

Unless otherwise noted, the publisher, which is the American Speech-Language-Hearing Association (ASHA), holds the copyright on all materials published in *Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders*, both as a compilation and as individual articles. Please see *Rights and Permissions* for terms and conditions of use of *Perspectives* content:

<http://journals.asha.org/perspectives/terms.dtl>

Providing Augmentative and Alternative Communication Treatment to Persons With Progressive Nonfluent Aphasia

Melanie Fried-Oken

Charity Rowland

Chris Gibbons

Oregon Health & Science University
Portland, OR

Abstract

Augmentative and alternative communication (AAC) intervention offers people diagnosed with progressive nonfluent aphasia (PNFA) an opportunity to continue to communicate even as verbal expression declines. To date, there are no well-controlled studies reporting the effectiveness of AAC intervention with people who present with PNFA. Further, there is a pressing need for evidence about specific AAC intervention tools, techniques, and training protocols for persons with PNFA and their communication partners. We have engaged in research studies at the Oregon Health & Science University to quantify low-tech AAC supports for people with PNFA in highly controlled, as well as naturalistic, dyadic conversations. Preliminary results suggest that AAC provides strong lexical support for people with PNFA during conversation. We predict that training participants and their partners how to use personalized, low-tech communication boards will lead to reduced conversational scaffolding by partners and prolonged effective communication as the disease course progresses. Clinical implications and future directions of our research are discussed.

Most speech-language pathologists who work with adults with neurologic communication disorders are now treating persons with primary progressive aphasia (PPA) in their practices. We propose that augmentative and alternative communication (AAC) principles and communication strategies should be central to intervention for this relatively new patient group. In this short article, we will describe the language disorder, present the rationale for AAC intervention and introduce preliminary results from a study that we are conducting on AAC-supported conversations for individuals with progressive nonfluent aphasia (PNFA).

Primary progressive aphasia is a degenerative language disorder that does not fit easily into the classical aphasia typology (Duffy & Peterson, 1992). PPA is a clinical syndrome that may overlap with Alzheimer's disease, frontotemporal dementia, corticobasal degeneration, dementia-lacking-distinctive-histology (DLDH), Creutzfeldt-Jakob disease, amyotrophic lateral sclerosis, asymmetric cortical degeneration, and Pick's disease (Kertesz & Munoz, 2002). Within neurologic syndrome identification, it has been categorized under the "Neary Criteria" for frontotemporal lobe dementia (Neary et al., 1998). Mesulam (2001) describes the symptom complex as showing (a) insidious onset and gradual loss of word finding, object-naming, or word-comprehension skills in spontaneous conversation; (b) all major limitations to activities of

daily living, attributable to language impairment, for at least 2 years after onset; (c) intact premorbid language skills; (d) absence of symptoms within the initial 2 years of language impairment that would fulfill diagnostic criteria for other dementia syndromes; (e) acalculia and ideomotor apraxia possibly present in first 2 years, but not substantially limiting activities of daily living; (f) language as the primary impaired function in the first 2 years with other domains possibly affected; and, finally, (g) absence of specific causes (i.e., stroke, tumor, infection, metabolic disorder) on neuroimaging. Age of onset is between 40 and 75 years old, with mean onset age of 60 years, and there is a preponderance of male patients.

PPA has been described with three variants (Gorno-Tempini et al., 2004). The most common variant is progressive nonfluent aphasia (PNFA). Semantic dementia (resembling a fluent progressive aphasia) and logopenic progressive aphasia are the other variants (see Ogar in this issue for a description). In this article, we will address treatment for adults with PNFA.

