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The Benefits of Alternative and Augmentative Communication: A Quality of Life Issue

This article summarizes the need for alternate forms of communication for those who are unable to use verbal speech. The importance of allied health professionals in understanding alternative communication is critical in patient care. The authors describe the various forms of augmentative and alternate communication devices that can be used to help a non-verbal individual communicate their wants, needs, and thoughts. Financial and social consequences for using these devices is discussed.

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Richard Dressler, Ph.D. has over 30 years of experience working with persons who have suffered neurogenic communication disorders. He has authored several publications of therapeutic materials including software to assist with recovery of language disorders. He has also directed a specialize program to assist students who have suffered brain injuries to achieve academic success.

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ABSTRACT

This article summarizes the need for alternate forms of communication for those who are unable to use verbal speech. The importance of allied health professionals in understanding alternative communication is critical in patient care. The authors describe the various forms of augmentative and alternate communication devices that can be used to help non-verbal individuals communicate their wants, needs, and thoughts. Financial and social consequences for using these devices is discussed.

INTRODUCTION

As humans, our reality is intricately based on our ability to perceive the world around us. What we hear, see, smell, taste, and touch creates our reality, which in turn becomes our thoughts; then our thoughts are formulated by the language that surrounds us. This rather complex, systematic process of translating thought into speech is something on which the majority of people never concentrate. We are born into a certain region of the world and raised to speak a specific language with seemingly no difficulties. However, for individuals who are born without the capacity to develop language normally or for individuals who lose the ability to communicate at some point in life, there must be an alternative means to express language. This population still deserves the chance to communicate and the opportunity to communicate with others.

Augmentative and Alternative Communication (ACC) aims to enhance communication for individuals with complex communication needs. Light and McNaughton describe life for individuals with disabilities in the past; "Thirty to 40 years ago, people with complex communication needs typically lived in large institutions, isolated from the community."¹ Thirty-one years ago, a small group of professionals concerned with this topic came together to form a society known as the International Society for Augmentative and Alternative Communication (ISAAC), and since then, it "has grown into a vibrant community with a membership greater than 3,700 from more than 60 countries around the world."² This organization aims at increasing awareness and acceptance of AAC, increasing cultural and linguistic diversity, recognizing changes in the scope of communication needs, and revolutionizing and advancing the current AAC systems.³ Alternative and augmentative communication is a rising field founded in basic human rights that needs to be studied and implemented into our society with greater success.

AAC helps encourage verbal communication for children or adults who may be functioning at a pre-symbolic level. Those are individuals who communicate with gestures, eye gaze, or using strategies other than word production. If language can be developed using an AAC system, their quality of life can be vastly enhanced.

The purpose of this article is to help allied health professionals understand AAC and how using alternate modes of communication with patients who have limited or no verbal communication can enhance the quality of care. In turn, the patients' quality of life is no doubt improved by being able to adequately communicate with all providers.

POPULATION, PURPOSE, AND PROCEDURE

One of the fundamental concepts of AAC is that it is extremely versatile. It applies to a wide population and there are countless modes of augmentative and alternative communication. AAC can be utilized in the lives of an individual of any age who has difficulty producing verbal speech. Traumatic brain injury, cerebral palsy, Down Syndrome, Autism, Amyotrophic Lateral Sclerosis (ALS), or any developmental disability are just a few of the many populations that can benefit from the use of AAC. An additional benefit that AAC offers is the variety and types of communication systems available for individuals, including both aided and unaided systems. Unaided systems, like signing and gestures, do not require an external device or special materials, while aided systems use picture charts, books, and specialized technology.

An assessment to determine the need for and appropriate type of AAC system is done by a team of professionals. The team may include physicians, occupational therapists, and physical therapists. They can contribute to the assessment from their professional perspective to assist the speech-language pathologist and family in decision making.

