

# Treatment of Traumatic Brain Injury in Youth: The Integral Role of the Family

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During my first year of child fellowship, I cared for a 16-year-old girl who suffered a traumatic assault with subsequent brain injury. “Alicia” had sustained stab wounds to her neck, large vessel injury, and cerebrovascular accident, necessitating numerous procedures, including a craniectomy. My path and Alicia’s would cross again and again during my various clinical rotations. As I worked with her and my colleagues to help her regain her health, her story proved instructive, not only about the rocky path to recovery for those with traumatic brain injuries (TBIs), but also about how that path might have been smoothed, particularly with the help of her family.

Though Alicia was medically stabilized one month after her injury and later transferred to a rehabilitation service for additional recovery, a return to full health would be long and difficult, in part due to the nature of her injuries. TBI occurs when a brain injury results in the disturbance of normal brain functioning; the severity may range from mild to severe.<sup>1</sup> In the United States, adolescents aged 15-19 have the second-highest rate of emergency room evaluations and hospitalizations for a TBI.<sup>2</sup> From 2002-2006 data, there were 129,211 and 186,089 total TBI-related emergency department visits, hospitalizations, and deaths among 10-14-year-olds and 15-19-year-olds, respectively. There is likely an underrepresentation of the number of youth with actual injury, impairment, and limitations, as these numbers do not account for those individuals who saw outpatient physicians or who did not receive medical care.

Children and adolescents with TBI often face cognitive, behavioral, social, and physical impairments. Addressing each area of possible damage, often requires a multi-specialty team consisting of surgeons, psychiatrists, social workers, and more. Further, family involvement is imperative to ensure treatment compli-

ance when the patient is discharged and continues recovery at home. In order to optimize functioning and rehabilitation, coordination between the medical services and family is essential.

The attack, which would have been devastating to someone with full mental health, was even more so for Alicia, who had struggled with substance abuse and family conflict, and had previously run away from home before the assault. And though she had a team of doctors on the inpatient hospital service including neurology, neurosurgery, rehabilitation medicine, and psychiatry specialists, it was difficult for her family to coordinate all of the care and rehabilitation follow-up. After her first discharge, her mother could not keep up with the many recommendations and appointments, and brought Alicia back to the hospital. During her complex recovery, she traveled between the medical floor, inpatient psychiatric unit, home, emergency room, and an emergency shelter. A primary factor in her inability to maintain placement was her family’s inability to play a central role in her care.

## Clinical Considerations

Symptoms associated with TBI may be varied and fluctuating. Patients may have trouble with memory, language, problem solving, attention, and executive functioning abilities. They may later experience academic problems, personality changes, anxiety, depression, posttraumatic stress disorder, behavioral concerns, isolation, and difficulties in school, home, and in relationships. Adolescents and children with TBI may exhibit emotional lability, disinhibition, anger, aggression, anxiety, apathy, paranoia, or amotivation among other possible presenting concerns. Personality change due to TBI can take the form of severe affective dysregulation. In youth ages 5-14 with TBI who were followed at

baseline and at 6 months, attention, processing speed, verbal memory, IQ, and executive function were found to be significantly associated with personality change in a recent study done by Max et al.<sup>3</sup> Personality changes may be linked to the severity of TBI injury as well as lesions in the dorsal prefrontal cortex, specifically the superior frontal gyrus.<sup>4</sup>

In Alicia's case, the physical trauma immediately addressed in the ER foreshadowed deeper injuries yet to manifest. Prior to the attack, she had never seen a psychiatrist, nor had she ever been hospitalized, although she did have a history of substance use, family conflict, and running away from home. After her injury, she experienced problems with behavioral control, communication, problem solving, and emotional lability. Her mood instability and impulsivity mixed with her fragile medical condition and nonadherence put her at high risk for re-injury or self-harm. Providers and staff were alarmed, understanding that should she seriously hit herself in the head or fall when refusing to wear a helmet before her injury was healed and protected by the final neurosurgical intervention, a devastating outcome could result. She commented that she did not care about this possible outcome and was occasionally verbally and physically aggressive with staff and her family. She also expressed suicidal ideation, and was eventually transferred to the psychiatric unit. Plans for neurosurgery were postponed due to concerns about her mental health. The neurosurgery team was apprehensive about her ability to comply with post-operative care, especially given her comments about suicide and attempts to hit, and therefore reinjure, herself.

There is an association, but not any definite causation, between pre-injury psychiatric illness and development of TBI. Whelan-Goodinson et al.<sup>5</sup> conducted a cross-sectional study looking at psychiatric disorder after TBI. Fifty-two percent of the sample received a psychiatric diagnosis preinjury, similar to data from Gould et al.,<sup>6</sup> who found that more than half of the participants with TBI had a psychiatric disorder, most commonly substance use, mood, or anxiety disorders.