Language intervention for adults with PNFA has been reported during the past 15 years (Cress & King, 1999; Murray, 1998; Rogers & Alarcon, 1998; Rogers, King, & Alarcon, 2000). Rogers and Alarcon present a management scheme based on the clinical picture of PNFA that is representative of most intervention reports. It includes three stages: (a) anticipatory implementation of communication strategies, since communication independence declines as the disease progresses, (b) disability-based intervention focused on early utilization of AAC, and (c) dyad-oriented intervention. In the early stage, intervention is based on the need to convey specific information in specific situations, such as telling your spouse what to buy at the store. In this stage, strategies for pacing, syllable segregation, word retrieval, and identification of topic and key words are recommended. Mid-stage treatment recommendations include reliance on printed materials, idiosyncratic gestures, communication boards or cards, speech-generating devices with language options, and partner/family training to provide multi-modal input to support comprehension for the person with PPA. Late stage treatment includes prompting, errorless training for pointing to referents and teaching the partners to provide basic choices for expression. These late stage strategies, although intuitively appropriate, are not yet supported by scientific evidence. As is evident, the goals for intervention change as the person with PPA moves from unassisted to assisted communication.

Clinical intervention for adults with PNFA can be set within an AAC framework where we are faced with two treatment challenges: to provide patients with visual lexical supports so that they can participate in daily activities as their language skills decline and to engineer the environment to support successful communication. Operationally, these two challenges are expressed as three treatment goals: (a) to compensate for progressive language loss (not to stimulate the language system to regain skills); (b) to start early so that the person with PNFA can learn to use communication strategies and tools as soon as possible; and (c) to include primary communication partners in all aspects of training, with outreach to multiple partners. Fried-Oken (2008) framed these goals within a five-stage treatment model that can be used as a clinical pathway for PNFA: Stage 1—No noticeable changes in expressive language; Stage 2—Detectable language lapses with hesitations and dysfluencies; Stage 3—Reduction in language use; Stage 4—Use of AAC tools and other techniques to augment expression; Stage 5—No functional language.

At Oregon Health & Science University, we are presently conducting a three-phase investigation into the use of low-tech communication systems for persons with PNFA to provide experimental data on the value of AAC for functional conversation. Study One includes up to 50 individuals with PNFA, recruited with stringent inclusion and exclusion criteria. A communication board is designed for each participant, based on a conversational topic of a past event that is chosen by the participant and his/her care providers or family members. The topic story is represented by 16 photographs with a label (24-point font) placed above each picture. Six highly scripted, personalized, 20-minute conversations are held between the participant with PNFA and a researcher. Three conversations are supported with the

customized communication board, as well as pencil and paper. The other three conversations occur without AAC supports. The order of these conversations is systematically alternated among subjects. Importantly, the interactions are not open-ended. Ten identical questions are embedded in experimental (with AAC) and control (without AAC) conversations in an effort to elicit specific target words represented on the communication board. The questions appear in the same order during each of the six conversations. Each question may be followed by up to two related probes or comments, if the subject does not respond accurately to the initial query. This downshifting or repair strategy is included to further stimulate lexical access (Light, Beesley, & Collier, 1988).

In the experimental condition, any combination of verbal response or pointing to the symbol on the board is accepted as correct as long as the specific target word or its synonym has been communicated clearly. In the control condition, a response is scored as correct if the subject verbally produces the target response or its synonym, such as saying "automobile" when the original target was "car." In both conditions, responses are scored immediately after the initial question or follow-up probes. A weighted "conversation score" for responses to the 10 questions is derived from this coding. Three points are awarded for correct answers to the initial question, two points for correct answers to the first follow-up probe, and one point for correct response to the final probe. This composite score indicates a subject's level of lexical accuracy and the amount of repair needed to elicit the correct responses. The total score for each conversation ranges from 0 to 30, with higher numbers reflecting greater participant independence and accuracy. We hypothesize that, in controlled settings, AAC-supported conversations, in comparison to unsupported conversations, will yield greater numbers of target responses and more successful nonverbal communication, resulting in less downshifting.

Study Two was designed to assess the effects of AAC in more natural settings, where conversations about daily activities are guided by primary communication partners with and without AAC supports. A second communication board is constructed that includes personalized pictures and labels selected by the user and partner relative to their daily schedule and needs. Partners receive standardized training on device use and identification of breakdowns and repair strategies. The primary communication partner and participant engage in conversation, such as discussing which grocery store to shop at today, if the communication board includes the various stores in their community. Three videotaped conversations with AAC support and three conversations without AAC support are held between the partners and participants. The role of primary communication partners should not be underestimated for the person with PNFA. 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 PNFA and the partner provides crucial leverage for successful conversation.

