

Introduction

Patient Population: Currently, 16,000 individuals in the U.S. are living with Amyotrophic lateral sclerosis (ALS).¹⁶ ALS is a neurodegenerative disease that impacts gross & fine motor movements, speech, swallowing, & breathing.¹

Site: Jay S. Fishman ALS Augmentative Communication Program at Boston Children's Hospital supports individuals living with ALS by providing alternative and augmentative communication (AAC) & assistive technology assessments & trainings.¹⁰ Occupational therapists (OTs) & speech language pathologists (SLPs) collaborate with individuals to support daily functional needs, social & vocational goals & overall quality of life.¹³

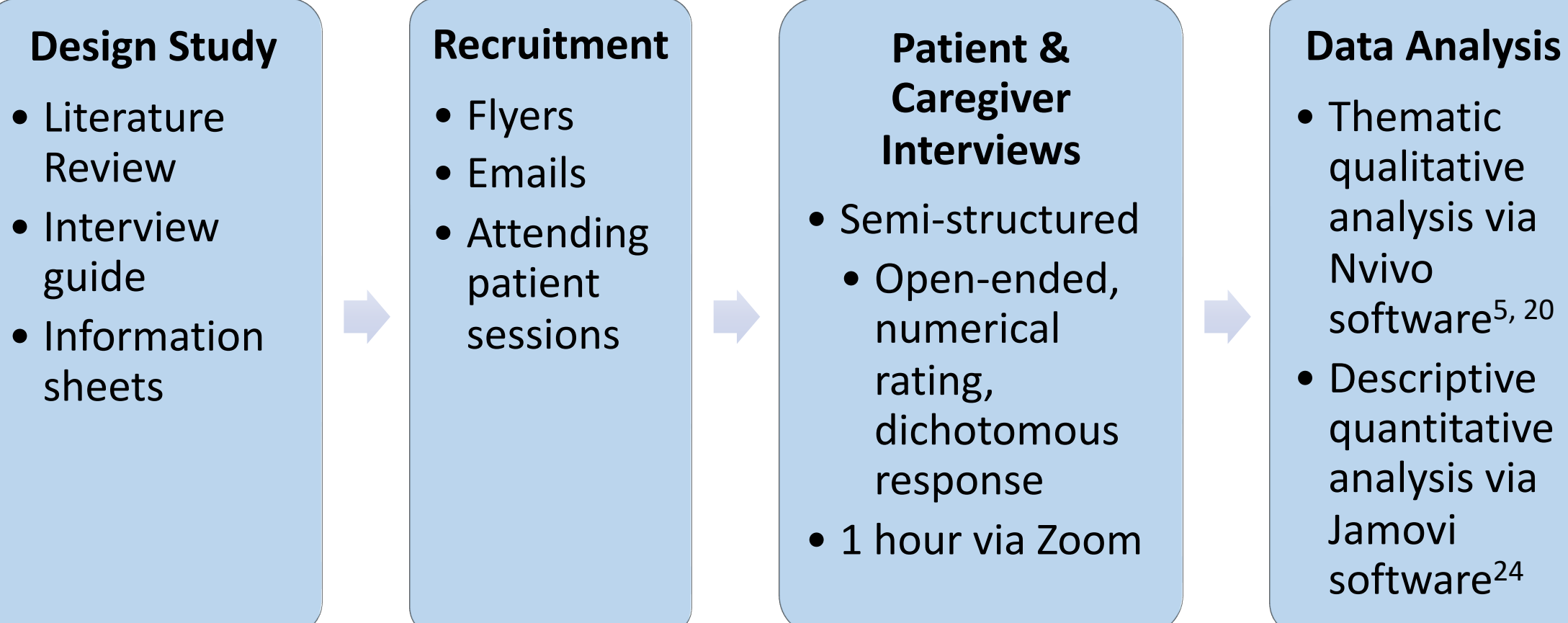
Need/Gap: Insurance companies will provide speech generating device (SGD) coverage only when a patient needs to generate speech. They neglect to cover devices if patients have intelligible speech but need alternative access to use other computer functions. OTs & SLPs believe these features are equally important & should be equally funded & obtained.^{8, 12}

Purpose of Study: To evaluate access to social participation and leisure activities, such as online gaming, emailing and social media, for individuals living with ALS.

