TBI has affected their child's ability to function and learn in school.

While the inclusion of TBI under IDEA in 1990 held promise for improved and more accurate identification of this population of students and their special needs, the training and skills of educators to accurately assess their needs and develop individualized education programmes has not been consistently nor comprehensively addressed

in the US. Many parents find themselves in the situation where their child is the first and only student with a TBI known to the local school. Thus, a frequent refrain of parents (and source of ongoing stress) is their concern about the qualifications of educators, the availability of appropriate supports and accommodations in the classroom and the recognition of challenges that are related to the TBI. Their over-riding concern is whether educators can provide the services and programmes that will enable and allow their child to achieve the fullest educational potential possible.

Even when parents find capable teachers and a responsive educational team, this supportive environment may change as the student moves from class-to-class, teacher-to-teacher and school-to-school. Additional needs of the student may become evident as the cognitive challenges of school become more complex. Parents often find that they must continually monitor and advocate for their child within the school system and this can be time consuming, frustrating and add to their cumulative stress.

The challenge is how to better prepare parents for this role as educational manager. The authority and responsibility of parents to advocate for their children is recognized by state and federal education laws because the parent is asked to sign and approve the formal special education plan. Yet, parents of students with TBI are usually initially unfamiliar with the state and federal resources designed to inform them of their rights and responsibilities. Just as families cite the need to receive information about neuroanatomy and the sequelae of traumatic TBI, there is an equally critical need to educate families about educational resources and programmes for children with special needs.

#### *(5) Conflicts about holding on and letting go*

As all children move from adolescence into early adulthood, there is an emotional, physical, financial and geographic separation that occurs as the child matures and eventually leaves home. The parents of a child with a TBI face some special concerns as impairments in judgement, attention and memory, communication challenges and cognitive and behavioural issues pose special challenges and risks for independence and community integration. The loss of friends and social isolation commonly reported among adolescents with TBI may result in greater reliance upon siblings and family members for social opportunities and emotional support. This complicates the physical, emotional and even financial separation as parents question, 'Who else will care as I do?'

While these concerns differ depending on the youth's abilities and needs, the underlying theme

among parents is the hope and dream of a meaningful life. For example, the parent who has provided full-time physical care inevitably reaches a stage where the limitations of an ageing parent cannot meet the physical demands of caring for a child who is now an adult. Yet, entering a community residence is a complex decision and transition that may take years to achieve. Another example is the parent whose adolescent/young adult is preparing for college and planning to live away from home for the first time. While physical care may not be a concern, the living environment (dormitory or apartment), social network and classroom must be conducive to supporting the cognitive strengths of the student or the potential for failure increases. Most families never forget the early shock and fear experienced when their child was first injured. Having almost lost their child once, it may be even harder to let go as the future becomes the present.

Professionals can use the following strategies to help prepare families for their multiple roles over time:

- Prepare and coach families effectively and succinctly providing information on the child's TBI by developing and rehearsing a brief summary that includes the medical history, treatment and current strengths and difficulties. This is an informational tool that may be used over time with community practitioners, educators and continuing care specialists.
- Provide multiple opportunities and methods for education by providing written materials, Internet resources and community contacts. The professional contact is a limited 'window of opportunity' to provide information and gives the family control by allowing them to choose if and when to use resources over time.
- Affirm the expertise of parents by gathering information about their observations of the child at home and in school and by including them whenever possible in the planning and development of rehabilitation and educational services.
- Refer families to support groups for parents of children with special needs. This serves a dual purpose for emotional support and developing relationships with other parents experienced in special education who may become mentors for negotiating services.
- Educate families about laws on the rights of children and adults with disabilities or special needs to help them become effective advocates.

### **Issue two: Educational resource challenges**

The economics of health care dictates that most students with TBI do not receive long-term

residential rehabilitation services. Thus, students resume their education in community schools, often times very soon after their injury. Upon returning to school it is likely that the majority of these students will be served in regular education settings within those schools as the field of special education continues to move towards an inclusive service model. Therefore, all educators (e.g. regular education teachers, special education teachers) who are involved in the inclusion model of education (predominately in the US) need to be knowledgeable about TBI and be prepared to help accommodate these students in any classroom environment. A brief discussion of key issues in serving students with TBI, including school reintegration planning, persisting effects of TBI and developing educational programmes follows. Suggested guidelines and resources for educators are also provided.

