

IMPROVING ACCESS TO SOCIAL PARTICIPATION AND LEISURE ACTIVITIES FOR INDIVIDUALS WITH ALS **Occupational** Therapy

Kayla Egan, OT/s; Peggy Dellea, MS, OT/L; Jennifer Buxton, MA, OTR/L, ATP, MEd; Mary Alicia Barnes, OT, OTD

INTRODUCTION



Amyotrophic Lateral Sclerosis (ALS), or "Lou Gehrig's disease": progressive fatal neurodegenerative disorder resulting in loss of voluntary muscle control, ultimately affecting movement, gait, speech, swallowing, & breathing.^{1, 2} ALS impacts function & participation in daily occupations, such as social participation & leisure.²



Augmentative and Alternative Communication (AAC): assistive technology supplementing or replacing natural speech.³ Occupational Therapy (OT) assesses & identifies adaptations, tools, & access strategies to promote communication & overall function in daily activities.⁴

Population & Site

face communication

Are virtual activities on AAC desired, important, & accessible for PALS?

activities are important to PALS

to accessing virtual activities





RESULTS

ILLUSTRATIVE QUOTES

"I would say that virtual activities make up a large portion of what I do. Without them I would live in my head a lot more." (Participant ID 6235)

"It's like a totally new mode of interacting with the world [...] Once the hands were gone, it's like I need something or I'm gonna have [caregiver] doing everything for me." (Participant ID 4732)

"Every human being that has a phone in general [...] this is how we all communicate and socialize. It's how we stay connected, whether we have ALS or not." (Participant ID 6235c)



DISCUSSION

PALS desire AAC access to virtual social participation & leisure activities.

- Asynchronous virtual communication (email & text) & FTF communication are most important virtual activities to access using AAC for PALS
- Suggests importance of social connection & utilization of multiple means of communication to maintain social participation
- Consistent with literature that supports asynchronous methods of communication for PALS to bypass communication barriers⁶

Each virtual activity possesses its own facilitators & barriers unique to the user.

- Comfort level varies between virtual activities & within each virtual activity Variability between activities seems to indicate variability in accessibility of
- each virtual activity, likely due to differing access methods & activity itself
- Wide range in comfortability per virtual activity suggests user preferences & abilities influence accessibility

Virtual activities' access method has changed secondary to ALS, but leisure preferences pre- and post- ALS diagnosis remain stable.

- Emerging theme revealed by participants' responses indicates that leisure interests do not change secondary to changes in physical capabilities for PALS
- Adult population with an acquired disease who have formed identities and preferences pre-diagnosis likely contributes to this finding

STRENGTHS & LIMITATIONS OF STUDY

Semi-structured Interviews In-depth Person-centered Data Limited Scope & Generalizability Subjectivity & Potential Bias

CONCLUSION



Future Implications: Analyze correlation between stages of progression of ALS & AAC usage or expand population beyond Boston Children's



End Deliverable: Created & publicly shared video tutorials of TD Control⁷ to supplement clients' use of AAC for virtual activities (see Materials)



Conclusion: Access to virtual activities that address holistic needs, not solely communication needs, is desired & important for PALS who use AAC

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Kayla Egan, OT/s: <u>Kayla.Egan@tufts.edu</u>

Contact Information

References

& Materials





Jennifer Buxton, MA, OTR/L, ATP, MEd: <u>Jennifer.Buxton@tufts.edu</u>