Pediatric Traumatic Brain Injury: Outcome, Assessment, and Intervention

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Abstract

Traumatic brain injury (TBI) is a leading cause of disability in children. This chapter addresses the unique challenges facing children with TBI. Outcome, assessment, and intervention issues are discussed in relation to injuries sustained during two stages of development: (1) infancy and early childhood and (2) school-age and adolescence. Two cases studies are presented to illustrate issues relevant to children with TBI.

Keywords

Pediatric traumatic brain injury • Academic outcomes • Educational accommodations

Traumatic brain injury (TBI) is a leading cause of disability in children [1]. Severe TBI often produces alterations in many domains of daily functioning that persist throughout life. In this chapter, we will discuss outcome, assessment, and intervention issues in relation to injuries sustained during two stages of development: (1) infancy and early childhood and (2) school-age and adolescence. We provide case studies to illustrate the unique issues and challenges facing children who sustain TBI during these different stages of development.

Epidemiological studies indicate that over one million children a year sustain TBI and approxi-

mately 30,000 have long-term disabilities [2]. Each year in the United States, approximately 475,000 children between the ages of 0 and 14 years sustain a TBI [3]. Children aged 0-4 years and older adolescents aged 15-19 years have a greater likelihood of sustaining a brain injury than other age groups [4]. The external cause of injury varies according to age. In infancy to early childhood, falls and bicycle/pedestrian-motor vehicle collisions are the most frequent causes of TBI [5]. Although assault is responsible for only approximately 5 % of brain injuries in children aged 1-4 years, assault produces 90 % of serious brain injuries [6]. Head trauma inflicted by child abuse is the leading cause of death in children under the age of 3 years. In school-aged children and adolescents, motor vehicle incidents are a primary cause of injury and more recently there is a growing recognition of sports-related TBI [7].

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Dennis and colleagues [8] postulated that brain injuries sustained in childhood can alter both brain reserve and cognitive reserve. Brain reserve is a proxy variable for the health of the brain and may reflect the influence of a variety of genetic/congenital factors as well as environmental insults, such as chemotherapy or TBI. Cognitive reserve is viewed as a combination of pre-injury and post-injury cognitive abilities, as well as environmental factors such as socioeconomic status and family environment. Brain reserve and cognitive reserve influence each other; their joint influence on outcomes may be moderated or mediated by injury-related variables such as the age at injury, time since injury, and type/location of parenchymal injury. The combined influence of these factors affects functional plasticity, which in turn affects physical, cognitive, and psychosocial outcomes.

The sequelae of TBI can vary greatly depending on many injury-related factors including severity of injury to the brain and body, age at injury, type and location of brain injury, as well as factors related to the child's pre-injury abilities and characteristics of the family environment before and following the injury. Although these cognitive and brain reserve factors interact in complex ways, severity of TBI is a major predictor of the quality of outcomes. Although many TBIs are considered to be mild and result in few long-term impairments, infants, children and adolescents with severe TBI sustain significant, chronic impairments [9].

Recently, the Pediatric Common Data Elements (CDE) Traumatic Brain Injury Outcomes Workgroup identified a common set of core and supplemental outcome measures for research in pediatric TBI [10]. Although initially developed for researchers, the recommended battery is an excellent resource for clinicians as well. The battery covers many domains, including adaptive and daily living skills, health-related quality of life, language and communication, attention and processing speed, executive functioning, memory, physical functioning, as well as social and psychological functioning. These domains often have overlapping influences. For example, neuropsychological deficits in executive functions, attention, memory as well as behavioral dysregulation are related to poor health-related quality of life [11], are predictive of parental stress and burden [12], and contribute to poorer social outcomes [13]. In addition to covering the same domains as the common data elements for adults, the pediatric elements include academic outcomes and family functioning/environment. Inclusion of these areas reflects the centrality of these domains for children's everyday performance. Interestingly, these latter domains were emphasized by Taylor [14], who described the role of the neuropsychologist as isolating the "signal" of TBI from the background "noise" by evaluating how post-injury functioning impacts home and school.

TBI in Early Childhood

Studies examining a variety of neuropsychological outcomes have identified widespread alteration in functioning after moderate to severe TBI. Young children who sustain significant TBI are at high risk for lifelong reduction of abilities in many domains, including cognitive and motor abilities as well as behavioral competencies. Due to a combination of injury-related and family environment factors, outcomes appear to be less favorable in infants with inflicted TBI than in children with accidental or noninflicted injuries [15]; see review by Ewing-Cobbs and Prasad [16]. Across the first few years after TBI, infants and preschool-aged children with moderate to severe accidental TBI show lower initial general cognitive scores and less recovery over time than seen following TBI in school-aged children or adolescents [9, 17–19]. In young children, recovery curves depicting the post-traumatic change in IQ scores across time are either flat, indicating no improvement in scores after the initial injury [19], or show a decline across time [20], indicating failure to develop new skills at age-appropriate rates. In particular, TBI acquired early in life may impede the progression of later-developing skills due to the combined negative impact of reduced general cognitive skills and diminished efficiency for learning and retaining new information [21].