### *Returning to school following TBI*

The importance of planning for the student's transition from hospital to school has been well documented in the literature and practical school re-entry protocols have been developed [8–11]. Ideally, hospital staff should immediately inform school personnel when a student is admitted to their health care facility and the family and/or attending physician formally requests that the school begin the evaluation process. However, hospital staff are not always efficient at recognizing the need for specialized educational services or planning for school re-entry, so school personnel should take an active role in this process by gaining parental permission to contact the hospital staff as soon as they are aware that an injury has occurred. In many instances, hospital staff that are aware of the educational challenges that may emerge over time can make the same contact with school personnel. School personnel and the child's doctors, therapists, hospital social worker, hospital teacher, psychologist and neuropsychologist can then begin communicating to gather relevant information and to start planning for the child's reintegration to school. Such information includes mechanism of injury; child's current medical condition; anticipated discharge date; child's present cognitive and behavioural functioning; anticipated long-term medical needs (including medications, need for special equipment, environmental accommodations); and anticipated therapy needs [8]. Even for students who were receiving special education services at the time of their injury (e.g. for a learning disability or a behaviour disorder), re-entry planning is needed, as research has shown that moderate-to-severe TBI can cause significant additional cognitive impairment in children with pre-existing learning difficulties and programming modifications are often needed after injury [12].

*Recognizing persisting effects of TBI*

Following TBI, students may experience a number of challenges—physically, cognitively and behaviourally. The pattern of deficits resulting from a TBI depends on a number of factors, including age, mechanism of injury, pathophysiology of injury, pre-injury personality and ability, family support and the availability of appropriate services [13]. While children who have moderate-to-severe injuries tend to have the most pronounced challenges, several major studies of children with TBI [14–16] have shown that even a so-called mild brain injury can create significant learning and behaviour problems for some children. For many children, the cognitive and behavioural deficits that result from TBI may persist for several years, if not for life for life [15]. Grattan [5] followed 1251 children with mild TBI, for a year post-injury. Eight percent continued to demonstrate symptoms of depression, sleep disorders, fatigue, personality change and headaches 10 months after the injury. In school-related reports, 5% were found to be experiencing problems with memory, concentration and overall behaviours at 10 months post-injury. Children with mild-to-severe injuries should be considered as having potential educational challenges and accommodated in the schools when needs arise. These deficits will affect daily functioning and have a major impact on educational achievement.

Memory impairments and disorders of attention have been identified as the most common cognitive effects of TBI [14,17,18]. Impairments in executive functions such as organization, planning, problem solving and judgement have also been noted [19,20]. Additionally, TBI has been found to be associated with decreased speed of information processing [21,22]. Since TBI has the most profound effect on learning of new information, even mild TBI can lead to academic impairment [23–25].

In addition to cognitive problems, the research has shown that students with TBI also tend to experience more behaviour problems than their typically developing peers [26–29]. Behaviour problems following TBI may include over-activity, impulsivity, low frustration tolerance, irritability, apathy, poor anger control, aggression and social disinhibition. Injury to the frontal lobe is associated with impairments in attention, executive functioning, reasoning and problem solving.

*Developing educational programmes*

Given the variety and complexity of cognitive and behavioural difficulties following TBI, it is likely that specialized programming will be needed when the child returns to school and such programming may

be required throughout the student's education. While long-term deficits following TBI are well documented, empirical research on the effectiveness of particular programming strategies or instructional practices for dealing with subsequent learning problems in students with TBI is lacking. Given this absence of research, educators must rely on best practice information from the field of TBI, as well as effective teaching practices and proven instructional interventions for students with similar types of learning and behavioural difficulties [30]. The process of developing an educational programme and choosing instructional strategies begins with identification of the student's needs.

