

Key References Influencing Development of the DynaVox Compass™:

Navigator Pageset

Timing for Introducing AAC to Persons with ALS (PALS)

Ball, L., Beukelman, D., & Pattee, G. (2002). Augmentative and alternative communication clinical decision making for persons with ALS. *Perspectives on Augmentative and Alternative Communication*, 11(1), 7-12.

It is estimated that close to 80% of PALS will benefit from augmentative and alternative communication (AAC) during the course of their disease. This research was conducted to identify clinical measures that can be used to determine appropriate AAC interventions, the timing of those interventions, and their outcomes. One of the findings was that speaking rate (typically 190-200 words per minute) tends to decrease before a significant reduction in intelligibility can be observed. Once the speaking rate reaches 60% of normal (approximately 90-125 words per minute), intelligibility begins to decrease at a rapid rate. These results were similar regardless of the type of onset (bulbar, mixed, or spinal).

Acceptance of AAC by PALS

Ball, L.J., Beukelman, D.R., Pattee, G.L. (2004). Acceptance of augmentative and alternative communication technology by persons with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, 20(2), 113-122.

The purpose of this study was to determine how many people with ALS accept and reject high-technology communication systems and why. Findings indicated that 90% of PALS in the study immediately accepted AAC, 6% accepted after some delay, and only 4% rejected AAC. PALS who readily accepted high tech AAC did so because they wanted to communicate effectively with family, friends, and medical professionals. Additionally, they wanted to continue to be active in their communities and, in some cases, at work.

PALS who did not accept AAC immediately indicated that family resistance was a primary reason for their delay. Once caregivers realized that it was difficult to provide adequate care without effective communication, and that they did not have effective communication without AAC, PALS tended to accept AAC. The limited number of PALS who totally rejected AAC demonstrated cognitive issues associated with pre-frontal dementia.

Focus on Increasing Participation

Baylor, C., Burns, M., Eadie, T., Britton, D., & Yorkston, K. (2011). A qualitative study of interference with communication participation across communication disorders in adults. *American Journal of Speech-Language Pathology*, 20, 269-287.

The purpose of this study was to determine how different communication disorders interfere with participation in community activities. Some of the study participants were PALS. Participants indicated that interference occurred in many different environments and activities. It resulted in both functional limitations (i.e., difficulties accomplishing tasks) and emotional consequences (i.e., sadness or frustration due to communicative or functional limitations). Because the types of interference and reasons why they happened were similar regardless of the participant's diagnosis, the study indicated that clinical interventions should focus on increasing participation regardless of the diagnosis.

Communication throughout Life

Fried-Oken, M. & Bardach, L. (2005). End-of-life issues for people who use AAC. *Perspectives on Augmentative and Alternative Communication*, 14 (3), 15-19.

This article reports the finding of a panel of professionals on the topic of end-of-life issues for adults who use AAC and their families. Their aim was to identify key issues related to end-of-life, and quality-of-life, and to establish a research agenda to further explore these issues. The article made use of many quotes from adult AAC users and their family members. Recurrent themes included the need for communication supports for: connectedness, intimacy, use through the end of life, and expressing end-of-life decisions. Future research should explore AAC interventions that can support these needs for adults with a variety of diagnoses.

Reasons PALS use AAC

Fried-Oken, M., Fox, L., Rau, M., Tillman, J., Baker, G., Hindal, M., Lou, J. (2006). Purposes of AAC device use for persons with ALS as reported by caregivers. *Augmentative and Alternative Communication*, 22 (3), 209-221.

The purpose of this study was to discover patterns related to AAC importance and use for a variety of communication purposes. Results indicate that individuals with severe ALS use AAC technology to call for help, get needs met, clarify needs, and give direction. In addition, as the severity of ALS increases PALS use AAC technology more frequently to support social closeness by comforting others, chatting, and engaging in casual conversations. A final important purpose of AAC technology is to share information with others. Much of the communication was face-to-face but email, telephone, and written modalities were also important.

Vocabulary Organization and Design

McCoy, K.F., Hoag, L., & Bedrosian, J. (2011). Next generation utterance-based systems: What do pragmatic studies tell us about system design? *Perspectives on Augmentative and Alternative Communication*, 20 (2), 57-63.

This article provides a review of previous research regarding the use of utterance-based AAC systems for faster/easier communication. Findings indicate that systems must have a combination of prestored text and tools to create new messages. Additionally, these two types of tools must work together seamlessly as stored messages will need to be edited and both types may be needed to communicate effectively. The authors indicate that InterAACt, the language framework upon which DynaVox Compass was built, allows for this seamless switching. They propose a model that would further expand this concept and inform the development of future technologies.

Communication Patterns for PALS

McKelvey, M., Evans, D.L., Kawai, N., & Beukelman, D. (2012). Communication styles of person with ALS as recounted by surviving partners. *Augmentative and Alternative Communication*, 28 (4), 232-242.

The purpose of this study was to identify communication patterns for PALS using AAC. The four patterns that emerged were: communication styles, use of AAC, decision-making, and lifestyle changes. While there were many changes in communication style before and after the introduction of AAC, the use of AAC did help support some carryover (e.g., maintaining sense of humor). The use of AAC included finding a system that supported communication of a range of things. While the AAC system should have both low- and high-tech components, AAC devices were found to be essential for PALS when making decisions and maintaining social roles. In many ways, decision-making increased (e.g., new medical decisions, future planning) after a diagnosis of ALS. Even so, this study found that the decision-making process, style, and role of PALS generally didn't change too much. Finally, spouses reported that it was important to adapt social activities to allow PALS to continue to be involved in the community and with family and friends.

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