Acquisition of academic skills, particularly reading, may be vulnerable following early brain injury. Barnes and colleagues [22] found that children who sustained a significant brain injury prior to learning how to read scored significantly lower on reading tasks than children injured at older ages. Children who sustained severe brain injuries between the ages of 3 and 7 years scored lower on measures of early academic development and cognitive functioning than children with orthopedic injuries [23]. These academic deficits appear to persist, resulting in significant academic challenges for children who sustain significant brain injury in early childhood. A follow-up study of children who sustained moderate to severe TBI prior to the age of 3 years found that nearly 50 % failed a school grade and/or required placement in self-contained special education classrooms. The odds of unfavorable academic performance were 18 times higher for children with TBI than for healthy comparison children [24]. Unfavorable vocational outcomes have been associated with children sustaining TBI early in life [25], even in some persons who achieved normal school performance [26]. Clearly, severe TBI sustained early in life is associated with a high risk for serious academic and vocational difficulties that may become increasingly evident later during development.

Recent attention has been given to the role of family environment and psychosocial factors in outcome from early TBI [27]. Authoritarian and over controlling parenting styles worsened behavioral outcomes for children who had sustained moderate to severe TBI [28]. Parenting style and family functioning were found to be related to behavioral aspects of executive function in children under the age of 7 with TBI. For children with moderate TBI, authoritarian parenting was associated with greater executive functioning difficulties at 1 year post-injury [29]. Young children with TBI were rated by caregivers as having significantly lower social competence than orthopedic controls at 6 months post-injury [30]. Children who had sustained TBI prior to the age of 4 years were found to have higher rates of social impairment at 8 years of age than children injured between the ages of 4 and 6 years [31].

Assessment of Young Children with TBI

There are no specific neuropsychological instruments per se for assessing outcomes in infants with TBI. Measures of general cognitive and motor development such as the Bayley Scales of Infant Development-3rd Ed. [32] or Mullen Scales of Early Learning [33] are often used. Both measures have been used in studies examining outcome from early TBI [15, 34-36]. These are comprehensive measures that provide subscale scores for cognitive, motor, and language functioning. Parent rating scales are useful in assessing social or behavioral issues in children over the age of 1 year. Commonly used measures include the Child Behavior Checklist [37] and the Brief Infant and Toddler Social Emotional Assessment [38]. Adaptive functioning measures also include scales regarding social and emotional functioning and have been used to assess outcome in infants and young children with TBI [39, 40]. Several measures assessing executive functioning are available for children as young as 18 months. The Behavior Rating Inventory of Executive Function-Preschool [41] is a parent completed questionnaire assessing early components of executive functioning. The NEPSY-2 [42] also has inhibitory control and other executive tasks that begin at the age of 2 years.

Intervention for Infants and Preschoolers with TBI

Young children are by their very nature dependent on adults and often their impairments following a significant brain injury may not be as readily apparent to families. As children age and more is expected of them, the impact of their cognitive impairments becomes more frank and families often find themselves unprepared for the challenges that the children are facing. Finding appropriate rehabilitative services for young children with TBI is challenging. We have found that most young children with severe TBI do not receive appropriate rehabilitative services. Infants and toddlers under the age of 36 months with TBI are eligible for therapeutic services under Part C of the Individuals with Disabilities Education Act (IDEA; Public Law 101-476) through state run early childhood intervention programs (ECI). To qualify for ECI services, a child must first undergo a screening evaluation conducted by ECI professionals. It is not uncommon for young children with TBI to be ineligible for intervention service because their performance on a developmental screening measure was found to be above the deficient range for their age. We have found that comprehensive developmental assessments using standardized measures such as the Bayley Infant Development Scales-III or the Mullen Scales of Early Learning are more sensitive to the cognitive and motor sequelae of TBI than screening measures. In addition, longitudinal studies do not show any significant "catch up" growth over time. Rather, severe TBI appears to reduce the level of performance in a given area; over time, the child continues to develop new skills, but at a slower rate. For example, a child performing at the 60th percentile prior to injury may score at the 20th percentile after injury and continue to develop skills at this level without closing the gap over time. As seen in the case study below, some scores may not stabilize and may continue to decline.

Changes in funding for ECI in some states have resulted in families being expected to share some of the cost of services. Unfortunately, these copayments can further burden a family that is dealing with the financial ramifications of their child's injury and hospitalization. The IDEA emphasizes the parent-child relationship as a tool for change although there is considerable variation among ECI programs as to how or if this occurs. In an informal survey of infants and preschoolers with moderate to severe TBI participants in our research study, only 13 % received direct services from ECI and 8 % received information on how to appropriately stimulate their child's development from ECI. Often parents are not aware that they can engage their children in stimulating activities that may help to improve their development. Most parents are not aware that ECI is mandated to educate parents on how to stimulate their child's development. ECI is a

valuable resource for infants and toddlers. After the age of 36 months, children are referred to their local public schools for services. The means by which children with TBI receives special education services through the public school systems is detailed later in this chapter.

