AAC to enhance communication between individuals with Dementia and their partners

Monica Francelia, RSLP
mfrancelia@cayabc.org
Communication Assistance for Youth and Adults
Vancouver Coastal Health, BC, Canada

Outline

• History of AAC intervention for Dementia

• AAC solutions for a male with early onset Alzheimer’s Disease (AD)
Dementia

“an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgment and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person’s ability to function at work, in relationships and in everyday activities.”

Alzheimer’s Society of Canada

Dementia

- Over 44 million people worldwide
- AD most common; 60-70%
- Other types:
  - Vascular Dementia,
  - Dementia with Lewy bodies
  - Frontotemporal dementia, a cluster of disorders which includes Primary Progressive Aphasia.
AAC and Dementia

- Historically pessimistic view of therapy provision
- Prior to late 1980s no known effective intervention
- Not a widely recognized area of AAC practice
- Individuals with dementia do not commonly receive AAC intervention
- CAYA program – relatively small number of referrals (.5% in late 2013 since inception 2005)

AAC intervention for Dementia

- View of dementia intervention has evolved
- WHO International Classification of Functioning, Disability and Health changed focus from impairments to increasing participation, quality of life and maintaining independence
- Research studies illustrated positive effects of intervention approaches (e.g. written reminder cards, memory books) to promote participation in daily activities
Memory Aids

- Biographical information conveyed through images and simple phrases
- Photos of family/friends, important life events
- Provide semantic support for information stored in long-term memory
- Provide concrete topics for conversation
- Support desire to communicate
- Improve quality of communication with others

Research evidence

- Bourgeois (1990): communication/memory wallets improved communication of 3 patients with AD and familiar partners
- Bourgeois (1993): training with memory wallets improved conversation between patients with moderate to severe AD
- memory aids compensated for semantic memory impairments and capitalized on preserved skills
Research Evidence

- Bourgeois, Dijkstra, Burgio, & Allen-Burge, (2001): Use of memory aids improved conversational interactions between nursing aides and residents with Dementia
- Fried-Oken, Rowland, Daniels, Dixon, Fuller, Mills, Noethe, Small, Still, & Oken, (2012): Provision of customized AAC device without training did not alter conversation of patients with mod AD; participants who received AAC priming in the form of spaced-retrieval exercises used AAC device more frequently, used more targeted words to discuss chosen topics in presence of AAC device

Research Evidence

  - systematic review of studies investigating methods to improve the spoken communication of individuals with AD and their caregivers
  - found the strongest evidence for the use of memory aids coupled with caregiver training
  - Memory aids improved patients’ discourse on topics in memory aids
  - Performance decreased over time in absence of follow up training
Case study - David

- 57 year old male
- Ph.D. in Forestry; research career in Forest Biotechnology
- Dx early onset AD age 52 (2008)
- Initial assessment for AAC in late 2012
- Lives at home with his wife
- Attended seniors centre 5 days/week

David – initial assessment

- Functional Goals Screening Protocol: Community Clients with Dementia (Bourgeois 2007)
- Impaired reading ability – moderately at word/phrase level, severe at sentence level
- Cognition mildly to moderately impaired
- Mildly impaired ability to perform ADLs
- Oriented to environment
David – initial assessment

• Moderately impaired language comprehension and expression - word finding difficulties, reduced semantic content, fragmented utterances, phonemic paraphasias

Conversational sample telling about family:
“One of my brothers is going way over there now. In Ontario, or it could be the next place. They’re gonna go way out somewhere. The one thing. I want to see him sometime.”

David – initial assessment

- Social communication
  - Able to express likes/dislikes
  - Able to initiate limited conversation
  - Required assistance with communicating wants and needs, and conversing with others
AAC system

David needed to participate in conversation about preferred topics, express needs and choices, share information

1. a communication book with vocabulary specific to David's interests, ADLs and social and community participation, represented through photos, logos, and Picture Communication Symbols paired with text

2. A memory book containing personally relevant photos and text captions

3. Identity card for community use

Sample communication book pages
Travel page

My name is David Cyr. I have Alzheimer’s disease, I have difficulty speaking, understanding language, reading and writing.

I use this book to help me communicate. I can point to words I have difficulty saying.

To help me converse with you please:
- Point to pictures in the book to signal a topic
- And help me understand what you are saying
- Turn to the page related to our topic
- Tell me what you understand if my message isn’t clear
- Speak slowly
- Use clear simple sentences
- Give me one place of information at a time
- Do not interrupt me
- Avert difficult conversations in noisy environments
- Avoid ‘quizzing’ questions that need specific answers
- Affirm what I try to communicate and expand on my message to reinforce my communication attempts.
Memory book

I was born on August 12, 1956 in Oshawa, Ontario.

My wife's name is Linda. We were married in 1998 in Vancouver.

Initial AAC system use

- David was motivated to use new system
- compensated for word finding difficulties
- capitalized on preserved spoken language and motivation to communicate
- marked increase in level of engagement during AAC supported conversation
AAC system training

- Minimal training was needed in home setting
- Provided training on facilitative strategies for staff at Seniors’ Centre
- David initiated use of AAC system and effectively used it to participate in conversation
- Staff described AAC system as a “useful tool”

Follow up and monitoring

- Future follow up revealed a decline in David’s memory, cognitive and communication skills
- David’s support needs exceeded available staffing resources at the Senior’s Centre
- Transition to home care provided by family member
Continued caregiver education

- communication skills training for family members providing care
- Identified supportive partner communication strategies
- Training on use of visual aids to assist David with participation in conversation
- Visual aids provided shared context
- means by which David could initiate a topic of conversation despite declining speech abilities

Video: David initiating by pointing to photo in memory book

Riding elephants in Singapore
Video: memory book photos facilitate engagement in conversation

Video: recalling travels
Video: communication book to express pain

AAC system adaptations

- Modified and added to AAC system based on caregiver feedback
- Memory book split into smaller books by topic
- Added interest albums on preferred topics/activities
Memory books

Facilitate interactions that maintain social closeness by rehearsing familiar personal history information

Video: memory book – remembering family

My father is Acadian from New Brunswick. His name is Alaire Cyr. He passed away in the late '90s.
Interest albums

Later stages

- Teach partners to use language, tone of voice, familiar objects, and touch to provide comfort and familiarity
- Look for nonverbal expressions of engagement/comprehension – smiles, pleasant vocalizations, attending to/patting/rubbing pictures
- Repetition can also signal engagement & participation
- Respond to all modalities
Summary

• Visual aids support communication in Dementia
• Obtain baseline Ax, provide intervention, then ongoing monitoring support
• Include caregivers in intervention
• Teach partner strategies to compensate for deficits and support preserved abilities
• Adapt visual aids and continue caregiver training as condition progresses

References


References