*Identifying student needs*

Determining the individual needs of a student requires careful evaluation of the student's current functioning. In order to obtain a comprehensive picture of the student's abilities and difficulties, assessment information from a variety of sources (e.g. neuropsychology, speech pathology, occupational therapy) must be combined with a functional evaluation of the child's skills. Evaluation of actual task performance in settings where the student's adaptive skills are called into play is critical, because relying solely on assessments given under ideal conditions do not reflect the kinds of difficulty a student may face in a busy classroom with less guidance and structure. Information regarding the student's academic functioning should be obtained along with information on cognitive processes (e.g. how will deficits in short-term memory, long-term memory and sequencing or organization affect performance in the classroom).

The individual needs of a student with TBI can be expected to change rapidly as the student continues to recover and as development comes into play. Thus, ongoing assessment of the student's functioning is required to give an accurate picture of needs at any given point in time [31].

*Strategies for addressing student needs*

Results of the comprehensive evaluation may reveal that the student has a number of specific deficits in cognitive and academic functioning. To determine which teaching methods may be most effective in meeting an individual student's particular needs, educators need to examine instructional interventions and effective teaching practices that have been proven effective for addressing similar deficits in students with other types of learning difficulties. For example, organizational impairments following TBI will necessitate proven instructional strategies for organization, such as task analysis (breaking a given

task into components or steps) and advanced organizational support (providing an oral or written preview of information to be covered in a lesson).

Effective teaching practices found to contribute to achievement for all students are also particularly helpful for students with TBI. Examples of such practices include structured lessons, guided practice, immediate feedback, clearly stated expectations, frequent review and small-group instruction. A variety of teaching strategies and accommodations can be considered for these students and used successfully in general education settings or in special education environments. For example, strategies to address attention and concentration problems include reducing distractions in the student's work area, dividing work into small sections and/or requiring the student to orally summarize information that has just been presented. Strategies to address memory problems include frequently repeating and summarizing information, teaching the student to categorize or chunk information to aid retention and providing experiential presentation of instructional materials. Comprehensive listings of teaching strategies for specific deficits following TBI are available [32,33].

Even with accommodations, some students may no longer be able to acquire information or skills using traditional teaching methods and curricula in general education settings. In such cases, specialized intervention techniques are required. For example, following a TBI the student may be unable to develop reading skills using the same instructional materials and methods as peers in his/her classroom, thus an alternative method for teaching reading is required. An intensive specialized phonics programme or the use of an approach such as Direct Instruction may be necessary [34].

For students with severe deficits following TBI, an alternative curriculum that concentrates on the teaching of functional skills, rather than strictly academic content, may be required. Instruction focuses on providing activities and opportunities for the student to acquire skills that will allow him or her to function as independently as possible in day-to-day living, while preparing the student for life beyond high school.

#### *Assessing teaching strategies*

A variety of accommodations and teaching strategies can be employed to address specific deficits a student may have. When these or other methods are employed, the effectiveness of the accommodations or instructional practices must be evaluated. Data based information should be gathered and analysed to determine if the student is making gains and, if not, what further accommodations or teaching

strategies can be implemented. In addition to charting progress of skill attainment (e.g. number of correct math facts, reading rate), there should also be a systematic analysis of targeted areas [35]. For example, if accommodations are employed for increasing the student's attention, then data on attention to task should be collected and analysed to determine if the student's attention is actually increased by the accommodation(s). Other examples of targeted areas could include student use of strategies to aid memory or student ability to follow directions.

Because of the diverse needs of students with TBI, no one set of accommodations or teaching strategies can be recommended that will be effective for all students. It is only through a thorough assessment of the student needs, implementation of accommodations and teaching strategies that address those needs and evaluation of the effectiveness of the methods employed will an appropriate programme be developed for the student.

#### *General guidelines for educators serving students with TBI*

Following are a listing of general best practice guidelines for educators to consider when serving students with TBI.