Case 1: Infant with Inflicted Brain Injury

Jessica sustained a severe inflicted brain injury at the age of 2 months. She was brought to the hospital unresponsive with a Glasgow Coma Scale score of 3T. An MRI of the brain performed 1 week post-injury revealed right hemisphere subacute subdural hemorrhage, laminar necrosis with diffuse swelling, infarction involving the right hemisphere, and leftward shift of midline structures. Jessica was discharged from the hospital to the care of her mother approximately 1 month post-injury. At the time of discharge, she had left arm and leg weakness and a preference for her right visual field. Jessica did not receive inpatient rehabilitation therapies.

The alleged perpetrator of the abuse was Jessica's mother's boyfriend. No charges were filed against the boyfriend and Jessica was returned to the care of her mother who continued to reside with the boyfriend. Prior to and for several months following the injury, Jessica's mother was gainfully employed and had health care insurance which provided Jessica with physical therapy and speech/language therapy twice weekly. Jessica's initial and 3-month post-injury evaluations are presented in Fig. 1. Jessica's baseline and 3-month post-injury scores are below average, indicating mild deficits in cognitive and motor development. However, observations of Jessica during the testing session suggested significant neurological impairments. She had significant left-sided weakness. Objects manipulated by her right rarely came to midline, objects were not passed through the midline, and her left foot was turned in and was weaker than her right foot when attempting to stand with support. More spontaneous motor activity was observed on the right side. By 1 year post-injury,



Fig. 2 Standard area scores of 89–111 are in the average range



Jessica had mild improvement in left-sided strength and was able to bear weight on her left leg and ambulate. She was very active and readily babbled to communicate. As demonstrated in Fig. 1, Jessica demonstrated marked growth in her cognitive and motor skills by 1 year postinjury. She was above expectancy in her cognitive development and demonstrated age appropriate motor skills despite having pronounced left-sided weakness. Although Jessica was clearly benefitting from therapeutic interventions, because her scores were at or above age expectancy, her insurance carrier declined to continue to cover physical, speech/language, and occupational therapies. She was also denied services through ECI. Her mother was unable to afford to pay out of pocket for therapeutic services. Soon after the 1 year post-injury mark, the mother left her boyfriend, lost her job, had a falling out with her family, and was evicted. She lived with various family members and boyfriends for the next several years. Not only was Jessica no longer receiving much needed therapies, there was also considerable instability and stress in the family environment. Her followup assessment at 2 years post-injury indicated a marked reduction in growth in her cognitive and motor skills. Given the devastating nature of Jessica's brain injury, it is not likely that she would have been able to maintain age appropriate cognitive and motor skills as she aged; however, the early loss of therapeutic interventions coupled with high environmental stress may have undermined potential gains in her development. At the age of 6 years, Jessica was found to have below average intellectual functioning on the Stanford-Binet Intelligence Scale 4th Edition and by 8 years of age, there was a further reduction in the growth of intellectual development (see Fig. 2). By her last follow-up assessment at the age of 8 years, Jessica was in first grade for the third time. Her mother had placed her in three different schools, including one accelerated Montessori-based program. The change in



Case 1 Scores on the Woodcock-Johnson-III Tests of Achievement



schools was prompted by her mother's desire to find a school that could address Jessica's learning difficulties. Jessica's performance on the Woodcock-Johnson-III Tests of Achievement (WJ-III) is presented in Fig. 3. Jessica's academic skills relative to her age group were in the Borderline range, consistent with her level of intellectual functioning. However, relative to her grade level, her scores were in the Average range. By Jessica's third year in first grade, she was able to demonstrate grade appropriate skills. Jessica's mom was committed to keeping her in first grade until she "learned what she is supposed to learn." Her mother believed that once Jessica mastered first grade skills, she would be able to move forward with her education without further issues. However, given Jessica's cognitive impairments it was unlikely that she would be able to maintain pace with a regular education curriculum without significant educational accommodations and supports. Jessica's teachers were aware of her learning challenges and recommended that she be placed in special education services. During the feedback meeting, we discussed the impact of Jessica's brain injury on her cognitive development and the impact of these deficits on the rate at which Jessica is able to master new academic skills. Her mother acknowledged that she was ready to accept that her daughter would have lifelong impairments and that she needed special education services and stability. Jessica was very much aware of learning difficulties. By the age of 8, she was questioning why she was different from other children and why this injury happened to her. Jessica and her family were referred to a therapist to help them begin the process of coming to terms with the injury.

TBI in School Aged Children and Adolescents

Meta-analysis of cognitive outcomes after pediatric TBI [43] found that the most significant chronic effects of moderate and severe TBI were evident in intellectual functioning, processing speed, attention, working memory, fluency, inhibition, problem solving, and delayed recall of newly learned verbal and visual information from memory. Improvement over time was greatest in Performance IQ, processing speed, and working memory [43]. In contrast, memory and learning did not show significant improvement over time. Impairments have been noted on tests of verbal and visual learning [44-48] for children with severe TBI. The persistence of learning and memory difficulties is unfortunate, since one of the major developmental tasks of childhood and adolescence involves learning the academic curriculum.

