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AAC for Adults with Acquired Neurological Conditions: A Review

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The purpose of this review is to describe the state of the science of augmentative and alternative communication (AAC) for adults with acquired neurogenic communication disorders. Recent advances in AAC for six groups of people with degenerative and chronic acquired neurological conditions are detailed. Specifically, the topics of recent AAC technological advances, acceptance, use, limitations, and future needs of individuals with amyotrophic lateral sclerosis (ALS), traumatic brain injury (TBI), brainstem impairment, severe, chronic aphasia and apraxia of speech, primary progressive aphasia (PPA), and dementia are discussed.

Keywords: Amyotrophic Lateral Sclerosis; Traumatic Brain Injury; Brainstem Impairment; Aphasia; Dementia; AAC Acceptance; AAC Use

INTRODUCTION

Adults with acquired neurological conditions develop their verbal communication and literacy capabilities as typical speakers and writers. They use these skills to participate academically, vocationally, recreationally, and socially. Then, depending upon their neurological condition, they gradually or suddenly lose their speech or language capabilities and are required to rely on augmentative and alternative communication (AAC) systems to meet their communication needs. In addition to the loss of their spoken communication, the impact of their neurological condition on their participation patterns is potentially profound with reduced ability to care for themselves, a reduction or loss of employment, and usually a sudden or gradual restriction of their social networks. During the past three decades, AAC technologies have been developed to compensate for these natural communication losses. The purpose of this article is to provide a state of the science review of the following types of issues: AAC acceptance; AAC use patterns; AAC limitations; and future AAC needs of adults with a number of different acquired neurologic conditions who rely on AAC systems (e.g., amyotrophic lateral sclerosis (ALS), traumatic brain injury (TBI), brainstem impairment, severe, chronic aphasia and apraxia of speech, primary progressive aphasia (PPA), and dementia). Of course, there are many AAC intervention issues in addition to technology; however, these exceed the scope of this summary article.

AMYOTROPHIC LATERAL SCLEROSIS

The AAC device is not just a machine... becomes a part of the person's personality...The grandkids – they thought that the AAC device was Tom's voice. (Rutz, 2005, p. 4)

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive neuromuscular disease of unknown cause and no cure. Initial characteristics vary, with some individuals experiencing bulbar (brainstem) symptoms involving speech and swallowing, others who experience initial spinal symptoms involving the limbs, and still others

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who experience a mix of bulbar and spinal symptoms. Recent reports have documented ALS occurring following an initial progressive apraxia of speech (Duffy, 2006). Onset of symptoms can occur across a wide age range, from the 20s to the 60s. The impact of ALS on one's participation patterns varies considerably, depending on the life stage when it occurs. Life expectancy also varies, depending upon the type of ALS, with those who experience initial spinal symptoms surviving approximately five times longer than those with initial bulbar (brainstem) symptoms. Life expectancy is longer for individuals who opt for invasive ventilation than for those who do not. According to a database review by Ball et al. (in press), the decision to use invasive ventilation extends the length of AAC use overall, as well as the duration of time during which AAC technology must be controlled with minimal or no limb or head movement. Artificial nutrition, such as a percutaneous endoscopic gastrostomy (PEG), improves the quality of life, and may extend the length of life somewhat (Haughty, Johnson, & Campbell, 2005). It potentially could have an impact on AAC use, in that individuals with ALS who use artificial nutrition spend less time eating, have more energy, and have more time to participate in the social activities of their choice. Often, such participation in social situations increases the need and opportunity for AAC use.

AAC Acceptance and Use

In a recent review of the Nebraska ALS Database, Ball, Beukelman, and Pattee (2004) reported that approximately 95% of people with ALS become unable to speak at some point prior to death. AAC acceptance and use has increased considerably during the past decade. Prior to 1996, approximately 72% of men and 74% of women for whom AAC technology was recommended, accepted and used the technology (Mathy, Yorkston, & Gutmann, 2000). However, in a recent report by Ball, Buekelman, and Patee (2004), 96% of people with ALS for whom AAC was recommended, accepted and used AAC; with 6% delaying but eventually accepting the technology. No differences were reported for males and females. In the review by Ball et al. (2004), those who rejected AAC demonstrated a co-occurring dementia or experienced multiple severe health issues, such as cancer, in addition to ALS; while 100% of those with ALS used their AAC technology until within a relatively brief period (a few days to 1 month) prior to death, when low technology strategies become predominant.

