Learning Outcomes

1. Understand language symptoms of Primary Progressive Aphasia (PPA).
2. Become familiar with an experimental study on Augmentative and Alternative Communication (AAC) for people with PPA.
3. Implement AAC tools and strategies within communication treatment for people with PPA.

Primary Progressive Aphasia (PPA)

There are a group of adults who cannot participate in conversations successfully because they are slowly losing their language.
Characteristics of PPA

- Age of onset 55-65 years old
- Preponderance of males
- In the community, they are still being diagnosed with Alzheimer's disease, but their non-verbal memory is intact.

Types of primary progressive aphasia

- Progressive nonfluent aphasia (PNFA)
  - Resembles a degenerative expressive aphasia
- Semantic dementia
  - Resembles a degenerative receptive aphasia
- Logopenic progressive aphasia
  - “Intermediate” between PNFA and SD with phonological loop impairment

Diagnostic Criteria for PPA

1. Insidious onset and gradual loss of word finding, object-naming or word-comprehension skills in spontaneous conversation;
2. ADL limitations attributable to language impairment, for at least 2 yrs after onset;
3. Intact premorbid language skills;
4. Absence of significant apathy, disinhibition, forgetfulness for recent events, visuospatial impairment, visual recognition deficits or sensory-motor dysfunction within initial 2 yrs of L impairment;
5. Acalculia & ideomotor apraxia may be present in first 2 yrs.
6. Other domains possibly affected during 2 yrs, but language most impaired fn.
7. Absence of specific causes (i.e., stroke, tumor, infection, metabolic disorder) on neuroimaging.

PPA is a clinical syndrome

- There are overlaps with:
  - Alzheimer's disease
  - Frontotemporal dementia
  - Corticobasal ganglionic degeneration
  - Diffuse Lewy Body disease
  - Dementia-lacking-distinctive-histology (DLDH)
  - Pick's disease
  - ALS or Parkinson's disease

PPA: First Symptoms

1) Anomia or "trouble thinking of or remembering specific words when talking or writing".
   - Substituting words (saying, "Michael Jordan" instead of "basketball")
   - Using circumlocutions (saying, "The one who stands in front of the class and talks" for "teacher")

2) Marked increase in speech errors (substitutions or distortions)
   - Substituting sounds in words (saying "brink" for "blink")
   - Distorting sounds in words (saying "joe-ful" for "joyful")
PPA: First Symptoms

3. Slow, hesitant speech frequently punctuated by long pauses and filler words.
4. Struggle for speech sounds, initial apraxia.
5. Difficulties understanding spoken words.
6. Problems with numbers and arithmetic (can't recite phone number correctly or give correct change from a dollar)

Progression of disease varies

- Yes/No confusion for responses
- Apraxia of Speech
  - Articulatory groping with difficulty self correcting
  - Vowel distortions and inconsistent errors
  - Increased frequency of articulatory errors as word or phrase length increases
- Mutism
- Written language often mimics spoken language problems.

A Patient's Course

- Awareness by the person or family member that communication skills are impaired.
- Comprehensive assessment with MRI scan to identify symptoms and rule out other neurological disease. Team members may include:
  - Neurologist and nurse,
  - Neuropsychologist,
  - Speech-language pathologist,
  - Psychiatrist or social worker.
- Recommendation for communication treatment.
Communication Treatment Goals

#1: To compensate for progression of language loss (NOT stimulate the language system to regain skills).

#2: To begin compensatory treatment EARLY. Be proactive so patient can learn to use communication tools.

#3: To include primary communication partners in all aspects of training, with outreach to multiple partners.

The Treatment Challenge

To put the patient’s residual lexicon visually in front of him so that he can access needed vocabulary to participate in daily activities as language skills decline.

The Research Challenge

There is little empirical evidence that AAC helps people with PPA with their daily expression. We only have case studies and clinical descriptions.

Our Research

To provide evidence that low tech AAC (communication boards) support adults with PPA during conversations.

To provide AAC to support lexical access so that individuals can participate in daily activities as language skills decline.
Three Studies: Study 1

Do personalized AAC boards in controlled conversations with researchers improve expressive communication?

Three Studies: Study 2

Do personalized AAC boards about daily activities used in conversations with frequent partners (spouse, child, caregiver) improve daily communication?

Three Studies: Study 3

Is there generalization and maintenance of AAC over 6 months?