Unlike infants and preschoolers, older children and adolescent survivors of severe TBI have acquired academic and other abilities prior to their injury, which may confer greater cognitive reserve. However, previously learned skills and abilities can appear relatively intact during the early stages of school re-entry following TBI, giving the false impression to educators and parents that the ability to learn, retain, and implement new skills is intact. Academic outcome studies have found that school-aged children and adolescents with severe brain injuries scored lower on measures of reading, spelling, and mathematics than children with moderate TBI [49] and struggled with mastering new information and skills [50]. Children with severe TBI from families with fewer socioeconomic assets are at increased risk for poorer academic performance [51]. Catroppa and Anderson [52] found that premorbid academic ability (based on teacher's ratings of academic skills) and verbal memory skills were significantly predictive of academic attainment. Children with pre-injury intellectual or learning disabilities are extremely vulnerable to post-traumatic exacerbation of their academic difficulties [45].

Are there alterations in metacognitive processes that underlie the post-traumatic disruption of diverse cognitive and academic skills? Metacognition is "knowing about knowing" and includes being able to use certain strategies for problem-solving and learning. Hanten and colleagues [53–56] have found that post-traumatic difficulties in metacognitive abilities, such as categorization, using learning strategies, and directing learning resources to the most important information, contributed to poor academic performance. Similarly, Barnes [57] found that children with TBI had specific difficulties making inferences to support their comprehension. Even when they understood and remembered factual information from a story, they were inefficient at holding different sources of relevant information in working memory long enough to make inferences. They also had problems knowing when an inference was required to understand what they heard. These examples highlight ways in which specific difficulties in working memory, selective attention, and metacognitive strategies may disrupt everyday cognitive and academic performance. Metacognitive difficulties may represent fruitful targets for intervention.

Childhood TBI has been associated with significant and persistent changes in social development and adaptive functioning [58–62]. Children with severe TBI have been found to have long-term issues in developing friendships and social contacts, and are more likely to exhibit social withdrawal [63]. Certain sequelae of severe TBI such as cognitive and behavioral functioning were more marked in the context of higher compared with lower levels of family burden or dysfunction [27, 51]. Studies examining neuropsychiatric outcomes at least 1 year postinjury have found elevated rates of emotional disorders, mixed emotional and cognitive disorders, attention-deficit/hyperactivity disorder (ADHD), major depressive disorder, and conduct disorders [64, 65]. Anxiety and mood disorders are commonly identified [65–71]. Prefrontal damage, as well as injury to deep gray matter structures such as the amygdala, places children with TBI at high risk for neuropsychiatric and behavioral difficulties [68, 71–75].

Family functioning has been found to be a significant predictor of outcome from brain injury in children. In school-aged children and adolescents with TBI, Yeates and colleagues [76] found that after accounting for injury severity, pre-injury family environment significantly predicted cognitive and behavioral outcome 1 year post-injury for children and adolescents with TBI. Taylor and colleagues [12] found that higher parent stress at 6 months post-injury predicted more child behavioral difficulties at 12 months post-injury and more child behavior problems at 6 months predicted worse family outcomes at 12 months post-injury. In essence, they found a bidirectional influence of child and family on outcomes following brain injury.

Assessment of School-Aged Children with TBI

Numerous measures are available to assess intellectual, neuropsychological, behavior, academic, and social functioning in school-aged children with TBI. The Pediatric CDE Working Group identified measures which were considered to be valid, robust, and widely used in clinical research with children with TBI [10]. Although a mainstay of neuropsychological evaluations, comprehensive assessment of intellectual functioning may not be as useful for rehabilitation planning and treatment as briefer and more focused assessment that can be repeated to track recovery. Assessment batteries should include tests that focus on areas that are commonly disrupted by TBI as well as tests of abilities that are targets of intervention.

Assessment of children with TBI includes many of the same domains as assessment of adults with TBI: executive functioning, memory, attention, processing speed, and motor skills. Perhaps the greatest distinction between the assessment of children with TBI and adults with TBI is the need for educational planning and treatment for the former. Although academic assessment is often not covered by third party payers, assessing the child's academic functioning is highly relevant for the child's habilitation. For children, school is the primary place where they are taught and are expected to perform. It is in essence their work environment. Many insurance carriers do not cover the cost of academic assessment because of an inappropriate expectation that the public schools are responsible for providing this service for the children. However, most school professionals do not have the background or familiarity with TBI to interpret the academic test findings in the context of the child's brain injury. Assessment of academic functioning should include basic word decoding, reading comprehension, math calculation and reasoning, and expressive writing skills. Given the cognitive and motor slowing that commonly occurs following severe TBI, performance on measures assessing academic fluency, or the speed and efficiency at which the child is able to work, are an essential component of any battery. Curriculum-based assessments are also valuable for assessing retention of academic material.