When embracing any new type of change there are always fears associated with the risks. Clinicians ask themselves countless "what if" questions and can become bogged down with the fear of uncertainty. AAC is a new and rising field that has been researched but not yet fully integrated into society. Sophisticated technologies have been developed to maximize the efforts of augmentative communication but can cause users to feel apprehension if they are unfamiliar with high-technology equipment. There is an increasing need for AAC stakeholders such as engineers, teachers, therapists, policy makers, funding agencies, and researchers to broaden the use and acceptance of AAC to those who need it.⁴

Parents of children with complex communication needs (CCN) often times become concerned that if their child is given a speech generating device then they will be less motivated to learn to speak. Topia and Hawking shared research by Beukelman and Mirenda:

"AAC systems [are] capable of enhancing communication development and social participation for anyone with communication needs. They further claimed that AAC interventions underpin the essential foundations for language development and can facilitate the development of natural speech."⁵

The underlying reason why implementing an AAC device into the life of a child with CCN actually stimulates natural speech is that the child begins to understand that they are capable of affecting their environment. Think of a three-year-old, non-verbal child with autism who for the first time has the power to determine even just a small part of his life. Instead of being told what he will eat for dinner or which toys he can play with because he cannot verbalize his desires, he can now push a button or sequence a small phrase on his device saying "I want applesauce" and feel empowered while making his own decisions. Once a child understands that language creates cause and effect, which in turn gives the child personal freedom and independence, he or she will begin to value it more and become a better communicator.

Furthermore, parents and professionals no longer resort to AAC after exhausting every other option when searching for methods of communication development. According to Light and McNaughton, "the population of children referred for AAC services has changed substantially in recent years to include much younger children, children with a greater range of disabilities, and children from more diverse cultural/linguistic backgrounds."² Due to advancements in medical technology resulting in decreased infant mortality rates of infants with disabilities, an increased focus on early intervention, and the rising number of students receiving special education services in the United States' public school system that come from culturally and linguistically diverse backgrounds, there is a surge of young children who could benefit from AAC.¹ Children in the United States who do not have the ability to produce natural speech deserve every opportunity to communicate and interact with their world.

Moreover, though AAC can be of great benefit to children with CCN, "AAC is an effective tool to support communication, language, and literacy development from an early age with children with limited or no speech, those at risk for speech development, and those that have speech that is difficult to understand."³ Oral communication remains the leading form of communication being that it is the most efficient and widely used, but research has proven that ACC is an effective method to spark speech development and the fundamental skills that go along with it for children who may be struggling with oral communication.

TYPES OF AAC DEVICES AND FUNDING

AAC is a versatile field that can be adapted to many individuals with a wide range of needs. There is a large population world-wide who can benefit from the use of ACC: from the young child with mild autism who has not yet begun verbalizing words to the 52-year-old woman with Parkinson's disease who lost much of her vocal quality making communication very challenging. Augmentative communication means anything that supports one's ability to speak and alternative communication means anything

that substitute's speech. Examples of augmentative communication can include gestures, sign language, body language, letter boards, and eye pointing. Examples of alternative communication include picture exchange communication systems, chat books, and static communication boards. In some cases, systems that augment one person's communication can serve as alternative communication for another person. All of the aforementioned systems are typically considered to be low-tech, meaning that they do not require equipment or devices to use.

A device is considered to be high-tech if it is a speech generating device (SGD). That type of system uses synthesized speech that can be heard once the client activates it.

Unfortunately, because high-tech devices use sophisticated technology, they are also the most expensive form of ACC. Tobii Dynavox and PRC (Prentke Romich Company) are two of the high-tech device companies. Purchasing one of their devices can cost between \$5,000- \$15,000. For most families, especially those who may also have additional medical expenses for a medically fragile family member, purchasing an AAC device may not seem like a priority. But as evidenced by previous arguments of this paper, there is great benefit, both short and long-term, in attaining an AAC device for individuals with communication challenges. Through the work of speech-language pathologists', other professionals advocating for these individuals, and their belief that cost should not be a factor in determining whether or not someone has the right to communicate, it is now easier to attain a speech generating device through various insurance policies.