Study 1 Methods

- Determine topic of conversation with participant and partners based on autobiographical memory.
- Make 16-item personalized boards with photo + label in open file folder.
- Train individuals how to use boards during conversation in their residences.
- Conduct 6 VERY controlled conversations with 10 scripted questions, with and without boards.
- Input from participant with PPA who was an SLP & now attends staff meetings.
Board topic: Garage Sales

Target word: Storage Unit

- Initial Probe: Where do you keep the bulk of your items for sales?
- Probe #1: This place is downtown
- Probe #2: You mentioned that you have a couch here
- Provide word: Storage unit

Study 1: Controlled conversations
3 questions for target word: Kenai

Participants

- Primary Progressive Aphasia: N=37
  (102 conversations)
### Demographics

<table>
<thead>
<tr>
<th>Women</th>
<th>9</th>
<th>Age range: 52-78</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean: 68 yrs.</td>
</tr>
<tr>
<td>Men</td>
<td>8</td>
<td>Male age range: 62-77</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean: 73 yrs.</td>
</tr>
<tr>
<td>Education range: 12-19</td>
<td>Education range: 12-24</td>
<td></td>
</tr>
<tr>
<td>Mean: 15 yrs.</td>
<td>Mean: 17 yrs.</td>
<td></td>
</tr>
<tr>
<td>CDR mean 0.94</td>
<td>CDR mean 1.08</td>
<td></td>
</tr>
<tr>
<td>BNT range: 4-69</td>
<td>BNT range: 2-52</td>
<td></td>
</tr>
<tr>
<td>BNT mean: 32</td>
<td>BNT mean: 19</td>
<td></td>
</tr>
</tbody>
</table>

### Demographics on 17 Participants

- Living environment: single family households (urban, suburban, rural farm), and assisted living facilities
- Conversational Partner: 1 female friend; 1 female paid caregiver; 8 male spouses, 7 female spouses
- Length of relationship between participants and communication partner: 1.5 to 60 years (mean 35-25)

### Mr. Ryderwood’s Board

![Image of Mr. Ryderwood’s Board]

### Sample of scripted questions

- You had an old Volkswagen in the Army, what was particularly unique about this car? [Turn signal]
- Who broke off one of these turn signals while you were in Germany? [Traffic Cop]
<table>
<thead>
<tr>
<th>Mr. Ryderwood’s control conversation</th>
<th>Mr. Ryderwood’s experimental conversation</th>
</tr>
</thead>
</table>

**Outcome measure:**
What is a correct response?

- With AAC: The subject says the target word or synonym with speech or by pointing to the board.
- Without AAC: The subject says the target word or its synonym.
- Researchers add up the number of correct responses for each of 1 to 3 probes and for each of 10 questions.

**Weighted conversation score**

<table>
<thead>
<tr>
<th>Target word: Sign</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 points: “How do you advertise for a sale?”</td>
</tr>
<tr>
<td>2 points: “You use cardboard &amp; a marker to make this.”</td>
</tr>
<tr>
<td>1 point: “You post it outside for people to see your sale.”</td>
</tr>
<tr>
<td>0 points: “SIGN”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Point Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 points: correct answer to the initial probe</td>
</tr>
<tr>
<td>2 points: correct answer to downshift #2</td>
</tr>
<tr>
<td>1 point: correct response to downshift #2</td>
</tr>
<tr>
<td>0 points: correct response provided by researcher after 3 trials without correct response</td>
</tr>
</tbody>
</table>
Study 1 Results: Verbal Responses

- Number of correct spoken words was higher with AAC support than without AAC support.
  - Mean Control (no AAC): 5.2
  - Mean Experimental (AAC support): 7.0
  - \( F(1, 82) = 32.887, p = .000 \)

- People with PPA retrieve the correct verbal responses to questions more frequently with AAC support than without AAC support.

Study 1: Response to initial question

Number of correct responses to initial questions was higher with AAC support than without AAC support.

- Mean Control: 4.5
- Mean Experimental: 7.2
- \( F(1, 82) = 75.221, p = .000 \)

People with PPA retrieve the correct responses to questions more quickly, requiring less effort by partners (downshifting) with AAC support than without AAC support.

Study 1: Weighted Conversation Score

- Weighted Conversation Score was higher with AAC support than without AAC support.
  - Mean control: 52%
  - Mean experimental: 82%
  - \( F(1, 82) = 79.521, p = .000 \)

Conversations between people with PPA and researchers are more successful with AAC. People say more correct responses with fewer probes from the partner with AAC than without AAC.
Study 1: Nonverbal Responses

- In experimental conditions, participants pointed to pictures on the board an average of 5 times per conversation.
- People with PPA are using the board to express themselves during conversations (and not just glancing at the board to cue themselves).

