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Augmentative and Alternative Communication Treatment for Persons With Primary Progressive Aphasia

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Abstract

Persons with primary progressive aphasia (PPA) are appearing more frequently in our AAC clinics. The syndrome is identified by the insidious onset and gradual loss of word finding, object naming, or word-comprehension skills with otherwise intact cognitive skills over a 2-year period in adults. Management of persons with this language-based neurodegenerative disease challenges our understanding of language competence and performance in adults. Clients present us with questions about when and how to provide intervention techniques and how to change the treatment as they slowly lose language skills. An AAC framework for intervention during the neurodegenerative language process seen in Nonfluent Progressive Aphasia is proposed. Tools and strategies are presented that have been reported in clinical cases for individual clients.

At the 2008, DAAC conference in Long Beach, California, Dr. LaPointe used the metaphor that language rehabilitation is the “raft” for the aphasic individual who experiences a “wreck.” I propose that augmentative and alternative communication (AAC) is the paddle for the raft. AAC provides a series of tools and techniques that the individual with aphasia can use to get that raft into a safe and secure harbor, anchored next to communication partners. With that clear picture in mind, let’s discuss AAC treatment for persons with primary progressive aphasia.

Let’s start with definitions. Primary progressive aphasia (PPA) is a degenerative language disorder that does not easily fit into the classical aphasia typology (Duffy & Peterson, 1992). Mesulam (2001) describes the typical symptoms: insidious onset and gradual loss of word finding, object-naming or word-comprehension skills in spontaneous conversation; activities of daily living (ADL) limitations attributable to language impairment, for at least 2 years after onset; intact premorbid language skills; absence of significant apathy, disinhibition, forgetfulness for recent events, visuospatial impairment, visual recognition deficits or sensory-motor dysfunction within initial 2 years of language impairment; acalculia and ideomotor apraxia may be present in the first 2 years. Other domains possibly are affected during two years, but language is the most impaired function. Finally, there is an absence of specific causes (i.e., stroke, tumor, infection, metabolic disorder) on neuroimaging. Age of onset is usually 40 to 75 years old, with a mean onset age of 60 years. There is a preponderance of male patients. PPA is a clinical syndrome which may overlap with

Alzheimer's disease, frontotemporal dementia, corticobasal degeneration; dementia-lacking-distinctive-histology (DLDH); Creutzfeldt-Jakobs disease; amyotrophic lateral sclerosis; asymmetric cortical degeneration and Pick's disease (Kertesz & Munoz, 2002). As a syndrome that often is followed by cognitive decline, PPA has been described with three variants. The most common variant is non-fluent progressive aphasia (NFPA) or PPA with agrammatism. These are the patients who will often be referred to our AAC clinics. The other variants are semantic dementia (resembling fluent progressive aphasia) and logopenic progressive aphasia (also referred to as PPA with comprehension deficits). PPA presents us with a clinical conundrum: language behavior is truly variable, and we don't know if we are looking at impairment of linguistic competence or performance. There is much diagnostic drama revolving around this relatively new syndrome. Within neurologic syndrome identification, it has been categorized under the "Neary Criteria" for fronto-temporal lobe dementia (Neary et al., 1998) and it has been considered simply a variant of Pick's disease (Karbe, Kertesz, & Polk, 1993).