Study Three is a generalization phase, where partners are taught to track use of AAC supports during conversations over a 6-month period.

To date, we have collected data on 7 subjects in Study One. Although each subject met criteria for PNFA, they were enrolled in our study at different points in disease progression. Participants were 3 males and 4 females, with an average age of 75 years (range = 71 to 78). Educational background ranges from 12-19 years of schooling, and living environment consisted of single-family households in a variety of environments (urban, suburban, rural farm) and assisted-living facilities. The length of relationship between participants and their primary communication partner ranges from 1.5 to 60 years, and the partners include 5 spouses, 1 friend and 1 paid caregiver. Scores on clinical tests at entry into the study are reported in the table below: oral agility, a subtest of Boston Diagnostic Aphasia Examination-3 (Goodglass, Kaplan, & Barresi, 2000); auditory comprehension, from the Western Aphasia Battery (WAB; Kertesz, 1982); picture naming, from the Boston Naming Test from the BDAE-3; object naming, a subtest of the WAB; functional reading, a subtest of The Reading

Comprehension Battery for Aphasia, First Edition (LaPointe & Horner, 1979); and matrix reasoning, a subtest of Wechsler Adult Intelligence Scale-IV (Wechsler, 2008). Total points possible for each clinical assessment or subtest are noted in parenthesis.

Subject	Oral Agility (26)	Auditory Comprehension (60)	Picture Naming (60)	Object Naming (60)	Reading (10)	Matrix Reasoning (26)
01	7	48	4	4	2	1
02	10	57	23	41	8	12
03	26	60	21	51	6	8
04	20	51	20	46	5	11
05	7	48	4	9	1	0
06	14	54	2	1	5	1
07	7	57	42	46	8	6

Results of an initial review of the weighted conversation scores indicate that, as predicted, the experimental condition resulted in significantly more correct responses, $F(1, 40) = 14.954, p < .0001$. The mean conversation score during AAC supported conversations (overall weighted score for correct response verbal and/or nonverbal) was 21, as compared to 10 in the control condition (range = 0 to 30).

This preliminary result strongly suggests that AAC, in the form of customized communication boards, provides meaningful lexical support during conversation for people with PNFA. It further indicates that AAC significantly reduces the degree of lexical scaffolding required by the conversation partner, leading to greater conversational contributions by participants. The improved lexical access observed during AAC-supported conversations suggests that this approach can be a valuable part of a PNFA treatment protocol. Our initial results support a report by Laurence, Manning, and Croot (2002), who suggested that impairment-based treatment alone is not effective for individuals with PNFA. In other words, working to remediate language functioning using traditional therapy approaches is not sufficient. As this project unfolds, we expect to further quantify the effect of AAC supports for persons with PNFA, to discover specific patient characteristics that are related to successful use of AAC and to develop clinical guidelines to teach patients with PNFA and their communication partners how to effectively use AAC.

Melanie Fried-Oken, a speech-language pathologist, is professor of Neurology, Pediatrics, Biomedical Engineering, and Otolaryngology at the Oregon Health & Science University (OHSU). As a leading international clinician researcher in augmentative and alternative communication, she provides expertise about assistive technology for persons with acquired and developmental disabilities. She has a number of federal grants to research communication technology for persons with Alzheimer’s disease, ALS, and other neurodegenerative diseases, and the normally aging population. She is a partner in the Rehabilitation Engineering Research Center on Communication Enhancement (www.aac-lerc.com) and a practicing clinician in the AAC Clinic at OHSU.

Chris Gibbons has worked extensively as an AAC specialist with a variety of stakeholders in environments ranging from university-based clinics to private practice, non-profit, outpatient rehabilitation and school district consultation. His work as a clinician, policy level project manager, disability advocate, and industry representative informs and inspires his research interests. He currently participates in ongoing research measuring the efficacy of AAC for people with neurodegenerative diseases and comparisons of alternative access to AAC as a staff scientist and research instructor in Neurology at OHSU.