Youth who suffer from TBI therefore have multiple physical and psychiatric vulnerabilities,<sup>7</sup> and they have many needs, including various rehabilitation services such as cognitive, occupational, physical, and speech-language therapies. But there are often barriers to obtaining the level of services needed. Distance from treatment can be a significant hurdle: not all communities have easily accessible inpatient rehabilitative services or outpatient programs. And high costs of required care, far distances to appointments, a potential lack of understanding or support about a child's condition or the system of care, and language barriers are other obstacles for families. Longer-term treatments after medical stabilization may be challenging to set up or continue because of specialist shortages. Cognitive services, including speech therapy, occupational therapy, and services provided by education specialists, neuropsychologists, and physicians are cited as the highest unmet and unrecognized need during the first year after traumatic brain injury.<sup>8</sup> Slomine et al. emphasize the importance of primary care/pediatric monitoring to ensure that patient needs are being addressed and assessed over time to optimize health after injury.

After she became used to the structure of the psychiatric inpatient unit, Alicia was deemed stable for discharge; however, she did not remain in the care of her family for long. Her family attempted but later reported an inability to care for her at home due to her behavior and her drastic personality change with mood fluctuations, threatening comments, and emotional lability. The extent to which her changeable moods were related to TBI was something debated at length by her medical team. Some thought her history of running away and drug use was predictive of her current state; some suggested her TBI was aggravated by posttraumatic stress disorder; others attributed her moods and behavior to the TBI alone. Whatever the cause, her caretaker wondered when she would be "back to normal," a benchmark she seemed to approach just enough to warrant transfer from the psychiatric unit to an emergency shelter, then backslide and necessitate a return to the unit.

## Family Support in Recovery

Alicia's family's inability to care for her was a major stumbling block in her rehabilitation, resulting in a further source of instability as she struggled to recover. Beyond medical services, an outside support system, such as the patient's family, is vital to recovery; they can supervise treatment adherence, coordinate follow-up appointments, and bolster flagging spirits so that rehabilitation continues once the patient is discharged. Family involvement in traumatic brain injury care has been shown to be a key factor in achieving quality care and improving functioning.<sup>9,10</sup>

But not every family is equipped to handle the demands of managing care for a TBI patient. Alicia's family tried to make the transition from hospital to home as seamless as possible, but they found keeping up with the recommendations and appointments difficult, in addition to managing her unpredictable moods and behaviors.

In order for families to successfully transition their child/adolescent to outpatient treatment, they must be properly trained in treatment adherence. TBI in particular is a medical condition that requires substantial psychoeducation and parent coaching. Similar to educating parents and families about schizophrenia and bipolar illness, education about TBI helps improve treatment adherence and encourages empathy. It is not sufficient to discharge a youth with TBI home with medication instructions and follow-up appointment details; there should be a family assessment, comprehensive discussion of why a patient may be acting or responding in a certain way, practical advice on how to help, and referrals to supportive services such as counseling.

It is important to recognize family strengths and potential barriers, including family dysfunction, when planning follow-up care and management of medical concerns at home. According to a prospective study investigating family functioning after TBI in youth, some families seem to be at an increased risk for relational dysfunction after brain injury. Looking at standardized family functioning interviews and self-report assessments, researchers found that the most important influences on family functioning after pediatric TBI included preinjury family

functioning, preinjury family life events or stressors, and postinjury development of psychiatric illness in the child or adolescent. They noted that identification and treatment of both family dysfunction and youth psychopathology may improve patient outcomes.<sup>11</sup> In a 2002 longitudinal study with 53 children with severe TBI, 56 with moderate TBI, and 80 with orthopedic, non-brain injuries, Taylor et al. found that post injury progress was influenced by the family.<sup>12</sup> For example, recovery of math skills was seen in those youth with low family stress, and academic decline was associated with disadvantaged backgrounds. In addition, social disadvantage was associated with and/or predicted worse behavioral outcomes and less progress in socialization skills. According to Potter et al.,<sup>13</sup> higher levels of authoritarian parenting and fewer family resources were associated with greater executive difficulties, which included emotional and behavioral regulation, after TBI. These study results support the importance of the social and family impact in youth recovering from TBI.

