Supporting Individuals who have Experienced Traumatic Brain Injuries

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People who experienced a traumatic brain injury (TBI) sometimes recover well and are able to move on with their lives. Successes are often attributed to individual's grit and determination, along with accommodating supports from caring people. On the other hand, individuals who experiences a moderate to severe TBI may not do so well.

A review of recent research finds that several challenges persist into the individual's adulthood, including social, behavioral, cognitive, academic and psychosocial complications (Gould, Ponsford, et al., 2019; McKinlay et al., 2016). For survivors of traumatic brain injuries there are often long-term consequences and challenges in each of these areas. If not addressed, behavioral changes can intensify over time (Gould et al., 2017).

Traumatic brain injuries occur when an individual experiences an insult to the head, such as in a vehicle accident or being hit with an object. Other types of brain injuries can occur when an individual has a brain injury due to health conditions such as a stroke or seizures. The term acquired brain injury is a broader term used to describe both health and trauma causes. In this information sheet, we will use the term TBI because the effects of such injuries are frequently found within the intellectually disabled population in residential care.

Cognitive Changes after TBI

Brain injuries are not all the same. Damage to different locations can cause different skill losses, as we discuss in detail below. These losses often impact the person's executive functioning skills. These include maintaining attention, memory, planning, organizing, flexible problem solving, self-awareness, and social compatibility (Ylvisaker, Turkstra & Coelho, 2005). Theory of mind, social perspective taking, and personality changes are also frequent challenges after a TBI. These cognitive changes can impact every aspect of the individual's life.

Behavioral Changes after TBI

Several types of challenging behaviors occur after an individual experiences a TBI. (Blasingame, 2018; Li & Liu, 2013) These, generally speaking, involve aggression, impulsivity and hyperactivity, withdrawal, anxiety, and depression. New-onset psychiatric disorders often occur, including personality changes, defiance and conduct disorders, and post-traumatic stress symptoms and anxiety disorders. Behavioral challenges that do not resolve within the year after the injury tend to persist and worsen over subsequent years. Sexual problems and offending behaviors, poor social behaviors,

poor problem-solving and aggressive responses to frustrations are not uncommon. Post-injury aggressions can be predicted by pre-injury levels of aggression, attention problems, and anxiety. (Li & Liu, 2013)

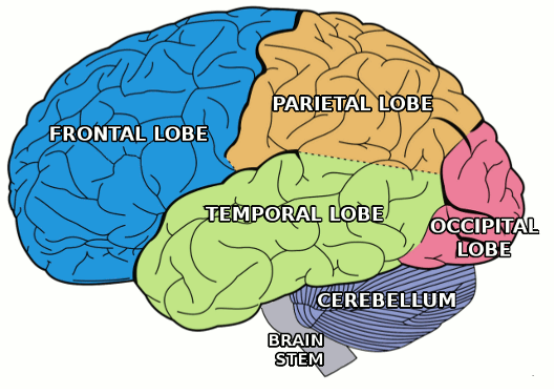
Researchers have studied the challenging behaviors which occur after a TBI. Sabaz et al. (2014) reported a frequency of 54% of the individuals in their study who exhibited challenging behaviors. These included inappropriate social behavior (33.3%), aggression (31.9%), and adynamia (23.1%). Thirty-five (35%) percent of their study sample exhibited more than one challenging behavior. When TBI are experienced in childhood or adolescent years, their cognitive development -due to neural system disruptions- and social competencies are often impaired. These lead to ongoing challenges with frustration management, learning, and self-regulation (Ylvisaker, Turkstra & Coelho, 2005).

TBI and Sexual Problems or Offending Behaviors

In one study, researchers studied 507 people with TBI, looking for inappropriate sexual behaviors exhibited within the previous 3 months. They found 45 individuals (8.9%) had done so. The highest frequency behavior was inappropriate sexual talk (57.9%), followed by genital and non-genital touching behaviors (29.8%), and exhibitionism or public masturbation (10.5%). These sexual behaviors were co-occurring with inappropriate social behavior and aggression in 43 of the 45 cases. (Simpson, Sabaz, & Daher, 2013; Blasingame, 2018)

Examples of Injury Impacts on Different Areas of the Brain

Below are examples of how injury to different areas of the brain may affect the individual. Many of these “scientific” terms are found in evaluations and reports that service providers may receive.