- (1) *Develop unique programmes:* As a group, students with TBI are different from students with other disabilities. Likewise, within the classification of TBI, there is great diversity. Thus, students with TBI should not be forced into existing programmes for students with other disabilities, nor should there be a standard one size fits all programme for students with TBI. Each student's programme should be developed based on his or her unique needs.
- (2) *Be flexible:* Given the unique needs of students with TBI, as well as the variability in day-to-day functioning that may occur, educators must be willing to adapt schedules and requirements to meet the needs of a student. Occasionally, planned activities must be dropped or revised on a moments notice to meet the student's present physical or emotional needs.
- (3) *Measure success in small increments:* Immediately following the injury, the child often makes rapid progress. However, as time goes on the student may encounter periods where progress levels off. Recognize that plateaus occur and celebrate any improvements, no matter how small.
- (4) *Communicate with families:* Ongoing communication with family members is critical to the success of any educational programme. Educators should establish a system for regularly

providing parents with information about the child's school progress, as well as a system for receiving information from the child's family.

- (5) *Develop a system for long-term monitoring:* Educators must continuously monitor the student's progress and performance to determine if the established programme and plans are appropriate. To review progress, monthly meetings should be scheduled for at least the first 6 months following the child's return to school. While meetings may not need to be held as frequently after that, a regular review schedule (e.g. at the beginning of each semester) should be established. Meetings to address key transition points (e.g. grade-to-grade, elementary-to-middle school) should be held well in advance of the event.

### **Issue three: Communication challenges following traumatic brain injury**

One of the major consequences of TBI can be the inability to communicate adequately. Children and adolescents can experience difficulty with speech, language and cognitive-communicative abilities that will interfere with adequate learning and social interactions [36–40]. Because learning is a primary task for youths and because learning is language based, it is often the inability to use adequate language skills in learning and social environments that interferes with successful interactions. Decreased communication skills sometimes lead to loss of friends, misunderstandings or poor performance on school or job tasks.

The terminology used to discuss cognitive communication disorders includes the following concepts:

- *Communication:* Communication is the use of listening, speaking, reading, writing and gesturing either to understand an idea or to express a thought.
- *Speech:* Speech skills are different from language skills. Speech is the production of sounds that make up words and sentences.
- *Language:* Language refers to the use of words and sentences to convey ideas.
- *Cognitive-communication:* Cognitive-communication skills require the ability to use language and underlying processes such as attention, memory, self-awareness, organization, problem solving and reasoning to communicate effectively.

Depending on the location and severity of the injury, any of the above functions can be impaired or spared. Additionally, a child can fail to develop new and more complex communication

skills and strategies over time. Recognizing the potential challenges and intervening to aid in the communication process will help youths to be successful in any communication environment. Characteristic behaviours that can occur and methods for communication partners to help follow.

Most children regain the ability to produce speech sounds and words after TBI. These skills usually improve with the physical recovery. When there are problems with paralysis, swallowing or other types of motor inco-ordination, there is a possibility that the individual will not recover the ability to speak or will have poor motor planning (apraxia) or muscle control (dysarthria) which results in unintelligible speech production. Characteristics of this type of speech may include:

- slurred production of words;
- drooling;
- difficulty swallowing;
- hoarse or nasal voice quality;
- slowed rate of speech because of motor control difficulty or increased rate of speech as the result of reduced self-inhibition and poor self-monitoring skill; and
- total loss of the ability to use verbal speech from paralysis of the vocal mechanism.

Because most children return to their pre-injury level of speech production ability, additional language and cognitive-communicative weaknesses can be overlooked. It should be remembered that speech production is only one part of a communication disorder.

There are three types of language abilities that can be affected after a TBI—receptive, expressive and pragmatic. Receptive skills or the ability to understand what is said or written can be affected. Behaviours that may indicate problems with receptive language include:

- poor comprehension of vocabulary;
- difficulty with the rate, complexity or amount of spoken or written information presented at one time;
- requests multiple repeats of information;
- lack of attention in social conversations or teaching situations;
- problems understanding or recalling what was read;
- difficulty remembering instructions or following directions;
- difficulty sequencing or following multiple directions; and
- unable to complete what was told to do even though can state what was told to do.