Dr. Charity Rowland is director of the Design to Learn Projects at the OHSU. Trained in developmental and experimental psychology, she has conducted extensive research efforts related to language acquisition and communication development in nonspeaking individuals with severe and multiple disabilities. Her research has produced new educational strategies, instructional materials, and assessment instruments. Her work has applications for many populations, ranging from young children with deaf-blindness or autism to adults with dementia.

Acknowledgment

This research is supported by grants #H133G080162 and #H133E080011 (Rehabilitation Engineering Research Center in Communication Enhancement) from the National Institute for Disability and Rehabilitation Research, U.S. Department of Education.

References

- Cress, C., & King, J. (1999). AAC Strategies for people with primary progressive aphasia without dementia. *Augmentative and Alternative Communication, 15*, 248-259.
- Duffy, J. R., & Peterson, R. C. (1992). Primary progressive aphasia. *Aphasiology, 6*(1), 1-15.
- Fried-Oken, M. (2008). Augmentative and alternative communication treatment for persons with primary progressive aphasia. *Perspectives on Augmentative and Alternative Communication, 17*, 99-104.
- Goodglass, H., Kaplan, E., & Barresi, B. (2000). *Boston Diagnostic Aphasia Examination—Third Edition (BDAE-3)*. San Antonio, TX: The Psychological Corporation.
- Gorno-Tempini, M. L., Dronkers, N. F., Rankin, K. P., Ogar, J. M., Phenegrasamy, L., Rosen, H. J., Johnson, J. K., Weiner, M. W., & Miller, B. L. (2004). Cognition and anatomy in three variants of primary progressive aphasia. *Annals of Neurology, 55*(3), 335-346.
- Kertesz, A., (1982). *Western Aphasia Battery*. New York: The Psychological Corporation.
- Kertesz, A., & Munoz, D. G. (2002). Primary progressive aphasia: A review of the neurobiology of a common presentation of pick complex. *American Journal of Alzheimer's Disease and Other Dementias, 17*(1), 30-36.
- LaPointe, L. L., & Horner, J. (1979). *Reading Comprehension Battery for Aphasia*. Austin, TX: PRO-ED.
- Laurence, F., Manning, M., & Croot, K. (2002, July). *Impairment based interventions in primary progressive aphasia: Theoretical and clinical issues*. Poster presented at The 10th International Aphasia Rehabilitation Conference: Past, Present and Future, Brisbane, Australia.
- Light, J., Beesley, M., & Collier, B. (1988). Transition through multiple AAC systems: A three-year case study of a head injured adolescent. *Augmentative and Alternative Communication, 4*, 2-14.
- Mesulam, M. M. (2001). Primary progressive aphasia. *Annals of Neurology, 49*(4), 425-432.
- Murray, L. (1998). Longitudinal treatment of primary progressive aphasia: A case study. *Aphasiology, 12*(7/8), 651-672.
- Neary, D., Snowden, J., Gustafson, L., Passant, U., Stuss, D., Black, S., Freedman, M., Kertesz, A., Robert, P. H., Albert, M., Boone, K., Miller, B. L., Cummings, J., & Benson, D. F. (1998). Frontotemporal lobar degeneration: A consensus on clinical diagnostic criteria. *Neurology, 51*, 1546-1554.
- Rogers, M. A., & Alarcon, N. B. (1998). Dissolution of spoken language in primary progressive aphasia. *Aphasiology, 12*(7/8), 635-650.
- Rogers, M. A., King, J., & Alarcon, N. (2000). Proactive management of primary progressive aphasia. In D. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *AAC for adults with acquired neurological disorders* (pp. 305-337). Baltimore: Paul H Brookes.
- Weschler, D. (2008). *WAIS-IV: Administration and scoring manual*. San Antonio, TX: The Psychological Corporation.