Aim 1: To identify which virtual activities hold most importance to individuals with ALS.

Aim 2: To evaluate facilitators and barriers to accessing most important virtual activities, given patient's current method of access & software available.

Methods



*IRB approved exempt study through Tufts University and Boston Children's Hospital

Participants

Patients

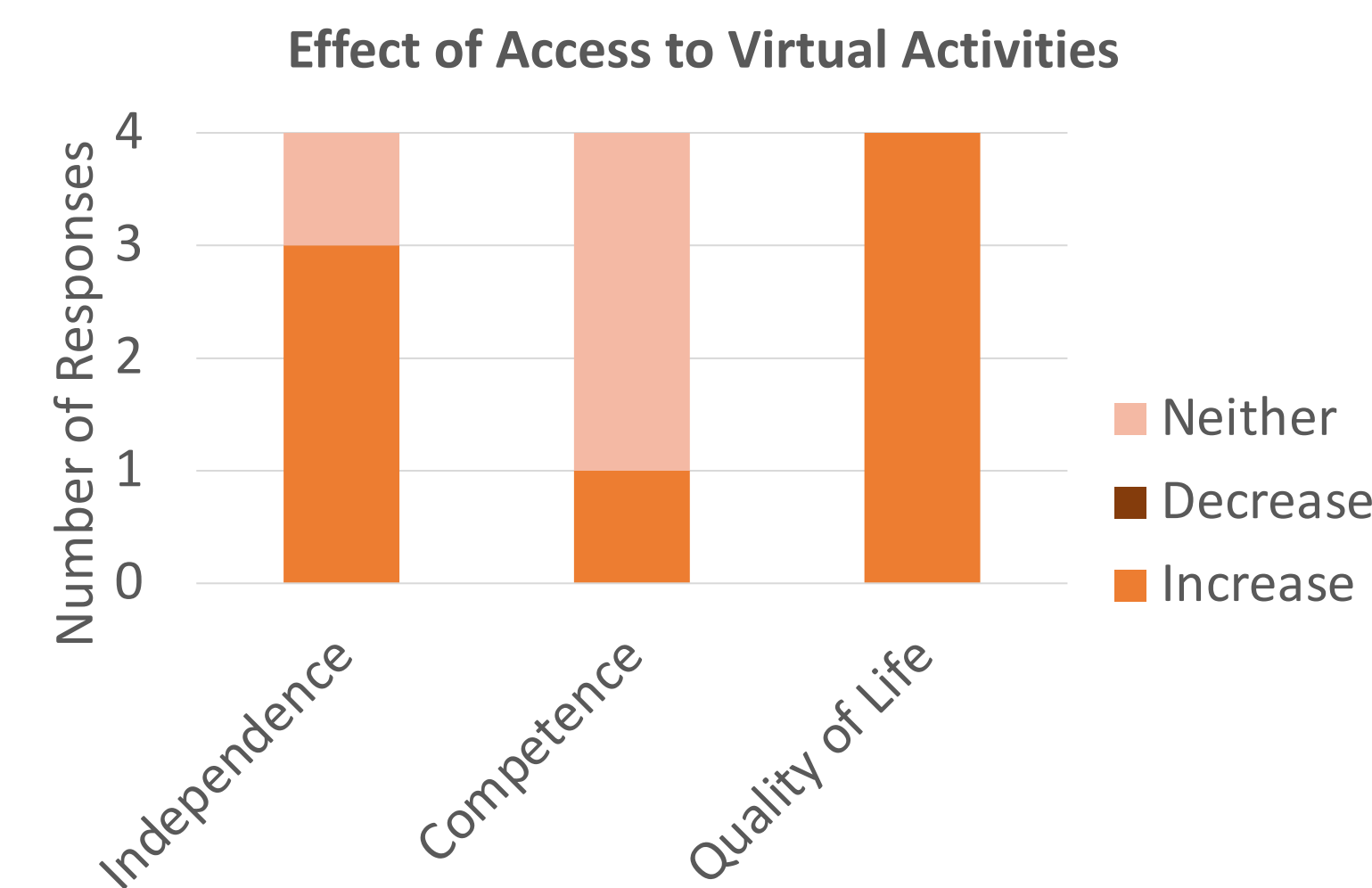