(https://anatomyinfo.com/temporal-lobe/)

Frontal Lobe: The frontal lobe is one of four lobes of the cerebral cortex (frontal, temporal, parietal and occipital lobes). A healthy frontal lobe manages social and

emotional skills, motor function, language, speech, thinking, reasoning, imagining, curiosity, and more. Executive functioning is associated with the frontal lobes. These functions include thinking and reasoning, problem solving, impulse control, self-monitoring of actions, anticipating consequences of actions, ability to modify or change actions based on feedback or information from the environment, and the capacity to generalize learning and experience from one situation to another. (Blasingame, 2018)

Damage to the frontal lobe, sometimes referred to as frontal lobe syndrome, can cause global impairments in the person's functioning. Damage to the frontal lobe can cause impairments such as impaired judgment, depression, difficulty controlling emotions, changes in behavior, poor attention span, easily distracted, reduce or increase sexual interest, odd sexual habits, impulsive and risky behaviors, communication problems, and more. (Vega, 2024; verywellhealth.com)

Contusions: Cerebral contusions from TBI have been associated with increased disability and death of the injured person. Contusions can cause permanent damage to the cerebrum. The initial brain impact creates a cascade of secondary injury responses that worsen the injury from the primary damage. Contusions overlie brain parenchyma with a loss of function. (Pellot & de Jesus, 2023; https://www.ncbi.nlm.nih.gov/books/NBK562147/) As such, contusions are viewed as the most devastating secondary injury in TBI cases. The initial contusion leads to ischemia and edema which progresses to the destruction of the tissues and reactive gliosis.

Gliosis and volume loss: Glial cells are normally involved in repairing damage to the brain tissue. Gliosis occurs when that repair process goes overboard and causes inflammation and scarring-type tissue to form. Acute gliosis is a temporary response to injury, while chronic gliosis is a long-term state of activation that can lead to ongoing inflammation and tissue damage. (https://neurolaunch.com/gliosis-brain/)

Gliosis in both the right and left sides of the frontal lobes suggest there was significant damage to both sides of the frontal lobes. Volume loss due to gliosis indicates these lobes have lost cell matter, i.e., there is less functional brain tissue in these regions. This process undermines the frontal lobes' capacities and connectivity to other regions of the brain.

Dilated ventricles: Cerebrospinal fluid is produced in the ventricular system of the brain. The ventricles of the brain are a communicating network of cavities filed with cerebrospinal fluid and located within the brain that extend to form the central canal of the spinal cord. The cerebral ventricles consist of the lateral ventricles, third ventricle and fourth ventricle. The third ventricle is involved with protection of the brain from trauma and a pathway for the circulation of cerebrospinal fluid. (www.cochranfirm.com/new-orleans/ventricular-dilatation/)

Following a traumatic brain injury the ventricles of the brain can become damaged and changed. Dilated brain ventricles occur when the two halves of the brain are abnormally enlarged or swollen. A study of trauma patients that provided an assessment on average 30 years after TBI found that lateral ventricular enlargement was significantly associated with impaired memory functions, memory complaints and executive function. (www.cochranfirm.com/new-orleans/ventricular-dilatation/)

Parenchymal volume loss: Parenchymal volume loss, also known as parenchymal atrophy, signifies the reduction in the volume of a specific organ or tissue. (https://radiologyinplainenglish.com/parenchymal-volume-loss/) Brain parenchymal atrophy refers to the loss of brain tissue volume. A TBI can cause this type of brain atrophy to occur.

Researchers reported that brain volume decreases after mild or moderate brain injury, presumably as a result of cellular loss, and that patients with loss of consciousness have a greater loss in volume. (MacKinzie et al., 2002)

Parenchymal volume loss can be localized in a specific area, or generalized / diffuse more globally across multiple regions of the brain. The more diffuse the atrophy is, the greater effect it has on the individual's ability to learn and function on a day-to-day basis.

Temporal lobe: The temporal lobe is another of the four major lobes of the brain. Within the temporal lobe lies the limbic region. The limbic region connects with several other regions of the brain. Within the temporal lobe the limbic system controls many aspects of human behavior, including automatic emotional responses such as the fight-or-flight response and threat responses. The limbic system is addressing key memory, learning, and attention processing structures such as the amygdala and the hippocampus. This brain area manages a number of automatic, unconscious biological functions, as considerably as unconscious emotional states, such as the sexual arousal and the appetite. (https://anatomyinfo.com/temporal-lobe/)

Damages to the temporal lobe can bring about many challenges for the person, including impairments of self-regulating behaviors, such as hunger, thirst, appetite, and sexual interests and appetite. (https://anatomyinfo.com/temporal-lobe/) Damage to the temporal lobe can also impair one's ability to speak, seizures, impaired memory skills, personality, emotional regulation, and spatial reasoning.