According to the American Speech-Language Hearing Association, "effective January 29, 2015, Medicare recognized speech-generating devices (SGDs) as Durable Medical Equipment (DME), which is a covered benefit for Medicare beneficiaries under the Social Security Act (Section 1861)."⁶ Medicare classifies SGDs as DME because they can withstand multiple uses, are medical devices used for injury or condition, and are appropriate for home use. The requirements for qualifying an AAC device for Medicare coverage are fairly extensive, but the pros far outweigh the cons once the device is obtained. Medicare will pay 80% to the manufacturer for the purchase of a SGD if the individual qualifies for funding. The remaining 20% has to be covered privately (e.g. insurance, family, charity). Once the beneficiary has full ownership of the device, it is recommended that they continue with therapy services to maximize use of the device and to obtain all the benefits it has to offer. Medicare, however, will not typically cover the purchase of a SGD for patients living in a skilled nursing facility (SNF). Medicare regulations require that the SNF assume the financial responsibility for patients' needs which would include communication.

Medicaid regulations vary from state to state so allied health practitioners need to consult the Medicaid guidelines in their state. Recipients can be children or adults who qualify based on income or other condition specified in a given state.

While there is no specific funding for AAC devices in the public school system, many districts will provide a SGD should it be deemed a requirement for the child to be successful in the classroom. The child's state Medicaid policies should be consulted as a possible funding source.

BENEFITS AND CHALLENGES OF AAC

Beyond the valuable impact AAC devices can make on the language development of children who are unable to produce clear speech, AAC devices also play a vital role in improving the quality of life of individuals with CCN. Researchers state that the ultimate measure of the success of AAC intervention is the degree to which it improves access and participation in valued activities and experiences of everyday life.^{3,7} Parents and families of individuals with CCN are far less interested in whether their loved ones can compute high-level math problems, recite the process of photosynthesis, or discuss the international affairs involved in World War II. What concerns them is whether or not their child is able to express their most basic wants and needs, contribute to the interactions and conversations around them, and feel empowered as a contributing member of society. If their child can have their most basic needs met while maintaining a feeling of happiness and contentment throughout life, then the family members will in turn be more at ease. Regardless of age, economic status, or ethnicity, every human wants to attain the ability to establish relationships and feel connected.

In a study by McKelvey, Kawai & Beukelman, surviving spouses of individuals with ALS, a degenerative neurological disease from which 95% of those lose the ability to meet daily communication needs, were extensively interviewed to discuss changes in their spouse's communication as the disease progressed.⁸ Persons with ALS typically loses nearly all physical and communicative abilities but they do not lose their cognitive capacity. For this reason, individuals with ALS are qualified candidates for advanced AAC devices that may otherwise be too complex for individuals with intellectual or developmental impairments. The study analyzed four categories: 1) communication styles, 2) AAC use, 3) decision making, and 4) lifestyle changes. Spouses reported that the AAC device enabled their loved one to express humor, provide parental advice, argue with their spouse, express disagreement/agreement, and maintain relationships with friends.

Lynn and Greg were one of the couples involved in the research study. Lynn was interviewed one year after her husband's death. Greg survived six years with ALS and passed away at the age of 46. Lynn and Greg were married for 18 years and had two daughters ages 7 and 16. When discussing the benefits of AAC Lynn describes Greg's SGD saying, "Greg's device basically preserved his personality. He was able to maintain his hobbies and interests. The device just made a big difference for him. Without his device, we wouldn't have had any quality of life".⁸ Greg's life was significantly changed by his illness; he transitioned from an independent man, father, and husband with a career in the U.S. Navy as a computer engineer to a completely dependent person, incapable of communicating his basic needs. While his story ended in death, the AAC device helped create many positive memories for him and his family. The use of his AAC device gave him the opportunity to interact with people even when his body and circumstances did not make it easy.

