

Brain injury (tbi) and or spinal cord injury (sci)



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1. Introduction

Children and youth who sustain a severe traumatic brain injury (TBI) and/or a spinal cord injury (SCI) often experience sequelae that can affect their ability to communicate effectively. In early phases of recovery, many children with TBI and SCI are unable to use their speech or gestures for a variety of neurological and medical reasons related to their injuries. As a result, they can benefit from augmentative and alternative communication (AAC) interventions that specifically address their ability to communicate basic needs and feelings to medical personnel and family members and ask and respond to questions. AAC approaches may include having access to a nurse's call signal; strategies to establish a consistent " yes" " no" response; techniques that help a child " eye point" to simple messages; low-tech boards and books that encourage interaction with family members and staff; communication boards with pictures or words; and speech generating devices (SGDs) with preprogrammed messages, such as " I hurt" " Come here," " Help me please!" " When's mom coming?"

As children with TBI and SCI recover from their injuries, many no longer will need AAC. However, some children face residual motor, speech, language and cognitive impairments that affect their ability to communicate face-to-face, to write and to use mainstream communication technologies (e. g., computers, email, phones, etc.). A few may require AAC and other assistive technologies (AT) throughout their lives to participate actively in the rehabilitation process and ultimately, in their families and communities as adults. Without the ability to communicate effectively, children with TBI and SCI face insurmountable barriers to education, as well as difficulties

establishing and maintaining relationships and taking on preferred social roles.

All AAC interventions aim to support a child's current communication needs while planning for the future [2]. However, the course of AAC treatment for children who sustain TBIs and for those with SCIs is different because the nature of their injuries is different. In addition, the focus of AAC interventions will differ for very young children who are just developing speech and language skills (e. g., 18 month-old with shaken baby syndrome) and for those who were literate and already had some knowledge of the world prior to their injuries (e. g., 16 year-old injured in a motor vehicle accident). For young children, the AAC team will focus on developing language, literacy, academic, emotional, and social skills, as well as ensuring that they have a way to communicate with family members, rehabilitation staff and others in their lives. For older children, AAC interventions often build on residual skills and abilities to help remediate speech, language and communication impairments while providing compensatory strategies that support face-to-face interactions and ultimately communication across distances (phone, email). In short, AAC intervention goals often seek both to remediate and compensate for injuries while promoting a child's access to social networks and active participation in family, education, community and leisure activities [4, 18, 25].

A variety of AAC tools, strategies and techniques are available that offer communication access, however, successful AAC interventions for children with TBI and SCI also require that medical staff, family members and ultimately community personnel know how to support their use. The needs of

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these children change over time so speech-language pathologists, nurses, occupational therapists, physical therapists, physiatrists, pediatricians, and rehabilitation engineers need to work collaboratively with the child's family and community-based professionals to establish, maintain and update effective communication systems. Ultimately, these children need to return to their homes, schools and communities and, as adults to take on desired social roles. AAC can help them realize these goals.

2. Pediatric TBI and AAC

AAC intervention for pediatric patients with TBI and severe communication challenges is an essential, complex, ongoing and dynamic process. AAC is essential to support the broad range of communication needs of children with TBI who are unable to communicate effectively. It is complex because of the residual cognitive deficits that often persist and because many children with TBI have co-existing speech, language, visual, and motor control deficits [11, 10]. AAC interventions are ongoing and dynamic [12] because children with TBI experience many changes over time and undergo multiple transitions. Light and colleagues [17] described the ongoing, three-year AAC intervention of an adolescent who progressed through several AAC systems and ultimately regained functional speech. DeRuyter and Donoghue [6] described an individual who used many simple AAC devices and a sophisticated AAC system over a seven-month period. Additional reports describe the recovery of natural speech up to 13 years post onset [15, 29].

2. 1. AAC Assessment and Intervention

Assessment tools can help identify and describe the cognitive, language and motor deficits of patients with TBI and can provide a framework for AAC

interventions. The Pediatric Rancho Scale of Cognitive Functioning [26] is based on the Ranchos Los Amigos Scale of Cognitive Functioning [13]. Table 1 describes general levels of recovery, based on the Pediatric Rancho Lost Amigos Scale, and gives examples of AAC intervention strategies that rehabilitation teams can employ across the five levels, as described below.

