

LOW-TECH AAC WITH PALS AND CALS

Amanda Simmons M.S. CCC-SLP

AMANDA SIMMONS M.S. CCC-SLP

Medical SLP

- Primary experience at a SNF (4 years)
- Endoscopy certified
- Run AAC Clinic for pALS (3 years)

Ph.D. Candidate at UTHSC (4th year)

- Focus on AAC education and training

Returned Peace Corps Volunteer

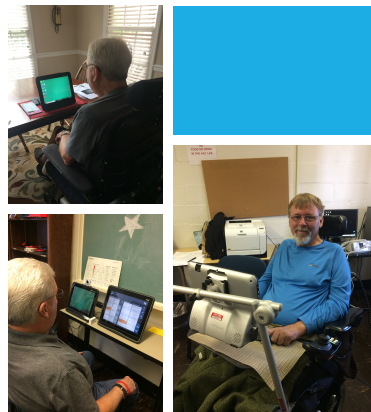
- Teaching and Research Philosophy



AAC CLINIC FOR PALS

AAC Clinic for pALS (ASHA LDP Project)

- 3 years
- ~15 pALS participating at any given time
- Provide voice and message banking support
- Provide education and training on low to high-tech AAC
- UTHSC graduate students assist



PURPOSE

There is literature addressing the benefit of using high-tech AAC with patients living with amyotrophic lateral sclerosis (pALS) with the use of eye-gaze technology (Doyle & Phillips, 2009; Mooney, & Peters, 2015) or brain-computer interfacing (BCI; Ahani, Moghadamfalahi, & Erdogmus, 2018; Babiloni, Cichocki, & Gao, 2007); however, limited research exists to discuss the benefit of low-tech AAC for pALS.

This research hopes to:

1. Identify communication needs for pALS, caregivers of pALS (cALS), and relevant healthcare professionals (e.g., SLPs, PTs, OTs, neurologists, nurses, etc.) through survey research.
2. Develop education and training tools for healthcare professionals to use with pALS and cALS
3. Look at quantitative and qualitative data: quality of life (QoL) measures for pALS and cALS following the use of low-tech AAC and preferences on specific low-tech AAC tools and strategies following education and training.

RESEARCH BACKGROUND

Best practices indicate early education for pALS and cALS on AAC (no-, low-, mid-, and high-tech) to support communication throughout the disease progression (Ball, Beukelman, & Pattee, 2004; Beukelman, Fager, Ball, & Dietz, 2007; Fried-Oken, Mooney, & Peters, 2015; McNaughton et al., 2018).

Much research has provided data on the impact of high-tech AAC education, training, and implementation for pALS (Brownlee & Palovcak, 2007; Caron & Light, 2015); however, little research has been conducted to determine the impact of low-tech AAC implementation for pALS and/or cALS QoL (Londral, Pinto, Pinto, Azevedo, & Carvalho, 2015; Simmons, 2015).

Low-tech AAC has a long-standing history with a strong evidence base for its use with individuals with complex communication needs; however, we hope to quantify the impact that it might have on pALS and cALS QoL. Additionally, we would like to identify pALS' and cALS' preferences for low-tech AAC strategies.

PROJECT DESCRIPTION

Three-pronged endeavor:

1. Surveys
2. Educate and train pALS and cALS on the use of low-tech AAC
3. Measure the impact of R2 through quantitative (QoL measures, surveys) and qualitative (short interviews) data.
 - a. QoL measures for pALS and cALS
 - b. Low-tech AAC method, strategy, and material preferences for pALS and cALS

SURVEYS

There will be one for three different groups focusing on communication experiences, wants/needs, and strengths/weaknesses. Surveys will be distributed statewide via the ALS Association, social media, word of mouth, and ALS multidisciplinary clinics.

pALS

cALS (spouse, child, relative, parent, friend, etc.)

Healthcare Professionals (SLPs, Neurologists, Social Workers, PTs, OTs, RTs, nurses, etc.)

SURVEY DATA TRANSFORMATION

Information gathered will be mined to alter basic outline of education and training curriculum.

Handouts and digital materials will be created to provide to pALS and cALS during education and training sessions.



LOW-TECH AAC EDUCATION AND TRAINING

Education:

- Communication Basics
- Communication strategies
- What is AAC?
- What is low-tech AAC?
- Partner-assisted scanning
- Tips and strategies for implementation

Materials Provided to pALS/cALS dyads

- Letter board
- Pencil and paper
- Personalized board
- VIDATAK EZ Boards
- Vidatak EZ Picture
- Vidatak EZ Board
- Vidatak EZ Spiritual Care



DATA MEASURES

Measure the impact of the education and training through quantitative (QoL measures, surveys) and qualitative (short interviews) data (initial, after 4-6 weeks post, 8-10 weeks post)

- Determine low-tech AAC's impact on quality of life (QoL) for pALS and cALS with communication ability taken into consideration
 - ALS Functional Rating Scale – Revised (ALSFRS-R)
 - McGill QoL (MQoL)
 - World Health Organization Quality of Life Questionnaire (WHOQOL-BREF)
 - Communication Effectiveness Index (CETI)
- Determine preferred low-tech AAC methods, strategies, and materials for pALS and cALS
 - Survey (pre and post)
 - Short interviews (pre, check-in, post)

RESEARCH QUESTIONS

What aspects of low-tech AAC education do pALS and cALS find most beneficial?