In recent years, there has been a call for better definitions of optimal family environments in recovery from early childhood TBI to improve interventions.<sup>14</sup> These findings that preinjury family functioning and postinjury behavior of children are linked indicate that there may be risk factors to consider in outcomes for TBI recovery.<sup>15</sup>

Supportive families may provide a hopeful attitude as well as assist with cognitive, social, and behavioral deficits. In a prospective cohort study examining family outcomes after pediatric TBI, families of 81 children aged 6-15 were followed for three years.<sup>16</sup> Lower levels of rigidity and higher levels of expressiveness were found to be associated with positive outcomes, promoting a flexible approach with good communication in TBI recovery. According to this study, successful adaptation to life with TBI involved families who "were more capable before the injury, had more social support and problem-solving skills, used resources more effectively, had greater involvement in activities, were more cohesive, had better family relationships, better communication, were more expressive, and had a more positive belief system than those who had poorer outcomes."<sup>16</sup> In contrast, higher

levels of family distress, mental illness, inflexibility, and a less positive belief system were associated with the greatest challenges. Rivara et al. concluded that families at risk for poorer outcomes should be identified early and strengthened to encourage positive change.

Quality information and preparation may help families know what to expect and facilitate care for their loved ones. Empowering families is a great strategy to promote quality care.<sup>17</sup> Interventions targeting family communication and caregiver psychological health may also help behavioral problems in adolescents with TBI.<sup>18</sup> Some researchers are investigating online positive parenting skills programs for pediatric TBI recovery that may help increase access, education, and support as well as lead to long-term improvements in behavioral problems and functioning.<sup>19–21</sup>

Numerous studies have shown that the influences of family and their interaction with the environment have an impact on outcomes of TBI,<sup>10,12,22</sup> and some families are more equipped than others to manage appointments and high-intensity needs at home. But even in families with strong communication, caregivers may find themselves under substantial emotional stress;<sup>23</sup> therefore, it is important for medical staff to be mindful of these effects on youth and the family system. The more stable the support network, the higher likelihood that the youth with TBI will get his/her needs met. A case manager or other team member may be able to assist in troubleshooting logistical details such as transportation, supplies needed, and respite care.

Alicia was eventually transferred out of state to continue her recovery because her family could not take her home, something that she came to recognize and understand. Without the support of her family, she found her own way to stabilize her situation: she prized the relationship security that she found in the hospital, preferring the same sitters and nurses to be with her during the day. And she became more able to express her feelings, such as her longing to return to her family. As her medical team began to learn how to manage her moods and behaviors—through understanding her concerns and insecurities, being mindful of coun-

tertransference—it became clear that communication, preparation, and psychoeducation were important for everyone involved in Alicia's care: her medical team, her family, and Alicia herself.

### Conclusion

Traumatic brain injury is a complex condition that may have psychosocial, cognitive, behavioral, motor, and physical effects. Clinicians, caregivers, and the community ideally should be involved in supporting youth who suffer from TBI. Currently, primary services for youth with TBI include psychotherapeutic and psychopharmacologic approaches to target symptoms that are the most troubling and impairing to the child or adolescent. There is a definite need for more research on treatments for pediatric patients with TBI. One crucial aspect in the rehabilitation of youth with TBI is family-centered care. Supporting and educating family members and encouraging service integration not only relieve stress and anxiety in caregivers, but also help to promote wellness and healthy development of the youth with TBI. More research is needed to identify specifics about the environments and support systems that might promote recovery.

### Take Home Summary

Youth who experience traumatic brain injury (TBI) have unique medical and emotional needs. Family support is essential in the recovery process of these youth. Discussion, preparation, and planning for aftercare should begin early with the assistance of the medical team. Barriers to providing quality care should be addressed to allow for troubleshooting of these difficulties. Clinicians should involve the family in the healing process as much as possible to ease the transition home and to promote adherence.

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### JAACAP March Issue — Coming Soon!



Pieter Bruegel the Elder's painting "The Fight Between Carnival and Lent" (1559) appears to be organized by one theme: chaos. A sixteenth-century precursor to *Where's Waldo?*, this village scene is populated by a man riding a keg and jousting with a meat skewer, another hanging out of a second-story window, a bagpiper leading a procession of lepers, and nuns going about quotidian activities. Two distinct and opposing human tendencies—revelry and sobriety—collide in this town square with visually striking and bizarre results. Within the realm of medicine, an analog to this conflict might be found in autoimmune diseases, where the body is at war with itself. In this issue of the *Journal*, Nielsen and colleagues (p. 234) examine the evidence for a relationship between autoimmune disease and the risk of developing attention-deficit/hyperactivity disorder (ADHD). Using data from a large cohort in Denmark, the authors found juvenile rheumatoid arthritis and autoimmune thyroiditis to be related to higher risk of ADHD in participants. Without additional information on such factors as lifestyle, environment, and sociodemographics, this study can only begin to explore this tangled relationship. Further study is needed to better understand these complex interactions—both in medicine and in Bruegel's art.