Levels V and IV. Shaping responses into communication

Pediatric patients at Levels V and IV on the Pediatric Rancho Scale are often in the PICU, the ICU, acute hospital or acute rehabilitation environment. At Level V (no response to stimuli) or Level IV (generalized response to stimuli), AAC interventions focus on identifying modalities that children can use to provide consistent and reliable responses. For example, staff can use simple switches, latch-timers and single message devices to support early communication (see Table 1 for some examples). Because children's early responses may be reflexive rather than intentional, the family and medical/rehabilitation team can also use AAC technologies to encourage more consistent responses. Families provide valuable input about the kinds of music, games and favorite toys a child finds motivating and the team can use these items to evoke physical responses from the child. For example, if a family identified the battery-operated toy Elmo® from Sesame Street®, the rehabilitation team might present Elmo singing a Sesame Street song and then observe to see if (and how) the child's responds. If the child begins to turn her head when Elmo® sings, the team might attach a switch with a battery interrupter to the toy and ask the child to "hit" the button and "play the Elmo® song". In doing so, the team can learn several things. For example, the team may note that a child is able to follow commands,

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indicating cognitive recovery. The team may also begin to consider alternative access methods for a child with severe physical impairments, noting, for example, that head movement may become a reliable way to operate an AAC device or computer in the future.

2. 2. Middle Levels III and II: Increasing ability to communicate with staff, family and friends and supporting active participation in treatment

Pediatric patients at Levels III (localized response to sensory stimuli) and II (responsive to environment) become more engaged in their rehabilitation programs as they recover some cognitive, language and physical abilities. Natural speech recovery is likely to occur during this phase and long-term deficits that affect communication become more apparent (e. g., dysarthria, apraxia, aphasia, attention, initiation, memory, vision, spasticity). Dongilli and colleagues [7] and Ladtkow and Culp [16] reported natural speech recovery in adults after TBI at these stages of recovery, and continued reliance on AAC strategies and technologies is typically due to persistent motor speech and/or severe cognitive-language deficits resulting from the injury [12].

AAC interventions at these levels typically focus on using a child's most consistent and reliable response to (1) communicate messages, (2) encourage active participation in the rehabilitation process and (3) increase interactions with family and staff. AAC interventions always take into account the child's developmental level and interests. Table 1 gives some examples of AAC technologies employed during Levels III and II. For example, Jessica was admitted to the hospital at 18-months with shaken baby syndrome. At Level II, she began responding to her parents by smiling and laughing, and

she also began to manipulate toys with her non-paralyzed hand when staff placed a toy within her intact field of vision. However, she did not exhibit any speech or imitative vocal behaviors and her speech-language pathologist noted a severe verbal apraxia. Nursing staff and family members reported that Jessica seemed frustrated by her inability to express herself. Prior to her injury, she could name over 30 objects (toys, pets, favorite cartoon characters) and was beginning to put two word sentences together (Momma bye-bye, Daddy home).

AAC interventions included the introduction of a single-message speech generating device (SGD) that enabled the staff and family members to record a message that Jessica could then “speak” during her daily activities (e. g., more, bye-bye, turn page). Because the device selected was colorful, large and easy to access, Jessica was able to “press the button” despite her upper extremity spasticity and significant visual field cut. Within a month, she was also able to use an SGD with an eight-location overlay that staff had programmed with words she used prior to her injury (e. g., mommy, daddy, more, bottle, book, bye-bye). Staff also designed additional overlays to encourage language development so she could construct two-word combinations (e. g., more crackers). Jessica began to express herself at a developmentally appropriate level when her communication partners gave her cues because she had residual memory deficits. For example, initially, she did not recall how to use her AAC system from session to session so staff needed to reintroduce it each time; but after several months, Jessica began to “search” for her SGD to communicate. Like many children with TBI at this

level, she was able to learn procedures and strategies with repetition and support [30].

2. 3. Level II and Level I. Supporting transitions and recommending AAC strategies and technologies for use at home and in the community

As pediatric patients transition from Level II (responsive to environment) to Level I (oriented to self and surroundings), they often move from an acute rehabilitation facility to an outpatient setting, their home or a care facility. Before discharge, therefore, AAC teams often conduct a formal AAC assessment and provide long-term recommendations for AAC strategies and technologies that will enable children to be integrated successfully back into community environments. Table 1 illustrates the types of AAC technologies and strategies employed at Levels II and I.