Appropriate timing of referral for AAC assessment and intervention continues to be a most important clinical decision-making issue. Within the last decade the accuracy of the prediction of speech deterioration and the subsequent need for AAC assessment, prescription, and purchase has improved considerably. Yorkston, Strand, Miller, Hillel, and Smith (1993) initially suggested that speaking rate reduction precedes decreases in intelligibility in individuals with ALS. The speech performance of 158 different people was evaluated at 3-month intervals from diagnosis to death (Ball, Beukelman, & Pattee, 2000, 2001, 2002). These authors recommended that individuals with ALS be referred for AAC assessment when their speaking rate reaches 100 to 125 words per minute on the Sentence Intelligibility Test (Yorkston, Beukelman, & Tice, 1996). The mean speaking rate on this test for adults without disability is 190 words per minute.

Finally, a database review has documented that family members with non-technical backgrounds typically serve as AAC facilitators for individuals with ALS (Ball, Schardt, Beukelman, & Pattee, 2005). Facilitator roles included mentoring and coaching unfamiliar listeners about how to communicate with the individual, programming messages, caring for equipment, trouble-shooting, and communicating with the AAC interventionist or representative of the commercial company that manufactured the communication device. In response to a survey, these primary facilitators preferred hands-on, detailed step-by-step instruction. They reported receiving slightly over 2 h of instruction and reported that amount of training as appropriate. Those with ALS received 3.5 h of instruction.

Fried-Oken et al. (2006) surveyed AAC caregivers. They reported very positive attitudes toward AAC technology. Those with greater AAC technology skills reported greater rewards associated with caregiving. They reported increased perception of social closeness to the individual with ALS and less difficulty in providing care.

Finally, recent data from the Nebraska ALS Database have revealed that individuals with ALS use their technology until within a few weeks of their deaths. Those with primary bulbar ALS used their AAC technology an average of 24.9 months. Those with spinal ALS used their AAC technology for an average of 31.1 months. Because 15% of the participants in this study continued to use their AAC technology at the time the report was completed and were supported by invasive ventilation, the mean duration of use reported likely underestimate the length of use for this sample of individuals with ALS who

relied on AAC and for individuals with ALS in general (Ball et al., in press).

Future Research Directions

Access Options

Individuals with ALS are using AAC technology for extended periods of time. There is a need for technology that can be adjusted to meet a range of motor capability demands, as it is not uncommon for users to utilize more than one access strategy. During the past decade, the effectiveness of dynamic touch screens has offered a range of interface options. In addition, the improving sensitivity and accuracy of headtracking technology has allowed for improved access to technology using head movement only: however, calibration issues remain for individuals with limited range of movement. Eye tracking technologies to access AAC devices continue to improve; however, they still are usually only effective under nearly ideal situations. Eye-tracking technologies that operate effectively and efficiently under a range of lighting conditions and postural conditions are still needed.

Speech Synthesis

Given the age range of individuals with ALS who use AAC and the age of other individuals who reside in long-term care settings with some of these individuals, there is a continuing need for synthesized speech that can be easily understood by elderly people in less than optimal situations. As new speech synthesis voices are introduced in speech generating devices (SGD), the effectiveness of these voices in adverse listening situations should be investigated and reported. In addition, the impact of the naturalness of synthesized speech on the acceptance and use of SGDs should be studied.

Access to other Technologies

Individuals with ALS present with a range of needs to use their AAC technology to connect them to the outside world (see DeRuyter, McNaughton, Caves, Bryen, & Williams, 2007). We have informally observed that younger adults with ALS use the Internet extensively to maintain their social networks. This use pattern probably occurs for several reasons. First, their generation has been active on the Internet since an early age. Second, their spouses often must be employed and their children are in school, which means there is limited support to maintain social net-

works. The qualitative research of McNaughton, Light, and Groszyk (2001) and McNaughton and Bryen (2002) has also shown that some individuals with ALS continue to use their AAC technology to program computers, do word processing, provide accounting services, or consult over the phone or Internet.

Facilitator Instruction

As previously mentioned, AAC technology facilitators for individuals with ALS are selected largely because of their availability rather than their technical expertise. Therefore, there is a continuing need for "just-in-time" instruction to support them in their facilitator role(s).

TRAUMATIC BRAIN INJURY

The individuals with TBI in this study generally accepted AAC recommendations. When (AAC) technology was abandoned, it usually reflected the loss of (AAC) facilitator support rather than a rejection of the technology (Fager, Hux, Beukelman, & Karantounis, 2006b, p. 37).