Expressive skills or the ability to use verbal or written skills to express an idea can be challenged.

Behaviours that may indicate problems with expressive language include:

- difficulty remembering the desired word when speaking or writing;
- rude or immature use of language;
- problems in developing and using new vocabulary;
- talks about unrelated topics;
- fails to maintain proper 'social graces' in social situations;
- makes up stories or explanations for situations;
- employs hyperverbal or rapid, non-stop talking;
- engages in lengthy, unorganized explanations;
- retells the same story over and over;
- demonstrates difficulty writing sentences;
- uses 'thing' or 'you know' rather than the noun or verb; and
- shows decreased ability to spell words correctly.

Pragmatic language or the ability to engage in the social interactions related to communication can be involved. Behaviours that may indicate problems with pragmatic language include:

- difficulty with turn taking, maintaining and requesting in conversations;
- unable to monitor quality of conversation;
- uses socially unacceptable words;
- unable to maintain adequate social space with other students;
- touches the teacher to gain attention;
- calls out to the teacher numerous times when told to wait; and
- continues talking when others indicate they are disinterested.

As a child/adolescent recovers from the initial injury, most receptive and expressive language skills necessary for routine communication may appear close to normal. Rarely will there be a problem with formulating a sentence or understanding everyday language. The more subtle problems with language and cognitive-communication are often overlooked. Standard tests for language problems often do not disclose major problems with language after a TBI because communication problems are often more evident in functional situations than they are in formal test situations. Sometimes previously learned information is recalled, test scores are inflated and children are thought to be functioning within normal limits, when in reality they are challenged in actual daily communicating, learning and social interactions. Therefore, it is important for family members and other communication partners to report communication behaviours they observe that seem to be causing problems for the child.

Many children appear to have little difficulty with language skills, particularly in non-stressful, structured situations. However, with added stress from

communication demands in school, work, home or community, language performance deteriorates more than what might be expected. Problems that may result include:

- (1) Poor organization of expressive language:
  - rambling conversation or written expression;
  - interruptions with irrelevant ideas;
  - minimal responses to questions with an inability to fill in details or offer other supporting information; and
  - decreased ability to organize thoughts to say what is on your mind.
- (2) Inability to maintain attention:
  - poor listening when teachers are lecturing or bosses are giving directions;
  - difficulty sustaining or maintaining attention to a task or activity long enough to complete it;
  - inability to watch a complete movie or television programme;
  - fussing with books, papers, pencils;
  - daydreaming;
  - calling for teacher's attention about a different matter; and
  - decreased ability to respond in conversation because topic is lost.
- (3) Difficulty with abstract language skills:
  - may not understand puns, sarcasm or humour and may take what is said literally; and
  - problems learning new information if generalizing or reasoning skills are needed.
- (4) Decreased rate of processing:
  - requires additional time to understand what others are saying;
  - slow reading rate;
  - decreased ability to understand what is read;
  - inability to keep up with complex sentences or vocabulary;
  - slower to respond to written or verbal directions, questions or repeats;
  - unable to form response to a question in usual time allotted for students to respond, even though may know the correct response or behaviour.

Cognitive-communication problems combine with language difficulties to make learning and applying what is learned more problematic in functional situations for youths with TBI.

#### *General guidelines for helping*

Communication occurs throughout the day in all environments and with many different communication partners. Be sure communication happens on a regular basis.

- (1) Use alternative means of communication such as pictures, reading, writing, gestures

Table I. Challenging behaviour checklist. Rating scale: 1 = never, 2 = some of the time, 3 = unsure, 4 = most of the time, 5 = all of the time.