For children who continue to use AAC and AT when they return to their communities, the rehabilitation team will identify a long-term communication advocate. This person, often a family member, collaborates with rehabilitation staff to prepare the child's educational staff, extended family and other caregivers to support communication across environments [9]. Having a link between the rehabilitation team and community professionals is essential because most teachers and community-based clinicians need support to manage the cognitive and physical deficits often associated with TBI. For example, McKenzie, a 12 year-old with a severe TBI secondary to a car accident, was quadriplegic with severe spasticity and no upper extremity control. She also had cortical blindness and significant communication and cognitive impairments. As she recovered, McKenzie used a variety of AAC systems (e. g., thumbs up/down for " yes" " no", two single message SGDs

to communicate choices, and a auditory scanning device that enabled her to access four messages so she could participate in structured activities). Prior to discharge, the rehabilitation team conducted a formal SGD evaluation and recommended a dynamic display SGD with synthesized and digitized speech output that McKenzie could access via a head switch mounted to the side of the headrest on her wheelchair. Using auditory scanning, she could create and retrieve messages. Because she had been literate prior to her injury and could still spell, the staff set up her device with an alphabet page as well as several pages with pre-programmed messages containing basic/urgent care needs, jokes and social comments. Her family and friends learned to use tactile and verbal prompts to help her participate in conversational exchanges. Even so, due to residual cognitive deficits, McKenzie had difficulty initiating conversations and remembering where pre-stored messages were in her device although when prompted, she would respond. She could also initiate questions and engage in conversations over multiple turns. Over time, she began to participate in meaningful, social interactions, often spelling out two-to-three word novel phrases using her SGD with the alphabet page.

McKenzie transitioned to a regional care facility that specialized in working with young people with TBI while her parents were preparing their home to handle her wheelchair, The acute rehabilitation team had identified McKenzie's aunt as her AAC advocate because she participated actively in earlier phases of McKenzie's recovery and knew how to charge, set-up and do basic trouble-shooting of her SGD, as well as could customize and program new messages into the system. The care facility staff met with

McKenzie's aunt weekly and learned how to support McKenzie's use of the SGD. Specific training objectives also included maintenance and basic trouble-shooting, set up, switch-placement and programming new messages for use in specific and motivating activities. Staff also learned how to modify the placement of McKenzie's switch when she became fatigued or her spasticity increased. Additionally, McKenzie's school staff (special education coordinator, speech-language pathologist, occupational therapist, and one of her regular classroom teachers) visited McKenzie to help prepare for her return home. They wanted to learn how to support her in school, given her physical and cognitive limitations.

2. 4. AAC themes in TBI

When working with pediatric patients with TBI, three AAC " themes" emerge.

1. Recovery from TBI is dynamic and takes place over time. In early stages of recovery, most children with TBI have physical, speech, language and cognitive deficits that affect their communication skills. Depending on the nature and severity of their injuries, however, most recover functional speech. For those with life-long residual speech, language and communication deficits, rehabilitation teams often need to maintain contact to employ AAC interventions that can support and monitor a child's changing communication abilities and needs over time.
2. The cognitive-linguistic challenges associated with TBI make AAC interventions particularly challenging for rehabilitation staff, as well as for families, friends and school personnel. Because of the complex nature of the residual disabilities caused by TBI, collaboration among

rehabilitation specialists, family members and community-based professionals is essential. Family members, friends and school personnel rarely know how to manage the severe memory, attention and/or initiation deficits that can affect long-term communication and learning outcomes of these children.

3. There is a need to plan carefully for transitions. Children with TBI are likely to experience many transitions over their lifetimes. While research describing these transitions in children is not available, reports of the experiences of adults with TBI describe multiple transitions. Penna and colleagues [22] noted that adults with TBI undergo a significant number of residence transitions particularly in the first year following injury and Fager [9] described the different transitions (acute care hospital, outpatient rehabilitation, skilled nursing facility, home with adult daycare services, and eventually assisted living) for an adult with severe TBI over a decade. She documented significant changes in cognitive abilities, as well as turnover of communication partners and support staff.