The range of communication disorders resulting from traumatic brain injury (TBI) is extensive and includes cognitive/linguistic as well as motor speech disorders. Two research groups (Dongilli, Hakel, & Beukelman, 1992; Ladtkow & Culp, 1992) have focused on the question of determining which individuals with TBI will experience persistent communication disorders that will require long-term AAC use. The results of these medical chart reviews are quite similar. Of those who were unable to meet their communication needs with natural speech early in their recovery, 55-59% recovered functional natural speech during the middle stage of recovery (Rancho Levels V and VI). Those who did not become functional speakers at this point of recovery typically were unable to speak because of chronic, severe, motor speech or language disorders. Many of these individuals relied on AAC for the longterm; however, there have been case reports of individuals who received long-term intervention for motor speech disorders and became functional speakers to meet some or all of their communication needs (Enderby & Crow, 1990; Light, Beesley & Collier, 1988; Workinger & Netsell, 1992).

Current medical interventions reduce the extent of acute brain swelling following injury, thereby reducing the brain damage resulting from obstruction of blood circulation. While the impact of these interventions on brain swelling is increasingly well documented, the impact of such interventions on the incidence of speech, language, and cognitive impairment has not been reported. However, anecdotal trends suggest that people with more recent injuries, who cannot meet their communication needs through natural speech alone, typically experience severe, residual cognitive/linguistic as well as motor limitations. Clinical observations suggest that there appear to be fewer people with relatively preserved cognitive function and severely impaired motor speech now than in previous decades. Given new medical interventions, additional research is needed to predict those with TBI who will and will not recover functional natural speech. Nevertheless. individuals with TBI still experience such severe brainstem damage that they require AAC due to the chronic motor speech disorders that persist. Because of the relatively young age of many individuals with TBI, the life expectancy of those who rely on AAC is extensive, although the average duration of AAC use has not been investigated and reported.

AAC Acceptance and Use

In a recently published clinical review, Fager et al. (2006b) investigated the long-term AAC acceptance and use patterns of adults with TBI. Following an AAC assessment, 68% of this sample was advised to utilize high-technology AAC devices, and 94% of these individuals and their decision-makers, accepted the recommendations. After 3 years, 81% continued to use their AAC technology, 6% had not receive the technology because of funding problems, and 12% had discontinued AAC device use because they did not have appropriate AAC facilitator support when they transferred to a new living setting. Of the group who relied on hightechnology AAC devices, 87% used letter-byletter spelling, while the remaining 13% relied on symbols and drawings.

Low technology AAC options were recommended for 32% of the total group of individuals with TBI. Of this sub-group, 100% accepted the recommendation. After 3 years, 63% continued to use their low-technology AAC strategies at least part time, while the remaining 37% discontinued use because they regained sufficient natural speech to meet their communication needs. The most commonly used strategy was letter-by-letter spelling, with one individual relying on symbols and drawings because he had been injured before learning to read and spell. It should be noted that there was less discontinuation of AAC use for this group of TBI participants than was reported by DeRuyter and Lafontaine (1987) nearly two decades ago, probably as a result of improved AAC technology and service delivery.

In summary, there was a relatively high level of acceptance of AAC systems by these individuals and their decision-makers. Those with TBI who relied predominantly on AAC utilized letter-by-letter spelling strategies, because their cognitive limitations interfered with their ability to encode messages and utilize other message formulation strategies. Those who discontinued AAC use because they had recovered natural speech reported a lack of funding, and lost the support of an AAC facilitator. None of the participants rejected AAC after receiving a low technology or high technology AAC option.

Future Research Directions

Reducing the Cognitive Load for Word/Message Prediction and Retrieval

Nearly all individuals with TBI prepare messages using letter-by-letter spelling, unless their injury occurred prior to achieving literacy. Occasionally, one may learn to retrieve messages using an encoding strategy and uses this strategy during routine communication interactions. There are few reports describing word prediction use. The authors of the current study have attempted to teach the use of encoding and/or word retrieval to several individuals with TBI who spell their messages using AAC technology. Some were able to learn the encoding or prediction strategy in the intervention setting; however, none of those taught used the strategy in their everyday communication, reporting that it was "too much work" and that they did not "think that way." There continues to be a need for a means to retrieve words and messages with reduced cognitive demands.

Supporting AAC Facilitator Learning

Over the years, we have observed extended AAC use by individuals with TBI. It is also becoming clearer that these individuals will make a number of transitions with regard to living arrangements. Often the long-term goal is to achieve assisted or independent living. However, in time, a number of these individuals choose to move out of their apartments into group living arrangements. In either case, it is apparent that an effective AAC facilitator is critical for continued successful use of AAC technology. In fact, the Fager et al. (2006b) review revealed that the use of AAC technology by two respondents was discontinued due to a lack of consistent facilitator support during their transitions to residential settings. "Just-in-Time" instruction may decrease the challenge of maintaining consistent facilitator support during residential transitions.