Putamen hemorrhage infarct: The putamen is a key component of the striatal complex, critical to the brain's reward system involving dopamine. The ventral striatal complex connects the putamen, nucleus accumbens and caudate nucleus within the limbic system and to the prefrontal cortex. This system is actively involved in pleasure seeking, including that from sexual activity, drug use, eating, gambling, and novelty seeking. (Arias-Carrion et al., 2010)

The putamen contributes to several types of learning and memory processes. Specific aspects include stimulus-response-outcome learning, working memory, episodic memory, cognitive control, and category learning. The putamen also contributes to aspects of motor learning. (Ell et al, 2011) Increased dopamine activity in the putamen can improve working memory function.

The putamen has direct connections with the neighboring nucleus accumbens as well as the prefrontal cortex. As such, the putamen is highly involved with the reward process. Anticipated rewards activate the putamen where withholding of rewards decrease putamen stimulation. (Ell et al, 2011)

Left putamen stimulation is normally associated with information to be ignored, i.e. prioritizing other stimuli in front of the person but ignoring others. The left putamen is involved with ignoring irrelevant information.

Connections between the putamen and prefrontal cortex are critical in cognitive control processes. Cognitive control involves performing task relevant processing despite other distractions or interference. As such, the putamen plays a role in cognitive flexibility such as changing one's strategies when the one used is not rewarding. Task relevant information cannot be used when the putamen is damaged, reducing cognitive control. A person may want to have better or more rewarding behaviors, but cannot use the feedback or information available to signal awareness of how to change that behavior. (Ell et al, 2011) Damage to the putamen can also effect learning that depends on rule-guided behavior.

Damage to the putamen can also cause functional problems for neighboring brain regions due to impairment of connectivity. The nucleus accumbens is a major component of the ventral striatum and is situated between the putamen and the caudate nucleus. Dopamine has been shown to be the major neurotransmitter of the nucleus accumbens and plays an important role in the experience of reward and pleasure. The nucleus accumbens is involved in various cognitive, emotional, and psychomotor functions. It serves as an important area for motivation, reward and pleasure, addiction, impulsivity, sexual gratification, and risk-taking behaviors.

Perhaps one of the putamen's most intriguing roles is in habit formation and procedural memory. Those automatic behaviors people perform without conscious thought – like tying shoelaces or typing on a keyboard – are, in part, due to the putamen's functioning behind the scenes. (https://neurolaunch.com/putamen-brain/)

These are but a sampling of the countless impacts of TBI on cognitive, social, and behavioral functioning.

Implications for Behavioral Support Interventions

Because of the range of brain injury effects, as discussed above, there will have to be a number of behavior support strategies put into place to assist these individuals. The use of Positive Behavior Support (PBS) strategies with survivors of TBI has been well supported by research. (Ponsford, Hicks, Gould, et. al., 2022; Gould, Hicks, et al., 2017; Ylvisaker, Turkstra, & Coelho, 2005) A combination of skill building, modifying environments, empowering support providers and carers, and training executive strategies to promote self-regulation are common general PBS strategies.

Broadly speaking, multicomponent behavioral interventions involving antecedent control and contingency management methods are needed. Individuals with intellectual disabilities and a TBI history are unlikely to be to plan or initiate any of these independently. They are dependent on behavior specialists and direct care staff members to make things happen. Here are some examples of how interventions can be crafted.

- Individual-specific knowledge: Staff members and others who support the individual need to have a good understanding of the person's life experiences, current capacities and have reasonable expectations. Training by a behavior specialist who has completed a functional assessment of the individual's behaviors can help staff understand the frequency and types of support needed in different circumstances. Staff also need to understand how to anticipate the individual's level of frustration tolerance. Tailored behavior support plans can be quite helpful for staff to know what supports to provide. In most cases, it can lower the individual's anxiety level when they see that their staff know them and see that staff behave as if they care and have respectful consideration for the person. Staff need to behave in ways the individual can recognize as caring about their quality of life and getting to that better future together.
- Focus on the right stuff at the right time: Survivors of TBI, especially injuries from a distant past injury, are often presented with tasks that are skill-focused rather than quality of life focused. Skill trainings may be needed, but these should not be the only focus -as if the person's identity is defined by their deficits. Rather, staff should learn what can we do to help your life be more satisfactory. *Goals for a better life* can be more enticing for the individual to participate with, and can become vehicles for indirect training opportunities without being labeled as such. Staff must be co-participants in the goal-focused activities and capitalize on teachable moments when the individual himself or herself wants to learn something.
- Make the right assumptions: Not everyone who has had a TBI will realize the impacts of their behaviors on others. They may not be motivated to change because they don't realize how they are affecting others. In some cases, the