3. Pediatric SCI and AAC

Pediatric patients with SCI often have intact cognitive skills and severe physical disabilities that can interfere with their ability to speak during the acute hospital and rehabilitation phases of recovery. In addition, they often have significant medical complications and may be left with severe neurological impairments that make it difficult, if not impossible, for them to write, access a computer or participate in the gaming, online and remote social networking activities embraced by today's youth (e. g., texting, email).

A subgroup may also present with a concomitant TBI. For them, AAC treatment must reflect guidelines that take into account both SCI and TBI.

As with TBI, AAC intervention for children with SCI is developmentally based and directed to the individual's special needs [27]. Initially, AAC interventions typically focus on ensuring face-to-face communication when speech is unavailable or very difficult; however, over the long term, enabling children to write and engage in educational, recreational and pre-vocational activities using computers and other mainstream technologies becomes the focus.

3. 1. AAC Assessment and Intervention

The ASIA standard neurological classification of SCI from the American Spinal Injury Association and International Medical Society of Paraplegia [1] is a tool that rehabilitation teams frequently use to assess patients with SCI because it identifies the level of injury and associated deficits at each level. It can help guide the rehabilitation team's clinical decision-making process for AAC interventions. As shown in Table 2, children with high tetraplegia (C1-C4 SCI) have limited head control and are often ventilator dependent. They may require eye, head, and/or voice control of AAC devices and mainstream technologies to communicate. While switch scanning is an option for some, it requires higher-level cognitive abilities, endurance, and vigilance and may be inappropriate for very young children and those who are medically fragile [28, 19, 23, 14].

Children with low tetraplegia (C5-T1 SCI) demonstrate limited proximal and distal upper extremity control. If fitted with splints that support their arm and

hand, some are able to use specially adapted mouse options (e. g., joystick mouse, switch-adapted mouse, trackball mouse), large button or light touch keyboards and switches to control technology. These children are also candidates for head tracking and voice control of AAC devices, options that can offset the fatigue and physical effort involved in using their upper extremities. A multi-modal access method to AAC technology and computers may include voice control to dictate text, hand control of the cursor with an adaptive mouse to perform other computer functions (e. g., open programs) and an adaptive keyboard to correct errors that are generated while dictating text and can be more efficient and less frustrating than using voice control alone. Table 2 provides examples of appropriate access options to AAC and mainstream technologies.

3. 2. Supporting face-to-face communication

For children with high tetraplegia, being dependent on mechanical ventilation is frightening especially for those who are unable to tolerate a talking valve [21]. Also, children with lower levels of injury can experience reduced respiratory control and be unable to speak as they are being weaned from a ventilator[2]. For any reason, providing a way to communicate is essential to recovery and a sense of well-being. AAC strategies and technologies can enable these children to interact with direct care staff, participate in their rehabilitation process, and maintain relationships with family and friends.

Pediatric rehabilitation teams may use a range of AAC strategies and technologies to support face-to-face communication in children with SCI. Some examples include low tech communication boards used with eye gaze

or eye pointing, partner-dependent scanning, an electro larynx with intra-oral adaptor and a laser light pointing to a target message or letter on a communication board [2, 3]. Introducing AAC and AT technologies early in the recovery process, particularly for children with high tetraplegia, begins to familiarize them with approaches they may need to rely on more extensively throughout their lives, even after their speech returns.

For example, Jared, a 17-year-old high school senior, sustained a SCI at the C2 level in a skiing accident. In addition to his injuries, he developed pneumonia and a severe coccyx wound that lengthened his hospital stay. He was unable to tolerate a one-way speaking valve due to the severity of his pneumonia and decreased oxygenation during valve trials. Although Jared had minimal head movement, he was able to control a head tracker to access his home laptop computer and could spell out messages he then spoke aloud using speech synthesis software. He used this AAC system to indicate his medical needs to caregivers and later reported that having the ability to communicate helped alleviate some of the anxiety he experienced due to his condition and extended hospitalization. When Jared could use a talking valve, his AAC program focused on computer access to meet written and social communication needs. Once his wound had healed and he returned home, Jared completed his GED and enrolled in online classes at the local community college using his AAC system.