Supporting the use of Residual Natural Speech

Individuals with dysarthria as a result of TBI typically wish to use their residual speech to communicate. Those with very mild dysarthria may use speech to meet most of their communication, while those with moderate dysarthria often need AAC to supplement their speech in adverse communication settings and to resolve communication breakdowns. Those with severe and profound dysarthria require AAC almost all of the time, and typically use their natural speech only with familiar people during highly predictable communication exchanges. There are a number of concerns associated with the relatively limited accuracy of commercial speech recognition systems for individuals with moderate and severe dysarthria. To begin with, the instructional strategies required by commercial recognition systems are often too difficult for many individuals with moderate, severe, and profound dvsarthria. In addition, recognition accuracy is relatively low for those with dysarthria who are able to complete the training protocols. As a result, there are no published reports of individuals with moderate to profound dysarthria who use speech recognition to meet their routine communication needs. Individuals with TBI are not the only individuals with motor speech limitations who strongly prefer to use residual speech. Some individuals with dysarthria due to brainstem impairment or cerebral palsy also express strong preferences to utilize their natural speech when they can.

BRAINSTEM IMPAIRMENT

S.J. made consistent progress with increasing his head movement using the safe-laser¹ system, even though he had been "locked-in" for 18 years....He was so encouraged that, when he entered the hospital with pneumonia, he changed his medical cold status from "do not resuscitate" to "full code" (Fager, Buekelman, Jakobs, & Karantounis, 2006a, p. 227).

Brainstem impairment damages the central nervous system structures that control speech production. Individuals with brainstem impairment often experience anarthria, that is, they are unable to speak at all, or experience dysarthria such that their speech is difficult to understand (Duffy, 2005). Reports of natural speech recovery vary from 0 to 25% (Culp & Ladtkow, 1992; Katz, Haig, Clark, & Dipaola, 1992; Soderholm,

Meinander, & Alaranta, 2001). Depending upon the severity of the speech impairment, these individuals require AAC, motor speech intervention or both. Nearly all of these individuals require AAC support soon after the onset of this condition, as most are unable to speak during the acute phase. However, many rely on AAC due to chronic severe motor impairment that may or may not be classified as locked-in syndrome.

AAC Acceptance and Use

AAC intervention for individuals with brainstem impairment has been reported for at least two decades. Beukelman, Yorkston, and Dowden (1985) describe the use of multimodal, low and high technology AAC strategies by two women with brainstem strokes. Both accessed their devices using head movement. Katz et al. (1992) reported a range of AAC strategy use by 29 individuals with TBI, including no-technology, facial movements, dependent scanning, and hightechnology alternatives. Culp and Ladkow (1992) reported that approximately half of 16 individuals relied on direct selection and half relied on switch access strategies to activate their AAC technology. Those with brainstem impairment who used direct selection relied on single finger or head movement access; while those who used scanning relied on eyebrow, head, or hand movement.

More recently, Soderholm et al. (2001) reported a follow-up study of 17 individuals with LIS between 1979 and 2000. All of the AAC systems were multi-modal in that they consisted of low-and high-technology strategies. Switch access sites included head movements, mouth, fingers, and hands. Assistive technology was used for communication, internet, email, writing, telephone, games, vocational duties, and faxing. One person acquired a computer-based system 15 years after onset of illness.

Fager et al. (2006a) described the impact of an intervention involving safe-laser pointing technology on six individuals with complete LIS. The six were invited to participate in this project (4 weeks to 18 years post onset of their brainstem strokes); none were able to use natural speech to communicate nor to access AAC technology. All communicated using eye movements (e.g., looking up or down, eye blinks, dependent scanning strategies with eye movement signals, or eye linking). One was a severely dysarthric speaker, who could be understood by only very familiar listeners. Following intervention with the Safe-Laser Access System, three of the six participants developed head movement sufficient to control AAC technology. Two individuals continued to develop head control; however, their progress had been

slowed by repeated illnesses. One has since discontinued his involvement with the project because of medical and psychological issues. These six participants represented consecutive referrals to the project.

The life expectancy of individuals with brainstem impairments who rely on AAC has not been documented. However, Katz et al. (1992) reported an 85% survival rate after 5 years. One of the people described by Fager et al. (2006a) had already survived for 20 years. The need for AAC to support communication is extensive in this population.

Future Research Directions

Motor Learning to Restore Head Movement or Body Movement

As is apparent from the previous section, there is some preliminary evidence that individuals with severe brainstem impairment are able to learn head movements, sufficient to access AAC technology, when provided with technology to provide them with precise, instantaneous feedback regarding residual movement and when given extensive practice time. Ongoing research is needed to determine the extent to which motor learning provides sufficient recovery of head movement to allow for the use of conventional head tracking technologies. There is also a need for head-tracking technologies that reduce the calibration problems experienced by those with inconsistent or minimal head movement.

