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

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; Baboli, 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, & Pottee, 2004; Beukelman, Pagar, 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)

1. 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)

2. 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?

DEVELOPEMBELS

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
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

June-July
- Completion of survey development
- Draft and submit IRB proposal

July-August
- Launch surveys with pALS, cALS, and healthcare professionals
- Propose dissertation

September
- Begin data collection - education and training on low-tech AAC with pALS and cALS

POTENTIAL ISSUES

Condensing Survey Data
- Usable information to develop communication curriculum

Clinical Population
- Recruitment
- Expand geographic location
- Consider other interaction methods - virtual meeting

Attrition
- Virtual meeting?
- Home visits?

Realistic Expectations
- Consistency of Data
- 2 groups?
- Consider time since diagnosis
- Sample size

REFERENCES