Return to School

A critical factor contributing to the identification of students with TBI for special education is the link between hospital and school [77]. The majority of children with severe TBI will require special education support [78]. For children with moderate to severe TBI, transition from hospital to school is done gradually. Children in inpatient rehabilitation units often receive onsite teaching services from the local school district. Following discharge, interim homebound teaching which is provided by the child's public school is recommended for many children with severe TBI. Children with mild to moderate TBI vary in their stamina, strength, and attention and some may require a gradual transition to school. Re-entry to the school environment for most children with TBI, regardless of injury, is recommended to begin with a half-day placement with time in school increasing as the child's stamina improves [79]. Children with mild TBI can suffer from physical fatigue and confusion that impact their return to school. Returning a child to full-day school too quickly can be detrimental to the child's well-being. Readjustment to the school environment depends on the transition plan designed by the student's rehabilitation or hospital team [80].

Often times, the mere presence of a brain injury is not sufficient to obtain special education services. An educational need must be demonstrated. In a study conducted by Glang and colleagues [77], only 25 % of children with TBI were identified for formal special education services. Over 41 % received informal supports (e.g., schedule change, extra time on tests). Injury severity and hospital–school transition services were predictive of provision of special education services. Clearly, children with TBI are under identified by school personnel and better linkages between medical and educational systems are needed.

Despite the high incidence of TBI in children, many school personnel are unfamiliar with TBI and this unfamiliarity with the sequelae of brain injury can lead to less than satisfactory educational services [81]. A comprehensive neuropsychological evaluation provides information that can be used to help justify educational need and help guide the family and school personnel in developing appropriate accommodations and interventions. Including links to the websites with resources for educators in the neuropsychological report provides an opportunity for educators to learn more about the challenges facing their students with TBI.

There are two paths by which a student with TBI can receive special education services in the public school systems. TBI is a qualifying condition for receipt of special education services under the IDEA, which was most recently reauthorized in 2004. Under this legislation, a child must be assessed in all areas related to his or her suspected disability. The evaluation must identify the child's needs for both special education and related services. Related services include speech-language pathology and audiology services, and physical and occupational therapy. In addition, psychological and social work services may be included. Based on the comprehensive evaluation, an individualized educational plan, often referred to as an IEP, is developed. The IEP must address the child's current level of functioning (sometimes referred to as performance), list annual goals, describe the measurement of progress to meet goals, and list specific special education services and accommodations.

The IEP is developed and written by a team that includes the parents or guardians, teachers, and other professionals at the school, most likely the school psychologist, speech/language therapist, and physical therapist. This team is referred to as the Assessment, Review, and Dismissal (ARD) committee. The ARD committee will convene a meeting to develop the IEP within 30 days of deciding that the child is eligible for special education services. The IEP must be reviewed every year to insure that it is meeting the educational needs of the student although the ARD committee can convene as often as needed. Particularly during the first year after TBI, the committee should meet periodically since improvement is likely to be uneven, with significant gains in some areas and less in others. IEP goals will need to be adjusted depending on the rate of recovery or improvement [82]. In addition, we often suggest to the IEP committee that safeguards be put in place regarding the child's safety. Children with severe TBI are vulnerable to manipulation and abuse by their peers. The school must take precautions to ensure a safe and supervised environment, taking into account the child's right to an education in the least restrictive environment.

Some students with TBI will need a Behavior Intervention Plan (BIP) to address the prevention of maladaptive behaviors associated with the brain injury. The BIP should focus on positive behavior supports and may include parent or in home training. BIPs are also important for students with TBI who are unable to follow the rules of conduct at school. Students with TBI may not respond to traditional contingency management protocols because of impaired selfregulation, poor initiation, and difficulties with contingency learning [83]. Positive behavior intervention and supports (PBIS) is an antecedent-based intervention that has been demonstrated to have some efficacy in students with TBI in a series of single subject studies [83–85]. PBIS differs from traditional behavioral intervention methods by focusing more on lifestyle changes through internal control of behavior. There is a focus on control of antecedents including events that occurred earlier as well as internal events such as loneliness. The environment is adjusted to meet the needs of the student so that that there is a high degree of success. The intervention is conducted in naturalistic settings such as home and school and involves the student's primary caregivers.

Another avenue by which students receive educational accommodations is by Section 504. Often simply referred to as "504," Section 504 is a federal civil rights law that prohibits discrimination against individuals with disabilities. Section 504 provides children with disabilities equal access to education and as such, they are allowed educational accommodations and modifications. These accommodations and modifications are for the general curriculum and do not include additional therapeutic interventions outside the classroom. The 504 plan does not provide an educational program that is tailored to the child's needs. For children with mild to moderate TBI, who are able to make adequate progress in the general curriculum with accommodations such as extended time for classroom assignments and tests, a 504 plan may be an acceptable option by which to receive accommodations in the schools. However, for children with moderate to severe TBI who have extensive cognitive and/or physical impairments, an IEP should be implemented at the school.