Eye-Tracking Technology under Less Than Optimal Conditions

Some individuals with severe brainstem impairment who are unable to develop sufficient head movement to control AAC technology might successfully use eye tracking to access AAC technology. To date the literature is limited regarding the use of eye tracking by these individuals. During the past decade, improvements in eye-tracking technology have occurred; however, the intervention experiences of the authors reveals that this technology remains difficult to use unless conditions are optimal and include at least the following: (a) proper lighting, (b) precise positioning of the technology, (c) limited residual head movement, and (d) precise calibration support. For eye tracking to be effectively employed by individuals with severe brainstem involvement, advancement in less than optimal conditions must be made with respect to

both individual (e.g., fatigue) and environment-based considerations.

AAC Systems Well-Connected to the World

Severe, chronic brainstem involvement results in dramatic lifestyle changes such as change in residence, loss of employment, and a shrinking of one's social network. Therefore, the Internet provides an opportunity to remain engaged with family, friends, former colleagues, and others with severe disabilities. Additionally, it supports educational, recreational, and volunteer activities. Of course, this can only be achieved through efficient interconnectivity among AAC technology and other communication technologies (see DeRuyter et al., 2007).

SEVERE, CHRONIC APHASIA AND APRAXIA OF SPEECH

After her stroke, our mother refused to attend (social) functions due to embarrassment of the challenges she faced when interacting with people outside of her immediate family...Her success (with a Visual Scenes Display AAC device) led to a renewed interest in attending family gatherings. Six weeks after the introduction of (the AAC device), she left her house for the first time (after her stroke), to engage socially – she went to a family holiday gathering" (Personal communication with the adult daughter of a woman with severe, chronic aphasia, Aimee Dietz, June 15, 2006).

Aphasia is an impairment that results from brain injury, usually due to cerebrovascular accident, that may impair language production, language comprehension, or both. Most people acquire aphasia after the age of 60 or 70 years. Approximately one out of 275 elderly adults in the United States has aphasia. The incidence is equal for males and females (National Aphasia Association, 1988). Up to 40% of individuals with aphasia have chronic, severe language impairment; life expectancy data are not available.

Traditional aphasia intervention has focused on restoration of functional communication by reducing the language impairment. However, individuals with severe aphasia often do not recover sufficient language capability to become functional communicators without compensatory support from a variety of AAC strategies, such as drawing, low-technology communication books and boards, remnant materials, gestures, writing, and high-technology AAC. Typically, these compensatory communication strategies support the

co-construction of messages by individuals with aphasia and their communication partners. However, language limitations in symbolizing meaning using printed messages or icons (representation), spelling, combining words, or sequencing icons into messages (formulation), and locating information in a book or electronic device (navigation), often restrict the ability of individuals with severe, chronic aphasia to use AAC strategies to meet their diverse communication needs (Garrett & Lasker, 2005). A detailed description of traditional language restoration interventions is beyond the scope of this article; however, AAC use by individuals with severe, chronic aphasia is discussed in the following sections.

AAC Acceptance and Use

Acceptance

Effective implementation and development of AAC strategies for individuals with severe, chronic aphasia necessitates a thorough understanding of attitudes toward and acceptance of AAC. Often, those with severe, chronic aphasia reject AAC secondary for fear of it interfering with, or impeding, the restoration of their natural language system. This idea of acceptance and attitude extends beyond individuals with aphasia and includes their family, friends, and peers. Families often prefer natural speech for their loved ones, whereas people less familiar with individuals with aphasia prefer AAC strategies (Lasker & Beukelman, 1999). In studies by Buekelman and Ball (2002), both families and peers agreed that they were uncomfortable with the AAC strategies, to a certain degree, because they worried that the implementation of such an approach might impede the return of natural speech. Additionally, the authenticity of the messages and stories that are stored in AAC systems is questionable, especially when SGDs are used. Lastly, a recurrent theme in the qualitative portion of Lasker and Beukelman's study (1999) was whether the individual with severe, chronic aphasia actually authored the messages.

Low-Technology AAC

AAC intervention options for individuals with severe, chronic aphasia are improving and are increasingly documented in book chapters and case reports. Garrett and Lasker (2005) and Lasker, Garrett, and Fox (2007) outlined five classifications of individuals with aphasia, described their communication characteristics, and

suggested intervention strategies. Case reports that describe low-technology interventions date back nearly 30years and include: communication and remnant books, drawing, photography, written words, messages, and written choices (Beukelman et al., 1985; Garrett & Huth, 2002; Garrett & Lasker, 2005; Hos, Weiss, Garrett, & Lloyd, 2005; Lyon, 1992, 1995; Lyon & Helm-Estabrooks, 1987).