3. 3. Supporting written communication and educational goals

At the time of their injury, some pediatric patients with SCI are pre-literate, others are developing literacy skills, and others have highly developed literacy skills. Most children with tetraplegia require the use of assistive

technologies to support written communication because their injuries preclude them from using a pencil and/or typing on a traditional computer keyboard. In fact, in a report describing the educational participation of children with spinal cord injury, 89% of the children with tetraplegia relied on AAC to support written communication needs [8].

For example, Max, a 6-year-old boy who suffered a C6 SCI after an All Terrain Vehicle accident, was reading age-appropriate sight words and developing his ability to write single words prior to his injury. Formal testing revealed that Max had no residual cognitive or language impairments; however, he faced significant barriers to his continued development of age-appropriate reading and writing skills, as well as his ability to learn and do math, social studies, science, play games, use a cell phone, etc. Max needed ways to access text and write, calculate, draw, play computer games (?) and so on. He learned to access a computer using a large button keyboard, joystick mouse, and adaptive hand-typers (cuffs with an attached stylus that fit on the ulnar side of the hand and allowed him to press keys on a keyboard). These technologies supported writing and computer access; and as a result, he was able to continue with his schoolwork and keep up with his classmates. After returning home during the summer and participating in an intense home tutoring program, he joined his classmates in the fall and performed at grade level in all his classes. Essential to Max's future educational success and development, as well as his future employment, is his ability to write, calculate and perhaps even draw using a variety of assistive technologies that support communication.

3. 4. Supportingsocial participation and pre-vocational activities

Access to assistive and mainstream technologies not only facilitates participation in education, but also has implications for future employment as children transition into adulthood. Assistive and mainstream technologies that can help individuals with SCI achieve gainful employment and participate actively in their families and communities are now available at modest cost. In addition, these technologies provide access to life-long learning, recreational activities and social networking opportunities. Specifically, computers are described as “ great equalizers” for individuals with SCI [20].

Social participation in the current technological age includes more than face-to-face communication. Social participation has expanded with the popularity of social networking sites (e. g., Facebook™ and MySpace™), video web-based communication (e. g., Skype™) and instant communication and messaging (e. g., Twitter™). Advances in the field of AAC have allowed individuals with the most severe injuries to engage in these social communication activities. For example, Crystal, a 10-year-old who sustained a C1 SCI due to a fall, had no head/neck control and her only consistent access method to computerized technology was through eye tracking. Using an ERICA eye gaze system from DynaVox Mayer-Johnson, Crystal was able to email and text her friends and family daily, communicate via her Facebook™ account, and engage in online gaming programs with her friends and siblings. This technology also allowed her to communicate with her school friends while she was still undergoing acute rehabilitation. Additionally, Crystal’s friends began to understand that while her impairments were

severe, she was essentially the same person with the same interests, humor, goals, and expectations as before her injury. Maintaining social networks is an essential component to emotional adjustment for children with SCI [8].

3. 5. AT/AAC themes in SCI

When working with pediatric patients with SCI, three AAC “ themes” emerge.

1. For those with high tetraplegia, AAC strategies and technologies may facilitate face-to-face as well as distant and written communication needs, depending on the developmental level of the child. Introducing AAC technology early, when face-to-face communication support is needed, helps these children become familiar with technology they may need to rely on after their natural speech has recovered.
2. Return to their homes and educational environments is a primary goal for children with tetraplegia. Many of these children return to school within an average of 62 days post discharge [24]. Development of written communication skills is an essential component to successful educational completion and future vocational opportunities [20].
3. Having access to written and electronic communication provides an opportunity for children with SCI to engage in social networks through email, texting, and social networking sites. Some of these children face a life time of potential medical complications [5], so an ability to maintain and develop new social connections via electronic media allow them to stay connected to friends, family and information when their medical conditions require them to be house or hospital-bound.

4. Conclusion

Communication is essential for the development of cognitive, language, social, and emotional skills. Children with TBI and SCI have physical and/or cognitive-language deficits that may interfere with typical ways of communicating. However, AAC strategies and technologies can support their varied and ongoing communication needs across environments and over time. A myriad of technology options are currently available that not only address face-to-face interactions, but also distant social networking, educational, leisure and employment needs.

AAC interventions in medical settings address the communication of basic medical needs and facilitate a child's recovery and engagement in the rehabilitation process. For those who continue to need communication supports, AAC technologies increase the likelihood that children with TBI and SCI will make successful transitions to their homes, schools and communities and as adults, can take on desired social roles.