In our experience, children with TBI are often erroneously classified for special education services with the most common classification being ADHD. Children with TBI may have premorbid developmental disabilities such as ADHD that necessitated special education services [45, 86]. However, comorbid TBI has a significant impact on the child's abilities and functioning and these changes need to be addressed by the school in order for the child to receive an appropriate education. To illustrate, we were contacted by the family of a boy who had sustained a severe TBI several years earlier. The family lived in a small community in a rural part of the state. The student had premorbid ADHD and had an IEP in place at school under the qualifying condition of "Other Health Impairment." The child's classification to receive services was ADHD, not TBI. Despite having an IEP in place at school, he was failing most classes because he was unable to pass tests. In a phone conference with the school, it quickly became apparent that although some members of the committee were aware that the child had been in an "accident," no school personnel were familiar with TBI and the sequelae from severe brain injury. In our conversation with the school, we ascertained that the student was consistently failing short answer and essay tests formats. An earlier evaluation of the child had revealed impaired performance on free recall verbal memory and verbal learning measures but

significantly higher performance on recognition or multiple choice format tests. When the child's impairments were discussed with the ARD committee, we suggested the use of recognition format for all examinations. The accommodation was accepted and the student's test performance significantly improved.

Case 2: Adolescent with Severe TBI

Ann was a 14-year-old adolescent who sustained a severe TBI in a motor vehicle collision. Prior to the TBI, Ann was an honor student who attended a private school. She excelled in academics and was a competitive gymnast. She had an extensive social network and was emotionally welladjusted. Ann had an admission Glasgow Coma Scale score of 6T. A CT of the brain conducted on the day of admission revealed diffuse axonal injury, bilateral frontal lobe contusions, a right subdural hematoma, and an intraventricular hemorrhage. Upon arrival at an inpatient rehabilitation unit, she was not verbal and only minimally responded to commands. After a 2-month stay in rehabilitation, she was discharged with a dense right-sided hemiplegia and dysarthria. Ann's initial neuropsychological evaluation was performed 1 day after discharge from inpatient rehabilitation, roughly 3 months post-injury. This evaluation allowed for documentation of Ann's impairments as well as data that could be used to track her recovery over the next several years. The initial evaluation was limited to 1.5 h of testing because of Ann's fatigue and attentional issues. Ann was not oriented to the day, date, or time. She was unable to name the facility she had been in for the past 2 months. She struggled with completing activities of daily living. She needed help sequencing self-care activities such as showering and brushing her teeth. The brief evaluation assessed her memory skills as well as basic academic skills. As indicated in Fig. 4, Ann had significant impairments on verbal and visual





Fig. 4 Scaled scores of 9–11 are in the average range

memory tasks on the Wide Range Assessment of Memory and Learning (WRAML). Her performance on the Woodcock-Johnson Tests of Achievement-Revised [87] was well below age and grade expectancies. She had a left visual field cut which greatly impaired her reading. She required cueing to start at the far left side of a sentence, following with her finger till she reached the end. She was unable to consistently recognize numerical operators and struggled with basic multiplication. When she was shown how to solve a math problem, she then was able to solve the next similar problem. Based on the results of this evaluation, we recommended periodic neurobehavioral status examinations, 1:1 aide at school, supervision for mobility, placement in a self-contained classroom, and ongoing speech/language, physical, and occupational therapies. The school requested that an intelligence test be administered to qualify Ann for special education services. Although we agreed to administer the Wechsler Intelligence Scale for Children-III, we indicated in the report that for children with moderate and severe TBI this measure in isolation does not address their unique cognitive issues. Often daily functioning is impeded after TBI by cognitive impairments, such as memory, that intellectual tests are not designed to assess. Typically children will score higher on some factors, such as Verbal Comprehension, than they can demonstrate in day to day functioning. Conversely, motor deficits such as hemiplegia may artificially reduce scores on timed tasks.

Ann received homebound teaching for 1 month following her discharge from rehabilitation and was then transitioned to her public school. Ann's cognitive and physical impairments necessitated educational accommodations and supports. Ann's medical records and neuropsychological evaluation were presented to the school and an ARD meeting was convened to consider the documentation presented by the family. To receive special education services under the TBI classification, the school required Ann's physician to attest to the presence of a TBI as well as describe the nature of her impairments. Ann's IEP contained goals for her basic academic development in reading, math, and written language as well as goals for speech/language, occupational, and physical therapies provided by the school.

Transitioning to the public school was challenging in many ways for Ann. She did not know students from the school prior to her injury and she struggled with learning the layout of the school. We created a memory book for Ann that she carried with her to her classes. The book contained pictures of her current high school, pictures of her teachers and their names, her schedule, and a brief history of Ann (information about herself, her family, and her injury). On the cover of the book was a monthly calendar which was very useful in helping Ann stay oriented to date. Ann frequently referenced this book during her first year at school. Ann was placed in self-contained special education classes which had students with a variety of developmental disabilities. The teaching format in the self-contained classrooms allowed for slower presentation of information. Ann was the only female student and the only student with an acquired brain injury in the self-contained classes. For the first 6 months, Ann had a 1:1 aid throughout the school day. The aid assisted Ann with classroom activities such as finding pages in a textbook, completing worksheets, and taking notes. As Ann's cognitive status improved, the aid's support was gradually reduced and eventually eliminated by 6 months. Because of right-sided hemiplegia, her gait was unsteady and slow. She was unable to transition from class to class safely. After the fulltime aid was discontinued, an aide was assigned to walk her to and from classes and she was allowed to leave classes 10 min early in order to avoid the hallway crowds at period changes. An aide was called to the classroom to escort Ann to the restroom if needed. Ann struggled to learn to write with her right hand but she persevered with the assistance of her occupational therapist and eventually her writing was mostly legible.