An ongoing concern regarding the routine use of low-technology AAC strategies is the lack of contextualization and personalization of communication books and boards given with aphasia. Although there are interventionists who provide personalized materials on a routine basis, in medical settings there is a tendency to provide commercially available communication boards in order to facilitate communication about pain, preferences, and health concerns while deemphasizing the importance of communicating to maintain social closeness, transfer new information, and express social etiquette (Light, 1988). Currently, there is limited technology (computer) support to assist clinicians in the preparation of high quality, personalized communication books and boards, although Weissling and Beukelman (2006) recently provide low-tech visual scenes templates (http://aac.unl.edu) to prepare such materials.

High-Technology Interventions

Computer-assisted language intervention for individuals with aphasia is available. Lingraphica² operates in the following manner: "The software provides graphic building blocks which are called 'icons' (small pictures, sometimes animated), 'windows' in which these icons are can be accessed, manipulated, and displayed, and 'cursor tools' which allow the individual to manipulate the icons and windows in various ways" (Steele, Kleezewska, Carlsons, & Weinrich, 1992, p. 186).

Another computer-assisted intervention found in the literature is Talking Screen.³ It operates similarly to Lingraphica and researchers report comparable treatment (Kroul & Harding, 1998). However, these authors also highlighted several critical issues that concern the implementation of this type of technology with individuals who experience severe, chronic aphasia: "...the question still arises as to whether this...performance can be translated into a functional AAC system." (p. 220). The majority of studies involving Lingraphica measured improvement by means of pre- and post-test methods utilizing only standardized tests. No pre- and post-treatment measures were reported to evaluate the change in the quantity or quality of conversational exchanges or community-based communication performance (Aftonomos, Appelbaum, & Steele, 1999; Lefkos, Steele, & Wertz, 1997; Steele et al., 1992).

In recent years, there have been increased reports of high-technology SGD AAC interventions for individuals with severe, chronic aphasia; however, most of these interventions have focused on supporting specific communication tasks such as answering the phone, calling for help, ordering in restaurants or stores, giving speeches, saving prayers, and engaging in scripted conversations (Garrett & Lasker, 2005). In an effort to develop an AAC device prototype designed to support common interactions dealing with a relatively wide range of topics, narratives, and experiences, researchers associated with the AAC-RERC (David Beukelman, Janice Light, and Howard Shane) initiated the Visual Scene Display (VSD) project. The Visual Scene Display for Adults⁴ was designed to provide those with severe, chronic aphasia (and apraxia) with visual-contextual support to facilitate navigation of a dynamic display SGD AAC system that would allow them to successfully communicate messages/intent (Dietz, McKelvey, & Beukelman, 2006).

Typically, a visual scene is contextualized, meaning that the elements in the scene are depicted in relationship to the natural environment (i.e., picture of a wedding or kids' soccer game). Such a scene establishes the context for a conversational interaction and provides individuals with aphasia and their communication partner(s) with information to support multiple communication exchanges. By contrast, a portrait contains limited, usually decontextualized information (i.e., a picture of a person with a plain background). Any additional information about the person(s) or object in a portrait must be generated by the individual with aphasia or speculated on by the communication partner. Because spontaneous generation of specific and detailed information is difficult for individuals with severe, chronic aphasia, the use of contextually rich visual scenes allows for mutual understanding and may decrease the need for extensive generative language use (McKelvey, Dietz, Hux, Weissling, & Beukelman, 2007).

Historically, most AAC systems have been organized in grids in which symbols/pictures/ icons occupy individual spaces at regular intervals. The demarcation of the individual squares isolates each symbol, thus requiring users to process individual symbols and combine them to formulate messages. Consequently, individuals with aphasia and their communication partners are required to formulate messages using iconic information that has little implied relation to one

another. In contrast, each element in a visual scene is pictured in its natural relationship and position to all other elements in the scene. The individual with aphasia and the communication partner co-construct "the gist" of the visual scene. The meaning of all elements and semantic associations are integrally tied together, creating a holistic context. In addition, contextualized pictures are paired with text and voice output to communicate specific messages, ask questions, and/or provide support for the communication partner.

As the VSD prototype is refined, preliminary research that describes learning, generalization, use patterns, and acceptance associated with its use by individuals with severe, chronic aphasia is ongoing. Additionally, McKelvey et al. (2007) report a single-subject design study that revealed that the VSD interface facilitated generalization of navigation skills across new themes, with minimal to no instruction, by a individual with moderate-severe, chronic aphasia. This trend was documented during one-on-one interactions with 20 unfamiliar communication partners.

Future Research Directions

Technology

Low-technology communication books and boards are increasingly used to supplement the communication efforts of individuals with severe, chronic aphasia. Advances in accessibility of commercial computer software, digital photography, and Internet tools must be incorporated into the development of personal and contextualized low-technology AAC materials.