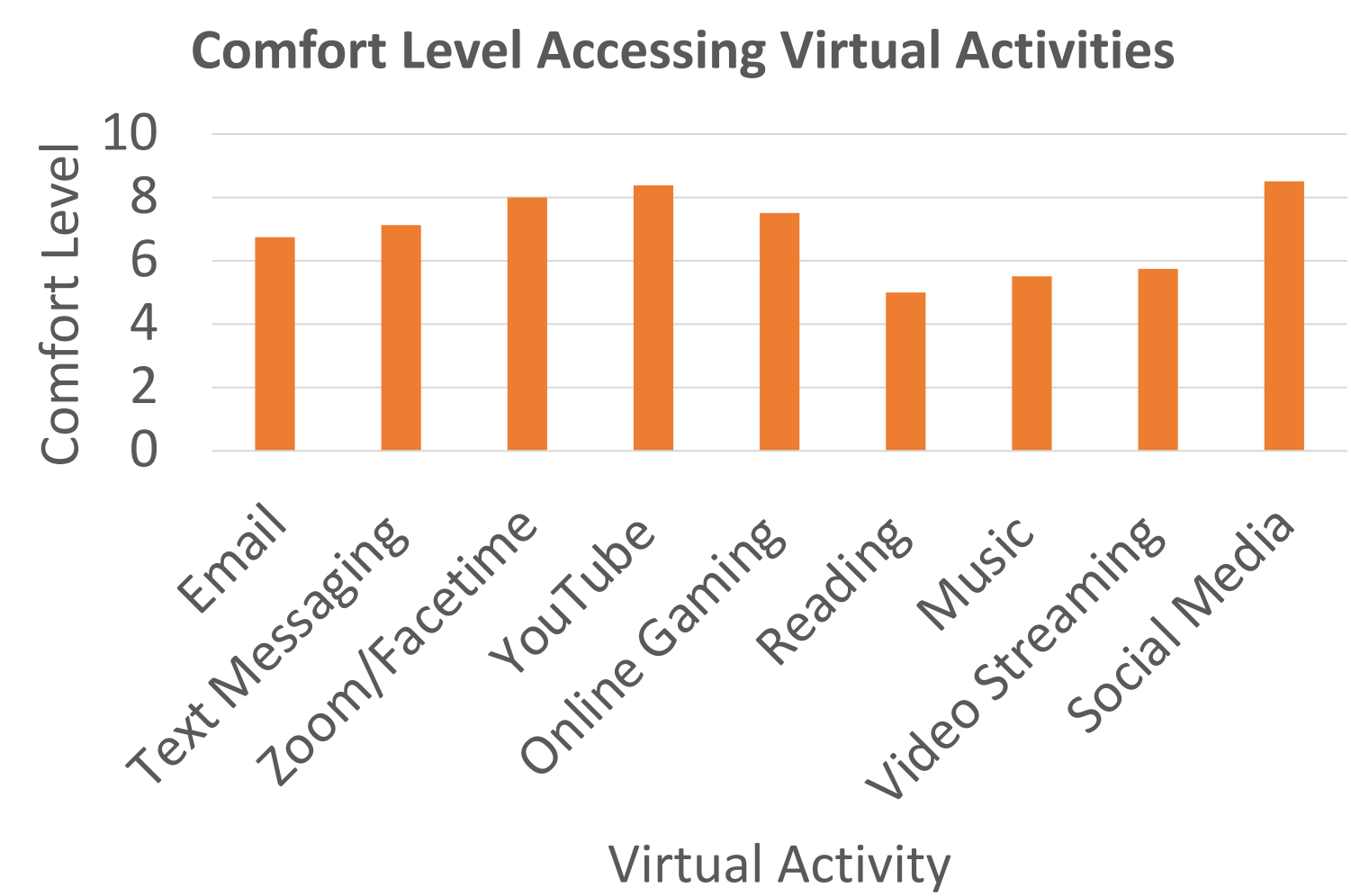
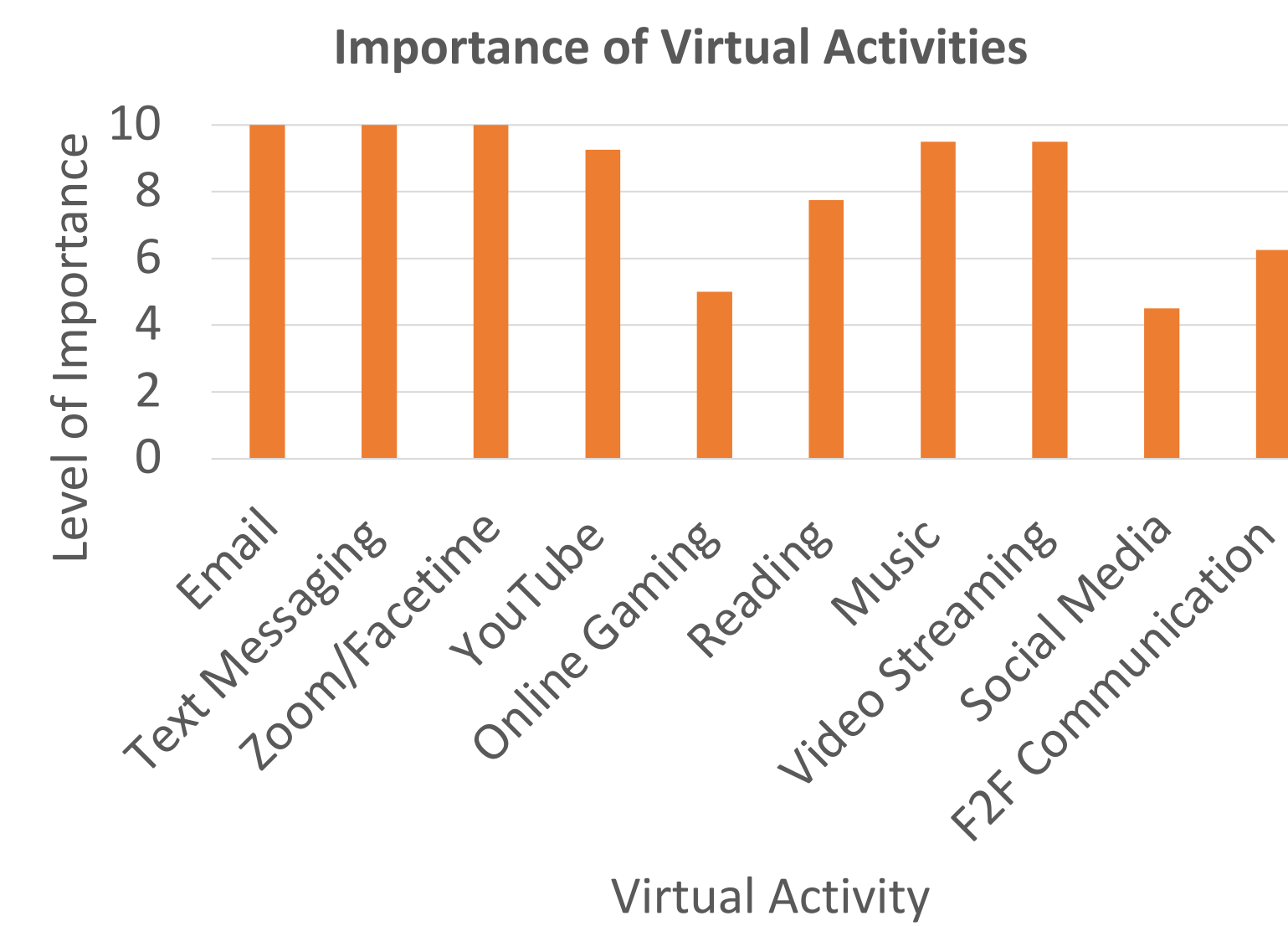
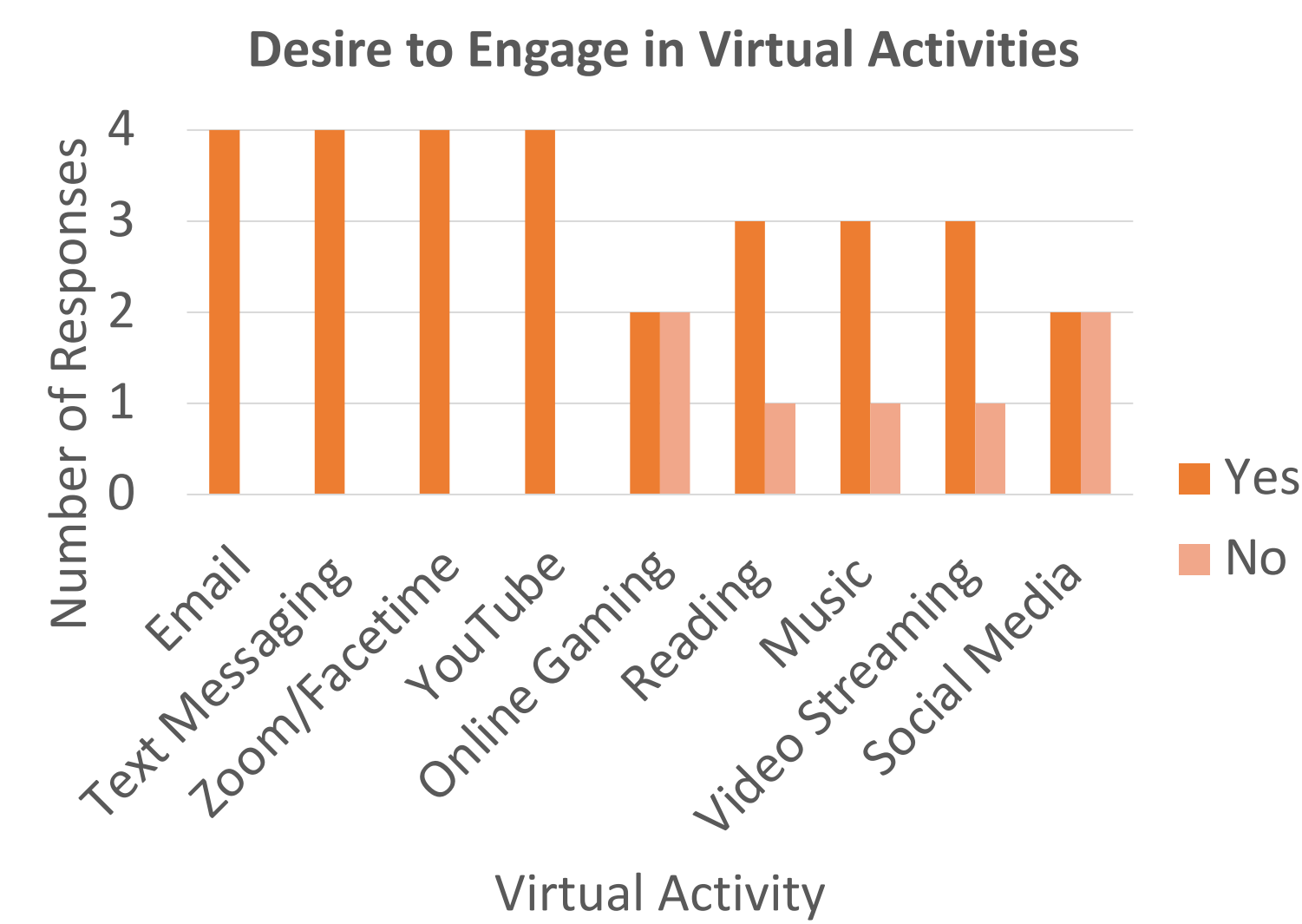
- N=4
- 2 male identifying, 2 female identifying
- Age range: 51-80 years
- All primarily reside in Massachusetts
- All identify as White
- Devices/Software: Windows computer, Tobii Dynavox I-13 & I-16²⁵
- Access Methods: Eye tracking, direct touch, switch, stylus, mouse & on-screen keyboard