A concern for her family was Ann's personal safety at school. She was a young woman who was very trusting of others and could easily be manipulated. These issues were raised with the ARD committee and they agreed that Ann would be supervised in all group settings. Because of



concerns about her safety in the school cafeteria, Ann was allowed to eat lunch in the counselor's office at school, an accommodation she maintained throughout her time in high school.

Ann was re-evaluated 18 months post-injury and these scores are presented in Figs. 4, 5, 6, and 7, along with Ann's baseline scores. Consistent with the literature, marked gains were noted on the Wechsler Intelligence Scale for Children-III Performance subtests [43]. Although Ann's performance improved by at least three scaled points on the three Performance subtests, her scores remained below average. Her performance on Wechsler Intelligence Scale for Children-III verbal subtests remained stable with a significant increase in expressive vocabulary. Ann's verbal and visual memory performance on the Wide Range Assessment of Memory and Language also significantly improved although her scores remained below average. Gains were less dramatic in Ann's academic skills as assessed on the Woodcock-Johnson Tests of Achievement-Revised. Her skills remained well below average. These findings were consistent with Ann's functional gains. By the follow-up evaluation, she was independent for activities of daily living such as bathing and dressing. She was also functioning independently in the classroom but continued to need accommodations such as extended time for completion of tests and assignments, use of a word bank for short answer tests, copies of the teacher's notes, and an aide for transitioning between classes.

Ann's parents struggled with the change in their child's functioning. As is common during the first year following injury, they held on to the belief that it was simply a matter of time before she would return to "normal." The results from our initial evaluation indicated below age and grade skills in most cognitive and academic areas. To help the parents understand the extent of their daughter's injury, we met with the parents and reviewed the various injuries sustained by the brain using a 3D model of the brain and copies of neuroimaging studies. Although the parents had been told of the CT/MRI findings over the course of the Ann's medical hospitalization, the information was presented at time when they were in acute distress about the child's survival and were not able to grasp the information. Understanding the nature of the damage sustained by their daughter's brain, although very upsetting to the parents, helped them eventually come to terms with their daughter's impairments. Often times, information regarding the injury needs to be repeated frequently with increasing details during the child's recovery [88]. Education of parents/guardians of children with TBI is an essential role of the neuropsychologist. Neuropsychological evaluations provide a critical opportunity for the child's strengths and weaknesses to be discussed in depth with the parents, to provide information about the functional impact of these deficits, to recommend appropriate interventions, and assist with long-term planning. It is important to provide parents with a listing of local, state, and national organizations for individuals with TBI. These organizations can provide an opportunity for parents to network with other families of children with TBI for support and to share information.

Family Environment

Family environment is a crucial factor affecting outcomes. Behavioral, cognitive, and social outcomes from TBI have been found to be

moderated by positive and supportive family environments [28, 76, 89, 90]. At the time of the accident, Ann's parents had been married for 20 years and had three younger children. Her father worked in a management position and her mother was a homemaker. The family dynamics were positive and during the first year post-injury, the focus of the family was on Ann's recovery. The parents worked as a team to meet her needs at home as well as her various therapy appointments. Her family had the financial resources to provide intensive therapies to improve her communication skills and her motility. The family had an extensive support system that helped provide care for the younger children in the family as the parents tended to Ann's needs. Ann's family environment was almost ideal in encompassing positive predictors of recovery. What was not evident to those of us who worked with the family was the toll the injury was taking on the parents themselves. One year after Ann's injury, her parents separated and subsequently divorced. Both parents reported that the stress of Ann's injury and recovery had strained their relationship.

Marital discord following serious illnesses and injuries in children is well documented in the literature and many of the same issues apply to families of children with TBI. Parental stress and family functioning has been found to be related to increased behavioral issues in children with TBI [12, 91]. In Ann's case, she experienced sadness and guilt regarding her parent's divorce and worked with a therapist to process her feelings. When working with a child who has sustained a TBI, it is essential to work with the entire family and support system [92]. Even those in the best circumstances can succumb to the stress and burden of a severe injury.

Transition to Adulthood

The extent of recovery for children with TBI cannot be assessed until the impact on adult function can be determined [93]. Many individuals with severe TBI have chronic, life-long impairments in executive functions, attention, processing speed, and memory. They face significant challenges as they transition from high school to adulthood. Many young adults with TBI flounder when the familiar structure of school and daily oversight by teachers and parents is withdrawn. When entering college or a vocational program, even academically able students may struggle with the expectations for greater independence in conjunction with fewer built-in supports and less supervision. Societal expectations of independent living may not be readily met by survivors of severe TBI and often, young adults with severe TBI experience social difficulties during their school years and as they transition to adulthood, they experience social isolation. In our experience with adolescents and young adults with TBI, the proliferation of social networking sites has brought both opportunities for social interaction and potential for maladaptive behaviors. For individuals with moderate to severe TBI, impaired judgment and impulsivity can negatively impact integration into social and work environments. Clearly, supports need to be extended well into adulthood.