A number of clinicians have published case reports on AAC intervention for individuals with PPA (Murray, 1998; Cress & King, 1999; Rogers, King, & Alarcon, 2000). Rogers and Alarcon (1998) clearly presented a continuum of behavioral and tool-based interventions for a client with PPA over a 4-year period as his communication skills declined. When the client presented early with syntax, phonology, or motor speech impairments, interventions were aimed at developing long-term probes, pacing and syllable segmentation; decreasing fillers; and identifying topics and key words. As access to semantic and orthographic information deteriorated, treatment options included gestures, writing, drawing, a communication book, speech generating device, and, finally, partner-focused guided communication. The involvement of the communication partner was a key component of treatment as message co-construction was required. Keep in mind that this treatment progression from unassisted to assisted treatment resembles the hierarchy that is standard for individuals with neuromuscular disease, such as ALS. Cress and King detailed the advantageous use of props or physical tools for two persons with PPA. They described the use of maps to talk about locations and events in specific places; a calendar and clock to talk about events in the past and present; a family tree to talk about relations; a generic "people" sheet to establish context for specific exchanges; and a self-generated blueprint of the client's house. A recipe box with index cards that included food labels or pictures of frequently purchased items was used. Drawings and gestures, natural unaided approaches, were reinforced as long as a communication partner knew what they represented. King, Alarcon and Rogers (2007) provide handouts for the AAC clinician that guide the clinical assessment and provide strategies for the person with PPA within a multimodal model for supporting communication.

All of the clinical case reports can be set within an AAC framework, where we are faced with two treatment challenges for the adult with PPA. First, we are challenged to find ways to place the clients' residual lexica visually in front of them so that they can participate in daily activities as his/her language skills decline. Second, we must engineer the environment to support successful communication. The challenges lead to three questions that drive our intervention plan: Where, on the natural communication continuum, can we intervene first with AAC treatment for the person with PPA and his/her partners? How do AAC strategies and devices change

with clinical progression of the syndrome? Finally, can AAC intervention change the functional presentation of the disorder?

Operationally, these two challenges are expressed as three treatment goals:

1. To compensate for progression of language loss (not stimulate the language system to regain skills).
2. To start early. Begin compensatory treatment as soon as possible. Be proactive so the person with PPA can learn to use communication strategies and tools.
3. To include primary communication partners in all aspects of training, with outreach to multiple partners.

These challenges and goals are not new ones for AAC clinicians who treat individuals with neurodegenerative speech impairments. As such, a treatment framework is proposed that will assist clinicians in planning and justifying intervention for this language-based neurodegenerative disease. The proposed framework resembles the Speech-Language Pathologist’s Clinical Pathway for Communication Changes in ALS that was developed by Trautman, Ourand, Bardach, Vess, Caves and DeRuyter (2004). In the ALS framework, AAC assessment and intervention are divided into five stages: normal speech processes, detectable speech disturbance, reduction in speech intelligibility, use of AAC, and no functional speech. A similar division can be used with patients who present with PPA that is based on language deterioration, rather than motor speech changes. A preliminary, scaled-down framework will help to continue to write about in the future.

Proposed Stages of Intervention during the Neurodegenerative Language Process: NPPA

| Stage | Treatment | Partner involvement |
|--|---|---|
| I: No noticeable changes in expressive language | Education | Education |
| II: Detectable language lapses with hesitations and dysfluencies | Behavioral strategies to support conversation | Partners learn how to ask questions, reduce time demands on conversation, provide choices, and alter verbal and physical environment to support communication |
| III: Reduction in language use (circumlocutions; paraphasias; simplification; agrammatism) | Introduction of low tech AAC with training on downshifting for most effective communication strategy | Partners learn strategies and message selection techniques to identify visual forms of mental dictionary. |
| IV: Use of AAC tools and other techniques to augment expression | Introduction of additional tools and techniques for multi-modal communication system, including speech generating devices | Partners learn strategies and operations of each tool. Continue message selection techniques to identify visual forms of mental dictionary. |
| V: No functional language | Reduce tool choice if options become too overwhelming; continue family/care giver education and environmental support for established multi-modal communication system. | Partners become pivotal in successful interaction. They may carry the content of conversation while supporting participation with multi-modal techniques. |

It is beyond the scope of this article to discuss the behavioral techniques for intervention, which closely resemble those used in intervention for adults with anomia or chronic expressive aphasia (LaPointe, 2004; Chapey, 2001). Certainly, tool use will vary with needs and abilities (language competence) as well as the demands of the situation (performance requirements). It would behoove the clinician to work within

the AAC chronic aphasia framework discussed by Garrett and Lasker (2005) as a foundation for PPA assessment and intervention planning.