Behaviour	Description	Comments	Rating
Inattention to task	Students who have difficulty attending to tasks may engage in unrelated tasks or behaviours. Example: A student may fidget, talk out of turn, leave the room, instigate a fight with a peer or stare out the window after a task has begun.		1 2 3 4 5
Failure to initiate tasks	Due to a frontal lobe injury, a student may have difficulty starting tasks. Example: The student may engage in unrelated tasks prior to working on the original activity.		1 2 3 4 5
Aggression	Aggression involves making physical contact with another person. It may include hitting, kicking and punching and may be directed towards teachers, peers or family members. Students may even hurt themselves. Example: A student may hit the teacher because s/he is frustrated by a difficult task or because of an inability to communicate effectively.		1 2 3 4 5
Destruction	Destruction includes throwing objects and damaging furniture, walls, etc. Example: A student may throw an object or punch a wall in response to a teacher's demand or a peer's teasing.		1 2 3 4 5
Perseveration	Perseveration refers to repetitive speech about a particular topic. Example: A student may talk incessantly about cars, sports or the next visit home.		1 2 3 4 5
Inappropriate speech and verbal outbursts	Inappropriate speech may occur sporadically or in bursts. Example: The student may use language that is not appropriate for the setting (i.e. saying 'Hey man, what's up?' to a teacher) or may use obscenities.		1 2 3 4 5
Difficulty waiting	The student may not be able to wait appropriately. When required to wait (i.e. during transitions, before meals, while in-line at stores), s/he may engage in any of the behaviours described above. Example: The student may leave the area, hit or kick the teacher, start a fight with a fellow student.		1 2 3 4 5
Age-inappropriate behaviour	As the child gets older, his or her interests may continue to be those of a younger child. On the other hand, a student may act older. Example: Students may show an interest in sexual activities at a very early age (see inappropriate sexual behaviour below).		1 2 3 4 5
Inappropriate sexual behaviour	Inappropriate sexual behaviour may involve making sexual advances to unknown peers, teachers, staff or even family members. Example: This behaviour may include verbal sexual overtures or non-verbal sexual behaviour, such as touching and groping.		1 2 3 4 5
Bolting/elopement	Bolting or elopement means leaving a designated area without permission. Example: A student leaves the school after being reprimanded by the teacher for verbal outbursts in class.		1 2 3 4 5
Non-compliance	Non-compliance is defined as refusing to follow instructions. Example: A student may be non-compliant by verbally refusing to do a task or by becoming aggressive.		1 2 3 4 5
Additional challenging behaviours			
1.			1 2 3 4 5
2.			1 2 3 4 5
3.			1 2 3 4 5
4.			1 2 3 4 5
5.			1 2 3 4 5
General comments:			
List the behaviours that were rated as a 4 or 5.			
1. _____		Comments:	
2. _____		Comments:	
3. _____		Comments:	
4. _____		Comments:	
5. _____		Comments:	
6. _____		Comments:	
7. _____		Comments:	
8. _____		Comments:	

and facial expressions if speaking does not seem to work.

- (2) Respond to any and all attempts to communicate rather than focusing on verbal responses.
- (3) Talk about familiar subjects and do not try to introduce new ideas without assistance.
- (4) Consult with a speech-language pathologist before beginning practice of specific techniques such as rate, breath control or oral exercises.
- (5) Understand that consistency in communication is essential. Be sure every team member understands the goals and procedures to be followed. Establish what methods for communication will be used and be sure everyone uses the same techniques. For example, if communication is to be completed by pointing to pictures, no one should be requesting writing or verbal expression.
- (6) Keep conversation simple and direct, but at the correct age level of each family member.
- (7) Ask questions and expect to be involved in the rehabilitation and compensation process. Learn the compensatory strategies that are being taught.
- (8) Enjoy your communication exchanges and successes, be they large or small [41].

In some instances, the child with TBI will be unable to adapt or compensate for his/her communication weaknesses. Therefore, people in the environment may want to consider what they can do to make the communication easier. Questions communication partners might ask in order to help include:

- (1) Did this child/adolescent understand what I said?
- (2) Was my rate of presentation slow enough?
- (3) Did I give clear, step-by-step directions?
- (4) Did I use puns or humour that was not understood?
- (5) Can I help the child/adolescent understand better by using pictures or writing the steps?
- (6) Am I distracting this child/adolescent with too many gestures, too loud a voice, too many pauses in my speaking?
- (7) Is the environment too loud, congested, bright, confusing?
- (8) Can I simplify this communication by speaking in shorter, clearer sentences?
- (9) Can I provide a more organized explanation of what I expect to be done?
- (10) Are there others in this situation who can help? ([41], p.39).