Impact of Context on AAC Interface Use

Due to the language limitations of individuals with severe, chronic aphasia, their messages are frequently co-constructed with their listeners. Thus, future AAC systems must allow for access and support for individuals when interacting with an AAC device. This access must be provided contextually, at a level that can be comprehended by both individuals. In addition, the system must contain navigation strategies that can be easily managed by both system users and their communication partner. Preliminary work with the VSD interface demonstrated that building upon the residual visual-spatial skills of individuals with severe, chronic aphasia (to formulate messages and support navigation) may be key to successful implementation of a high-technology SGD.

High-Quality Speech Output

Current speech synthesis technology often interferes with the communication partner successfully understanding messages produced. Given the age, hearing, and auditory comprehension ability of many individuals with severe, chronic aphasia, as well as their communication partners (i.e., spouses, friends, adult children), the need for natural-sounding, intelligible speech output is essential.

Integration of Contextually Relevant Information into Traditional Aphasia Interventions

Typically, AAC strategies are used sparingly, if at all, during the restoration phase of intervention for individuals with severe, chronic aphasia. Clinicians tend to introduce AAC only after the restoration of language skills has plateaued. This approach may impede the acceptance and successful learning of a multi-modality approach to communication. Furthermore, the clinicians responsible for the provision of services for this population (i.e., in-patient and out-patient rehabilitation, aphasia support groups, and long-term care centers) may have little AAC expertise. As AAC strategies for those with severe, chronic aphasia become increasingly more effective and available, there will be a need for an extensive and sustained effort to prepare interventionists to support this population. A number of excellent chapters have been written in this area (Garrett & Lasker, 2005; King, Alarcon, & Rogers, 2007; Lasker et al., 2007; Rogers, King, & Alarcon, 2000).

Acceptance and Use of AAC for Individuals with Severe, Chronic Aphasia

As AAC strategies for those with severe, chronic aphasia are developed and refined, there is a need to prepare them, as well as other decision makers (i.e., family, caregivers, physicians, and speech language pathologists) to recognize the need for and the potential of AAC options across the rehabilitation spectrum (acute care to outpatient to home-health care). Research focusing on the attitudes and acceptance of these decision-makers regarding use of AAC in a range of communication settings is very limited.

PRIMARY PROGRESSIVE APHASIA (PPA)

Proactive management (for PPA) is planning ahead. You would plan ahead if you were to travel to another country where the language is

different from your native language. You would prepare by asking yourself what messages you will need to express and anticipate situations where you will need to communicate (King et al., 2007, p. 221).

Primary progressive aphasia (PPA) is now recognized as a distinct clinical condition resulting in the gradual progression of language impairment in the absence of more widespread cognitive and behavioral disturbances for at least 2 years (Mesulam, 2001; Rogers et al., 2000). The mean age of onset is 60.5 years (Duffy, 2005), with a 2:1 ratio of men to women. After a long history of symptoms, some individuals with PPA demonstrate cognitive symptoms consistent with the diagnosis of dementia.

Rogers et al. (2000) describe a three-stage plan of AAC intervention that relies extensively on low-technology AAC options such as communication notebooks consisting of photos, icons, and collections of remnants that represent an experience or an episode. Usually these items are accompanied by printed names or messages to assist individuals with PPA and their listeners. Beyond the above description, AAC interventions for individuals with PPA are limited. Typically, individuals with severe, chronic aphasia utilize AAC strategies.

Future Research Directions

Research documenting the type, effectiveness, and timing of AAC intervention strategies for persons with PPA, as well as AAC facilitator instruction and training is, essentially, non-existent (Cress & King, 1999; King et al., 2007; Rogers et al., 2000). There is an ongoing need to document all aspects of AAC intervention with these individuals. One would assume that initially this research will take the form of case and small N reports.

DEMENTIA

The aim of the interventions...is to maximize communicative and memory functioning to maintain (or increase) activities, participation/engagement, and quality of life for people with dementia across the disease progression. Furthermore, these interventions may also increase the quality of life and decrease the stress of family and professional caregivers of individuals with dementia (Bourgeois & Hickey, 2007a, p. 243).

Dementia is a condition characterized by acquired, chronic, cognitive impairment that may involve a variety of domains, including executive function, attention, organization, visuospatial function, praxis (movement) or

language. This population is projected to grow considerably over the coming years. Currently, 10% of people aged 65 years and 47% of people 85 years and older have been diagnosed with Alzheimer's disease (AD), a form of dementia. Presently 4 million people in the United State have a diagnosis of AD; this number is expected to increase to 14 million by the year 2050. Fried-Oken, Rau, and Oken (2000) provide a summary of the cause(s), diagnosis criteria, clinical symptoms, staging and medical management of individuals with dementia. Given the range of symptoms associated with the dementias, the impact on communication needs and capabilities is extensive (Bayles, 1984; Bourgeois & Hickey, 2007b; Ripich, Carpenter, & Ziol, 2000a; Ripich, Fritsch, Ziol, Durand, 2000b; Ripich & Terell, 1998).