Several retrospective studies identified the lifelong challenges facing survivors of childhood TBI. Anderson and colleagues [94] conducted a retrospective study of 124 adult survivors of childhood TBI who were injured between the ages of 6 and 12 years. Injury severity ranged from mild to severe with the majority of participants having mild injury. Across the sample, participants were less likely to complete high school and more likely to be unemployed, with one-third of the sample not working. Mental health issues were two times more prevalent in participants with TBI. Less favorable long-term outcome was predicted by greater injury severity, younger age at injury, psychological problems, and inability to complete high school. Cattelani [95] found that social maladjustment and poor quality of life were issues for adults who had sustained TBI in childhood. Telephone interviews conducted with individuals 21 years after they sustained TBI in childhood found frequent reports of psychological and family issues as well as lower educational achievement and poor vocational attainment [96]. In all three studies, injury severity was found to be significantly related to outcome, with greater injury severity associated with worse outcomes.

Many students with significant TBI pursue post-secondary education. Identifying goals for individuals with TBI that are consistent with their long-term aspirations is a key factor in educational achievement [97]. Students with TBI are able to receive accommodations at colleges and universities who accept federal funding because these institutions must adhere to the IDEA. Developing a proper plan for accommodations and support is the first step for students with TBI. Students with TBI often benefit from the following accommodations: note taking assistance, copies of the professor's notes, extended time to complete examinations, access to scribes or computers on tests that require written responses, and audiobooks. Accommodations in college are more challenging because students are often expected to alert their professors to their need for accommodations and arrange for these accommodations. A strong support network is essential for college students with significant TBI. Students with TBI who have been successful in attaining their educational goals often draw support from peers, professors, and family members [50].

Our client, Ann, graduated from high school and was on the honor roll each semester. She expressed a strong desire to attend a large state university but because of her cognitive impairments, attending a 4-year college was not possible. She attended a junior college near her home, taking no more than two classes per semester. The college provided note taking assistance, extended time on examinations, audiotaped books, and modified tests. Her family provided transportation and she worked with a tutor for all her classes. Ann was able to successfully complete an Associate's degree. She entered a job training program with the state's rehabilitation commission and worked for several months at a state agency. With the assistance of a job coach, she was able to manage the demands of a clerical position. However since completing her degree several years ago, she has been unable to secure employment.

Conclusions and Future Directions

In regards to the Dennis [8] model, young age at injury may be associated with lower brain and cognitive reserves. In general, young children do not recover as well from diffuse or multifocal injury to the brain, such as TBI, as they do from more focal brain insults [98]. TBI sustained early in life may disproportionately reduce cognitive reserve, particularly in general cognitive functioning, learning, social competence, and executive control domains. Young children are very sensitive to environmental influences, such as family resources and parenting style, which can potentiate negative effects of injury or buffer the effects of injury and promote more positive outcomes. Even in young children, behavioral outcomes are influenced by brain injury factors; specific outcomes are related to structural neuroimaging measures characterizing the size and location of abnormalities [99].

School-aged children and adolescents can be viewed as having broader cognitive reserve assets than younger children by virtue of their greater repertoire of pre-injury skills and abilities. Other pre-injury factors also exert major influences on reserve characteristics. For example, pre-injury learning disabilities or psychiatric disorders could be a marker of lower brain and cognitive reserve. Conversely, pre-injury placement in an academic honors program and strong social skills could represent positive reserve factors associated with more favorable cognitive and behavioral outcomes. Cognitive and brain reserve can also be enhanced or diminished by environmental factors, such as level of socioeconomic advantage, access to social and material supports, and the quality of family adaptation. Environmental characteristics, including parenting behaviors, have been related to specific characteristics of children's brain and cognitive development [100–102]. Cognitive and behavioral outcomes are also significantly affected by specific characteristics of the brain injury. To illustrate, children with injury to the superior frontal gyrus in the frontal lobe [71] or to the amygdala [68] would be at increased risk for elevated anxiety. Elevated

anxiety could influence a host of outcomes ranging from social integration and competence to academic performance. Using a personalized approach, anxiety could serve as a specific target of symptom prevention and intervention efforts for this subgroup of patients.

Variables that influence outcomes have potential to inform targets of intervention. These targets may range from providing social and educational supports to children and families after injury, to specific skill-based interventions, to cognitive behavioral interventions to reduce stress and enhance problem solving. Further research is needed to identify factors that positively influence the trajectory of specific outcomes. This research would inform the development of evidence-based interventions that capitalize on variables that promote change. Personalized approaches that tailor patient characteristics, such as integrity of specific brain networks identified through neuroimaging, to specific interventions, such as attention network training, may also enhance recovery.

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