Lund and Light studied long-term outcomes of AAC interventions in a group of seven men, aged 19-25 years who had used AAC devices for 15 years or more.⁹ All of the men had cerebral palsy, significant speech impairments (speech not sufficient to meet daily needs), and data available regarding their communication and interaction skills as preschoolers. Outcomes for this study were measured in the following domains: a) receptive language, b) reading comprehension, c) communicative interaction, d) functional communication, e) educational and vocational achievement, f) self-achievement, and g) quality of life. Although all of these domains affect one's quality of life, analyzing the results from the quality of life section provided a clear description of how the use of an AAC device contributed to the happiness of the participants in the study. Scores were scaled from -10 to +10. A score of 5 or higher contributed to a positive quality of life score, a score of 0-5 indicated areas that contributed some quality but could be enhanced, and a negative score indicated an area that detracted from quality of life. Results showed that all participants scored positively on the measure indicating "positive aspects to their quality of life".⁹ The difficult in measuring quality of life is that the opinions of individuals surveyed related to items differ as contributing positively or negatively to quality of life. Although challenging to identify cut-off scores, it is critical to place a greater value on this aspect on human life. Although it may be difficult to measure "quality of life", it is essential to continue the quest for bettering the quality of life of individuals with complex communication needs.

Nevertheless, as professionals, family members, and compassionate friends, there are still many hurdles to be crossed before AAC can be fully implemented into our culture and provide all members of society with an equal opportunity for communication. In light of the technological developments in the field of AAC and the ever-growing population of individuals with CCN, there seems to be a stagnant number of people truly utilizing and benefiting from AAC devices to the best of their potential. In addition, a high rate of device abandonment has been reported in individuals who attempt to use AAC.

Ballin et al. hypothesized that device abandonment can be explained by several factors: difficulties in obtaining therapy services, barriers to AAC-based communication, and communication partners who lack skills in supporting successful communication.¹⁰ For an individual who receives an AAC device for the first time, a key factor in determining successful implementation into daily life is proper education and training on how to use the device. If the AAC user and their primary communication partners lack sufficient knowledge on how to use the device, they will not be encouraged to use it in public or private settings. It may be difficult to control a family member's motivation to learn about the device and how to use it but providing valuable and supportive education on the use of the device is completely controllable. Ballin et al. stated, "people experienced in using AAC are not included in the delivery of communication therapy interventions, nor in the training and practice needed to master a new SGD".¹⁰ In order to properly educate users and the community, it is practical to hire skilled AAC users as the educators. The skilled AAC users can be family members of AAC users, experienced speech-language pathologists in the field of AAC, or any highly trained professional.

Therapy services provided to families and individuals novice to the use of SGD are often limited and sometimes offered by professionals who lack proper training. This issue is commonly reported by family members seeking help and if resolved, would alleviate some of the other barriers in the field of AAC. With properly trained professionals, the families and patients with CCN can be educated on the function and integration of their device into everyday life. The professionals can also offer educational classes to the public on ways to be sensitive to AAC users and the ways in which the community can assist in meeting the needs of the users. The trained professionals can also promote further research on practical issues within the field of AAC that will ultimately benefit ACC users, families, educators, and the public.

Allied health professionals can encourage their patients to seek an AAC system when diagnosed with a condition in which the use of an AAC device may seem beneficial. These professionals can encourage families and patients in using the devices when seeking treatment or services. Blackstone and Pressman pointed out that in a healthcare environment where patient satisfaction is being measured and valued at an increasing rate, providers will want to use every mechanism possible to help patients communicate.¹¹

In conclusion, in our modern world, human rights remain a pressing issue. Impaired communication, which was once viewed by society to be a mere inconvenience, is now viewed as a significant problem that individuals have the right to address. The ability to communicate should be held with great prestige and honor, for it is what allows us to be human and connect with others. AAC is a growing field; with further research and education, it will be implemented into our world-wide culture and globally accepted. AAC helps encourage verbal communication in pre- and minimally symbolic children, is governmentally supported through public insurance, and, above all, improves quality of life for individuals without a voice. Consider becoming an AAC stakeholder.

“If all my possessions were taken from me with one exception, I would choose the power of communication, for by it I would regain all the rest.”

----- Daniel Webster

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