How is quality of life (QoL) impacted for pALS and/or cALS following training and use of low-tech AAC?

What low-tech AAC strategies and tools are preferred by pALS and/or cALS?



This Photo by Unknown Author is licensed under CC BY

DELIVERABLES

This research hopes to add to the current knowledge base of survey data regarding pALS' and cALS' thoughts on communication, as well as providing QoL data, low-tech AAC preferences, and tangible education and training materials for future implementation.

Tangible Take-aways:

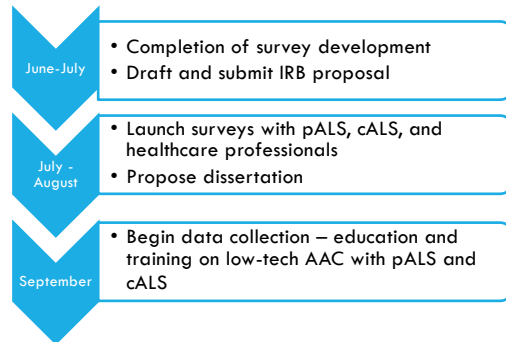
- Survey Data from 3 groups
- Education and Training Materials
- QoL Measures Based on Impact of Low-Tech AAC for pALS and cALS
- pALS and cALS Preferences on Low-Tech AAC



This Photo by Unknown Author is licensed under CC BY

TIMELINE

This is a proposed preliminary timeline for the initiation of this project - including the current project design and launch this summer and early fall



POTENTIAL ISSUES

Condensing Survey Data

- Usable information to develop communication curriculum

Realistic Expectations

- Consistency of Data
 - 2 groups?
 - Consider time since diagnosis
- Sample Size

Clinical Population

- Recruitment
 - Expand geographic location
 - Consider other interaction methods – virtual meeting
- Attrition
 - Virtual meeting?
 - Home visits?

REFERENCES

- Ahani, A., Moghadamfalahi, M., & Erdogmus, D. (2018). Language-model assisted and icon-based communication through a brain – computer. *IEEE Transactions on Neural Systems and Rehabilitation Engineering*, 26(9), 1835–1844. <https://doi.org/10.1109/TNSRE.2018.2859432>.
- Babiloni, F., Cichocki, A., & Gao, S. (2007). Brain-computer interfaces: Towards practical implementations and potential applications, 2007(ix). <https://doi.org/10.1155/2007/62637>.
- Ball, L., Beukelman, D. & Pattee, G. (2004). Communication effectiveness of individuals with amyotrophic lateral sclerosis. *Journal of Communication Disorders*, 37(2004), 197-215.
- Beukelman, D., Fager, S. Ball, L., & Dietz, A. (2007). AAC for adults with acquired neurological conditions: A review. *Augmentative and Alternative Communication*, 23(3), 230-242.
- Brownlee, A. & Palovcak, M. (2007). The role of augmentative communication devices in the medical management of ALS. *NeuroRehabilitation*, 22(2007), 445-450.
- Caron, J. & Light, J. (2015). "My world has expanded even though I'm stuck at home": Experiences of individuals with amyotrophic lateral sclerosis who use augmentative and alternative communication and social media. *American Journal of Speech-Language Pathology*, 24(November 2015), 680-695.
- Dayle, M., & Phillips, B. (2009). Trends in augmentative and alternative communication use by individuals with amyotrophic lateral sclerosis, 4618. <https://doi.org/10.1080/08031230.2009.167172>.
- Fried-acker, M., Mooney, A., & Peters, B. (2015). Supporting communication for patients with neurodegenerative disease, 37, 69–87. <https://doi.org/10.3233/NBE-151241>.
- Londral, A., Pinto, A., Susana, P., Azevedo, L., & De Carvalho, M. (2015). Quality of life in amyotrophic lateral sclerosis patients and caregivers: Impact of assistive communication from early stages. *Muscle & Nerve*, (December), 933–941. <https://doi.org/10.1002/mus.24659>.
- McNaughton, D., Giambalvo, F., Kohler, K., Nazareth, G., Caron, J., Fager, S. (2018). "Augmentative and Alternative Communication (AAC) Will Give You a Voice": Key Practices in AAC Assessment and Intervention as Described by Persons with Amyotrophic Lateral Sclerosis. *Seminars in Speech and Language*, 39(5), 399–415.
- Simmons, Z. (2015). Patient-perceived outcomes and quality of life in ALS. *Neurotherapeutics*, 12(2015), 394-402.