person can tell us the right answers about appropriate social behaviors but they cannot put those answers into right social behaviors. That's not just to be difficult. It's often due to the damaged connections within their brain. Transferring from knowing to doing may no longer be an automatic process. Staff should assume there is some kind of disconnect rather than an intentional resistance.

- Routines and schedule adjustments: Consider the time of day when the individual is the most alert and has their best energy level. Staff should schedule critical tasks during this time of day, even if that is not during "customary" times. For example, some individuals experience great difficulty waking up in the morning, so a 9am appointment may not go well. Rather, schedule the person's appointments after 1pm. Another example is to schedule the individual's recreation activities or shopping trips during the time of day when the person is most cooperative or alert. Shopping in the evening may be the better match for some individuals. Finally, don't over-schedule too many expectations on any given day. Make schedules that accommodate the individual's capacities for attention, focus and energy. Staff should avoid time-pressured demands. Do today only what we can do today, and not more.
- Set them up for success: Many individuals who have experienced a TBI have great difficulties with impulsive behaviors. Staff can help the individual manage their impulses by being thoughtful about the environment the person is to be in. Helping the individual avoid risky or frustrating situations and promoting pro-active planning and positive routines can help much more effectively than simply waiting to react to impulsive behavior after the fact.
- Maximize modeling and support strategically: Having individual-specific understanding of the impact of the TBI and realistic expectations can help us know what life components need to most or least amount of support. Whenever we want to train a skill set, we need to guarantee that the individual is receiving the appropriate amount of role modeling and support on an ongoing basis, not once or twice. Role modeling, rehearsing, and receiving supportive feedback are critical, and must be done repeatedly. Since the individual's optimal time of attention, focus and energy may be limited, staff need to plan activities and interventions in shorter bursts of time. It may be helpful for the staff person to negotiate how much time will be spent doing certain tasks so as to not wait until the person is too exhausted emotionally to continue, or reaches a point of frustration.
- Visual cues: Some individuals who have IDD and a TBI history are more visually oriented than they are to verbal instructions. Providing graphics or pictures of the desired behavior may help the person to organize themselves for different tasks or desired behaviors. An example might be to use pictures to help the person connect certain behaviors with the likely consequences of that behavior, since

people with TBI often struggle with learning from past unhelpful behaviors. Another example might be to use pictures to show other peoples' likely reactions if they were to see a certain behavior being done. This later example can help the person learn social perspectives that they may not otherwise be able to think through on their own.

- Create momentum: Initiating activities and starting new challenges is a frequent point of resistance for TBI survivors. In many cases, if the staff don't initiate an activity, the activity will never happen. Staff should engage in easy and engaging activities *with* the individual before introducing a new or more difficult task. The idea is to set the person up for success *with* staff support. Staff should plan to do activities *with* the individual. Stringing together a couple of lesser or easier activities into one combined activity, called chaining, is helpful at creating a positive sense of momentum. Staff should plan to repeat these short sequences of activities many times, providing smiles and high fives as reinforcers for the simplest participation by the individual. This repetition helps the individual maintain previously acquired skills and reinforces the memory needed to do them.
- Know when to quit pushing: Many times, we forget how much mental and emotional energy it takes to learn new things or change old habits. This is even more challenging for persons with IDD and the long-term effects of a TBI. When doing specific task-focused activities or learning procedures, staff should discuss an escape plan with the individual being supported. For example, some individuals may be able to say directly, "I'm pretty tired. I need to stop now." Other individuals will need to simply use a code word, such as saying "okay, done" or "no more." Staff of course must respect the individual's use of the code word even if there wasn't much effort spent that day. The point is to reinforce even the smallest amounts of effort in the right direction, and hopefully make it a positive experience that the individual will take another run at tomorrow.

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