Interpretation of Results

- Low tech AAC gives people with PPA meaningful language support during structured conversations.
- Low tech AAC significantly reduces the amount of language support needed by the conversation partner.
- This approach should be part of a PPA treatment protocol.

Study 2: Conversations with Natural Partners

Does AAC support conversation between participants with PPA and their spouses, family members, care providers?

- More natural conversations
- About daily activities
- With frequent familiar partners
Study 2 Methods

- Choose 4 functional daily activities with participant and partners.
- Make new communication boards with 4 pictures for each daily activity.
- Train partners how to converse using communication boards.
- Videotaped and transcribed 3 conversations with the board (AAC-supported) and 3 without the boards.
- Randomly choose 8 words (2 per activity) to target during each conversation.

Study 2 Quad-board

Functional activities board
### AAC-supported Conversation with Spouse

### Study 2 Outcome Variables

- # partner prompts for 8 target versus non-target words
- # correct verbal responses by participant for 8 target versus non-target word
- # correct nonverbal responses in experimental condition (points to board)

### Study 2 Results: # Partner prompts

Number of partner prompts for target words was higher in condition without AAC than with AAC, but the difference was not statistically significant.
- Mean Control (no AAC) for targets: 11.9
- Mean Experimental (with AAC) for targets: 8.1

AAC support may reduce the need for partner prompts, but the result is not yet significant.

### Study 2 Results: # Verbal responses

Number of correct verbal responses to prompts was higher in condition with AAC than without AAC for the 8 Target words.
- Mean Control: 2.3
- Mean Experimental: 4.8
- \( F(1,16) = 10.274, p = .005 \)

With AAC support, people with PPA are more successful at using the correct verbal responses to questions for the 8 targeted words in functional conversations with partners.
Study 2: Nonverbal responses

- In experimental conditions (with AAC), people with PPA pointed to pictures on the board an average of 3.6 times per conversation for Targeted words and 1.5 times per conversation for Non-targeted words.

Study 3: AAC maintenance and generalization over 6 months

- Does AAC knowledge and use continue after training and videotaping is discontinued?

- Communication partners are taught:
  - What are natural AAC supports
  - How to use natural AAC supports during the day
  - How to tally board use with tracking tools

Questions asked via telephone or e-mail

- Since last time we talked, how many times has the person with PPA used the communication board?

- Since the last time we talked, how have you used the communication board(s) for conversations (e.g., in what context)?

- Do you have any other examples of ways conversation has changed in the past week (e.g., the use of a skill from the guidelines sheet helped, we used a map to talk about travel, other AAC)?

What AAC tools are subjects using after study completion?

- Address book (2/13)
- Ads
- Calendar (2/13)
- Children's bible stories
- Comm. Board (8/13)
- Comm. photo booklet (5/13)
- Computer
- Cookbook
- Electronic photo frame
- E-mail
- Flashcards
- Gestures/ sign language/ pantomime (3/13)
- Guideline sheets (4/13)
- Letters
- Magazine (1/13)
- Mail
- Maps (1/13)
- Museum
- Newsletters
- Newspaper (5/13)
- Numbers
- Paper & pen/writing (3/13)
- Photos & photo albums (8/13)
- Post it notes
- Resident/staff directory
- Scrap book
- Show Me
- Singing
- Skype
Spontaneous Use in Study 3

- Pointing to weather pictures in newspaper to indicate time of day
- Pointing to framed boards on the family picture wall at eye level
- Discussing health conditions using pain intensity continuum line
- Flipping through photos in address book during a family visit
- Visiting a museum: Using photos to discuss what the home town looked like

Benefits of boards

- Helped communication between 2 adults with language impairments
- Helped conversation between husband and wife with dysarthria from TBI
- Provided means for sharing new information: “Our granddaughter came by while you were out.” Subject initiated message with board.
- Helped person with PPA come up with new words: “rock grille” on board stimulated “build, steel”.

Importance of Starting Early

From research to practice:
What we learned and can apply
Clinical “deliverables”

- Visual language support for an internal dictionary is useful for people with PPA.
- Include AAC tools in PPA treatment early.

- Handouts for families (with this webinar)
  - “Guidelines for communicating with persons who have language difficulties”
  - “Helpful hints for conversation”

- How to make communication boards:
  - File folder templates for 1-topic and 4-topic boards (with this website)
  - Visual scene templates at http://aac.unl.edu

Book and website references

- **AAC-RERC.ORG**
  - additional webcasts, references and links
- Beukelman, Garrett & Yorkston 2007 book through Brookes Publishing
- Cognitive Neurology & Alzheimer’s Disease Center at Northwestern University:
  http://www.brain.northwestern.edu/ppa

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