Interventions are designed to maintain function, compensate for lost function, and/or to counsel the individual or family regarding conditions and options for managing the symptoms of dementia. Compensatory support can take many different forms and may include low-technology communication cards and books, pictures, drawings, and printed reminders. Such interventions often are designed to support those with dementia to remind them of temporal or semantic information. High-technology support for visual or auditory information is also available such as computerized memory aids (Bayles & Kim, 2003; Bourgeois, 1994; Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001; Fried-Oken et al., 2000; Hanson & Beukelman, 2005). These products are typically designed to support the individual, rather than to support his or her communication interactions, per se. However, if the definition of AAC is expanded to include internal communication (communication with self) (Beukelman & Mirenda, 2005), these supports might be considered AAC interventions.

AAC Acceptance and Use

AAC interventions for individuals with dementia are relatively new, but there is mounting evidence of their effectiveness (Bourgeois, 1990, 1992, 1993; Bourgeois, Schulz, & Burgio, 1996, Bourgeois et al., 2001, 2003; Hanson & Beukelman, 2005). Most of the interventions involve low-technology memory and communication books and high-technology displays that are positioned within one's living space. Additional techniques include modifications of the communication partner's behavior during communicative interactions: (a) reduction of distractions, (b) using short simple sentences, (c) reducing questions to yes/no format, (d) allowing time for the

individual with dementia to respond, and (e) word finding strategies, such as word description if it cannot be retrieved (Bourgeois & Hickey, 2007a; Small, Gutman, Makela, & Hillhouse, 2003).

Future Research Directions

As can be seen from the previous review, research into low-tech AAC and memory support for persons with dementia is ongoing. However, high tech support options are much more limited. Fried-Oken, Rowland, Oken, Small, and Baker, (2005) are currently examining lexical representation formats with and without voice output that are to be used by individual with dementia who rely on communication and memory aids. Alm et al. (2004) are working on a high-tech multimedia system that supports reminiscence interactions. It contains photos, video, songs, and sounds that are accessible through a touch-screen display. Research that investigates the use of AAC and cognitive support technology by persons with dementia is encouraging. However, research that focuses on use of such technology to enhance communication interaction and social engagement is essential.

SUMMARY

In summary, the impact of AAC services and technology is inconsistent across the various groups of individuals with acquired, neurologic conditions. For example, both AAC acceptance and use have increased for individuals with amyotrophic lateral sclerosis (ALS) and traumatic brain injury (TBI), and are being more completely studied and documented than a decade ago. In addition, the effectiveness of AAC options for some formerly underserved populations (aphasia, brainstem impairment, and dementia) is steadily improving, although these new strategies have not become standard practice. There are several under-served groups of individuals with neurologic conditions such as Parkinson's disease, Huntington's disease, multiple sclerosis, and myasthenia gravis. One would assume that some of these individuals are receiving AAC interventions; however, a review of the literature over the past decade revealed little systematic activity to document or improve AAC intervention services for these individuals.

The role of communication partners and AAC facilitators has received increasing attention during the past decade. The need to provide targeted instruction and support for these individuals as well as those who rely on AAC remains an important future goal for the AAC field.

A general awareness of the impact of severe communication limitations on social engagement and participation of adults who rely on AAC has been documented consistently in the literature. However, the extent and patterns of these social restrictions have received limited systematic investigation. The development of AAC technologies and strategies to more effectively connect people who rely on AAC s to "their worlds," in order to support social engagement and involvement, remains an important challenge.

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Notes

- 1 Safe Laser Assess System is a prototype being developed by InvoTek, Inc., 1026 Riverview Drive, Alma, AR 72921. This laser pointing system operates at high power when pointed at a laser sensing service and switches to a lowpower, eye safe mode when pointed away from that surface.
- 2 Lingraphia software is available from Lingraphiccare, Inc., 580 Second St., Suite 210, Oakland, CA 94607, USA. Tel: +1 510 302 0500.
- 3 Talking Screen software is available from Words +, Inc., 42505 10 Street West, Lancaster, CA 93534-7069, USA. Tel: +1 661 723 6523.
- 4 Visual Scene Display for Adults (Aphasia and Traumatic Brain Injury) is available from Dynavox, 2100 Wharton Street, Suite 400, Pittsburgh, PA 15203, USA. Tel: +1 412 381 5241.

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