Caregivers

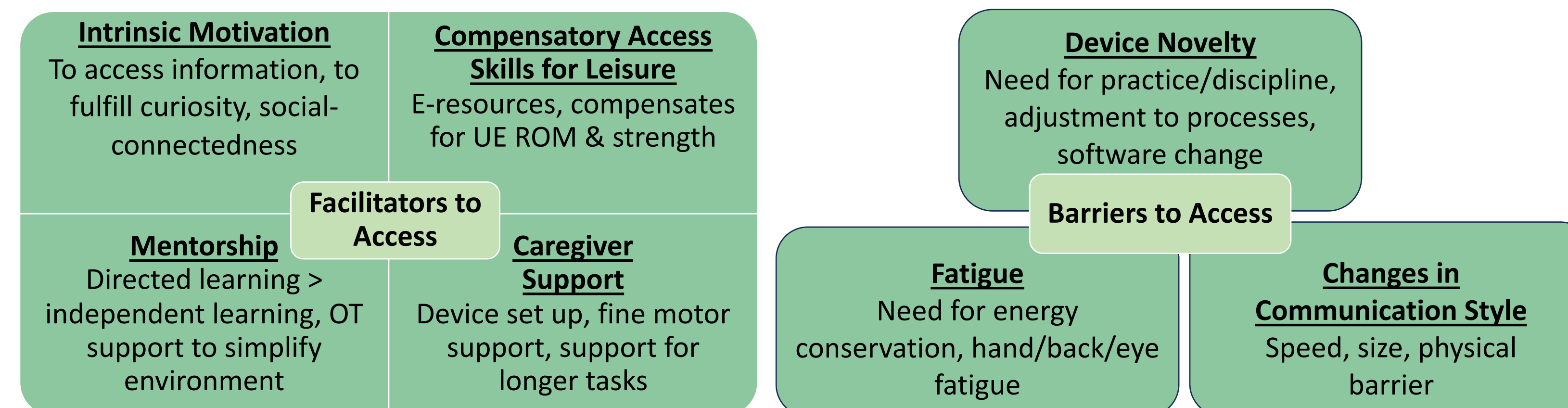
- N=2
- Both female identifying

Results

Aim 1: Virtual Activities Holding Most Importance to Individuals with ALS



Aim 2: Facilitators and Barriers to Accessing Virtual Activities



Illustrative Quotes

- "Yeah, but it's like anything, it's, you do better with the teacher. You know, the independent learning is not as productive as directed learning." (BC4; Question 8a).
- "And also, it's a physical barrier between, you know, I know there's a screen on the back side of it, but that's then saying, okay, there's a wall between her and anyone she's potentially communicating with" (BC2; Question 16).
- "Just having ALS itself is demanding physically. Just, the silliest things take more time. And so, you end up with not a lot of discretionary time during your day and so you're going to figure out how you're going to use that without just completely burning yourself up" (BC4; Question 14).
- "I mean right now I can open my Mac and get going right away. On my Tobii, I have to remember how to do I do this and how do I do this, it takes practice" (BC9; Question 10).

Discussion

- Results indicate that AAC devices are utilized for far more than just face-to-face communication.
 - Individuals with ALS demonstrated a strong desire to engage in virtual activities and indicated high levels of importance for these virtual activities.
 - Of the 10 virtual activities inquired about, 7/10 activities received a higher rating of importance than face-to-face communication.
 - Emailing, text messaging and Zoom/FaceTime were both most desired and most important to individuals with ALS.
 - Patients listed managing finances, utilizing Microsoft Office, and practicing mindfulness as other important virtual activities.
 - All participants reported that access to virtual activities has increased their overall quality of life.
- With the implementation of the clinical recommendations and the continuation of this study, additional research will improve outcomes for individuals with ALS and cultivate the evidence needed to increase funding for these devices.