#### **Issue four: Behavioural challenges**

Many children also experience behavioural challenges following TBI. The most frequently observed

unwanted behaviours associated with TBI include: inattention to task, aggression, perseveration, verbal outbursts, bolting, property destruction, non-compliance and inappropriate sexual behaviour [42]. These behaviours can disrupt activities in the home, classroom or community setting. Behaviour is usually not the result of a single event, but a contribution of factors. Initially, unwanted behaviours may be related to other physical, cognitive and sensory deficits that are associated with TBI. For example, verbal outbursts and physical aggression may be the direct or indirect result of frustration related to memory deficits, disorientation, slow processing and/or poor communication skills. Challenging behaviours may also occur as a result of environmental factors, such as temperature, noise level and lighting. For instance, a child who is sensitive to noise may bolt out of the room when several people in the room talk too loudly. Or, a child with an aversion to warm temperatures may show a tendency to be more aggressive during the summer. It is also not uncommon to find that unwanted behaviours escalate over time. As children get older, injuries to the brain that were damaged, i.e. frontal lobe injuries, may become more pronounced leading to a whole host of new behavioural challenges.

Critical to managing unwanted behaviours in children with TBI is to use antecedent-based interventions (i.e. manage the behaviour *before* it happens) rather than rely on consequence-based interventions (i.e. disciplining the behaviour *after* it has occurred). Antecedent-based interventions involve changing the events or variables that exist *before* the behaviour occurs, hence changes to the environment (e.g. providing reminders for upcoming tasks; reducing the demands of the task; interspersing demands and social comments; and allowing choices for the child) can decrease the likelihood of a challenging behaviour occurring and increase the likelihood of a desired behaviour occurring [42].

Antecedent-based interventions are relatively easy to implement and can be done without confronting or punishing the student. Unlike consequence-based interventions, antecedent manipulation involves arranging the environment to promote positive interactions and skill development before the behaviour occurs rather than after. In school, this is done by making changes to such things as the seating arrangement, amount of work presented at one time and the way in which a transition is communicated. Several practical antecedent-based strategies include: reducing task demands, presenting demands in the context of social comments, simplifying tasks and incorporating preferred topics or interests are techniques that may reduce challenging behaviours associated with demand situations. In addition, visual schedules, reminders and

self-monitoring may increase on-task behaviour and task completion. Antecedent-based strategies can be implemented alone or in conjunction with other antecedent or consequence-based strategies.

Lastly, children with or without TBI act differently in different settings and with different people. It is not uncommon in team meetings for one person to report that a student does not follow instructions while another person claims that the student always follows instructions. It is also not uncommon for behaviours to simultaneously improve in one setting and become worse in another setting. Professionals should address these issues by considering the environmental factors that exist in each setting. These factors may include the presence of particular teachers and peers, reward systems, task content, lighting and room arrangement. Once the contributing variables are identified, the team can determine the best way to rearrange the variables so that the behaviours are less likely to occur.

The Challenging Behaviours Checklist (Table I) may be useful in making decisions regarding behaviours and in developing ideas for managing them.

## Conclusion

This article has provided the reader with an update about four challenging issues for youth after TBI. Information provided is from both empirical (where available) and best practice experience of the authors. It suggests methods for working with children and families regardless of the extent of the injury. The current under-identification of children with TBI results in confusion and challenges for the child at home, in school and in the community. Consequently, communities and countries may not place the necessary emphasis on providing services that are indicated for this population. Educational systems are often the best services to address the needs of these children, especially the cognitive, communication and behavioural challenges. The needs of families for support and training is critical to the long-term success of these children. Professionals and families need to work collaboratively if one is to make a true difference in the lives of children with TBI.

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