As discussed in previous case reports, the multi-modality communication system is the key to successful expression by the person with PPA. His/her visual communication system will expand as verbal skills decline. Options for low tech devices might include customized brag books (small photo albums for pictures, symbols, words lists) and remnant boxes, where small items are placed inside to provide topic or content cues for discussion. Many AAC manufacturers offer simple devices that may be chosen by clients as support in certain environments. Single message devices, such as the GoTalk® One or Personal Talker by Attainment Company, talking photo albums or simple digitized devices, such as the Bluebird II or Chatbox by Saltillo, are examples of relatively easy-to-use devices for expression.

One AAC tool that has received much attention in Europe but is not yet widely used in the United States is Talking Mats™ (Murphy, 2000). Talking Mats™ is a visual framework using PCS™ symbols to help people with communication impairments secondary to neurodegenerative disease or stroke to interact more effectively (Murphy, Tester, Hubbard, Downs, & MacDonald, 2005). It is a supported means of expression for choice making, goal setting, sharing opinions, and directing individual options. Talking Mats™ presents topics in a structured, consistent, and visual means for both comprehension and expression. This interactive tool consists of three sets of picture symbols (topic, options, visual scale) that are backed with Velcro™ and adhere to a textured mat. The clinician presents three symbols to the client: happy, unsure, not happy, and asks the client to place relevant images under one of the three symbols to show preference. In a recent study that showed the effectiveness of this nonelectronic visual language tool for persons with different stages of dementia, Murphy, Gray and Cox (2007) asked elders to discuss four aspects of wellbeing (activities, people, environment, self) in three types of conversation: unstructured interaction; structured interaction where topics were subdivided into a number of options that were discussed in turn; and conversation using Talking Mats™. For all topics, Talking Mats™ was found to be a visual communication framework that helped elders express their views, offering them some independence, decision-making support, instant visual feedback and record of his/her choices, and a means to structure a conversation with friends/relatives during social visits.

The addition of speech generating devices to the multi-modal communication system is dependent on the client's skills and needs for participation. Consider the purposes of communication (Light, 1988) that have been documented for adults with motor speech impairments who rely on speech generating devices (Fried-Oken et al., 2006). The team might choose to use the Communication Device Use Checklist (Fried-Oken et al.) to determine what communication purposes might be met with the SGD. When determining the appropriateness of an SGD, messaging needs become paramount. Svoboda (2001) has developed a list of one hundred autobiographical memories for elders that might be queried for topics. For some individuals with PPA, a dynamic display SGD that functions as an electronic communication book organized for external lexical access is desirable; for others its operational and strategic demands may be deleterious to natural interaction.

The role of partners should not be underestimated for the person with PPA. As an individual loses skills, the partner assumes more responsibility for the interaction and message co-construction. The level of familiarity between the person with PPA and

the partner provides a crucial balance for conversation. We have all met the couple who has been married for 50 years and no longer needs to speak to know what his/her spouse is thinking. They have a shared lexicon that is based on context and gestural or body language. Based on this “gold standard partnership,” a number of goals can be developed to support the person with PPA at all stages of language degeneration. Partner training goals include, but are not limited to, identify vocabulary for external lexicon, support use of tools in familiar communication settings, identify new opportunities for communication with tools, offer or confirm choices, model facilitative language behaviors for other potential conversants, and initiate conversation during late stages of PPA.

Information for families and persons with PPA is available on the Internet at www.brain.northwestern.edu/PPA. It is time for AAC specialists to integrate the PPA information with our multi-modal communication philosophy and incorporate language assessment and intervention techniques into our AAC practice. Providing timely and appropriate AAC assessment and treatment for the person who is experiencing a degenerative language disorder is within our clinical prevue.

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