Strengths

- Semi-structured interview method
- Format & duration of interviews
- Recruitment methods

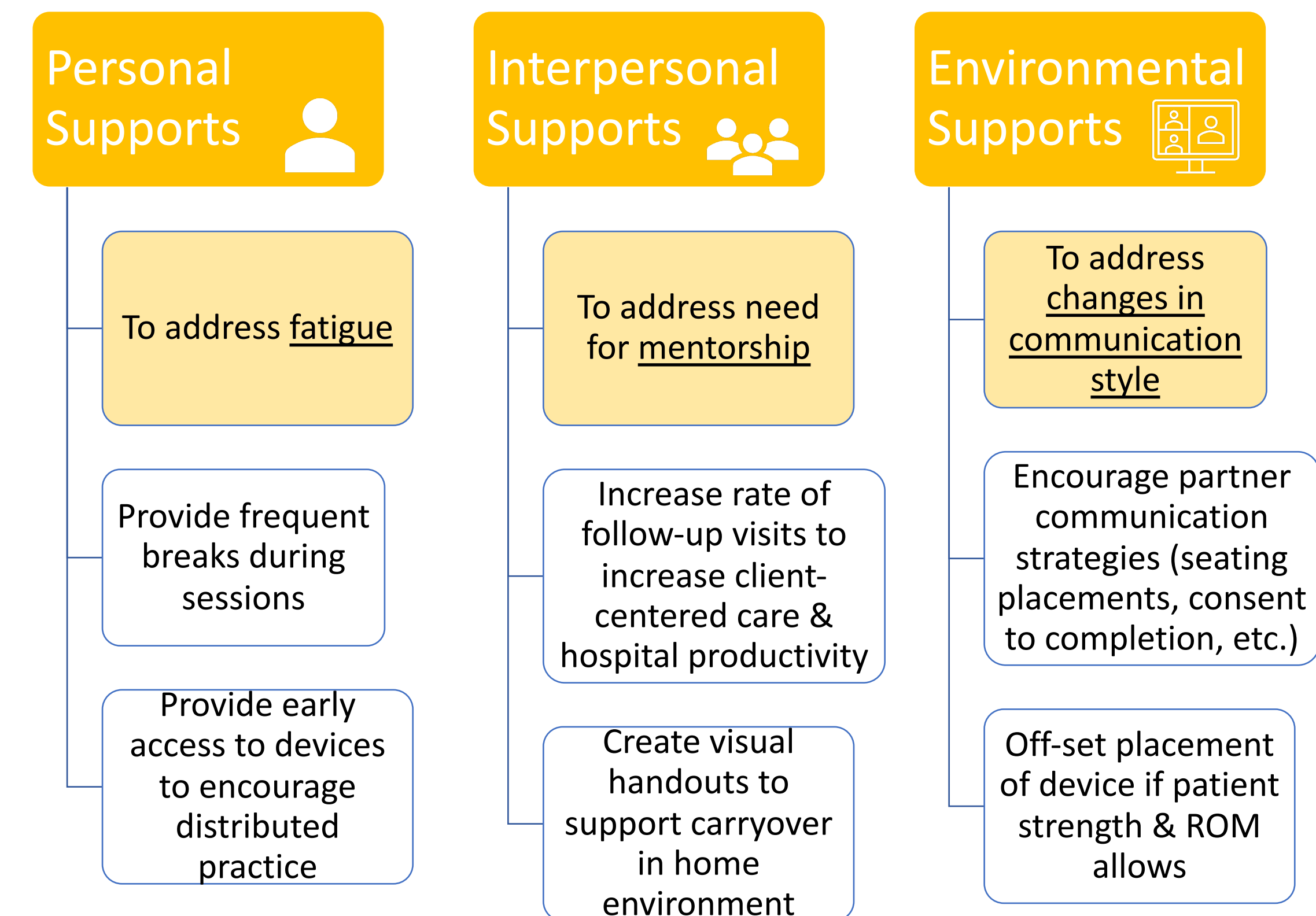
Limitations

- Small research team sequenced over time
- Lack of insight around dichotomous questions

Future Directions

- Consistency, training & adherence to codebook & instruction manual
- Modified interview guide
- To expand study population to more experienced AAC users

Clinical Recommendations



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References

